UNIVERSITY OF CAPE TOWN
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SOCIAL AND BEHAVIOURAL SCIENCES DIVISION

INFLUENCES ON THE CONTINUITY OF CARE FOR PATIENTS WITH MYCOBACTERIUM TUBERCULOSIS REFERRED FROM TERTIARY AND DISTRICT HOSPITALS

Thesis submitted to the Faculty of Health Sciences, University of Cape Town,
for the degree of Doctor of Philosophy.

By

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Declaration

I know that plagiarism is wrong. Plagiarism is to use another's work and pretend that it is one's own.

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ABSTRACT

South Africa is one of the countries with the highest burden of Mycobacterium tuberculosis (TB) in the world. The fact that adult patients diagnosed with TB frequently do not attend their primary healthcare clinics after discharge from hospital for continued treatment remains a challenge for public health in South Africa. This qualitative study employed semi-structured interviews, focus group discussions and observations explored the experiences of patients, their families, healthcare workers and policy makers, with continuity of TB care following diagnosis in hospital. The key research question was what factors were shaping patients' attendance at primary healthcare clinics following TB diagnosis and start of treatment in tertiary and district hospitals. Sub questions were: how did patients diagnosed with TB interpret and act upon their diagnosis and treatment at the tertiary/district hospital? What roles did patients play in the discharge process? What were their home circumstances and experiences at the clinics they were referred to, regarding their registration and follow-up plan? What were the perceptions of patients, healthcare workers and policy makers on what influences patients' attendance/non-attendance at clinics? The objective of this study was to contribute to our understanding of patients' experiences and perceptions of treatment of TB and how services to patients could be improved to enhance better continuity of care. I drew on a three-fold theoretical framework: patient-centred care, Foucault's concept of the 'medical gaze' and social determinants of health. My study built upon previous and ongoing research on the topic of continuity of care for TB in Cape Town. I argued that problems in the provision of TB services to hospital patients could be understood as failures of the services at the hospital to achieve some of the core components of patient-centered care. Furthermore, I argued that better systems for following-up patients from the hospitals to their homes and clinics would provide more understanding of the challenges patients faced when they have been referred from a tertiary or district hospital to continue with their treatment. Insights gained from qualitatively following patients from diagnosis to discharge and their home circumstances helped to better understand the problem South Africa faced with continuity of care for TB treatment.

TABLE OF CONTENTS

LIST OF TABLES AND FIGURES

TABLES

FIGURES

ACRONYMS

AIDS	*Acquired Immune Deficiency Syndrome*
ART	*Antiretroviral Therapy*
ARVs	*Antiretrovirals*
CHWs	*Community Health Workers*
CoC	*Continuity of Care*
DOTS	*Directly Observed Therapy/Treatment Short-Course*
DR-TB	*Drug-resistant Tuberculosis*
FGDs	*Focus Group Discussions*
HAART	*Highly Active Antiretroviral Therapy*
HBCs	*High Burden Countries*
HCWs	*Healthcare Workers*
HIV	*Human Immunodeficiency Virus*
IPC	*Infection Prevention and Control*
MD	*Medical Doctor*
MDGs	*Millennium Development Goals*
MDR-TB	*Multi-drug Resistant Tuberculosis*
MO	*Medical Officer*
NSP	*National Strategic Plan*
PHC	*Primary Healthcare*
PLWHAs	*People Living with HIV and AIDS*
PN	*Professional Nurse*
SANAC	*South African National AIDS Council*
SDH	*Social Determinants of Health*
SANDoH	*South African National Department of Health*
SAT	*Self-Administered Therapy/Treatment*
TB	*Tuberculosis*
UIPC	*Unit for Infection Prevention and Control*
WCDoH	*Western Cape Department of Health*
WHO	*World Health Organisation*
XDR-TB	*Extensively Drug-resistant Tuberculosis*

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I developed the idea to pursue this topic while I was working as a Research Assistant in a larger study headed by Prof Lilian Dudley at one of the hospitals in the Western Cape. I enjoyed working with this team of researchers on this larger study. Many thanks for their support and encouragement as I pursued a different angle of the concept of continuity of care by looking at patients' perspectives of TB treatment.

I started my PhD studies in the Sociology Department. I got initial guidance from my former supervisors, Dr Judith Head, who later retired from the university, and co-supervisor, Dr Frederick Marais, who moved from the university to work with the South African National Department of Health. I am thankful to both of them for helping me develop the initial proposal, which I submitted to the Sociology Department.

A big thank you goes to Elizabeth le Sueur who proofread my thesis and provided many useful corrections. Reading through a thesis with limited turn-over time could be very daunting. She was very positive, prompt, yet detailed in her responses. I am so grateful to have met her.

DEDICATION

I dedicate this thesis to all health workers who make relentless efforts to eradicate tuberculosis.

CHAPTER ONE: BACKGROUND AND INTRODUCTION TO STUDY

INTRODUCTION

Mycobacterium tuberculosis (TB) is a persistent global health problem. The World Health Organisation (WHO) TB Report (2017:21) stated that 10.4 million people fell ill with TB in 2016. According to this report it was projected that there was a total of 1.3 million deaths from people who were HIV negative and 374,000 from those who were HIV positive (WHO, 2017). In South Africa TB incidence was 834/100 000 population, which was a projected 450,000 new infections and accounted for 8.4% of all natural deaths in 2015 (South Africa's National Strategic Plan for HIV, TB and STIs 2017-2022:7). The global trend of and deaths from TB are still high. Africa faces not only a rising incidence of TB, but also weak health systems (Chaisson & Martinson, 2008:1089). South Africa features among the countries that have a triple burden of infectious disease, which are TB, Multi-drug Resistant TB (MDR-TB) and Human Immunodeficiency Virus (HIV). TB is one of the leading causes of deaths in the country (STATS SA, 2017:32). South Africa could also not reach the global target set to reduce HIV and TB by 50% by 2015 (South African National AIDS Council (SANAC) Annual Report 2015/16, 2017). The Government has tried a number of strategies, including Self-Administered Therapy (SAT) and Directly Observed Therapy Short-Course (DOTS) to minimise the threat of TB by striving to eliminate it. Despite some significant improvements in the health system that followed the shift from an apartheid-racialised health system, there have remained many challenges in TB control. Some of these challenges involve the health system itself and others relate to the lived experiences of patients in their homes and in their communities. For example, there are still too few healthcare workers (HCWs) given the high numbers of TB cases. There is evidence of race and class inequities in the health sector. There is also a high level of poverty among people infected with TB in disadvantaged communities, such as Khayelitsha (where much of this study was conducted). The poor living conditions are not helped by administrative and clinical challenges in the health sectors of South Africa (Von Holdt & Murphy, 2007; Kapp, 2009; SANAC, HIV and AIDS and STI National Strategic Plan 2012-2016, 2011). As a result, many people drop out of TB care or do not adhere to treatment and become sick again. This study focused on trying to better understand one specific but crucial aspect of the health systems' TB control effort — referral from hospital to clinic during TB treatment. This is a frequent point of dropout and understanding how to prevent this was an important part of overall TB control efforts.

A few studies (Edginton et al., 2005; Edginton, Wong & Hodkinson, 2006; Dudley et al., 2018; Jacobson, 2015; Marais, Kallon & Dudley, Forthcoming; Nkosi et al; 2013) have tried to understand this process of referral. They have done so either by looking at the numbers of patients that attended or did not attend the clinics after referrals, or by drawing on the perspectives of HCWs. The patients' perspectives of treatment in the hospitals and clinics as well as their home circumstances—and its impact of their TB treatment—have not been explored. The findings of these studies and details of gaps are discussed below.

The concept of continuity of care (CoC) is useful when trying to understand the question of referral and the factors that promote or prevent successful referral. The CoC concept has a number of core components. Foremost is the patients' interaction with HCWs and clear and effective transfer of information from one health centre to the other as well as mechanisms that should be put in place to follow-up patients after referrals from either a hospital or clinic (Gordon & Krauthoefer, 2007; Nkosi et al; 2013; Hjortdahl & Laerum, 1992:137). I used a three-fold theoretical framework in this study to understand what influences CoC for patients. These are patient-centred care (PCC), Foucault's concept of the 'medical gaze', and the social determinants of health (SDH). Patient-centred care (PCC) involves how HCWs should engage with patients' needs, feelings and how they (the HCWs) should consider the patients as partners in the treatment process (Epstein & Street, 2011:100; Henbest 1989; Stewart, 2001; Little et al., 2001). Regarding the 'medical gaze', Foucault analyses how patients are constructed and treated as objects in their interaction with HCWs (Foucault, 2003:65). Social determinants of Health (SDH) are essential to understanding the social, political, economic, and environmental factors that affect the health status of people (Marmot, 2005). Most importantly for the purpose of this study, SDH are relevant for understanding how people are retained in health care (Farmer 1996; Sanders et al., 2009; Sanders, 1985; Sinanovich., et al 2003).

In this study I used CoC as the broad framework for tracking patients' movements from hospital to their clinics and homes. I did this by interviewing 54 people: 17 patients (10 were followed-up after discharge from two different hospitals); 10 HCWs in the hospitals; 19 HCWs in the clinics; six family members of patients, and two policy makers from the Western Cape Department of Health (WCDoH). The key findings were, firstly, there were significant lapses in PCC in the hospitals. These were seen in not adequately exploring patients' needs and feelings about their treatment and discharge. The reasons for these lapses included the huge workload of HCWs, time constraints on HCWs, cultural and linguistic challenges, and patients' limited knowledge of TB prior to hospitalisation. As a result of high workload and time constraints, nurses and doctors did not embark on a structured and consistent education programme with patients, which is one of the core elements of PCC. Secondly, there has also been poor collaboration between health centres, where patients move from one health centre to another with not enough clarity on what lies outside the hospital. There were similar reported cases in the clinics of inaccurate dissemination of TB information to patients, signalling part of the poor linkages between the clinics and the hospitals. HCWs explained that patients' poor health-seeking behaviour occurred because of drug and alcohol abuses. Thirdly, patients who had not attended clinics during their treatment expressed feelings of being scared and confused and being abused at home by family members. Feeling scared, confused and embarrassed by improper behaviour of some nurses occurred because of lapses in PCC. Patients who attended the clinics consistently reported strong family support and high internal personal motivation. Patients who attended the clinics also had better socio-economic status.

Continuity of care (CoC) was not only affected by lapses of the health system, but also by influences of patients' socio-economic circumstances. My study built on previous and ongoing research on the topic of CoC for TB in Cape Town. I argued that problems in the provision of TB services to hospital patients could be understood as failures of the services at the hospital to achieve some of the core components of PCC. Furthermore, I argued that better systems for following up patients from the hospitals to clinics and their homes would provide more understanding of the challenges patients faced when they have been referred from a tertiary or district hospital to continue with their treatment. Insights gained from qualitatively following patients from diagnosis to discharge and their home circumstances helped to better understand the problem South Africa faced with CoC for TB treatment.

THE BURDEN OF TB GLOBALLY, IN AFRICA AND SOUTH AFRICA: CAUSE FOR CELEBRATION AND CONCERN

The global landscape of TB

TB has killed many people over a long period of time. This is seen in the global collection of TB statistics since the early 1990s (Packard, 1990; Spence et al., 1993). Untreated TB can result in death and active pulmonary TB is infectious. Furthermore, incomplete TB treatment as well as poor access to proper diagnosis and inadequate infection prevention facilities can lead to the development of Multi-drug Resistant TB (MDR-TB) and Extensively Drug Resistant TB (XDR-TB) (Streicher et al., 2012). In 2014 alone, 1,5 million people died from TB; 890 000 men, 480 000 women and 140 000 children (World Health Organisation (WHO), 2015:8-9). The report also showed that TB and HIV were the leading causes of death in 2014 (WHO, 2015:9). This global TB report also indicated that “about 90% of total TB deaths (among HIV-negative and HIV-positive people) and 80% of TB deaths among HIV-negative people occurred in the African and South-East Asia Regions in 2014” (WHO, 2015:22). The baseline target set in 1990 was to reduce TB by 50% by 2015. From 2004 on, some regions, including the Americas, have already reached half of this target (Glaziou, Sismanidis & Raviglione (2015:7). The Western Pacific Region reached the expected 50% reduction of TB prevalence in 2012. This target was achievable in South-East Asia. However, for Africa and the Mediterranean regions, the targets were not expected to be reached because even the “prevalence rates increased substantially during the 1990s, and by 2007 were still far above the 1990 level” (Glaziou, Sismanidis & Raviglione (2015:7). The most recent TB statistics puts TB incidence at 10.4 million people in 2016 of which 1.3 million people died including 374,000 HIV positive people (WHO, 2017:7)

From 2000 to 2015, the global approach to TB was based on the Millennium Development Goals (MDGs), which incorporated the move to “halt and reverse TB incidence” (WHO, 2017:7). In 2016, the Sustainable Development Goals (SDGs) replaced the MDGs. In the global SDG consultations it was agreed by all member states to end TB by 2030, along with AIDS, malaria and other communicable diseases. Following this agreement, there were 13 targets set for ending TB by 2030 (WHO, 2017:9). By 2015, global deaths from TB were 47% lower compared to deaths in 1990, due to scale-up of proper diagnosis and treatment plans (WHO, 2015:8). The Global TB Control programme reported that 1,7 million deaths were caused by TB in 2009 as compared to 1,5 million in 2014 (WHO, 2010:7; WHO, 2015). This report also indicated that since the MDGs that were set in 2000, millions of lives have been saved as a result of the availability of proper diagnosis and better treatment plans. TB incidence has also been reduced in six WHO regions and in 16 of the 22 countries with the highest burden of TB cases (WHO, 2015).

Although the world has seen an encouraging advance regarding the downward trend of TB deaths, the disease still stands as a major global threat. It is estimated that every year about 9 million new cases of TB emerged and nearly 2 million people died of the disease (WHO, 2010:7). India and China both have the highest burden of global cases of TB (about 35%). It appeared that even approaching 2010 there were still some problems of improper diagnosis around TB (LÖnnroth et al., 2010; Sanders et al., 2009), which are still having a major impact on people in terms of not only high death rates from TB, but also poor health.

Another major challenge to these advances of TB control is drug-resistant TB. Multi-drug Resistant TB (MDR-TB) is diagnosed when there is a resistance to first-line treatment with drugs such as isoniazid and rifampin. First-line treatment for TB is a combination of drugs that are included in the initial treatment of the patient. A second-line treatment may be recommended based on the resistance to the first-line treatment or the severity of the health condition. Extensively Drug-resistant TB (XDR-TB) is an extreme form if TB that resists almost all second-line treatment drugs such as fluoroquinolones and amikacin or capreomycin (Cox et al., 2010; Dheda et al., 2010; Sanders et al., 2009; Streicher et al; 2012). Data on MDR-TB have been collected since 1994. A 2010 WHO report indicated that there were an estimated …

> *… 440 000 cases of MDR-TB in 2008 … The 27 countries (15 in the European Region) that account for 86% of all such cases have been termed the 27 high MDR-TB burden countries … The four countries that had the largest number of estimated cases of MDR-TB in absolute terms in 2008 were China (100 000; range, 79 000–120 000), India (99 000; range, 79 000–120 000), the Russian Federation (38 000; range, 30 000–45 000) and South Africa (13 000; range 10 000–16 000). By July 2010, 58 countries and territories had reported at least one case of extensively drug-resistant TB (XDR-TB)* (WHO, 2010:7).

South Africa also has a high burden of other health problems, such as HIV, diabetes, injuries, high maternal and infant mortality, making the situation very serious. These MDR-TB (as well as XDR-TB) rates, along with other health challenges in South Africa, will be discussed at greater length below under the heading, "Situating TB in the South African context".

TB in Africa

Chaisson and Martinson (2008:1089) report that Africa has 11% of the world's population, but carries 29% of the global prevalence of TB. Drawing on the WHO estimates, Chaisson and Martinson (2008:1089) show that the "average incidence [TB] in African countries more than doubled between 1990 and 2005, from 149 to 343 per 100,000 population". Africa has nine of 22 countries with the highest burden of TB, including South Africa. These 22 countries account for about 80% of the global TB cases. TB is the eighth most common cause of death in low and medium-income countries (WHO, 2010:8). In Sub-Saharan Africa particularly, it is noted that there is …

> *… resurgent spread of 'old' communicable diseases once thought to be controlled … while 'new' epidemics, notably HIV/AIDS, threaten last century's health gains … At present, co-infection of mycobacterium tuberculosis and HIV together with emergence of multi-drug resistance (MDR) and extensively drug-resistant (XDR) tuberculosis present a major health concern* (Sanders et al., 2009:162).

A key explanation given for Africa's rising incidence of TB has been the relationship TB has to HIV infection (Badri, Wilson & Wood, 2002; Chaisson & Martinson 2008; Coetzee et al., 2004:11). Chaisson and Martinson (2008:1089) reported that …

> *Autopsy studies show that 30 to 40% of HIV-infected adults die from tuberculosis … Among HIV-infected children, tuberculosis accounts for up to one in five of all deaths. As HIV prevalence increased in Africa — most strikingly in the 1990s — and the cellular immunocompetence of populations became impaired, susceptibility to tuberculosis grew dramatically*.

Other reasons for Africa's rise of TB incidence include lack of funds and insufficient qualified medical personnel and laboratory equipment (Chaisson & Martinson, 2008:1090). These problems, as well as poor adherence to treatment (Cox et al., 2010; Dheda et al., 2010; Streicher, 2012), also contribute to the emergence of MDR-TB in the continent. It was also reported that in 2006 there was a rise in XDR tuberculosis in the southern parts of Africa (Chaisson & Martinson, 2008:1090-1091). These studies further support the claim that Africa, "where more than half a million people die each year from tuberculosis" (Chaisson & Martinson, 2008:1091-1092), would be unable to attain the goal for TB prevalence reduction set by the WHO in 1990.

From the global and African landscapes provided, we do not only know that TB is a persistent problem, but there are many other problems, including weak health systems and other infectious diseases, Africa faces to effectively combat the growing incidence of TB. I now turn my attention to South Africa.

SITUATING TB IN THE SOUTH AFRICAN CONTEXT

Prevalence of TB, HIV and MDR-TB in South Africa

The South African National AIDS Council (SANAC) has reported that the "number of cases detected for all forms of TB has steadily increased from 148 164 in 2004 to 401 048 in 2010" (SANAC, National Strategic Plan 2011: 24). By 2017, based on the 2015 global targets that were set, South Africa failed to attain 50% reduction of TB (SANAC Annual Report, 2015/16, 2017:). Furthermore, TB is the most common co-infection with HIV/AIDS in South Africa (Karim et al., 2009). Approximately five million people were thought to be living with HIV in South Africa up to 2011 (Badri, Wilson & Wood, 2002; SANAC, HIV and AIDS and STI National Strategic Plan 2012-2016, 2011). Presently, the SANAC Annual Report, 2015/16 (2017) puts the HIV prevalence at "7,03 million people … making it the single biggest cause of premature death and disability in the country. An estimated 150 341 people died from HIV in 2015". TB is one of the most common opportunistic infections (OIs) linked to HIV. It is important to examine the prevalence of both infectious diseases as they share strong influences on each other.

South Africa also has a growing burden of DR-TB. The South Africa National Department of Health (SANDoH) (2011) states that there has been an increase of MDR-TB and XDR-TB since 2004 (although there were decreases from 2009-2010, for which there were no clear explanations). The total number of MDR-TB cases was 3219 in 2004, but reached 7386 in 2010 (SANDoH, 2011:4). KwaZulu-Natal, Western Cape and Eastern Cape have a larger burden (a total of 5236) than the rest of the country (SANDoH, 2011:4). Streicher et al., (2012:693) concluded that …

> *The majority of MDR-TB cases in South Africa are probably a result of the poor programmatic treatment of specific and efficiently transmitting MDR strains. The high incidence of TB and MDR-TB … and the use of delayed DST [drug susceptibility testing] are fueling the continual dissemination and amplification of resistance thus, perpetuating the emergence of XDR-TB*.

The above quotation points to the health system-related causes of MDR-TB. In addition, there is a large body of work on factors related to treatment failure, both in South Africa and elsewhere (Ayisi et al., 2011; Cox et al., 2010; Dheda et al., 2010). These include patient-driven factors (although these factors are intertwined with structural influences), such as feeling too ill to go to the clinic, lacking the money for the fare to reach the clinic, needing to work, or difficulty in taking time off work to go to the clinic, and lack of family support. They also include health service-driven factors such as insufficient patient education about TB and communication breakdown between staff and patients (Sissolak, Marais & Mehtar, 2010), periodic lack of medicines, irregular sputum testing and lengthy delays in returning test results, long waiting periods in clinics (Department of Health, 2004), and ill-treatment by healthcare professionals (Jewkes, Abraham & Mvo, 1998; Lane et al., 2008).

It is not surprising to see that by early 2000, AIDS, which is strongly linked to TB, has become one of the leading causes of death in South Africa (Department of Health, 2005) and the use of highly active antiretroviral therapy (HAART) has become vital for minimizing the impact of HIV and TB. HAART, which South Africa effectively rolled out in the second half of the past decade, improves the health of people with AIDS and reduces opportunistic infections such as TB (SANAC, 2007; SANAC, HIV and AIDS and STI National Strategic Plan 2012-2016, 2011; SANAC, Annual Report 2015/16 2017). From 2013-2015 TB has been the leading cause of death among men as well as the leading cause of death among youth aged 15-24 (STATS SA, 2017:32). Chaisson and Martinson (2008:1091) established that in KwaZulu-Natal province …

> *Half the XDR cases in patients with HIV infection were acquired in hospitals or clinics, and several occurred in healthcare workers. Mortality exceeded 95% — chilling evidence of the critical importance of preventing the nosocomial spread of tuberculosis. XDR tuberculosis will undoubtedly continue to emerge elsewhere in Africa*.

This quote explains that the health situation in South Africa is worsened because even the HCWs who should be taking care of sick patients are themselves being infected with DR-TB. Hence the urgency to also respond to occupational health hazards. Thus far I have identified several issues that outline the background leading to the specific research problem in this study. Before delving into this specific problem, it is important to highlight some of the challenges and successes in the health sector in South Africa to provide a better context for this study.

Race and class in the epidemiology of TB and HIV in South Africa

There is an extensive literature on morbidity and mortality as a result of TB among low-income groups and predominantly African/black and Coloured populations in South Africa (Bradshaw et al., 2006; Head, 1999; Kagee, 2008; Sanders, 1985; Sanders et al., 2009; Sinanovich., et al 2003; Spence et al., 1993). A study in Khayelitsha, where most of the participants in my study resided, recorded that "close to 6000 tuberculosis cases were notified…giving an estimate case notification rate of 1158/100 000 per year…" (Cox et al., 2010:2). It is clear that TB has a strong relationship with the socio-economic situation of peoples in any given community. Although the South African government has made important interventions to reduce poverty, the poor, mostly African/black and Coloured populations, still suffer the greatest burden of morbidity and mortality. With regards to HIV, the incidence among the African/black population is 13% compared to 0.6% among white and 1.9% among Indians. Infant mortality is 67/1000 births among African/blacks compared to 7/1000 in the white population. Life expectancy is 50% longer in white women than black women (Coovadia et al., 2009:824). There are also inequalities in health between provinces, where, for example, "in 2000, mortality rates for children under five years ranged from 46/1000 live births in the Western Cape to that of 116/1000 live births in KwaZulu-Natal province" (Coovadia et al., 2009:824).

There is also a literature that examines the role played by the colonial and apartheid governments regarding the spread of TB among low-income groups in South Africa. The segregation of African/black and Coloured populations and movement of these groups to work in unsafe and overcrowded environments away from families fueled poverty and the spread of TB (Anderson, 1990; Bradshaw et al., 2006; Coovadia et al., 2008; Department of Social Development 2004; Head, 1999; Packard, 1990). In situations of political instability and abject poverty, TB spreads at alarming rates because some groups can be socially marginalised and disadvantaged (Crofton et al,. 1992; Head, 1999). Head's study (1999:20) of TB patients in the Ravensmead and Uitsig communities found that "most of the people interviewed lived from hand to mouth … most people go hungry on a regular basis ... most of the people interviewed are small and very thin – some indeed are emaciated". Further, this study found that in "11 of 13 households visited … there was overcrowding. In some cases, it was difficult to imagine how everybody who lived in the house managed to fit in, let alone stretch out and sleep" (Head, 1999:21). In addition, some people had little income and food.

Unemployment and poverty are phenomena that have continued to have major impacts on the lives of South Africans (Nattrass & Seekings, 2010). Other studies in South Africa shed light on social constraints to TB and HIV care. Daftary and Padayatchi (2012:1481-1484) documented several influences relating to access to income and health services by different classes and races. These included co-infected patients, mainly women, lacking the resources to sustain themselves while on treatment because their spouses had abandoned them; many people with TB living with extended families because they could not afford to live on their own; those who had jobs had to "discontinue work temporarily to access care. Formally employed patients received some compensation for TB, but most others engaged in informal/part-time work received no support". With regards to access to government grants they indicated that …

> *Tuberculosis did not guarantee approval. That ART and TB chemotherapy raised counts [CD4 counts] above the eligibility threshold left many patients feeling powerless and resentful of the social assistance program. HCWs echoed how grant criteria neglected patients' social circumstances, with potential negative clinical consequences. They had treated patients who defaulted from care to maintain low CD4 counts*.

In addition to the above problems, Verver et al. (2005) have shown that some people who are deemed cured are re-infected with a new strain of the bacillus. Their study also showed that there were more cases of re-infected TB than new cases. This makes the situation of TB in South Africa among lower income groups very serious. Verver et al. (2005:1434) conclude that there are:

> *People who have been treated successfully for TB are at higher risk of developing TB from reinfection than the general population. This suggests that a subgroup of individuals is intrinsically vulnerable to TB. For national TB control programs in areas with a high infection risk, patients who have been successfully treated for TB should be made aware of their high risk of recurrent disease, and contact tracing should get more attention.*

This quote points to the fact that even though re-infection is not only limited to communities where people live, there is evidence that it occurs where people live. Living in poor and crowded environments with limited income and food TB may cause further spread of the disease. I now discuss health sector factors driving TB.

Health sector factors driving TB

The above confirms that there are social circumstances, such as poverty and living in poor conditions, which may fuel the spread and impact of TB among specific groups. They also highlight the higher rate of TB re-infection among groups who have been treated with TB. Despite poverty and high rates of TB and HIV, there have been positive strides from the South African Government. One of the pillars of the Government's strategy to address the burden of disease was the transformation of the health services. In 1994 and beyond, the 14 health administrations of what was previously called the Bantustans and of South Africa were consolidated into one national and nine provincial health departments (Coovadia et al., 2009: 828). The Bantustans were homelands which were created as separate settlements with the purpose of providing needed labour in the apartheid segregated regime, rather than populations of people being integrated as part of the citizenry of South Africa (Soderbaum, 2004). Health facilities were desegregated (in the late 1980s). Primary healthcare (PHC) delivered through a district health system was made the cornerstone of the health policy:

> *The public health system was transformed into an integrated, comprehensive national service, driven by the need to redress historical inequities and to provide essential health care to disadvantaged (especially rural) people. The clinic infrastructure programme was revitalised and 1345 new clinics were built and 263 upgraded. Primary health care became available without cost to many users* (Coovadia et al., 2009: 828).

These developments have been marked as significant steps towards better health service delivery to mostly disadvantaged people in South Africa. However, nurses have been overburdened with work owing to the rising incidence of disease. Travis et al., (2004:900) concurred that "experience to date suggests that if the health systems are lacking capabilities in key areas such as the health workforce ... they may not be able to respond adequately to such opportunities". Von Holdt and Murphy (2007:315), in their analysis of the conditions in which HCWs operated, described the context as a "highly stressed institution due to staff shortages, unmanageable workloads and management failures". Soon after assuming office, the health minister re-echoed this shortage of staff at all levels in the country (Kapp, 2009), which makes it difficult to respond to the burden of disease in South Africa. One of the former health ministers before Aaron Motsoaledi, Manto Tshabalala Msimang, declared in the TB plan for South Africa (2007-2011) that:

> *In order to achieve effective TB control a coordinated multi-sectoral approach must be adopted throughout the country. This plan provides a framework of what needs to be done to reduce the burden of TB and eventually eliminate TB in the country to pursue the vision of ensuring that everyone have access to good quality TB services whilst also providing an environment that is conducive to health free of infection. The plan highlights the need for availability of skilled human resources, sustained adequate funding, partnership building, mobilising communities and fighting poverty to accelerate economic and social growth is critical for the success of this plan" (SANAC, HIV and AIDS and STI National Strategic Plan 2006: 4).*

Drawing on the recent National HIV/AIDS and TB plan of 2012-2016 (SANAC 2011:16), there is the projection that "implementation will be coordinated through revised governance structures and strengthened secretariat services". The aim was to have "a broad, appropriate and consistent representation through amended structures with increased accountability and responsibility at all levels of implementation and coordination". These revised structures included "bottom-up governance", "accountability and responsibility" and "transparency" (SANAC 2011: 16). Even though it has been affirmed that there should be coordination between structures, the health sector in South Africa has struggled with implementation of policy. In addition, addressing poverty has been one of the policy goals which has not been realised since the end of apartheid.

Another theme, one that is not unique to TB, has been the often difficult relationship between hospital staff, particularly doctors, and patients (Lane et al., 2008; Shelmardine, 2011; Savett, 2002). Shelmardine's research was an in-depth exploration of power dynamics, medical culture and patients' perception of these concepts in the health space. It is often documented that doctors wield so much power in the clinical space that it renders the patient as an object (Foucault, 2003; Gastaldo & Homes, 1999). On the other hand, there are instances where the doctors perceive themselves as powerless to change the health system. Shelmardine stated that:

> *There are occasions in which the emergency room doctors can be heard articulating the helplessness that they feel in the face of the often overwhelming realities that impact on their ability to successfully treat their patients. This counter discourse of powerlessness offers insight into the enormous difficulty of the position in which the doctors find themselves, opening the door to a more compassionate reading of process that all too frequently lead to their abuse of power* (Shelmardine, 2011:256).

This excerpt resonates with what Von Holdt and Murphy (2007) explored in their study of hospitals in South Africa where they described the health system as a "highly stressed institution … [with] poor labour relations" among staff (von Holdt and Murphy, 2007:315-316). In addition, poor working conditions, staff shortages, lack of essential inputs and equipment, and the workload of nursing affected the performances of nurses and doctors. Some nurses were so frustrated, they left the profession (Hall, 2004). By 2004, almost 20 percent of nurses in South Africa no longer practised their profession (Hall 2004:30). Breier, Wildschut and Mgqdozana (2009: 52) found that nurses left the profession because of "work pressure … [and] high patient-to-nurse ratios". They added that "hospitals do not replace nurses who leave, which leads to stress [and] exhaustion …" Travis et al. (2004:900) argued that the MDGs have led to a concentration on specific diseases that put further pressure on HCWs. There was a concern that already weak systems may be further compromised by over-concentrating resources in specific programmes, leaving other areas further under-resourced (Travis et al., 2004:900).

Current TB control efforts in the health sector

Directly Observed Therapy Short-Course vs Self-administered Therapy

In spite of all these challenges described above, the South African government has been making strides (although not free from problems) to control TB. The South African government has employed two main strategies for TB control. These are Directly Observed Therapy Short-Course (DOTS) and self-administered therapy (SAT). According to Karumbi and Garner (2015:37, cited in Zwarenstein, 1999; 2000), DOTS requires new patients to attend the clinics five days in a week for eight or 12 weeks. At each visit, patients will be observed when they are taking their treatment. After this initial period, the patients should come to the clinic three days in a week where an adherence card will be signed by the nurse during each visit until treatment is completed. Directly Observed Therapy Short-Course (DOTS) can also be monitored by a lay health worker or community health worker (CHW). If the patients did not attend the clinic for a day, the CHW will visit the patient at home to ensure that the patient has taken his/her TB pills. DOTS can also be implemented by family members. The CHW could be a staff member, for example, from the South African Tuberculosis Association (Karumbi & Garner, 2015). For SAT, patients will normally attend the clinic once a week to collect their TB pills. Patients will complete their own adherence card anytime they collect their TB pills. They will give their adherence card to the nurse every week they attend the clinic (Karumbi & Garner, 2015).

Although DOTS has been the widely used strategy, its usefulness over that of SAT has been questioned. DOTS is seen as a strategy to enable TB patients and those co-infected with HIV to adhere to their treatment and has been widely implemented in South Africa for over 15 years. As mentioned above, people diagnosed with TB are treated at their local clinic. A nurse, family member, friend or CHW – also referred to as multi-skilled worker or community care worker (CCW) – is supposed to observe the patients taking their daily treatment. To succeed, the DOTS strategy requires an 85% cure rate (WHO, 2010). Unfortunately, even though the cure rate has been "improving over the years from 54% in 2000 to 71% in 2009", it is still far below the 85% target (SANAC, 2011:24). The South African National Tuberculosis Control Programme's Practical Guidelines (2004) highlight four key areas of the DOTS strategy. These are the "detection of smear-positive pulmonary tuberculosis using sputum microscopy in patients presenting themselves to public clinics; directly observed treatment with short-course chemotherapy; guaranteed continuous drug supply; and a case recording system tracking treatment outcomes" (Obermeyer, Abbott-Klafter & Murray, 2008). DOTS has made some notable progress in treatment outcomes in cases where DOTS workers have a lesser number of people to monitor. Ntshanga et al. (2009) found that fewer patients per DOTS worker guaranteed a higher cure rate. They stated that on average, one to five patients per DOT supporter had high cure rates (55,8%) compared with those with 6–10 and 11–20 patients per DOTS supporter, who had cure rates of 49,9 and 48,5%, respectively" (Ntshanga et al., 2009:573). It seemed that what actually influenced better treatment outcomes related mostly to the number of patients allocated to a DOTS worker than the system itself.

Other studies within and outside South Africa have explored the effectiveness of the DOTS strategy over that of SAT (Pasipanodya & Gumbo, 2013; Das et al., 2014). From the meta-analysis study done by Pasipanodya and Gumbo (2013), including a South African study done in Cape Town in 1999, patients on

SAT had better treatment outcomes than those on DOTS. Even though Das et al., (2014) showed a slightly better treatment outcome under DOTS compared to SAT, among internally displaced persons in India and in a conflict-stricken environment, they recommended the use of SAT as an alternative treatment strategy as well. Karumbi and Garner (2015:37, cited in two South African studies by Zwarenstein, 1999, 2000), reported that there were no significant differences between patients who used DOTS treatment compared to SAT. Even though the authors found that treatment completion was low among patients who used SAT, DOTS did not offer a better alternative. There were also no significant differences between where CHW and family members monitored patients on DOTS.

In patient-centred care, which my study explored in depth, the DOTS strategy has also been questioned. Koch (2013) analysed the DOTS strategy and patients' expectation of compliance to treatment. He claimed that the DOTS system worked well when the patient was brought to the centre of care (cited in Fassin 2007 & Nguyen 2010:83). Koch's (2013) ethnographic studies explored health workers' patient-centred care approach in administering DR-TB medication to some patients. In this process patients and health providers negotiated best practice by using approaches that encouraged patients' active involvements in care of their own bodies. Some patients preferred to adhere to ART than TB medication because they thought that ART carried less stigma, having smaller number of pills and easier to consume than that of TB pills (Daftary, Padatyachi & O'Donnell, 2014). The dissemination of information about DR-TB became a concern also among some patients, which created fear among them as relatives found it hard to have a shared space with the sick patients (Daftary, Padatyachi & O'Donnell, 2014). Health workers also found it hard to come close to patients who were infected with DR-TB. Hence patients felt isolated. One interesting point was that patients desired to have the opportunity to receive treatment in similar ways as those on ART after having been educated about DR-TB (Daftary, Padatyachi & O'Donnell, 2014). Non-adherent behaviour is not the same for all regimens because patients perceived side-effects differently, which needs to be considered with implementing DOTS.

O'Donnell et al., (2015:432) similarly emphasised a comprehensive care that included integrated steps and considering the social needs of the patients alongside clinical needs of the patients. Incorporating early diagnosis, there must be "comprehensive patient education and support, infection control…and retention in dual care" (O'Donnell et al., (2015:432).

The dual demands of patient-centred support and that of infection control of DR-TB were explored by Harper (2010). This author drew on works that explained that the DOTS programme did not consider the poor social structures TB patients resided. Other authors maintained that the DOTS strategy had diverted funding from other health care interventions that strengthen health system in general (Cited in Porter & Ogden, 2002; Janes & Corbett, 2009). Another issue Harper (2010) raised was the difficultly of explaining what compliance entailed and how emerging literature had made attempts to focus on the health system failures rather than blaming the patients for responding to treatment. A study of some patients with TB in Nepal revealed that traveling and medical costs before getting diagnosis impacted negatively on compliance to treatment. Other problems included patients not trusting health workers, lack of social inclusion and limited knowledge of patients' socio-economic challenges by CHWs (Harper, 2010). These aspects explored by authors should also be considered in the implemenatation of DOTS.

Standard of care protocols for TB

An important part of TB control in the health sector pertains to the protocols for any individual that accessed any health facilities in South Africa for treatment. Any individual who has been persistently coughing for more than two weeks and goes to any health facility should be considered a "tuberculosis suspect" (SANDoH, 2004:14). Other symptoms include: shortness of breath and chest pain, loss of appetite and weight, tiredness, night sweats and fevers. These symptoms indicate that an individual is likely to be suffering from TB and should be tested. Commonly a sputum sample is collected from the patient and a microscopic examination is done by a TB laboratory to confirm a TB diagnosis. The length of time, as well as the outcome of the test, may be affected by "human and material error" or "bad quality of specimens, process errors and lack of quality control" (SANDoH, 2004:15).

Ideally, the PHC clinic should be the first health centre where individuals are tested and treated for TB (Atlanta National Centre for HIV/AIDS et al. 2010, 2010). However, some people are first diagnosed with TB at a tertiary or district hospital when they come for other kinds of medical problem other than TB. In other advanced or complicated medical cases that cannot be handled by PHC, patients are referred to the tertiary or district hospital. If a patient is hospitalised, he/she will be treated for a few days to often two weeks before they are discharged. On discharge, patients with TB are normally given seven days' TB medication (pills) and a referral letter to take to a PHC facility close their home. The connection between the hospital and referral clinics is not always effective (Department of Health, 2004; Edginton, et al., 2005; Dudley et al., 2018). One of the major hindrances, which has been noted above, is either inadequate or no communication between staff and patients diagnosed with TB who are leaving the hospital to go to clinics as well as non-adherence to treatment. The next section will look at attendance at clinics (as an aspect of CoC), but also discuss non-adherence to treatment because of its close relationship to non-attendance at the clinic.

Attendance at clinics and adherence to treatment

The connection between the tertiary/district hospital and the clinics pertaining to the attendance of patients diagnosed with TB has been a focus of study (Edginton, 2005; Dudley et al., 2018, Marais, Kallon & Dudley, Forthcoming 2018). Although not in the area of TB, Gordon and Krauthoefer (2007: 937) established that proper collaboration, especially in the area of clear notifications, referrals and follow-ups between primary and tertiary health institutions enhances the health of patients … (conversely) "the lack of care coordination and communication among healthcare professionals contributes to duplicative and inadequate health care, patient and family dissatisfaction and stress, decreased safety, and increased cost". However, patients' socio-economic conditions, coupled with problems faced by HCWs in the hospitals and clinics as they transmit information to patients, are also crucial factors that this study explored. Understanding the factors affecting clinic attendance after hospitalisation is the focus of my study.

Though my study does not look directly at adherence to TB treatment, it is still a commonly discussed topic in the literature, not only for TB, but HIV as well (Ayisi et al., 2011; Cox et al., 2010; Edginton et al., 2005; Dheda et al., 2010; Lane et al., 2008; SANAC, HIV and AIDS and STI National Strategic Plan 2012-2016; 2011:24). Adherence is crucial because of the global impact of MDR-TB and XDR-TB. Gebremariam, Bjune and Frich (2010:2) define 'adherence' as a broader outlook on patients' response to treatment that also includes factors that enhance or affect better treatment outcomes. There are some patients diagnosed with TB who have started treatment at some point, but discontinued or decided to go to another clinic. There are others who are co-infected with HIV and may report for one kind of treatment that he/she deems more important than the other, or less stigmatised/victimised (Daftary, 2012) when accessing a particular clinic for TB treatment. Recent literature on TB treatment, both for TB alone and TB and HIV infection (Ayisi et al., 2011; Buregyeya et al., 2012; Hasker et al., 2010; MØller et al., 2011), identify other factors affecting adherence to TB treatment. These include stigma, lack of food, lack of family support (Ayisi et al., 2011; Gebremariam, Bjune, & Frich, 2010), breakdown in communication with health personnel (Sissolak, Marais, & Mehtar, 2011), and poor conditions in clinics, including over-crowding and long waiting times at clinics (Department of Health, 2004; Hasker, et al., 2010).

RESEARCH PROBLEM STATEMENT, AIM, OBJECTIVE AND QUESTIONS

Research problem statement

Adult patients diagnosed with TB frequently did not attend their primary healthcare clinics after discharge from hospital for continued treatment (Edginton et al., 2005, Dudley et al., 2018). This problem remained a challenge for public health in South Africa. A few studies have explored this particular breakdown in CoC from HCWs' perspectives and/or quantitatively, investigating the numbers of patients who attend or do not attend at primary healthcare clinics. The patients' experiences and perceptions regarding what influences their attendance/non-attendance at clinics have not been adequately explored. Socio-economic influences are also important factors to consider when assessing CoC. Not attending clinics after discharge from hospitals pose a serious problem for public health in South Africa.

Aim, questions and objective of the study

I analysed factors that influenced the continuity of TB care when patients move from the tertiary- or district-level hospital to the primary healthcare clinics. The key research question was what factors were shaping patients' attendance at primary care clinics following TB diagnosis and start of treatment in tertiary and district hospitals. Key sub-questions included:

- How did patients diagnosed with TB interpret and act upon their diagnosis and treatment at the tertiary hospital?
- What roles did patients play in the discharge process?
- What were their home circumstances and experiences at the clinics they were referred to, regarding their registration and follow-up plan?
- What were patients' perceptions of what influences their attendance/non-attendance at clinics?

- What were the perceptions of healthcare workers and policy makers on what influences patients' attendance/non-attendance at clinics?

The objective of this study was to contribute to our understanding of patients' experiences and perceptions of treatment of TB and how services to patients can be improved to enhance better CoC.

GAPS AND CONTRIBUTIONS TO THE EXISTING LITERATURE

Conceptualising continuity of care

Continuity of care (CoC) has been explored in two major ways. Before delving into these two broad areas, some related concepts need to be explained. Two of these concepts that were linked to experiences of the patients I followed were 'diagnoses' of disease and 'care' of the patient. Salaniponi et al (2000) explained that key components of TB control programme were early diagnosis and fast and effective treatment (care). Even though a significant number of patients accessed hospitals for treatment (70%), about 30% of them went to either a traditional healer, a nearby grocery store or local vendor (Salaniponi, et al 2000:328). Understanding what caused a breakdown in health is a crucial part in seeking continuity of such a care, but also the trust in the health provider became another important area of seeking care. Knowledge gained in accessing care may inform further practice. Although distances to home played a significant role in patients' health seeking in unconventional places, "lack of schooling, and not knowing another person with TB were associated with a lack of realisation of the diagnosis". The authors maintained that expanding TB education in these "unorthodox" places could help improve the knowledge of the disease among TB patients (Salaniponi et al (2000:330).

Engel et al, (2015) explored the essence of receiving quick diagnostic tests of many diseases, including TB, but also of great importance was the relationship between the health provider and the patients. Even though this study was done in India where the diagnostic processes were different from South Africa, it shod light on the essential component of PCC, which was the relationship between the health worker and the patient in the diagnosis of their diseases. In private hospitals, although it was normally good coordination between health workers coupled with good human and material resources, unnecessary lab testing of other diseases other than the main disease caused delay and doubt on the part of the patients (Engel, 2015). Where coordination was maintained in the private hospitals, there was very much lacking among health workers in public hospitals. There were high workloads, lack of manpower leading to shifting blame (Engel, 2015).

Patients are expected to seek care timeously and effectively, but "patients' initiative is often compromised by a lack of counselling and trust in the interaction between practitioners and patients. Challenges with material and spaces as well as high cost of testing further discourage patients' initiative and disrupt these social relations" (Engel, et al, 2015:11). In South Africa, however, the main challenges to timely and effective diagnosis include transport delays, poor electronic database systems, type errors and limited personnel to transport results from laboratories to hospital wards. These problems can lead to loss of patients' records and delayed diagnostic results.

Some of the literature, mostly from the global north, discussed CoC as patients' interaction with the same physician over time (Alazri et al., 2007; Cabana & Jee, 2004; Freeman, 1984; Gullifford, Naithani & Morgan, 2006; Hjortdahl & Laerum, 1992; Mainous III et al., 2001; Saultz, 2003). According to American Family Physicians, CoC is defined as "the process by which the patient and the physician are cooperatively involved in ongoing healthcare management …" (cited in Guillifford, Naithani & Morgan, 2006:248). Guillifford, Naithani and Morgan (2006) highlighted the importance of patients having satisfactory experiences of their relationship with the physician or clinician over a long period of time. For Hjortdahl and Laerum (1992:137), CoC ranged from the "basic availability of information about the patients' past to a complex interpersonal relationship between physician and patient characterised by trust and a sense of responsibility". Mainous III et al. (2001) also provided evidence that patients' trust in their physicians is one of the most essential features of CoC. They operationalised this concept by evaluating how many times patients see the same physician over time. They interviewed participants in the USA and UK and found that a prolonged relationship is correlated with trust that the patient had in the physician.

Schulz and Albedaiwi (2004:445), drawing on the work of many other authors through a search of Medline database between 1966-2006, divided key aspects of CoC into three levels. The first level is what they referred to as "Informational continuity", which explains how information is transferred and accessed by different health centres. The second one is called “longitudinal continuity”, which explains the use of health service in one health centre and the same personnel. The third level is “interpersonal continuity” that has to do with the loyalty or a trusting relationship that exists between the patient and the HCW that is being consulted. Schulz and Albedaiwi, (2004) asserted that “interpersonal continuity” can also be considered a type of longitudinal continuity because trust is developed over a period by patients receiving services from a particular physician.

The other way CoC has been explored concerns how patients are referred from one health centre to the other to continue with their treatment. This includes the transfer of information between the two health centres and patients’ interaction with HCWs in this process (Edginton et al; 2005; Edginton, Wong & Hodkinson, 2006; Dudley et al., 2018; Jacobson, 2015; Marais, Kallon & Dudley, Forthcoming; Ponthieu & Incerti, 2016). For example, Ponthieu and Incerti’s (2016) work on CoC with mobile (displaced) populations in Southern Africa is remarkably different from the materials reviewed from the global north. These authors looked at referrals of patients diagnosed with TB and HIV from a health centre in one country to continue treatment in another country. Hence, their understanding of CoC is not necessarily about a patient seeing the same physician over a period, nor developing trust in that relationship with one physician over time. Rather it is a continuation of treatment with different sets of health providers.

The aspect of CoC I focused on in my study was the referrals of patients from the tertiary or district hospital to the primary health care clinics for continued treatment of TB. The rationale for using this aspect of CoC was because the pattern of treatment designed for TB patients diagnosed in hospitals was to start treatment in tertiary care and then continued their treatment in the community by accessing primary healthcare. Furthermore, their treatment had a set time frame, which was six months for drug-susceptible TB or about 18 months to two years for the treatment of MDR-TB. I therefore explored patients’ experiences and perceptions of their treatment received from health professionals in the different health centres as well as the discharge planning and transfer of information about their treatment. In short, I used the concept in the context of referrals, the transfer of information between different health centres and the patients’ experiences of treatment in both health centres. In addition, CoC, as argued in this study, was not limited to activities in the hospital and clinics, but is also affected by patients’ lived experiences at home. In other words, I acknowledged that failures of the health system can impact patients’ CoC as much as patients' socio-economic circumstances. Hence, I integrated home/community contexts into the CoC model.

My study contributed to a small body of literature (Edginton, 2005; Dudley et al., 2018, Jacobson et al., 2015; Marais, Kallon & Dudley, Forthcoming) investigating issues around the referral and follow-up of TB patients at primary care facilities for continued treatment following the diagnosis of TB while hospitalised. So far the literature has predominantly focused on TB care received in hospitals (Meressa et al., 2015; Satyanarayana et al., 2015), on referral from the community-level to TB treatment facilities (Lorent et al., 2008; Ayou et al., 2008), and the experience of TB in the community and in primary care (Chimbindi et al., 2015; Horter, et al., 2014; Mudzengi et al., 2017). Studies which have looked at the process of being diagnosed with TB while hospitalised and being referred to primary care for continued treatment are less common. Edginton (2005, Jacobson et al. (2015), and Dudley et al. (2018), are the few examples found.

Edginton et al. (2005) investigated the outcomes of patients referred from a district hospital to continue with their treatment at PHC clinics. At the beginning of 2000, Edginton (1999) had already documented that rural clinics can achieve similar tuberculosis treatment outcomes to hospitals. She recommended that a sustained infrastructural support for personnel and a committed district coordinator could improve CoC and treatment outcomes in rural clinics. However, in their 2005 study, only 50% of the 407 patients referred to clinics reported at the stipulated time after the first set of TB drugs were finished (Edginton et al., 2005:400). In addition, 20% of these referred patients were lost; either they did not produce correct addresses or they moved to another location. Forty-three percent of these patients who did not attend were traced and interviewed. The targeted patients were those diagnosed with TB in the Medical and Paediatric specialties in a hospital in Johannesburg who were referred to district clinics. The researchers identified the sources for referrals from hospital, the patients' knowledge of and attitudes to TB and health service experiences. The results showed that half of the patients had no idea that they had to take further treatment, 12 of them were too sick to attend the clinic and six expressed personal or clinic-related problems (Edginton, 2005:401). Some interventions, such as teaching patients about TB, were implemented to bridge the gap of patients' inadequate knowledge of TB and the non-attendance of some patients that were referred to clinics. The interventions in the hospital to enhance CoC also included a TB care centre situated on the hospital grounds that addressed patient education of TB and ways to facilitate patients’ attendance at the clinic. However, the patients’ experiences of TB education at the hospital prior to discharge were not documented, and the way their home lives, and socio-economic factors shaped their ability or decisions to attend primary care for continued treatment was not explored in this study.

Referrals from both hospitals and clinics in South Africa were evaluated by Nkosi et al (2013). The focus of their study was to understand why confirmed patients diagnosed with TB in both hospitals and patients were not referred for specialist care. Even though this angle of research did not actually follow up patients after referral from a health centre, they found some factors that resonated with my study and opened up some gaps for further investigation. Patients who could not be referred were because of loss to follow-up. One of the key reasons for this was that HCWs were not aware of the national TB guidelines (Nkosi et al; 2013:3). Again, this study focused their examination drawing on Healthcare workers’ perspectives. My study did not only examine the challenges of patients who were referred from the hospital to the clinic, but also drew on the patients’ journey on TB care from the healthcare facility to their homes.

Jacobson et al.’s (2015), using a similar methodology to Edginton et al. (2005), studied treatment outcomes following referral of patients diagnosed with TB who were co-infected with HIV. Using a quantitative survey, they found good treatment outcomes for patients who were referred to PHC. Key results were: out of 657 patients that were included in the analysis from a TB treatment at a hospital in KwaZulu-Natal, South Africa, 82,2% were cured; 10,5% died while still on treatment and only 7% failed to adhere to treatment. The main reasons provided for the treatment failure was that it was more likely for patients to stop treatment if they were not on antiretroviral therapy (ART) or those who had TB before. Useful information in this study was that the researchers concluded that for better treatment outcomes, patients who were referred to PHCs need to have proper counselling, which resonated with Edginton et al.’s (2005) study. There should also be “improved health systems…to assist patients in successfully linking to the primary care level without delay” (Jacobson et al., 2015:6). In addition, they maintained that there should be “formal communication between PHCs and district hospitals …” as they follow up on patients who have the propensity to stop treatment (Jacobson et al., 2015:8). They should also make use of CHWs not only to trace patients who may be likely to stop their treatment, but also to facilitate direct communication between the hospital and the clinics (Jacobson, 2015).

Dudley et al. (2018) used a similar quantitative approach to describe risk factors for poor CoC among TB-patients discharged from hospital. They found that patients in rural areas, patients who were not tested for TB in the hospital before discharge, and low quality of care at the hospital, including poor information systems linking to primary care, are major risk factors for better CoC, including treatment outcome. Dudley et al.'s (2018) study ran concurrently with a qualitative study, on which I was a Research Assistant, at a tertiary academic hospital in the Western Cape (Marias, Kallon & Dudley; Forthcoming). This qualitative component focused only on HCWs' perspectives of CoC in the hospital. Patients' perspectives were not explored; nor were the perspectives of HCWs in the clinics. In Dudley et al.'s (2018) quantitative study investigated outcomes for 788 hospitalised TB patients starting TB treatment. The authors reported that out of the 788 hospitalised TB only 284 (36%) continued TB treatment in the Western Cape. Of these, 207 (72.9%) were recorded in the ETR.net or EDR.net (electronic database for recording TB patients upon discharge), and 77 (27.1%) in the facility TB register, which were not in electronic formats. Only three patients (1%) were discharged to the Eastern Cape. There were no records of outcomes for these one discharged to the Eastern Cape. Dudley et al.'s (2018:5-6) further states that:

> *A total of 125 (15.9%) patients completed TB treatment and an additional 66 (8.3%) were cured, totalling 191 (24.2%) with successful treatment outcomes. Another 36 (4.6%) patients died, 26 (3.3%) defaulted, 11(1.4%) transferred out, and 7(0.9%) were treatment failures based on the TB registers.*

Better CoC was associated with adults, urban residence, bacteriological TB tests in hospital and TB medication on discharge. Fragmented hospital TB data systems did not provide continuity with primary health care information systems (Dudley et al., 2018). The concept of CoC taken for this study in sum refers to the referral of patients from tertiary care to primary care for continued treatment. Rather than be referred to TB-specific institutions, patients were referred to primary healthcare facilities espousing integrated or comprehensive care, meaning that PHCs are equipped to provide care for multiple co-occurring illnesses, such as TB and HIV treatment in individual patients (Chimbindi et al., 2015). A comprehensive primary healthcare service is one that ensures CoC through efficient and cost-effective systems of referral to and feedback from, secondary and tertiary hospital service (cited in Grone and Garcio-Barbero, 2001:1-2; Coetzee et al., 2004). My study focuses to identify the factors which complicate or support CoC from the tertiary level to the primary care level by interviewing health professionals and policy makers and following patients qualitatively from the time of diagnosis in hospital to over one year after – by which time TB treatment should be completed. Though few studies have looked at CoC in this direction (referral down from tertiary to primary), the more general TB literature highlights some of the factors we would expect to be important, and those which have been less well studied. These include, overburdened and poorly coordinated services, healthcare worker training and involvement in TB care and poverty and costs associated with continuing TB treatment.

Factors reported to affect continuity of care in the wider TB literature

Overburdened and poorly coordinated services

Some studies (Breier, Wildschut & Mgqdozana, 2009; Hall 2004; von Holdt & Murphy 2007:315) have discussed how high work load and poorly coordinated services have affected the proper functioning of hospitals in South Africa. These problems have affected HCWs to their tasks effectively to enhance patients' CoC. For example, von Holdt and Murphy (2007:315) gave a detailed review on HCWs, from mostly resource-poor hospitals, complaining of being in a "highly stressed institution". They clarified the meaning of this saying:

> *By 'stressed institution' we mean that institutional functioning is stressed (weak functioning, problems and breakdowns not addressed, dysfunctional management, lack of systems), staff are stressed (high workloads, stressed health, high levels of conflict, poor labour relations), and public health outcomes are poor (inadequate patient care, poor and inconsistent clinical outcomes, increased costs of poorly managed illness*

Coming from a racialised past and the growing number of infectious diseases in South Africa it is virtually impossible to respond to needs of patients within hospitals (von Holdt & Murphy, 2007). Even though democracy has led to significant changes in the health sector, another problem, urbanisation, has increased the population in some areas and that has compounded the problem in some hospitals. For example, some patients "simply bypass clinics or district hospitals and go directly to higher-level hospitals" (von Holdt & Murphy, 2007:318). Furthermore, Travis et al., (2004:900) have argued that many areas of the health sector are left under-resourced. In other words, despite the fact that some hospitals do not have adequate resources, some programmes in hospitals need to be prioritised (Travis et al., 2004:900).

Another recurring theme is the staff shortages in nearly all areas of the health sector (Breier, Wildschut & Mgqdozana, 2009; Hall 2004; Kapp, 2009). Von Holdt and Murphy (2007:329) record that "s*taff shortages have an impact on all the public hospitals we visited…. Nurses consistently complained of stress, exhaustion and low morale as a result of the heavy workload they have to bear.*

In mental health, Luitel et al (2015:10) also found that HCWs were not only overburdened with work, but the different institutions who provided services found it difficult to have well-coordinated and holistic treatment approaches. There was not enough integration of mental services to other key sectors, such as educational institutions, sporting sector and social welfare. Furthermore, there were lapses in the referral systems of patients from hospital to clinics and vice versa. These were no designated people to coordinate health strategies between health centres and no personnel surpervising the services that were rendered (Luitel et al (2015:11).

Gordon and Krauthoefer (2007:937) studied referrals to clinics after treatment in hospitals among children with special needs. Although not in the area TB referrals to PHC, they identified problems of inaccessibility to treatment as well as high cost, because the referral systems were not "comprehensive" enough to be a "family-centred, and "well-coordinated treatment plan. They indicated that developing a tertiary-primary care centre. They found that in "partnering with the family", "close involvement during hospitalisation" and a "proactive outpatient care" are factors that facilitated better CoC (Gordon & Krauthoefer: 2007:938). Another factor reported by these authors that has been associated with difficulties in achieving CoC are the actual processes of notifications, referrals and information sharing between tertiary and primary care institutions. Gordon and Krauthoefer (2007: 937) established that inadequate care coordination between health professionals as well as between health centres breeds duplication of services and increases the cost of service. It also causes "patient and family dissatisfaction and stress". A good partnership that includes families in decision making informs us of this critical phase in understanding of how the PHC institution fits within a holistic approach to care for the patient.

Health worker training and design of TB-care delivery

One of the factors that the global TB research literature in general has identified as an important factor for explaining fragmented care is poor knowledge and practices among healthcare practitioners.

Satyanarayana et al. (2015:751) embarked on a systematic review of TB care in hospitals in India and found that in both private and public spheres, “only half of the healthcare providers were aware of the importance of suspecting TB in persons with cough of 2-weeks’ duration ...” They also indicated that “only a third reported using DOT or a supervised approach for treatment support” (Satyanarayana et al., 2015:759). They recommended training HCWs to follow through with global and national guidelines with TB. The authors of the study in India also recommended there should be constant observation of HCW’s “knowledge and practice [which] should become a part of the routine TB surveillance system so that necessary corrective steps can be undertaken, and progress can be tracked …” (Satyanarayana, et al., 2015:760).

In the African context, not only training of staff but also design of services for the delivery and management of TB-treatment were important factors raised when considering CoC. Meressa et al. (2015) compared Ethiopia and South Africa and found that South Africa reported higher drop-out rate among MDR-TB patients (more than 20%) than in Ethiopia (5.9%). The reasons for lower rates in Ethiopia were that Ethiopia employed community health workers to implement DOTS, including monthly visits to patients’ homes, treatment sites and providing food baskets and social support for most deprived patients (Meressa et al., 2015:5-6). These programmes were done alongside training programmes for staff and patients and intensive laboratory testing for TB and MDR-TB (Meressa et al., 2015:5-6). Although the review was on MDR-TB patients and not directly on referrals from hospitals to clinics, it is an example of considering the impact of socio-economic circumstances on patients diagnosed with TB.

Poverty and costs associated with continuing treatment

In the area of TB referrals to tertiary or district hospitals, there were several factors that affect patients’ CoC. One of these factors waspatients’ delay to seek treatment after referral has been done (Ayuo, et al., 2008; Lorent et al., 2008). Patients’ minimal household income was the main reason for delays in the Western Kenyan study carried out by Ayou et al., (2008). The authors noted that costs to cover long distances to referrals incurred by patients who mostly poor affected CoC to referrals to hospitals. The other key factor included not having adequate knowledge of TB (Ayuo et al., 2008; Lorent et al., 2008). Even in South Africa where PHC is “free”, Chimbindi et al. (2015:8) found that monthly costs were “estimated at … ZAR122 for TB patients”. They further stated that the patients reported that these amounts were too high, more so when there was “high unemployment rates and dependency on social grants, representing over a third of median per capita income (ZAR401)" They argued that the high cost patients incurred when accessing health services led to "financial distress" is about a third of the patients sampled (Chimbindi et al., 2015:8). They also foresaw a situation where these high costs would impact not only patients' adherence to treatment.

Mudzengi et al. (2017), is another recent study in South Africa, 45% of people (TB and HIV patients) sampled complained about financial costs of care being approximately 25% of their monthly income (Mudzengi et al., 2017:51-54). The authors clarified that these costs were not direct medical costs, but indirect costs incurred by patients, for example, food supplements and transportation costs to access integrated care. They also stated that it does not mean that if patients attended the same health centre for multiple medical problems, the costs on patients would be reduced. The cost of TB care as a barrier has also been reported in India and Pakistan (Khan, et al., 2000; Rajeswari et al., 1999).

SIGNIFICANCE OF THE STUDY AND CONCLUSION

The South African Government has recognised the need for a practicable integrated health system to achieve the goal of better health for all (Grone & Barbero, 2001; Lewin et al., 2010; Uebel et al., 2011). Currently South Africans are overburdened by TB which not only shortens lives but also leads to poorer health over one's life. We know from previous research that CoC is complicated by patients moving from one level of care to another. So far attention has been paid to patients being referred up (for example from a community clinic to hospital), rather than those referred down (those diagnosed during inpatient care and referred to local clinics). The few studies in South Africa have shown that an important number of patients diagnosed in hospital and referred to primary care to continue treatment do not end up attending the clinics or attend later than they were supposed to. This is especially important as the phenomenon of starting treatment and stopping before completion fuels the growing epidemic of MDR-TB. Mostly research has focused on investigating the issue at a specific period of the treatment journey (for example, in hospital or in clinics). Studying the issue from time of diagnosis in hospital, to start of treatment in hospital, to discharge planning, to actual discharge, to continued treatment in the community and home and follow-up in local clinics can reveal so much more about why some patients don't continue receiving treatment. This approach is not about studying 'compliance' and 'adherence' in a traditional public health sense. Rather, the focus on CoC turns the focus towards the patient journey and the process of receiving care. This study reveals both patient-specific factors and health system factors that shape CoC and will help inform service provision and wider public health policy for TB in South Africa, as well as demonstrate the advantages of a qualitative and ethnographic approach for other countries and settings.

In this chapter I have traced the global, African and local landscapes to provide a wider context of the impact of TB. I have identified the under-studied issue of CoC specifically for patients diagnosed during inpatient care and referred to primary care for continued treatment. Finally, I have reviewed the predominant factors affecting CoC described in the wider TB literature. In Chapter Two I will outline the theoretical frameworks underpinning this study, namely patient-centred care (PCC), social determinants of health (SDH) and Foucault's concept of 'medical gaze'. Chapter Three will give a description of the methodology, including shifting strategies and techniques of data collection and analysis used in the study. Chapter Four presents a description and analysis of hospital treatment from both the patients' and HCWs' experiences and perceptions. The descriptions and analysis will include the patients' initial diagnosis and their understanding of the treatment at the hospital. Chapter Five presents a description and analysis of patients' experiences of the discharge system and their roles played in the discharge process. Chapter Six delves into patients' experiences of treatment after discharge, looking at the fabric of their daily lives, socio-economic circumstances and activities in the home. Chapter Seven will discuss the findings presented in Chapters Four, Five and Six. It will give an interpretative explanation of what influences CoC of patients diagnosed with TB referred from a tertiary and district hospital. It will also include a section on reflexivity, addressing my experiences conducting this research and possible influences on my study findings. Chapter Eight summarises the key findings in the study, including limitations of the research, and provides recommendations for possible policy interventions and for future studies.

CHAPTER TWO: THEORETICAL FRAMEWORKS

INTRODUCTION

In this thesis I have used a three-fold theoretical framework to understand and explain patients' and HCWs' responses in relation to patients' hospitalisation and discharge from hospital. These theories were patient-centred care (PCC), Foucault's concept of the 'medical gaze' and social determinants of health (SDH). As patients spent time in the hospitals and clinics, it was essential to have an understanding of the core elements of PCC to examine how HCWs engage with patients as they roll out treatment and how they conduct in-patient/out-patient education or counselling that may affect CoC. It was a useful theory to identify and explain points where medical care broke down and had a potential impact on patients' CoC on TB treatment. Although there were various models of PCC, the patient being the centre of concern in the treatment process has been consistent in the literature (Barry & Edgman-Levitan, 2012; Henbest, 1989; Jardien-Badoo, van Booyen & Ricks, 2016; Little et al., 2001; McCormack & McCane, 2006; O'Donnell et al., 2016). This is so because a focus on treating disease rather than the patient has been one of the dominant approaches in medicine. Exploring patients' 'needs' and 'feelings' and allowing partnership between the patient and HCW has historically been overshadowed by the clinical treatment of patients (Little et al., 2001).

Foucault's idea of the 'medical gaze' has some parallels with PCC. This was seen in decision-making and the patient not being a partner in the treatment process as well as when patients were embarrassed by HCWs in the clinic. The medical profession seeks to help the patient get well, but this relationship sometimes objectifies the patients (Foucault, 2003; Gastaldo & Homes, 1999). This means that the patients engage with a health system that values medical knowledge and places more emphasis on knowing and acting *on* the patients rather than understanding the individual complexities of the patient and engaging them as subjects in their own care. The patients do not have much of a role to play in their own treatment journey. Foucault's analysis of the 'medical gaze' sheds light on this aspect of the patients' treatment.

The final component in this three-fold framework was patients' socio-economic circumstances, which featured in all phases of patients' treatment, most especially in retention in care. The patients I followed up came from a background of many socio-economic problems and disadvantages. Entering into a space for a treatment of six to 24 months does not erase their lived experiences and the daily fabric of their lives, including experiences with family support. Drawing on these theories informed us not only of the failures of the hospital and clinic to enhance CoC, but also of the complexities of the patients' lives from the clinical spaces through to their homes and communities. SDH and Foucault's 'medical gaze' were two theoretical strands I reviewed in the literature before data collection. These two theories informed framing of most of the questions in the study. The medical gaze was also used to analyse the health system in the hospital and the clinic. During and after data collection I started discussing patient-centred care as a third angle based on responses by the participants. This theory also helped in the analysis of patients' experiences of treatment in the hospital and the clinic. Therefore, both the literature review and activities of the health system and participants' behaviour informed which theories best explained the behaviour of the participants and/or the medical system itself.

PATIENT-CENTRED CARE

Meaning of patient-centred care

PCC is explained differently by various authors, but all of them agreed that treating the patient as an individual subject was more important than treating the disease/illness. Some authors have used it as a conceptual framework (Little et al., 2001), while others like McCormack and McCane (2006) have developed PCC as a mid-range theory to explain how activities in the care of patients meet certain elements of PCC. I have also used PCC as a theory in this thesis for the ways it helps to explain how the treatment and education activities that take place in the hospitals and clinics may have an impact on patients' CoC. One of the research sub-questions asked how patients understood and acted upon their diagnosis at the hospital. Another sub-question was how the patients described their experiences at the clinic. According to Henbest (1989), PCC meant that the HCW should know how the patients understand their treatment. The HCW should also understand the patients' "unique individuality, his tensions, his conflicts and problems" (Henbest, 1989, 454 (cited in an anonymous Lancet editorial, 1967)). Stewart (2001) suggested that, in as much as PCC has been widely used in medical circles, it has not always been properly understood, and proposed that it was important to grasp what the concept was not. He claimed that it was not "technology-centred", "doctor-centred" or "hospital/disease-centred" (Stewart, 2001:444). According to Stewart (2001), researchers at this time have been asking what the concept really was, if patients wanted it, whether doctors practised it and what its benefits were. Little et al. (2001) asserted that patients needed HCWs to explore the main reason for their visits to the hospital or clinic, what their concerns were and their need for information. Hence, PCC required a detailed understanding of the "patients' world – that was, their whole person, emotional needs and life issues" (Stewart, 2001: 445).

In addition to understanding the patients' life situation, there are certain mechanisms that should be put in place in a PCC approach to address these concerns and problems. These include the HCW and the patient reaching a consensus about their health problem and seeking ways to address it. It also includes improving health promotion through educational strategies and enhances the continuing relationship between the patient and the HCW. According to Stewart (2001), patients in Britain, Canada and South Africa agreed on these aspects of PCC.

Little et al. (2001) used PCC as a conceptual framework in their study. One of the key areas among the elements was to encourage the idea that the patients should be given an opportunity to express their views about what matters to them, how they feel and what their expectations are. The patients should be encouraged to express their needs and feelings about their treatment procedure in the clinical space. The patient's family should also be included in the treatment process. Most importantly, evidence of "sharing power" is the enhancement of doctor-patient relationship in the treatment process (Little et al. (2001:2). PCC stresses that it is not enough for patients to simply access healthcare, but also about how effective the care is to the benefit of the patient including the proper implementation of the concept (Aronis, et al, 2017). According to Campbell, Roland & Buetow (2000) and Ogden, Barr & Greenfield, (2017), this kind of care is measured including how HCWs respond to the needs and feelings of the patients and how the patients describe their experiences of treatment and perceptions of the treatment.

Other authors have intensified the discussions of these core elements discussed above (Barry & Edgman-Levitan, 2012; Epstein & Street, 2011; Jardien-Badoo, van Booyen & Ricks, 2016; McCormack & McCane, 2006; O'Donnell et al., 2016). For Epstein and Street (2011:100) the care given to patients should encompass a "deep respect for patients as unique living beings". That means they should be understood "in context of their own social worlds, listened to, informed, respected, and involved in their care – and their wishes are honoured (but not mindlessly enacted) during the health care journey" (Epstein & Street 2011:100). In other words, in measuring patient-centredness at hospitals or clinics, these aspects should be part of the treatment procedure. A patient is firstly recognised as a unique person who will have a different life situation compared to another patient. Secondly, their views and decisions, although not the same views or knowledge displayed by HCWs in the clinical space, should be respected. Hence, HCWs must be trained to be "more mindful, informative … [understand] their role … from one characterised by authority to one that has the goals of partnership … and collaboration" (Epstein & Street 2011:101). Jardien-Badoo, van Booyen and Ricks (2016:397) agree that PCC is the kind of care that focuses on the "understanding of illness from the patients' perspectives". The authors drew on the South African Constitution in 2003, which states that patients have the right to care that treats them with respect and considers their needs and values. They also drew on the Batho Pele White Paper of 1997, which gives several principles that include the patients' having "a choice" on what services are being offered to them, having access to education that explains the services that are rolled out to them, and also a timely response to patients' complaints about services received" (Jardien-Badoo, van Booyen & Ricks 2016:398). Trainings on patient-centred care has also been offered in South Africa targeting social workers that (Zlenick, et al., 2018). These training sessions included topics that dealt with patients' knowledge of medications and side-effects, planning how to deal with these side-effects and patients' personal goals when accessing treatment.

The use of patient-centred care in this study

This study began its examination with the first contact the patients with TB had with the health system. The patients were received, diagnosed and started on treatment. The concept of PCC helped me to make sense of the interaction between the HCWs and the patients as treatment and education and counselling are rolled out to patients. This study explored how the activities in the hospitals and clinics met core elements of PCC. Drawing on the meaning of PCC, we knew that there were concerns regarding the focus of treatment being on "patients' needs" rather than "evidence-based" medicine. It is understandable to think, for example, that a focus on patients' needs would not provide the answers to the medical interventions that the patient needs. What it does, is to provide an opportunity for the patient to participate in the healing process of their own bodies. According to Epstein and Street (2011) some authors warned about the dangers of placing too much value on patients' needs. However, this argument has not developed much traction since most authors have maintained the "value and values" of the PCC model. Epstein and Street 2011 agreed with other authors regarding other components of PCC, which included the involvement of family members in the treatment programmes. The family's involvement in the treatment of patients was explored as well because family support was considered relevant if patients should continue with their treatment. Firstly, it was important that the family was informed (or counselled) to enable to render more help to the patients. This should be seen in terms of them also understanding the treatment plan of the patients. Secondly, knowing the home situation and how families related to the patient can enhance better strategies to explore when leaving the hospital and accessing the clinic. These were explored in this thesis.

Educating patients and their families should be done in a proactive manner. The authors warned against superficial attempts at showing care to patients by using what they called models used by "boutique hotels with greeters, greenery and gadgetry" (Epstein & Street 2011:101). This means that having an indoor plant in the passageway or having high-tech equipment in the clinical space does not necessarily mean you are showing care to the patient. Having a comfortable hospitalisation experience that may include a warm greeting at the entrance, decorations and high-tech medical equipment is good, but it is not the same as showing care or providing education to the patient. A noteworthy statement by Epstein and Street (2011:101) was that PCC called for "infrastructural changes [that] strengthened the patient-clinician relation, promotes communication about things that matter, helped patients to know more about their health, and facilitates their involvement in their own care". I explored these processes in the hospital and the clinic. These were discussed not only in the experiences and perceptions of the HCWs, but also in the experiences and perceptions of the patients themselves.

Another aspect of PCC, which resonated with Foucault's concept of the 'medical gaze' (that will be discussed below) was what Barry (2012) refered to as "shared decision making". He recounted that over the years, activities in the medical field have created a gap between physicians and patients. As a result of this, patients and their families have been excluded from important decisions affecting their lives. He drew on the 1998 Picker/Commonwealth Program for PCC, which he argued actually coined the term "patient-centred care", to raise the awareness among HCWs to turn their attention to the patient rather than the disease or illness. Patients' "needs" should be at the fore. Hence, the patients should be an important partner in their care and treatment. Barry (2012:780) adds that PCC is about the …

> *… respect for the patients' values, preferences, and expressed needs; coordinated and integrated care; clear, high-quality information and education for the patient and family; physical comfort, including pain management; emotional support and alleviation of fear and anxiety; involvement of family members and friends, as appropriate; continuity, including through care-site transitions; and access to care …*

In respecting "patients' values" and "needs", the patient must be considered an active partner in the treatment process. This will be explored to make sense of the responses of the HCWs and the patients. Supporting this framework, Barry (2012) explained the outcomes of PCC by referring to 86 randomised trials that were published as of 2009 in which the use of patients' contributions in the treatment process "led to increased knowledge, more accurate risk perceptions, a greater number of decisions consistent with patients' values … and fewer patients remaining passive or undecided …" (781). He proposed that HCWs should be asking questions such as "What matters to you?" as well as "What is the matter?" In addition, "… If we can view the healthcare experience through the patients' eyes, we will become more responsive to patients' needs and, thereby, better clinicians" (Barry, 2012:781). Staff education in developing this understanding of how to respond to patients' needs became an integral part of achieving PCC. In addition, finding ways to achieve better outcomes was equally important. O'Donnell et al.'s (2016:431) work also considered that the PCC model for DR-TB patients emphasised education of patients. They conceptualised PCC as …

> *… a holistic model of healthcare delivery that considers the patient as the central figure in the process or continuum of care. A patient-centered approach is therefore not a one-size-fits-all solution to the multifactorial patient-related barriers to MDR/XDR-TB/HIV treatment adherence that have been identified, including high TB pill burden and adverse drug effects, lack of patient education and counseling, provider supervision of anti-tuberculosis treatment, inability to access care in the community, and the stigma of public TB notification … [it] depends on engaging each individual patient with tailored education/counselling, understanding their motivations, and enhancing behavioral skills within the context of local social, structural and cultural factors.*

PCC was used as a theoretical framework in the thesis to help interpret how the hospital and clinics performed in relation the core elements of PCC and how this performance in turn affected CoC. A lack of PCC then became one of the key influences on CoC in this study. Information about patients' diagnosis was received. The level of education or information given to patients about their diagnosis, patients' and their family's involvement in discharge planning, and shared mitigation strategies wre also explored. Pelzang drew on a the theoretical framework for PCC that started with: 1. Structure that must included the qualification and skills of the healthcare professional, such as being competent and having interpersonal skills; 2. organisational set-up, which included, "time", "health workers' role", and "power sharing"; 3. the patients' attributes, which included their perception of care and illness and their participation in the care given to them (Pelzang, 2010: 913). Following this structure, some processes should take place. These processes, which have been mentioned above, included engaging with patients, meeting their needs (physical, psychological, social and cultural), being sympathetically present and working towards shared decisions. After this process, the outcomes will include: patients being satisfied with the improved care provided to them, being involved in the care and having better health (Pelzang, 2010; Vijen et al., 2012).

The theoretical framework put forward by Pelzang (2010) was relevant to the structure and tasks of the HCWs, including the time they needed to carry out their tasks. This framework examined the processes of PCC in the hospitals as well as how the patients evaluated these services rendered to them before leaving the hospital. Using this framework in the hospital informed us of the processes leading to patients' decisions as they commenced their treatment journey. Pelzang's (2010) analysis of PCC clearly established how it can influence CoC.

Little et al. (2001) suggested that it may not be useful to attempt to apply all the components of PCC if they were not relevant to the patients' perspectives. Three areas of PCC that were more relevant to the groups of patients interviewed and followed up to their homes and clinics. These may not be the only or the most important aspects of PCC, but they were the ones most relevant to understanding the data in this study. The first area was health education, which created an opportunity for patients to be informed or educated on the disease that was affecting them. This area of PCC did not only disseminate information or education to patients, but also provided patients the opportunity to ask questions or express their own views about their own treatment. The second area of PCC was where HCWs engaged with patients to understand their needs and feelings about the treatment. This brought in the crucial component of PCC, which was the wholeness of the patient that also recognised the complexities of the patient’s life. The third aspect was where patients were involved in decision-making. This aspect of PCC was mostly explored when patients were planning to leave the hospital. Key features that may inform better CoC included when patients wre least anxious or confused and saw themselves as active participants in their own treatment plans. The three intersecting parts of the PCC framework explored are represented in the diagram below.

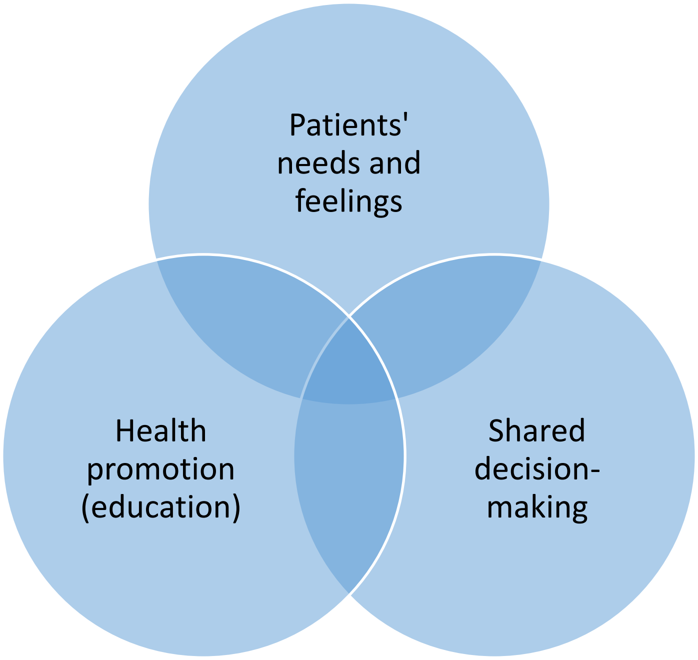

Figure 1: The core tenets of Patient-centred care in this study

An understanding of patients’ needs, and feelings intersects with the information provided to them as well as how they are positioned to be involved in the treatment processes. These three elements interact with and reinforce each other. Patients do not enter a clinical space as a blank slate. They are aware of their needs and may be able to articulate these needs adequately if they are given the chance to do so. Heath education is not simply disseminating information for the next party to digest and implement. It involves the ability of both the educator and learner to participate actively for the learner to make better health choices. The engagement between patient and HCW should tease out what the patient has internalised. The decisions of the patients should then be explored and not be discarded. Barry’s (2012) research unraveled the invaluable contributions patients can make for better treatment outcomes. These contributions do not require clinical understanding and dissemination of the biological implications of the disease. Rather it involves, for example, asking simple questions such as what matters to the patient and how they feel about the treatment.

Gaps in these core elements of PCC could affect better CoC. The patients in this study were newly diagnosed at the hospital. The initial education or information, a response to their needs and feelings and ability to be active partners in the process were crucial for CoC. In addition, the next layer of healthcare, which is the clinic, should be in position to bridge any gaps that may have been created in the hospital. I argued in this thesis that this has not been adequate.

FOUCAULT'S CONCEPT OF THE 'MEDICAL GAZE'

The meaning of the 'medical gaze'

The third aspect of PCC, which was shared decision-making, has a close link to Foucault's concept of the 'medical gaze', although the latter focusedon the medical system itself. Foucault provided a very useful way of understanding the ways clinicians are trained to objectify patients and focus just on their disease and not the patients' lived experiences or fears and anxieties. Foucault (2003) maintained that biomedicine replaced the medieval clergy. The 'gaze' at the human body lends itself to viewing the patient as a case of observation producing scientific knowledge, but the patient does not contribute anything else of value (Foucault 2003:65-66) [1]. In his book he wrote of the "the old age of the clinic" and "lessons of the hospital": "it was this constant gaze upon the patient, this age-old, yet ever-renewed attention that enabled medicine not to disappear entirely with each new speculation, but to preserve itself, to assume little by little the figure of a truth that is definitive".

He put forward some interesting reflections about medical practitioners' relationship with the patient. The 'medical gaze', according to Foucault, involved the relations between staff and patients in the clinical

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[1] Note: this book was first published in French in 1963. It was first accessible in English ten years later. The latest re-published edition was used, which was in 2003.

space. He argued that there was a power relation in which the patient was subordinate. It must be mentioned that the book is about 18th-century medical practice. Despite this, the reflections are still relevant to present-day biomedicine. HCWs, especially doctors, wield power based on their knowledge and manner of work (Gastaldo & Homes, 1999; Shelmadine, 2011). Even the medical jargon used in the naming of diseases and explaining how they affect the human body, already puts the clinician in a position where the patient has no alternative but to listen. This is so because medical terms are often not in easily comprehensible language. The clinician has work paraphernalia, such as the stethoscope and the white apparel (Shelmadine, 2011) that add to the aura of displaying so much power in the clinical space. Most importantly, patients are in clinical spaces needing the help of HCWs who determine what they must do to get well. In other words, if they listen and obey what the doctor says, they will get better.

Foucault's work also focused on experiences in academic teaching hospitals as well as clinics. Foucault argued that we should examine the impact of this knowledge production, how it is disseminated and "the discourses and implementation of practices" by the health professional (Gastaldo & Homes, 1999:235). An engagement devoid of the patient's contribution to better health is relegated to a medical practice that becomes simply "the examination" of an individual (Foucault 2003:68). Foucault also drew on the work of "Abus" in the *Dictionnaire de Medecine, Vicq d'Azyr,* where he also did not support the 'medical gaze' of patients, but also went further to question this knowledge production of medical practitioners in the first place. He formulated some thought-provoking questions regarding medical teaching and practice (Foucault 2003:78). He asked:

> *Diseases and death offer great lessons in hospitals. Are we benefiting from them? Are we writing the history of the illnesses that strike so many victims in our hospitals? Do we teach in our hospitals the art of observing and treating diseases? Have we set up any chairs of clinical medicine in our hospitals?"* (Foucault, 2003:78).

He recounted some of the misguided training and subsequent medical malpractices that accompanied them. He explained how some people have been disgruntled by the services of these so-called trained professionals as he draws on the work of his peers, stating that "the public has been subjected to a host of ill-taught individuals who, on no other authority but their own, have set themselves up as masters of the art, who hand out remedies quite indiscriminately and threaten the lives of several thousand citizens"

(Foucault 2003:78). Hence, on the flip side of this discussion, there were some medical practitioners who were not as "knowledgeable" as one thought they were and subsequently can pose a danger to the public. Either way, doctors wielded a lot of power over the patient and it often appeared like it was within their prerogative to share this power with the patient, which should not be the case.

Using Foucault's concept of the 'medical gaze' in this study

Two of the sub-research questions of the study were how patients interpret the information provided to them about their illnesses and the role they played in the discharge process. The 'medical gaze' was used to explore another factor that may affect CoC. Patients receive information that is often considered—both themselves and the clinicians providing it—as the "restitution of an eternal truth in a continuous historical development" (Foucault, 2003:68). This means that when patients receive information from HCWs, especially doctors, that information has the propensity to shape behaviours and actions. Patients consider medical practitioners as knowing how their body works. Any information given without adequate explanation or counselling may trigger anxiety, even a sense of concern. Also, even in areas when patients are given information, they do not have the chance to share their own experiences and feelings. The HCWs should be able to include views on how to implement best practices that may create a balanced power play between them and the patient. These are the main areas explored in this study.

The first main area, the 'medical gaze' was used, was in the very nature of the work of the medical practitioner. I explored the work that the HCWs were involved in when the patient arrived in the hospital or clinic. What aspects of the HCWs' work demanded more time and effort explained what was central in the treatment of the patient. It also involved what was not being said or done. For example, if investigating the patients' role in a medical process, such as discharge planning, the way the HCWs described their experiences of treating the patients may reveal what was the core principle that drove that aspect of their work. If the patient was the focus and not necessarily the disease *per se*, the pattern of work and how the patient wass involved in this pattern would be different.

The second area in which the 'medical gaze' was relevant, was in what the patients also expressed about their treatment. This included the ways they articulated their needs and the way they would have liked to be "respected" and "cared for". If the patients saw themselves as active partners in the process of their treatment, it wiould explain that they had a part to play in the decisions that directly affected their lives.

Patients may not have the medical knowledge to treat their disease, but they did understand ways that their treatment might have had an impact on their social, economic and cultural life.

In other words, the ‘medical gaze’ firstly exerted a knowledge power in the HCW or doctor that may significantly impact the way patients feel, such as powerless and hopeless in a space where their bodies were constantly being examined. This is so because the patient often received indisputable information from medical practitioners, which, not being backed by adequate explanation and time spent with the patients, made patients felt powerless and hopeless.

Secondly, in such a situation the patient did not contribute anything of importance. Therefore, when leaving the health facility, there were many problems that the patient could have articulated that were not considered. Some of these problems were socio-economic circumstances, which will be discussed below, that may help the patients be retained in health care. Gastaldo and Homes (1999:236) supported Foucault’s view as they said if patients’ views were not considered, then “the patient is reduced to an object to be described and loses her/his complexity”. They believed that “a Foucauldian interpretation revealed caring as related to control of the patient and of the environment, and to the creation of knowledge that empowers the nurse” (Gastaldo & Homes, 1999:236). They also asserted that “in the process of producing discourses of control, nurses generally do not challenge the hospital functioning; rather they perpetuate the status quo” (Gastaldo & Homes, 1999:236). The aspect of nurses’ behaviour puts the interpretation of the ‘medical gaze’ in context.

On the one hand, nurses (as well as doctors) are engaged in emotional labour (Hochschild, 1983; Grandey, 2000; Shelmadine, 2011). This means HCWs are involved in treating patients that are sometimes in excruciating pain or coming from poverty-stricken situations (such as patients followed up in this study). In doing this work, HCWs are expected to be professional, for example, by not showing that they feel sorry for the patient, rather focusing on their job, which is to make sure that the patient gets well. This does not mean the HCW may not be emotionally affected by the pain or suffering experienced by the patient. But in the process of protecting themselves and establishing a distance from their patients, HCWs, especially nurses, objectify patients by implementing medical practice that could seem like a form of abuse of the patient (Shelmadine, 2011). When the work of the HCW becomes emotionally as well as physically demanding, they themselves feel as helpless as the patients. In such situations, the patients bear the brunt of workload or stress of the health environment by receiving sometimes harsh treatment by HCWs.

The ‘medical gaze’ is thus another mode of explanation for what influences patients’ CoC. This wasseen in the ways patients in this study interacted with HCWs, including their experiences of treatment both at the hospital and the clinic. It paid close attention to how patients have been a passive participant in the treatment that pertained to their own bodies. The use of such a theory in this study was notso much as perusing the ill-preparedness of the medical practitioner, both in the academic teaching hospital and the clinic, but rather about focusing on the patient as ‘gazed’ upon as a case and not necessarily as a person (Gastaldo & Homes, 1999).

SOCIAL DETERMINANTS OF HEALTH

The meaning of social determinants of health

What is happening in the health system and the internal organisations of care was only one part of the picture. The social determinants of health (SDH) became another explanatory factor on influences of CoC. Craig et al. (2016:91) asserted that SDH “include a range of social, political, economic, and environmental factors that determine the health status of populations ...” Marmot’s (2005) analysis of SDH following the MDGs focused on inequalities between countries and the ways these inequalities determine peoples’ life expectancy. He also suggested that it was essential for countries to control major diseases by improving health systems. One of the most important aspects of SDH was poverty. Marmot (2005: 1009) argued that it wasimportant “to address not only the major infectious diseases linked with poverty of material conditions but also non-communicable diseases …” Craig et al. (2016:91) believed that despite the substantiation that wealth indicators and inequalities inform TB rates in some countries, the “social determinants of TB were overlooked given the dominance of biomedical approaches which still emphasise case detection, case management, and screening and surveillance …”.

WHO publications argued that SDH have to do with direct and indirect forces that affect people’s daily lives, including where they live, work, access school and health facilities (WHO, 2010; WHO, 2015). These forces also included socio-economic policies from political systems, which were considered as indirect forces. The direct forces were living conditions, including physical or built environment and access to health facilities, which were also relevant for this study. Engels' "conditions of the English working class in 1844" wasone of the first empirical studies to illustrate this relationship (Engels, 1995). The socio-economic conditions of people determined by their class and income levels clearly influenced their health status. Numerous studies (Crofton et al., 1992; Farmer 1996; Head, 1999; Krieger & Moss, 1996; Sanders, 2009; Williams, 1999) throughout the 20th century have confirmed this. In the 21st century, SDH have once again become a major focus of health research (Bradshaw et al., 2006; Kagee, 2008; Sanders et al., 2009; Sinanovich et al., 2003). Krieger (2001) traced the evolution of other theories concomitant to this concept, including social production of disease and political economy. The role of social factors in health outcomes is not new. Berkman and Kawachi (2000) gave a historical perspective of these influences by depicting the works of Villerme and Virchow in the mid-1850s that outlined a parallel between social class, of which income and living conditions are integral facets, and disease. They also highlighted the work of Durkheim in the late 1800s on social integration and its relationship to different forms of mortality.

Subsequently, having been informed by this knowledge of the association between social life and health outcomes, many countries' public health policies considered the physical space, the hygiene of that space, diet and the roll-out of adequate inoculation (Berkman & Kawachi, 2000). These authors established that "social inequalities in health remain. These persistent patterns called for an epidemiologic approach to understanding disease etiology that incorporates social experiences" (Berkman & Kawachi, 2000:3). The authors also looked at the behavioural patterns of communities and how these can also affect one's health. They wriote that "people who are poor, have low levels of education, or are socially isolated are more likely to engage in a wide range of risk-related behaviors and less likely to engage in health-promoting ones" (Berkman & Kawachi, 2000:7). While this may appear to be blaming the victim, they also noted that "environments place constraints on individual choice" (Berkman & Kawachi, 2000:7).

Whitehead, Dalgren and Gilson (2001) put forward several issues regarding inequities of health, its causes and the ways to minimise the impact in the globe. The authors highlighted that before a policy was drafted there should be a proper diagnosis of the causes of the problem. They maintain that in order to draft "a robust and appropriate policy response of health inequities [it] requires action across a broad spectrum of areas: first, establishing values; next, describing and analysing causes ..." (Whitehead, Dahlgren &

Gilson, 2001:309). They start off by saying that "many of the causes of inequities in health are social in origin" (Whitehead, Dahlgren & Gilson, 2001:313). Inequities of health are not biologically driven, by genetic factors, for example, that make one more susceptible to infection than others. Rather, inequalities are a socially constructed phenomenon, like political and economic systems design policies owing to their "shared values" (Whitehead, Dahlgren & Gilson, 2001:309). If there were shared values and subsequent response to the geographically unique socio-economic processes of countries, there would be viable ways to maintain and improve them.

The use of social determinants of health in this study

One of sub-research questions tried to understand the socio-economic circumstances of patients in their homes or communities. From the discussions above it was acknowledged that firstly, SDH explained how people got sick. Before the patients, such as those followed up in their homes, accessed the hospitals or clinics, they were constrained by many socio-economic factors, including poor living conditions and low income. They came from homes that were overcrowded. Low education backgrounds and lack of income can also contribute to stress. They lived in violent areas with minimal social support that can contribute to their insecurities. All these factors have had an impact on the patients before accessing the hospital or clinic. Secondly, the use of the SDH was seen in patients' retention in care after leaving the hospital. The many pathways highlighted above that caused patients to be sick in the first place, did not disappear when patients left the hospital or the clinic. Patients in this study continued to have challenging experiences in relation to their economic and social well-being.

One of the most common causes of ill-health is, therefore, poverty. The patients I interviewed were not only mostly poor, but also came from poorer environments where they sometimes struggled to access health information and accessed better health services compared to more affluent areas. The SDH framework was one of the useful ways to explain influences on CoC after referrals from hospitals to disadvantaged communities (Cox et al.,2010). Patients' lack of income and cost of treatment emerged in the literature, emphasizing that much has changed since the end of apartheid regarding poverty and inequities in South Africa (Nattrass & Seekings, 2010). Also, it is well documented that poverty or poor living conditions have a direct relationship to poor health (Engels, 1995; Farmer, 1996; Coovadia et al., 2009). In other words, SDH – poverty being a key determinant, among other factors – described not only the causes and occurrence of ill-health, but also treatment experiences and outcomes like CoC. There is wide-ranging body of work on the relationship between poverty and social inequality and the burden of disease discussed in this thesis.

To understand patients' socio-economic circumstances in this study I explored the living conditions of the patients, both within the communities in which they lived and their daily lives at home. How these impacted on their retention in care was important. In addition, the relationships of family in the midst of poverty and other forms of social deprivation were discussed. Hence, it wasexpected in this thesis that SDH may stoodd out as among the most significant influences on whether participants continued with their treatment after referrals from hospital or tertiary health facilities.

TB affects people to a greater degree who live in poorer conditions with little or no ventilation where they stay, with not enough food and family support, but these conditions have an influence on the outcome of treatment as well. Farmer's (1996) work was useful in explaining how these two factors interrelated, identifying TB, particularly MDR-TB, as one of the emerging infectious diseases that should be taken seriously. Irrespective of the great strides rich industrialised countries such as the United States and England, have made, there were many people in poor countries (as well as poor settlements in rich countries), where pitiable and stifled environments caused diseases to spread. He said, "one place for diseases to hide is among poor people, especially when the poor are socially and medically segregated from those whose deaths might be considered more important" (Farmer, 1996:263). Therefore, social inequalities affect not only "the distribution of emerging diseases, but also the course of disease in those affected by them, a fact that is often downplayed" (Farmer, 1996:265). This means that if patients remain poor and marginalised it is difficult for diseases to be cured effectively as well as the patients leading healthier lives.

SDH have also been useful in examining the inequality that persists in communities, inequalities that are linked to the broader political economy. Political economy, a concept that is linked to SDH, sheds light on why such inequalities occur in the first place and ways in which these inequalities could be dealt with (Dahlgren & Whitehead, 2007). HCWs and patients are engaged in healthcare that has been shaped by many government policies. Interestingly, patients' living conditions are often linked to policies about who gets access and support to social amenities. These include income, for example, in the form of social grants. In other words, apart from the activities of HCWs in the clinical spaces and patients' home situations, the political economy emerged as a useful concept as I discussed SDH. Often policies that are implemented for the health facilities are drafted by larger structural players, such as governmental or provincial sectors. An exploration of how policies are implemented (or not implemented) in the hospitals and clinics, however briefly, wasalso worth noting. The argument in this thesis is, therefore, that the socio-economic life of patients needs to be a strong factor in CoC. This is not only seen in the causes of diseases, such as TB/MDR-TB, but also in the factors that cause the patients to be retained in care or continue with their treatment. This is represented in the diagram: 'Theories explaining continuity of care in this study'.

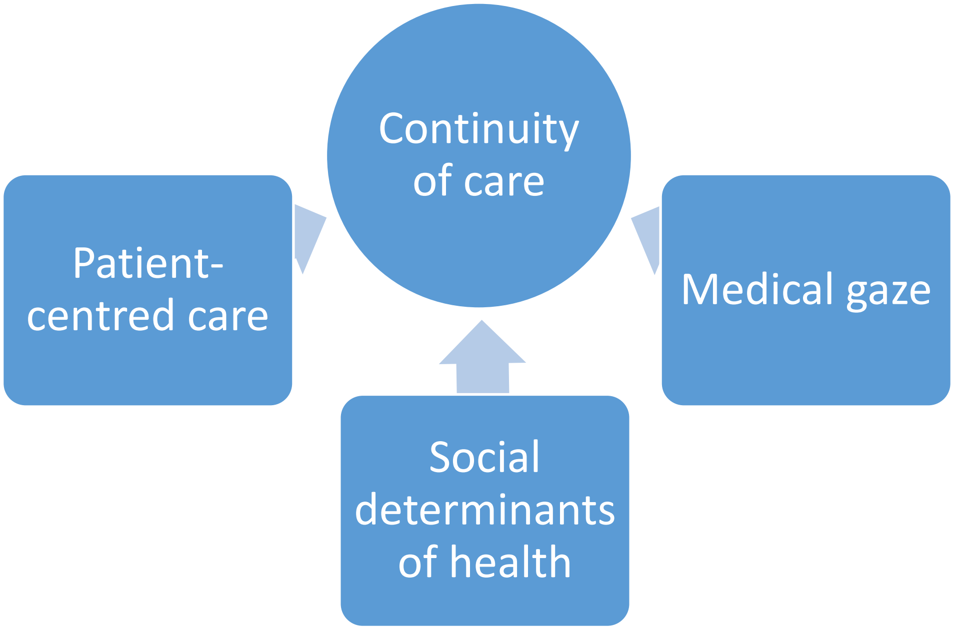

Figure 2: Theories explaining continuity of care in this study

CONCLUSION

This three-fold theoretical framework identified a wide range of factors that ultimately affected CoC for TB patients during their referral from hospital to clinic. The diagram above depicts how the theories relate to CoC. These theories showed that activities in the hospital and clinics as well as social determinants, such as patients' living conditions and income, affected CoC. The patients with TB that were followed in this study were positioned in low-income areas, with limited support systems that affected their continuation of treatment. However, firstly, the patients accessed the health setting where their needs and feelings were significant aspects of the treatment that should be explored. The PCC model helped to explain how patients internalised their diagnosis and the continuing relationship between them and the HCWs. The other key area of PCC was shared decision-making. This third aspect of PCC had a close link to Foucault's concept of the 'medical gaze', although the latter focused on the medical system itself. When patients' needs and feelings about their treatment are considered, it brings their living conditions as a whole to the treatment process. Hence, they should be given the opportunity to express concerns about their treatment.

Foucault (2003) similarly analysed the way clinicians work, which has been the dominant processes in clinics and hospitals that basically left no room for patients' knowledge to be deliberated. His work shod light on the ways the patient was stripped of his "individuality". Even if the patient has anything of value to say that would ignite ways of a better treatment outcome, the medical structure did not create the opportunity for this. This framework was more valuable in understanding the discharge planning process and the behavior of HCWs in the clinics. Patients know their home circumstances better than the HCWs. Asking questions of what they feel, how they would be able to continue with treatment juxtaposed with their living conditions, is as important as treating the disease.

SHD then became final key explanatory factor for CoC. Poverty and social marginalisation, for example, have a link to the production of poor health, but they also have a link to enhancing health-seeking behaviour or staying in care. The patients in the study were constrained with many socio-economic circumstances. They also lacked education and family support. This theory underpinned the influences of CoC in this very significant area of the patients' lives. It must also be noted that there were larger factors at play that were linked to SDH, which was political economy. Policies on TB treatment as well as access to better housing and other social amenities are set up by government and provincial sectors. Policies on clinical and administrative practices are very important areas to consider. On the other hand, the SDH framework also discussed the practices of the HCWs in implementing certain policies in the clinical space.

This three-fold theoretical framework explained that patients encountered a myriad of clinical, administrative, socio-economic factors that were linked to CoC of patients diagnosed with TB. The human subjects' state of health, particularly TB in South Africa, has a strong parallel with their historical setting, socio-economic, clinical, cultural or environmental situation (Fisher & Fisher, 2002; Sanders, 1985; Spence, 1993; Stillwaggon, 2006).

CHAPTER THREE: METHODOLOGY OF THE STUDY

INTRODUCTION

In this chapter I described the methods used in this study. This description included a preliminary section on reflexivity, which is what I (as a researcher) brought into the research space. I gave a more detailed discussion on reflexivity in the discussion chapter. I started by explaining the research design, which was a qualitative case study. I also discussed how and where I recruited the participants in this study. The research settings were one tertiary and one district hospital and five primary healthcare (PHC) clinics in the Western Cape. I used pseudonyms for these hospitals. They were referred to Hospital 1 and Hospital 2. I named the five PHC clinics Clinic 1– 5[2]. I discussed the sampling procedure used (purposive sampling) as well as inclusion and exclusion criteria. A total of 54 individuals, including 17 patients, participated in the study. Ten of these patients were followed up to their homes and the clinics they attended for CoC. I proceeded to explain the strategy for recruiting participants and collecting data. A combination of multiple semi-structured individual interviews, focus group discussions (FGDs) and observations were used in this study. Multiple individual interviews were used with patients, as I followed them up to their clinics and homes. Individual interviews were mostly used with healthcare workers (HCWs)[3]. A few FGDs were conducted with HCWs as this strategy was preferable, due to participants' availability and manner of work. In the last sections, the trustworthiness, data analysis and ethics of the study were discussed.

RESEARCH DESIGN

To answer the question of what factors influenced CoC for TB treatment post discharge, a qualitative case study design was employed. I used a qualitative approach by following up a group of patients who were diagnosed with TB at Hospital 1 and Hospital 2 in the Internal Medicine ward. These patients were followed up with interviews after they were referred to continue with their treatment at primary care clinics. A qualitative approach was used because this approach allows a researcher to gain a more detailed understanding of the context the participants are operating in (Punch, 2005:141). Von Holdt and Murphy

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[2] I was supposed to visit another clinic (Clinic 6), but the patient passed away before starting treatment. Therefore I did not interview HCWs at this clinic.

[3] HCWs comprised of doctors, nurses, social workers (in both hospitals and clinics) and community health workers (CHWs), (who work predominantly in the communities and the homes of patients.

(2007:2) assert that the strength of such an approach is that it can provide "a more complex analysis of cause and effect as well as permitting the 'experience from below' to be captured and explored, thus contributing new insights". Further, my study focused on patients' lived experiences and the meanings they attach to these experiences rather than attempting to produce highly generalisable descriptions or interpretations (Punch, 2005; De Vaus, 2002).

I used the case study method to explore the perceptions and experiences of the target population. I engaged in the patients' journey from the Internal Medical wards because it was one of the specialities with a consistently high burden of TB. I also studied other participants who had interactions with the patients and/or their knowledge of continuity of TB care within the scope and context of the study (Punch, 2005). Yin (1984:23, citied in Punch, 2005:145) argued that a case study is an empirical inquiry because "it investigates a contemporary phenomenon within its real-life context, when the boundaries between phenomenon and context are not clearly evident, and in which multiple sources of evidence are used". The related literature review has discussed the complexities of TB attendance and/or adherence, using a case study design which helped to determine phenomena within specific environments and unique attitudes and behaviours from different participants.

STUDY SETTING

This study recruited participants from two hospitals, Hospital 1 and Hospital 2, in the Western Cape Province of South Africa. These hospitals treat and refer people diagnosed with TB to PHC clinics to continue with their treatment, including those co-infected with HIV (Dudley et al., 2018; Cox et al., 2010). Hospital 1 is in one of the suburban[4] areas in Cape Town. Internal Medicine focuses on the diagnosis, prevention and treatment of diseases including TB in adult patients. There are several wards that fall under this umbrella module at the hospital. The Surgical module works closely with Internal Medicine. An adult may be diagnosed with TB in Internal Medicine, but may also require surgery and thus be sent to a surgical sub-category to continue with his/her treatment. One of the wards was selected for the data collection in the Medical specialty. Hospital 2 is a new hospital located in one of the townships in South Africa. Hospital 2 was established to redress the inequality in access to healthcare experienced by black South Africans during apartheid. It was also built to ease the burden on other hospitals that they work

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[4] Suburbs are residential areas that are mostly properly built with many accessible social amenities, such as water, better sanitation facilities and schools.

with who would receive many different cases of sick patients The Medical ward where the patients were recruited received many patients who are diagnosed with TB at the hospital who were most times hospitalised for a week or two.

Patients admitted into these wards are sometimes referred first from clinics where they have already started with TB treatment, but as indicated in Chapter 1, I focused only on patients diagnosed at the hospitals. There were five clinics to which the patients I followed were referred, which I named Clinic 1–5. They were in two townships in the Western Cape. I chose these clinics because the patients who agreed to be interviewed after discharge from hospital were referred to them for continuation of their treatment.

STUDY SAMPLE

Sampling strategy

I used purposive sampling in this study. Potential participants meeting the inclusion criteria were identified by searching through a list of patients in hospital registers and/or laboratory results of patients who had been newly diagnosed with TB. Purposive sampling gives the researcher the option to select and interview patients that fulfil certain criteria (Jacob, 1998; Punch, 2005). Most importantly, decisions made about who to include in the study were based on the aims of the study. Most participants spoke IsiXhosa and Afrikaans at home, but all could speak English – some more fluently than others. All but one of the patients are situated in Khayelitsha sub-district, which is identified as a disadvantaged and overcrowded community and has a high incidence and prevalence of TB among these population groups (Cox et al., 2010:2; Kritzinger, 1999). The other patient resided in Langa, another Cape Town township, but attended a clinic in another township.

Recruitment

Prior to commencing my PhD field research, I was employed as a Research Assistant in a TB study at Hospital 1 and worked in the Unit for Infection Prevention and Control (UIPC) at the same hospital for nearly two years as Data Administrator. I had affiliations with nurses and doctors who helped to refer me to some potential interviewees in the hospital and clinics as well as clerks and some policy makers in the

Western Cape Department of Health (WCDoH). Some former colleagues at UIPC have also helped me gained access to the ward where patients benefitted under the interventions piloted in the Internal Medicine Specialty. At Hospital 2 I also became acquainted with some of the staff members who referred me to other participants in this study. Most of these participants were approached by email and through telephone conversations. All participants were given cover letters and consent forms by me, which were also explained during the face-to-face interviews.

Inclusion criteria

- Patients who were diagnosed with TB while in hospital.
- TB patients co-infected with HIV and those diagnosed with DR-TB were also included.
- HCWs and policy makers who dealt directly with the targeted patients were included as well as those who had knowledge of the referral and discharge systems and understanding of CoC as a whole.
- Adults (18+ years) capable of describing their experiences and perceptions without the help of a parent/guardian were included in the study.

Exclusion criteria

- Patients who met the inclusion criteria above, but who, according to the hospital reports and from my own observation, were too sick to speak about their experiences or perceptions.
- HCWs and policy makers who were not dealing with or did not work with patients diagnosed with TB, were excluded for reasons mentioned above. Those who did not have any idea of the referral or discharge systems and influences of CoC were also excluded.
- Patients with DR-TB who were not assigned a community health worker (CHW) or professional nurse (PN) were excluded because such patients may potentially have been a risk to interviewers. This is because this type of TB has a complicated and difficult treatment plan. However, during the course of the interview, two patients who were either not entirely sure of the kind of TB they had or did not know the role of the CHW or PN assigned to her, were still followed. This was because of one of them discovering their TB status late after follow-up from hospital and, as already stated, the other not understanding there was a CHW assigned to help her.

- No potential participants were encouraged to participate if they appeared anxious or worried.

Sample size

The total number of participants was not predetermined, but rather determined based on theoretical saturation (Punch, 2005). Theoretical saturation is applied when the researcher collects and analyses the data concurrently. Theoretical saturation is achieved when similar themes were emerging from the participants interviewed, suggesting no new information being captured (see data analysis below). This approach to sampling also determined the number of hospital and clinic HCWs and policy makers that were interviewed. Sample size in qualitative research does not lend itself to a fixed number before the start of the study. This is so because the researcher cannot predict the responses of the participants of a study as compared to knowing a sample size that is significant for a quantitative study. Hence *a priori* imposition of a certain number of people before the study does not often work well in the field of a qualitative study (Punch, 2005: 172). Onwuegbuzi and Leech (2007: 24) argued that a programmed number of participants to be interviewed in a qualitative study may not necessarily provide the “context” that is required to understand the experiences and perceptions of the target population.

Fifty-four people participated in this study: 17 patients, six family members, policy makers, 10 HCWs in hospitals, 19 HCWs in clinics, and two TB policy makers. Of the patients, all were interviewed in hospital, 10 were additionally interviewed after discharge from hospital, one passed away before completion of treatment; two were diagnosed with DR-TB who were expected to complete their treatment in 18 to 24 months. Of the 10 HCWs in hospitals, there were six nurses, two doctors, and two social workers; of the 19 HCWs in clinics there were seven nurses, four CHWs, four TB counsellors, two social workers and two doctors. All HCWs who were approached accepted to be part of the study. Two patients only accepted the interview at the hospital, but declined to be followed to their homes. They did not provide any reason for not wanting to be followed-up to their homes. I could not locate the addresses of two of the 17 patients interviewed at the hospital. The remaining four patients I could not follow up to their homes because I could not get hold of them through their cell numbers they provided to me when I interviewed them at the hospital.

A total of 62 semi-structured individual interviews and three focus group discussions FGDs were conducted between October 2015 and February 2017. The kinds of data collection, number of participants and numbers of interviews held are listed below in Table 1: Data collection tools.

Table 1: Data collection tools

Participant category	Number of participants	Individual Interviews or Focus Group Discussions (FGDs)	Number of interviews
Patients in hospital only	17 (total)	Individual interviews	17
Patients in clinics and home	10[5]	Individual interviews[6]	19
Family members	6	Individual interviews	6
HCWs in hospital	10 (total)		
Nurses	6	Individual interviews	6
Doctors	2	Individual interviews	2
Social workers	2	Individual interviews	2
HCWs in clinics	19 (total)		
Nurses	4	FGDs	1
	3	FGDs	1
CHWs	4	FGDs	1
TB counsellors	4	Individual interviews	4
Social workers	2	Individual interviews	2
Doctors	2	Individual interviews	2
Policy makers	2	Individual interviews	2

Patients' demographic information

All 17 patients were interviewed in the Internal Medicine ward at Hospital 1 (13 patients) and Hospital 2 (four patients). As indicated above, ten of these 17 patients were followed up to their homes, whose experiences will be explained in the next chapter. The average age of the group of patients interviewed

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[5] It must be noted that this number of participants were recruited from the initial number of 17 patients interviewed at the hospital.

[6] Two more interviews held with the 10 patients followed-up to homes and clinics, (expect only one patient who passed on), with whom I conducted only one more interview instead of two.

was 35 years. The average schooling completed within the group was grade 10. Only one patient attained a tertiary level education. Eleven of the patients classified themselves as black/African and five of them as Coloured[7]. All the black/African patients spoke IsiXhosa[8] as their first language, while the Coloured group spoke Afrikaans. However, all of them communicated in English as well. Only two of the patients were married; 11 had children, 12 patients were unemployed, and five were employed.

Table 2: Patients' demographic profile

Patients Pseudonym	Sex	Age	Highest education completed	Race	Mother tongue	Marital Status	Children	Employed
Bianca	Female	28	Grade 7	Coloured	Afrikaans	Single	Yes (2)	No
Shane	Male	29	Grade 12	Coloured	Afrikaans	Single	No	No
Bongani	Male	31	Grade 7	Black/African	IsiXhosa	Single	No	Yes (Contractor)
Kaitlin	Female	48	Grade 2	Coloured	Afrikaans	Single	Yes (4)	No
Buhle	Female	29	Grade 12	Black/African	IsiXhosa	Married	No	No
Fezeka	Female	49	Grade 7	Black/African	IsiXhosa	Single	Yes (3)	Yes (Domestic Worker)
Aphiwe	Male	26	Grade 10	Black/African	IsiXhosa	Single	No	No
Lulama	Female	41	Grade 12	Black/African	IsiXhosa	Single	Yes (2)	Yes (Call Centre Attendant)
Nandipha	Female	30	Grade 12	Black/African	IsiXhosa	Single	Yes (1)	Yes (Baker)
Mncedisi	Female	18	Grade 11	Black/African	IsiXhosa	Single	Yes (1)	No
Ndiliswa	Female	43	Grade 11	Black/African	IsiXhosa	Married	Yes (4)	No
Yaseen	Male	37	Grade 7	Coloured	Afrikaans	Single	Yes (3)	No
Morne	Male	50	Grade 6	Coloured	Afrikaans	Single	No	No
Thandiwe	Female	42	Grade 11	Black/African	IsiXhosa	Single	Yes (1)	No
Zintle	Female	29	Tertiary	Black/African	IsiXhosa	Single	Yes (1)	No
Babalwa	Female	29	Grade 11	Black/African	IsiXhosa	Single	Yes (2)	Yes (Photographer)
Themba	Male	29	Grade 11	Black/African	IsiXhosa	Single	Yes (2)	No

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[7] Coloured is one of the official racial groups in South Africa. The others are white, African/black, Indian or Asian and other.

[8] One of the languages spoken in South Africa by predominantly black/African population. Other main languages included Afrikaans, isiZulu and Sesotho.

DATA COLLECTION METHODS

Individual hospital, clinic and home-based interviews

Using a semi-structured interview guide, interviews were conducted with patients who were diagnosed with TB in the Internal Medical specialty wards of the tertiary and district hospital. I led all interviews in hospitals with HCWs and patients. I also led all the interviews in clinics and with policy makers, except interviews with families and four patients who could express themselves better in isiXhosa. These were led by my Assistant Researcher though I was also present. My Assistant Researcher was not only versed in these local languages, but had worked in the communities of the target population, so acted as an interpreter and translator whenever needed. All the interview questions were written in English, but were translated and explained in the local languages of the participants by the Assistant Researcher. Most of the other participants, apart from patients, were able to communicate in English. The Assistant Researcher led some of the interviews in homes with family members who could communicate more fluently in isiXhosa. The Assistant Researcher was also qualified in dealing with such target groups as well as sensitive topics on HIV/AIDS and TB. Under my direct supervision, the Research Assistant also probed on sensitive questions in the study.

The interviews at the hospitals with patients ranged from 30 minutes to an hour, depending on the patient's physical state and desire to engage with us. The interviews were conducted when the HCWs had finished their rounds with the patients. They were then followed up after discharge. One interview was done between one to three months after discharge from hospital, and one interview on completion of their treatment. The interviews done after discharge from hospitals lasted a little longer because almost all the patients were experiencing improved health. The time ranged from 45 minutes to one hour per interview. The interviews of seven patients at the hospital who were not followed up to the clinics and their homes were also used. Some of these patients did not give me their correct addresses. Others did not provide me with correct contact numbers. However, the data of these seven patients were used only in the analysis of patients' experiences and perceptions before discharge from hospital.

The way participants responded to the individual interviews informed further probing on some questions. This process, where the responses of participants also informed probing questions, provided further context to understand what was more important to the patients. This process enhanced the case study approach used in the study (Onwuegbuzi and Leech, 2007: 240). All HCWs as well as policy makers who consented to be interviewed were interviewed in mostly quiet spaces and offices in the hospitals and clinics. Some patients in hospitals were unavoidably interviewed, albeit individually, in wards of sometimes four to five patients in separate beds. Nonetheless, they were a few metres from each other. In spite of the distance between each bed, it is unavoidable that some patients could hear the interviewing of patients in the study. After discharge, patients as well as families were interviewed in the convenience of their homes and at agreed convenient times for both interviewers and interviewees. Their families helping them with TB treatment and CHWs assigned to any participant were also interviewed individually, separate from the patients.

Ritchie and Lewis (2003:141) identified some important features offered by the semi-structured individual interview technique. One such feature is to "combine structure with flexibility". The researcher always has some insights or pre-conceived themes before conducting any research. This permitted me to properly organize a topic guide before the interview, a process that also allows "responses to be fully probed and explored and to allow the researcher to be responsive to relevant issues raised spontaneously by the interviewee" (Ritchie & Lewis (2003:141). Another key feature is the use of "a range of probes ... to achieve depth of an answer in terms of penetration, exploration and explanation" (Ritchie & Lewis, 2003:141). This technique aimed to delve into certain pre-conceived themes, but the participants sometimes mentioned topics of concern which I explored further. This technique also allows for a deviation from preconceived notions and encourages complexity to generate more questions and/or other research areas on the same topic (Jacob, 1998). The participants were therefore given the opportunity to delve into as many other areas as they considered of importance.

It was sometimes difficult to track down some of the patients and their families in the field, either because they had problems with their phones or they have travelled to another province. One of them did not allow me to go into her home to interview her family members even though she had agreed earlier. However, she agreed to be interviewed telephonically. All participants, except three, allowed me to interview them as well as use an audio tape recorder. I did not probe them to explain the reasons as this would have created some uneasiness on the part of the interviewees. However, they allowed me to take notes. Field notes, mostly from the observations, were taken in order to capture incidents that could obviously not be recorded. However, field notes did not always serve as detailed information compared to recorded tapes because it was virtually impossible to remember every response from a participant when taking down notes. All data were stored in password-protected computer. Only researchers (my Assistant Researcher, my supervisors and I) who were linked to this study and so understood the ethical implications involved in the study, had access to the data.

Focus Group Discussions

I conducted three FGDs with nursing staff in two clinics, Clinic 1 and Clinic 3. As with the individual interviews, I used a semi-structured interview guide in the FGDs. Some nursing staff and CHWs were available to meet as a group. The discussions helped to explore their perceptions as they were able to clarify each other's themes or concepts. They were able to report on the challenges of their own work and how they were coping with these (von Holdt and Murphy, 2007). Furthermore, the hospital and clinic staff in the FGD were conversant with the context and activities of the referral process and were able to give insights (Onwuegbuzi and Leech, 2007: 240) into the communication between them and patients. FGDs among these groups were more feasible because of the homogeneity of some of the practices in the clinic because they formed a team in responding to matters of patients treated with TB at the clinic.

Although FGDs are important techniques to collect data among diverse groups as well (Kritzinger 1994), it has been established that it can be a useful technique to use among compatible participants (Morgan, 1997:60). HCWs in the same modules and clinical space experience similar interactions with patients unlike individual patients who come from different backgrounds and may have different levels of understanding of their treatment processes. Kritzinger (1994) outlined some other benefits using FGDs as data collection techniques. These include the interaction of participants, listening to each other's statements, the use of anecdotes and reflections on participants' experiences. These interactions can provide comprehensive experiences of phenomena that can be explored by the researcher. He further maintained that "group processes can help people to explore and clarify their views that would be less easily accessible in a one to one interview" (Kritzinger, 1994: 299).

However, FGDs pose some methodological and ethical issues that were taken into consideration and were addressed, based on reviews of some published works (Giorgi, 1997, Kritzinger & Barbour, 1999; Webb & Kevern, 2001) in the nursing field, where FGDs have been widely used. Hence, at the methodological level, I came with topics that were to be explored based on the research questions. These topics guided interview processes rather than entirely focusing on the ideas and expressions of a particular phenomenon by the participants (Webb & Kevern, 2001; Giorgi, 1997). Secondly, FGDs pose some ethical issues at different points of the research; at the centre of this is confidentiality (Kritzinger & Barbour, 1999). According to the Medical Research Council's *Guidelines on Ethics for Medical Research*, confidentiality could be addressed by not presenting data to people who are not part of the research process or people who could identify participants who took part in the study. This standard was upheld in the FGDs. However, the process does not guarantee that participants may not share information discussed in the group with other people who were not part of the group. More details on the ethical aspects of the study are discussed in the Ethics section of this thesis.

The topics that guided the individual interviews for patients included an understanding of the reasons patients were admitted, an understanding of the kinds of TB they had, their knowledge of the following: TB, the discharge process in the hospital and the role played on the discharge process. The topics also included the conditions in which the patients resided, the support they received at home, the manner in which they use medication at home, the health centres and their experiences of services rendered in the two health centres. The Individual interviews and FGDs with HCWs included their experiences of working with patients with TB, their understanding of the links between the hospital and the clinics, their knowledge of the roles of different stake holders in treating patients with TB. Similar topics were used in the interviews of families and policy makers. These topics and codes generated key themes that are outlined in the results sections of the thesis. More information on topics explored with the participants is in Appendix B: participants' interview guides.

Observations

Observations of HCWs and patients and how they interacted with each other in different environments was done at all phases by my Assistant Researcher and me. This included the routine practices in the health settings and the patients' homes. These observations were done in order to understand some experiences of patients and or HCWs that were not captured in the face-to-face interviews (Sandelowski, 2000; Miles and Huberman, 1994). This technique was not necessarily a "participant observation" *per se*, which may require a prolonged activity and involvement by the researcher, but rather a limited period when the data collection in the hospitals and clinics and in the homes was done. Nonetheless, important activities and processes regarding TB treatment and referrals that were of importance were captured.

Observations in the clinics and hospitals have been quite helpful to researchers and have helped in describing phenomena in qualitative studies (Sandelowski, 2000). However, sometimes without verification from participant responses, interpretations from merely observing participants could be misleading. I was mindful of such limitations (Bailey, 1994) as participants sometimes alter their behaviours when they are being observed (Goffman, 1959).

A doctoral research study by Shelmerdine (2011) gives some insights about possible ways to do in-depth observations in a health facility. She explores different mechanisms, ranging from being present when rounds are done, participating in meetings held by some personnel and being involved in discussions held between patients (Shelmerdine, 2011:114). Drawing on similar approaches, I was present on certain meetings held with all staff dealing with patients diagnosed with TB. Also, based on a good working relationship established between myself and some of the HCWs, I was involved in informal meetings and discussions both in the clinical space and patients' homes. In the patient homes these meetings were just friendly/informal chats on different aspect of their lives that they shared with me. They were not interviews. I used these moments to observe the interactions between family members.

My relationship with staff members in the target facilities was very useful when doing these observations. In other words, the participants never considered the observations as if someone was "spying" on them and reported of any wrongdoing. In some circumstances I observed when HCWs were assigned to specific patients in wards. I observed the way the HCWs did their normal rounds, and the way they spoke to patients. These talks included the way they embarked on disseminating pieces of information regarding taking their medication and/or on discharge and referrals. I also observed the way patients also discussed among themselves regarding their understanding of these interactions in both health centres.

ASSESSING TRUSTWORTHINESS

Reactivity and reflexivity are elements of trustworthiness in qualitative research (Punch, 2005). Reactivity occurs when research tools may cause participants in a study to alter their behaviour. It also happens when individuals are influenced by other participants. Goffman's (1959) presentation of self draws a parallel with reactivity where members put up an act based on a preconceived notion of how they will be received by their audience. Reflexivity is more focused on what the researcher brings to the interview space that may have an effect on the way the patients shared their stories and understanding generated in the research space. Mays and Pope (2000:51) advise that "personal and intellectual biases need to be made plain at the outset of any research reports to enhance the credibility of the findings”. The gender, class, age or occupation profiles of researchers could create responses from participants that may affect the credibility of the data collected (Punch, 2005). These concepts resonate with reliability and validity (Krefting, 1991) that are commonly used in quantitative studies. Reactivity and reflexivity were considered in the interaction between my Assistant Researcher, me and the participants during interviews (Bailey, 1994). As mentioned above, in all interviewing techniques used, the effect of being observed is often unavoidable because participants are aware of the fact they are being observed, so they may consciously alter their behaviour and/or responses (Bailey, 1994; Goffman, 1959). This may skew the data being generated because it might not capture what was intended. There is also a tendency for participants to get used to having the researcher around, so that while they might alter their behaviour at first because of feeling self-conscious, this effect tends to wear off over time. A repeat or prolonged observation is important for counteracting this potential source of skewed data.

In the process of minimising any negative effect on the participants I took note of what I brought to the interview space, such as language, knowledge, gender and/or ethnicity. Attempts were made to minimize any negative effects as well as endeavour to record honest responses from participants and/or the limitations in recording behaviours or responses. An honest response is when a participant responds to a question without any form of intimidation, coercion or fear. It is difficult to determine what is an honest response or not from a participant. The use of probing questions helped to determine this. Firstly, throughout the interview process participants, especially patients and CHWs, were encouraged to give their honest opinions because the study may inform better health practices and outcomes. They were assured that their responses were not linked to their names. As explained above, the real names of participants as well as names of places were not used. The process not only enhanced confidentiality, but it also contributed to trustworthiness. Secondly, to enhance trustworthiness, participants who could not express themselves fluently were allowed to use the languages, such as isiXhosa and Afrikaans, with which they were comfortable. Communicating in English is sometimes intimidating for some participant, which can lead to them either withdrawing from a conversation or giving a partial description of their reality. Most importantly, I had multiple encounters with participants for over a year, especially with patients, a trusting relationship was established. For example, one participant revealed key themes regarding her failing to attend the clinic at some point in time, but she explained the reasons for her non-attendance during the third interview, which was at the end of her treatment. She said she could tell that I had concern for her and so felt she could share this with me.

Two areas where the trustworthiness of the study may have been affected were interviews held in hospital wards where the patients were not far from each other. These were unavoidable circumstances because the patients could not be moved outside the wards to be interviewed. Nonetheless, most of the hospitalized patients spoke softly, and were not audible enough to be heard by other patients. Furthermore, the patients were a few metres away from each other to allow better ventilation as they were being treated for TB. MDR-TB patients were in single rooms. The other area had to do with the translation of interviews from isiXhosa to English. It is always a challenge for researchers who understand and speak only English to effectively interview participants who speak another language. Skilled interpreters or translators, such as my Assistant Researcher, help a great deal to be as accurate as possible, but this does not guarantee that every sentence was accurately translated into English. These translations formed part of the data to be analysed.

DATA ANALYSIS

Data analysis was done simultaneously with the data collection, followed by another round of in-depth analysis after data collection was completed. I used Miles and Huberman's approach to qualitative data analysis (Punch, 2005; De Wet & Erasmus, 2005). Miles and Huberman (1994) highlighted the interactive nature of qualitative research, useful for uncovering patterns, hypotheses, themes and insights in an inductive manner (Punch, 2005). The three main interwoven components of this approach to data analysis are: data reduction, data display and verifying conclusions. Data reduction is further separated into three phases, which do not have to occur in a linear fashion. The first stage, involving reading, editing and segmenting the data. This was mostly done during and after data collection. The second stage occurred through coding and memoing[9] and finding themes, clusters and patterns. The third stage involved

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[9] Memoing is the jotting down of ideas as the researcher reflects on key issues in the data. Memos can be theoretical or methodological ideas that enhance the emerging of key themes in the final phase of developing propositions, which include abstraction and comparison.

conceptualizing and explaining these themes, clusters and patterns from the data. The objective of data reduction was to reduce the bulk amount of data without “significant” loss of any data and without stripping data from their context (Miles and Huberman, 1994). Data reduction, data display and drawing conclusions further involved three main operations: coding, memoing and developing propositions. The process of coding is “how you differentiate and combine the data you retrieve and the reflections you make about this information” (Miles and Huberman, 1994: 56). This process took the form of anything expressed in words that may remind the analyst of his thoughts about certain issues about the data. Codes are “tags or ‘labels’ for assigning units of meaning to the descriptive or inferential information compiled during a study” (Miles and Huberman, 1994: 56). The process of coding started by identifying key words and statements which gradually reduced the big chunk of data I had to analyze (Fielding & Lee, 1998).

There are several steps of data reduction where initial coding was done. This commenced by using open codes, also referred to as first-level coding. This is mostly descriptive because it is the researcher’s understanding of the data based on initial ideas from the data with very little inference or interpretation of these ideas (Miles and Huberman, 1994). In the inferential stage, which is the second-level coding, linkages were made to generate the emerging themes that led to the findings. This level of coding focused on patterns in more meaningful and constructive units. However, from the first-level coding, the researcher started to identify emerging themes, which were normally recoded in a journal.

The second stage of data reduction involved not only coding, but memoing[10] and finding themes, clusters and patterns. Memoing and developing propositions are also important features of this kind of analysis. At this stage, one can compare notes and reflections on some portions of data from one’s supervisors/Assistant Researcher. One of my supervisors looked at some portions of the data and offered overall reflections that helped to generate some themes. This is not exactly the same as what Miles and Huberman (1994) referred to as “inter-coder reliability", where two or more researchers could read and code the same manuscript and compare codes/themes (De Wet and Erasmus, 2005:32). However, the

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reflections on the data by someone else confirmed/questioned some of the themes generated in this study. In addition, there was constant changing and reorganizing of some portions of the data during reviews and feedback from my supervisors. This interaction helped clarify the categories of these themes. Regarding the observation data, which was generated by taking fields notes, Miles and Huberman (1994) established that the "inter-coder reliability" is also an important technique where researchers compare notes and evaluate their humanistic perspectives or 'emic' approach in capturing the data. I took most of the notes, but also documented verbal reports from my Assistant Researcher.

The third stage involved conceptualizing and explaining these themes, clusters and patterns from the data. This is a stage leading to presentation of findings. Although there is constant shifting/reorganising of portions of data, the main themes would have been captured. At this stage the data reduction is complete, not necessarily in the bulk of words expressed by the participants, but how the researchers have captured the themes that answered his/her research questions.

I used the NVivo 11 software package (NVivo qualitative data analysis Software, 2012), which helped in the electronic coding and analysis of data. This package helped in the storage process of data and prevented the loss of any data (Dey, 1993), which could be a limitation if one solely relies on manual coding and analysis. This does not mean that one cannot lose data using the software package, but the software helps to locate and retrieve documents to reorganize as well as help in making necessary corrections in several documents virtually at the same time. As the data were being coded, memos and journals on the same screen were developed without referring to several notepads/books. The codes were easily and quickly seen in order to compare key events in the data (Dey, 1993). The search option also made it easier and quicker to look for key words in the data that could lead to the development of key themes and subsequently key findings. However, with all these helpful tools, the NVivo software package is a tool that only helps to manage one's data and facilitates the coding process, but it does not analyse the data for the researcher. As it is with any electronic/mechanical tool, if one's data have not been stored on another device as one analyses the data, an unfortunate software or hardware breakdown can make one lose data. To avoid such possible problems, the data being analysed were constantly saved on other devices.

ETHICAL CONSIDERATIONS

To uphold ethical standards with human subjects (Hardon and Posel, 2012; Giorgi, 1998; Kritzinger, 1994) many clear processes were undertaken. The study only proceeded after I had received ethical clearance from the Human Research Ethics Committee (HREC) at the University of Cape Town. Upon ethics approval from the HREC, I secured permission from the Western Cape Province and the City of Cape Town (that covered the clinics I accessed).

Interviewing human subjects most frequently poses ethical problems; especially when one is investigating a problem that is related to TB and HIV/AIDS. Research indicates that HIV/AIDS or TB patients can become reticent about certain aspects of their medical condition (Hardon and Posel, 2012). The research study was carefully explained by the Assistant Researcher and me in the patients' preferred language. Participants were notified that a coding system would be used to identify them and not their real names. They were also notified that information received would be in the public domain once the thesis is written. Cover or information forms were distributed to each participant, clearly stating the voluntary terms of engagement with human subjects. The study ensured the privacy of all participants when they were discharged. In the hospitals, as previously mentioned, most of the patients were interviewed in a space where there would be four to six patients in a ward or room. However, each was interviewed individually and, as mentioned above, stayed a few metres from each other. Some patients were alone in certain wards. After discharge, the interviews were conducted in a place of participants' choice and in their preferred language. During all phases of the research in the hospital, clinic and homes, no risks to the patients were identified. Furthermore, the data collection process did not interfere with healthcare provision and did not impact health service delivery.

The sensitivity of some topics that could cause discomfort to some of the participants, especially in the FGDs, was avoided. This was done by carefully choosing topics that would make participants more relaxed to participate and that would not personalize any discussion (Kritzinger 1994). There were moments where some participants would respond to questions expressing the desire for the gods to take their lives. Even though this may not count as a suicidal tendency, it was ethical for me to discuss this issue with the nurses, which I did. This was done to at least give an indication that a particular patient in the hospital should be given special attention. I also reported similar cases to my supervisor, especially in the case of one of the patients, Bianca, who eventually passed away. My supervisor provided advice on how to handle unforeseen situations where patients' lives might be at risk. I explained similar circumstances to the social worker to respond to both issues.

Confidentiality was not maintained within the FGDs because the discussions were done in a group. However, participants were assured that their comments would not be communicated in the public domain by the researchers using their actual names; secondly, each participant was advised not to discuss the views or perceptions of their colleagues in the FGDs with people who were not part of the FGDs. Participants in the FGDs were informed about their obligations and the risks involved in disseminating information discussed in these meetings. Even though I might not know if anyone would uphold the ground rules set during the interview, it was ethical to explain it.

Particpants were not paid for their particpation in the study. However, a small amount was given to repondents who incurred transport costs, especially after discharge, and were given light food and drink refereshments during each interview.

Interviewing patients diagnosed with TB posed a health risk to the Assistant Researcher and myself. I enquired from the nurses about the severity of the health condition of each particpant that we followed before commencing interviews. Apart from the two patients diagnosed with MDR-TB, whose actual diagnosis was known later, all infection prevention measures were taken where appropriate. One of the prevention methods was the use of a N95 respiratory face mask any time we were conducting interviews in the hospital or clinic. There has been the risk of transmission of TB among HCWs as well as patients and their families, so the N95 mask is one of the measures used to prevent the spread of TB from one person to another in the hospital. In fact, every person entering the wards must wear an N95 respiratory mask. The mask covers the nose and mouth tightly by two strings attached to the back of the head. The HCWs use the N95 respiratory mask when they treat patients, so it is possible that the patients would not be bothered if researchers wore the mask to interview them. However, it does feel awkward to wear a mask when speaking to someone. I did not feel too comfortable having the mask on, but it was both a public health and ethical imperative to do so. It must be noted that the N95 mask prevents one from contracting TB. Patients do not wear N95 masks. They are given surgical masks. Surgical masks only prevents one from transmitting TB to someone else, but it does not protect one from contracting TB. Patients were not considered at risk upon discharge. Therefore after discharge, patient interviews in homes were done in an open window area with better ventilation. Patients who were considered infectious were not discharged from hospital.

CONCLUSION

This chapter gave a breakdown of the method and approaches used in the study. The study engaged in a qualitative approach by following up a group of patients who had been diagnosed with TB in the Internal Medicine specialty at Hospital 1 and Hospital 2. It was noted that these two hospitals in the Western Cape treated and referred a large number of people diagnosed with TB to continue with their treatment at PHC clinics. I used a purposive sampling procedure where potential participants who met the inclusion criteria were selected by searching through a list of patients in hospital. The total number of participants in the study was based on emerging themes reaching theoretical saturation. Following a case study approach, I used a semi-structured interview guide in the in-depth interviews as well as FGDs conducted. Observation of participants and how they interacted with each other in different environments was also done in both hospitals and clinics. I took note of reactivity and self-reflexivity, which are key elements of trustworthiness in qualitative research. Throughout the interview process participants were especially encouraged to answer questions honestly as the study may help improve consistent attendance rates at clinics. It may also drive better policies to address some of the problems faced by patients in CoC. Due to the fact that I had been employed as a Research Assistant in the ongoing study at Hospital 1 and worked at the UIPC gave me the opportunity to work with some staff members who were very helpful. I used the Miles and Huberman's approach to qualitative data analysis because the approach enabled me to develop categories in my mind before entering the research space, as well as helping me to display data in connection to those patterns. I upheld ethical standards throughout the contact with human subjects.

CHAPTER FOUR:

DESCRIPTION AND ANALYSIS OF PATIENTS' AND HCWS' EXPERIENCES OF TB TREATMENT IN THE HOSPITAL

INTRODUCTION

In this chapter I described and analysed patients and healthcare workers' (HCW's) (mostly doctors and nurses) experiences of TB treatment at the hospital prior to discharge planning. Using patient-centred care (PCC) as a theoretical framework I focused on three important elements of this framework. These were the importance of: 1. doing patient education; 2. engaging with patients in ways to understand their needs and feelings about their treatment; 3. involving patients in decision making (Epstein & Street, 2011; Jardien-Badoo, van Booyen & Ricks, 2016; Little et al., 2001; Stewart, 2001; O'Donnell et al., 2016). The third aspect wasexplored further in the next chapter as it was discussed under discharge planning. This chapter started by reflecting on the key tenets of PCC and the clinical spaces where the patients, some of whom were followed up to their homes, commenced their treatment journey. It continues by identifying how the patients understood their reasons for hospitalisation. The HCWs' experiences were also discussed as they not only rolled out TB treatment, but also informed patients about their TB diagnosis. These observations were compared to the ideals of PCC and highlighted where these hospitals were either falling short or performing better in patient education of TB and engagement with patients' needs and feelings about their treatment.

In this chapter, I argued that the problems in the provision of TB services to hospital patients could be understood through the lens of PCC and the failure of the services at the hospital to achieve some of the core components of PCC. This affected continuity of care (CoC) as patients were introduced to a treatment that would be a significant part of their life for the next six or 18 to 24 months. As this problem of inadequate PCC was explained, I discussed reasons why PCC was not adequate. These included time constraints and workload experienced by HCWs. In spite of these problems, there was also a level of emotional labour and concern displayed by HCWs. Patients valued some services rendered to them where they did not only have access to treatment, but received their medication on time; hence they felt relaxed and comfortable. This aspect of PCC was important because patients responded favourably to having received good services at the hospital. Some of them responded positively regarding their interaction with

HCWs. However, according to the core tenets of PCC, on the whole, patients' interactions with HCWs at the hospital represented a failure to provide patient-centred care, which in turn had negative consequences for CoC.

PCC was an important theoretical framework when trying to explain better or worse CoC outcomes. Many authors interested in PCC have focused on patients' consultations with HCWs (Little et al., 2001, Nelson et al., 2016). They looked at registries – mostly on patient data about their diagnosis – and patients' consultations with HCWs. They have also recognised that patients should be involved in the medical processes of their treatment. According to Little et al. (2001), a patient-centredness model looked at the patient as a whole, which included patients' perceptions of their problem, their feelings about this problem and their expectations. It also included understanding their relationship with their families and how they could partner with the HCWs to achieve a better health outcome and improve the patient-HCW relationship. Two of the core tenets of PCC was used to explain how the hospital rolled out services to patients in the hospitals. There should be patient-centred TB education at the hospital that should warrant infrastructural changes. These should incorporate ways to ensure that patients understand their medical problem and also explore shared or coordinated ways to address this problem that include patients' families (Epstein & Street 2011:101). Patients' needs and feelings should also be understood (Barry & Edgman-Levitan, 2012; Epstein & Street, 2011; Jardien-Badoo, van Booyen & Ricks, 2016; O'Donnell et al., 2016). PCC aimed to make the patients feel that they were "cared for" and "respected" (Epstein & Street, 2011). The HCW must also strive to understand the patient's "unique individuality, his tensions, his conflicts and problems" (Henbest, 1989, 454) and the life situation including "emotional needs" of the patient, as explained by Stewart (2001: 445). Failures of PCC may leave some patients feeling anxious and hopeless, especially after receiving information about their diagnosis.

OPENING VIGNETTE: CLINICAL SPACES AND REASONS FOR HOSPITALISATION

Before looking at these two components (engaging in patient education and understanding patients' needs and feelings), it was important to understand the clinical spaces in which the patients resided during hospitalisation and how they understood the reasons for their hospitalisation. There were always constant movements of hospital staff with their unique paraphernalia befitting the kinds of work that are done at the hospital. These included an N95 mask, denoting a need for protection from known or unknown diseases in the hospital. One of the points of emphasis was to always wear one's N95 mask when entering some designated wards, especially those with patients diagnosed with TB/MDR-TB, and also adhering to hand-hygiene rules after every contact with patients. In as much these rules were standard operating procedures (SOPs) in most hospitals and clinics, with the knowledge of high burden of TB among staff during the time I worked at Hospital 1, there was always a sense of anxiety and caution when moving around the hospital. One often saw many patients being carried briskly on hospital beds or held up by family members going in and out of wards.

Unlike Hospital 1, Hospital 2 is located in an area that was prone to high levels of violent crime, including burglary and assault (Ohuabunwa et al., 2015) amidst high incidence of TB and abject poverty, as described in Chapter 1. In both hospitals visited by the researcher, there were security guards at the entrances to the wards and staff offices. There were outpatient areas for day consultations as well as wards for in-patient hospitalisation. The lobby, corridors and toilets were always clean and tidy. However, sometimes there were not always rolls of toilet paper available. Some wards were bigger than others, ranging from about 4-12 patients in a ward. There were, however, wide spaces (about 3-4 metres) between patients. Patients diagnosed with MDR-TB were placed in similar wards, usually isolated from the other patients until it was certain there was no or low risk of transmission to other patients or staff. The doors to wards where patients were diagnosed with TB were often closed. However, during one of the researcher’s visits, the main door to the target wards in one of the hospitals was open and one of the nurses was heard reminding a staff member to always close the doors. Also, she reminded them to always wear the N95 mask, and to wear it properly.

I never saw any hospital bed left unoccupied in either hospital. There were always patients needing hospital beds. From observations and brief corridor chats with one staff personnel, it was not uncommon for patients to be sometimes hurriedly discharged to make room for more urgent cases. Entering the actual wards where the patients were one was immediately struck by the emaciated-looking patients in beds, some of whom could barely open their eyes. Most of the patients spoken to looked frail and weak. Some of them were barely audible.

One such patient was Bianca, lying in a hospital bed not too far away from four other patients diagnosed with TB being treated in the same ward. As shown in the demographics of the patients (Chapter 3, Table 1), Bianca, a young female aged 28, attained a Grade 7 education. She was unemployed and residing with her grandmother in one of the resource-limited communities around Cape Town. She had two children.

Even though she was feeling acute pain, Bianca came to the hospital by herself. She never had a visit from any family, neither was she expecting anyone. Bianca did not have a good relationship with her mother. Her grandmother, to whom she was closer, was old. She did not inform any of her family members that she was in hospital. I later learned that Bianca passed away two months after discharge from the hospital.

The ward was very quiet, except for the sound of heavy breathing and intermittent coughing from some of the patients in the ward. When asked about the reasons for her admission to hospital, Bianca – as with many of the other patients – expressed having felt pain or some sort of physical discomfort before admission to the hospital.

> *Idriss: Please tell me the reason you were admitted to the hospital.*
>
> *Bianca: I was feeling pain in my stomach. I didn't take my ARVs for a while so ... I was feeling very sick.*

Bianca immediately linked her pain to her not taking her ARVs, which indicated that she was not only co-infected, but that hospitalisation was necessary because of the pain and discomfort she was feeling. Most of the patients also felt that different forms of physical discomfort led to their hospitalisation. Kaitlin, a 48-year-old woman, and Buhle, a 29-year-old young lady, had a similar responses.

> *Kaitlin: Everything I eat is stopping here (pointing to her chest). I was asking what's going on. I was becoming thin and thin.*
>
> *Buhle: Yoh, I was very weak and my eyes were so yellow. I couldn't eat. I was so weak.*

Aphiwe*,* one of the patients with DR-TB, was the only one in his ward. Patients who were either diagnosed with DR-TB or DR-TB suspect were normally isolated. He was a 28 years old. He stayed with his mother in Khayelitsha. He had attained a grade 10 education and was unemployed. Aphiwe was very outspoken and analytical. Even though he felt weak, he engaged with me quite well as he was also trying to make sense of the pain that he had.

> *Aphiwe: And I was coughing. I said ah, ah man, I am not coughing normally. I started pulling blood from my mouth, but more and more …They couldn't stop it so they sent me to Hospital 2.*

Thokozile, a 41-year-old woman, expressed having a medical situation, which was compounded by TB.

> *Thokozile: It was ulcer that I started with. The doctor gave me antibiotics. I kept on coming back. Then one day I collapsed at home and I said, 'ah ah sana [a slang word meaning my child]. I am gonna die here'.*

Patients felt that the pain or physical discomfort for which they were hospitalised could have been treated at a clinic close to their homes. There could be other reasons for hospitalisation that the patients did not express. However, patients' expressions of feeling pain, weakness or nausea denoted that there was an expectation that their problems could be solved at the hospital or at least that their health problems could be minimised. Even though some of them understood that their sickness was quite acute due to physical discomfort as in the case of Aphiwe and Thokozile, for them, hospitalisation related to their experiences of pain, nausea or/and disturbing symptoms. Excessive pain or nausea, could of course, be linked to a particular stage of TB infection, though none of the patients explained it as such. Most of the patients in fact could not explain their hospitalisation for any other reason than feeling acute pain, nausea or weakness. This does not mean they might not have had an idea that they had TB. It must be noted that patients were being interviewed were newly diagnosed with TB at the hospital.

Patients were not always reluctant to be hospitalised. They sometimes bypassed the PHC clinic for several reasons including avoiding possible stigma (Ayisi et al., 2011; Daftary, 2012). Only Aphiwe mentioned a referral from one health centre to the other. Referrals to hospitals, whether tertiary or district hospitals, normally indicated further complications that the patients are experiencing that could not be adequately treated at PHC (Gordon & Krauthoefer, 2007). Alzari et al. (2007) highlight that even though PHC forms the cornerstone of CoC, where services are not accessible, patients sometimes move to secondary care (or a tertiary or district hospital care in this instance). Subsequently, this bypass of the PHC affects CoC (Alazri et al., 2007: 198). Many health services including, TB services, are offered in most clinics in South Africa (SANAC, 2016). Bypassing clinics may create certain problems. This may include difficulty in tracing patients' records because there were no referrals. Furthermore, it is possible that such patients might not attend a clinic close to their home when referred from the hospital. With regard to health education and its impact on CoC, Thokozile expressed having a known health problem (ulcer) before coming to the hospital. It is possible that without any explanation from the doctor or nurse, Thokozile might not have been anxious for information or clarification of what caused her pain or nausea or weakness due to "an ulcer". This does not mean that patients would not have had an idea that they had TB, but yearning for knowing what was wrong with them and ways to address it at the hospital may reduce fears and anxieties. The responses of patients regarding how they ended up in the hospital and the navigation from PHC clinics to hospitals would have been an interesting angle to probe. However, this study focused on the initial diagnosis of TB at the hospital and not on the reasons for not attending PHC for any health problem that the patients reported.

TB EDUCATION

Inadequate health promotion in the context of patients' TB education

I now move on to describe the core elements of PCC, starting with TB education of patients, and analyse how the hospital roll out services to the patients in the hospitals. The nurses and doctors in the hospital said that minimal or insufficient education had been given to patients with TB in the wards. This was mostly based on their understanding of what their roles were as well as the workload that they were subject to. Some nurses would educate patients about TB if they had the time to do so. There were, however, no clear guidelines on education of patients about TB or a shared understanding of what the treatment strategies would be after discharge from hospital. Other nurses and doctors argued, though, that their roles should incorporate education and counselling of patients.

> *Idriss: Do you educate patients about TB?*
>
> *Matilda (Professional Nurse (PN)): We don't always speak to the patients, but at times we will speak to the patients if they know about the results … if not we will briefly explain and say why we want the patient in transmission-based precautions … and explain to the patient that TB can be cured and the type of TB that they had and they need to take the treatment the months as they are prescribed … We do not have a structured programme to train or educate the TB patients. We have a structured programme to train our staff.*

The structured education programme for staff is an integral part of the infection prevention and control (IPC) programmes in the hospital, which did not include patients in the hospital. Even though there is no clear guideline as to educating patients and some do it when they had time, some doctors believed it should be their role to educate patients. At Hospital 1, Dr Christopher (Medical Doctor (MD) confirmed similar experiences as explained by Matilda:

> *Idriss: Does your role include educating patients with TB?*
>
> *Dr Christopher (MD): It will depend on how much time you actually have with the patients. If you are very busy and in a bigger hospital you don't always have the time to sit with the patient. If you are in a small hospital I think it is a little bit better. I don't think we are as good at educating the*

> *patients as we should be, especially given the scale of how big TB is. I think sometimes we might think that they are already aware of the spread and things like that, but if you take the time you will find out that they don't really understand.*
>
> *Idriss: What kind of support do you give to patients with normal TB and DR-TB?*
> *Dr Christopher: So what we will do, mostly in the medical background, so if they are started on treatment and they are having complications with taking the medications, swallowing the medication, then you usually try to find what is around that.*

Dr Christopher's second statement places emphasis on the medical treatment of the patients. The reasons provided for not doing adequate patient education of TB will be discussed later, but at this stage it is noted that the priority here is to make sure the patients are given the medical attention needed, including whatever complications may arise.

> *Idriss: Do you educate patient about TB?*
> *Ntombi (PN): No, no. If we have enough time, yes. I have the booklet. We tried to teach the nurses to give the patients that booklet we have. Tell them in their own language this is how the lungs look, but we can't do all of that. We have too little people.*

Apart from insufficient time, it is noted that Ntombi highlighted teaching nurses "to give patients the booklet" that they have. If this is a manner of education, then it does not necessarily mean that when one gives patients the booklet to read, they would immediately understand the complexities of the disease. This further explains the fact that there is insufficient patient education at the hospitals. In addition, some HCWs' interpretation of what they were required to did not include teaching the patients about TB. This can only be done at their leisure time or convenience.

Policy implications of poor health education

Dr Bayley (MD) mentioned that even though educating patients about TB was not happening, it was their duty to educate the patients and that should be done effectively at the hospital.

> *Dr Bayley (MD): I think we should do it. At the primary health centres our patients are quite sick. Obviously we do try to counsel them to look out for the symptoms of TB, night sweats, loss of weight … .Before we offer TB therapy we should actually be counselling them that there are going*

> *to be side effects and the importance of compliance. It is also our duty as well, which we often don't do because we often get caught up or are busy, but I think when we refer (them) to the TB hospital, because they will focus on the TB therapy, I think they (the patients) will do quite well if they (the hospital) offer a lot of counselling ….*

Dr Bayley recognised the importance of patient education and explained this particular task of the hospital staff. She believes that treating TB should is equally as important as educating the patient. The patients' knowledge of TB is also important as it gets to the point of helping their family members at home as well. Dr Bayley continued to explain.

> *Dr Bayley (MD): TB is an important part so there should also be counselling on symptoms of TB if they need prophylaxis. And also if they had TB contacts, they should inform them to have themselves tested. If they have children, to give them prophylaxis – yes, which I think probably is not being done enough.*

Joan, one of the Western Cape Department of Health (WCDoH) staff and a policy maker, gave a lengthy response regarding what has been a driving policy based on the limited knowledge that patients have about TB. She emphasised what the ideal situation in the hospital should be based on the WHO declaration that was also adopted by the WCDoH.

> *Joan (WCDoH): Now, let's give some more attention to the Alma Ata declaration. You note with post-94 [after apartheid], all of a sudden you realise that, but your TB patients are ignorant about the disease because it was like, you have got TB, you come to me, I give you your tablets, end of discussion,… about 22 years later I still see that we are still neglecting educating the patient around the disease. And even with the HIV where HIV management started with education of the patients and you can see the difference,… Education should happen everywhere.*

Joan clearly stated, in line with the WHO protocol, that education "should happen everywhere", meaning at all levels of care, both at the hospital and the clinic. In other words, the health policy stipulates that education of patients is part of PCC which is not being carried out effectively at the hospitals. The second aspect I focused on will be discussed below.

ATTENTION TO PATIENTS' NEEDS AND FEELINGS

Diseased-focused instead of patient-focused approaches

Joan also spoke about the manner in which education should incorporate the cultural values and needs of the patients:

> *Joan (WCDoH): And I think the education should not be disease-focused. Assumptions … we are not asking the patient, what do you know? What do you feel? What are your fears? What is your challenge? We are not asking, we are assuming we know it. So we respond to our own assumptions. For example, with the adherence counselling, if you look at the content of the training of an adherence counsellor, it is still not bridging the gap between the nurse or doctor, and the patients. We are just creating another level of nurse-doctor to talk to the patients. So we are not addressing the patients' needs.*

The above response puts in perspective the feelings and anxieties of some patients who would only receive information about their diagnosis with no adequate interaction with the HCW about what that information meant. It also brings into the limelight the shared power that the patients have to express their views about their needs and feelings, including fears and anxieties. Instead the patients would receive the information about their diagnosis, but would not have the chance to express what they thought about it.

Aphiwe expressed concern about the drugs given to him, but also made a statement that showed he was not pleased that they only gave medicines to him without any engagement. He said*:*

> *Aphiwe: No. They will not ask how you feel. There is nothing they are going to share with you, like lessons. There's nothing. They are just treating here with medicine. What I saw yesterday was not good because these legs (pointing to his legs) have started … and when I saw the tablets that I am drinking here tonight, I saw they expired in October 2015. So I don't know whether it is that tablet that affected me, these legs.*

Surprised by this information I asked to see the expired medication, and saw for myself that it was as Aphiwe had said. When urged to tell the nurse, he said he was not sure he could because she was not friendly. The above responses showed that Aphiwe was not only concerned about the "expired" drug, but also whether he could learn anything about TB from the nurses or doctors. Some patients explained positive experiences about their interactions with HCWs, which will be discussed below under the heading 'TB and emotional labour'. Aphiwe had had a less than good experience; he caught my attention not only because he explained having an unpleasant experience at the hospital – but thus far he was concerned about the kind of TB that he had, and also very worried about not receiving enough information about TB. Nonetheless, he had displayed the knowledge of how TB was transmitted, which will be shown below under 'Patients' knowledge of TB prior to hospitalisation'.

A sense of hopelessness

This information about the TB diagnosis was not always accompanied by the proper explanation of the implications that followed. The patients were asked how they had felt when they heard that they had been diagnosed with TB, the kind of TB they had, and how they felt about taking treatment for TB.

> *Idriss: Please tell me about your experiences of treatment at the hospital.*
>
> *Bianca: What can they do now about my stomach? All they can do is to give me my tablets. Yes, they cannot do anything now … I can't just lie here. All the doctors have done everything for me. So I can't just lie here for nothing.*

Bianca hastily said what she perceived her status to be. She was more concerned about the state of her health as a whole based on the information she had received. Her internalisation of the news about her diagnosis was a sense of hopelessness. It seems at this stage it is essential to counsel patients to ensure one of the core elements of PCC. In addition, having an understanding of how the patients perceived what was being said to them, is crucial. I continued to ask Bianca why she thought her TB would not get better if she finished the drugs given to her.

> *Idriss: Do you think you would get better when completing the treatment of TB?*
>
> *Bianca: No, it is not going to get better.*

It is not clear whether Bianca said it was the information she received from the nurse or the doctor. When I tried probing by asking the reason(s) she thought she would not get better if she took the drugs, she did not respond. More information will be provided on her home and family situation in the Chapter Six.

Ndiliswa also expressed a sense of hopelessness when she got her result. She complained about the way it was reported to her, which may create some confusion about the kind of TB that she might have had. Her situation depicted a sense of hopelessness due to inadequate PCC.

> *Idriss: Do you know the kind of TB you have been diagnosed with?*
>
> *Ndiliswa: So there was a sister who was working at night. They were sitting discussing... I didn't know what they were discussing. I was coming from the toilet and I said hi and I was not in my ward. So, the sisters came to me and said, 'Did the doctor come and tell you what is going on with you?' I said no the doctor didn't come. I was waiting for him to come and explain to me what is going on with me. The sister said, 'The doctor told me that I must tell you that you have got MDR'.*

The interesting issue is that firstly, Ndiliswa noticed a discussion which pertained to her diagnosis. The situation at this time was already prone to cause anxiety in the patient. Secondly, the nurses came to her and asked if she had been approached by the doctor regarding her diagnosis, which may have already caused continued tension. Thirdly, most importantly, when the news was finally revealed, it was not revealed by the doctor, whom Ndiliswa was hoping would come speak to her. Ndiliswa may have valued the doctor's knowledge. In as much MDR-TB is an often fatal form of TB, the dissemination of the impact of the disease and what the patient is required to do to manage it could have been handled in a manner where the anxieties and feelings of the patients would have been considered. Ndiliswa displayed anxiety and a sense of hopelessness that the HCWs who treated her may not even have noticed. This area of PCC was not only about respecting the patient, but also about asking how she felt after receiving the information in the manner she did and having shared ways to manage it henceforth.

Kaitlin explained how she was not going to be drinking all her medication (TB pills) because she was overwhelmed, not only about the medication but also because she was concerned about her living conditions. She did not have this conversation with the nurse or the doctor.

> *Idriss: Please tell me about your experiences of treatment at the hospital.*
>
> *Kaitlin: Sometimes I feel ... [Kaitlin's voice cracks as if she wants to cry]. I have to take three, three. I can't drink all seven [pills], If I drink [take my pills] all I will die. I drink it the whole day, but it's finished now. Yes, it is alright. It's my skin – I can't even buy lotion, look at it! I feel … I want to go home and sort out my children … I feel depressed.*

Kaitlin's mention of depression is a strong word. Her needs and feelings should have been explored to have a better understanding of how she was coping with the treatment. She firstly identified that the treatment was affecting her and might cause her death and that she in fact needed to attend to her family situation. Kaitlin's life situation is equally as overwhelming as her compliance to her treatment at the hospital. More of this will be discussed in the next chapter, which looks at discharge planning and the link to poverty and family support.

The questions posed by Joan fell within the TB education as well as understanding needs and feelings of the patients. However, the question about policy implementation in patient education in hospitals should be juxtaposed with the fact that most facilities are short-staffed and have cultural and linguistic challenges as well as patients' limited knowledge of TB, all of which are discussed below.

WHAT IS BEHIND PROBLEMS OF HEALTH EDUCATION AND PATIENT–STAFF RELATIONSHIPS?

HCW Workload

I considered possible reasons for having an established education programme for staff, but not an established education programme for patients. How would that affect patients' understanding of their diagnosis and treatment plan before leaving the hospital? On what was this model of treating patients based? The HCWs said that workload had affected them doing patient education. This was because there was not sufficient time for them to engage in patient education. This affected PCC in terms of proper health promotion and their ability to properly understand patients' needs, feelings, emotions and anxieties. This theme emerged in both hospitals. Dr Bayley also indicated the lack of families' involvement in the treatment plan of the patients, another integral part of the PCC model. In this model the patient emerges as a partner and one who actively participates in the treatment process rather than as a passive recipient of treatment services from a health centre. Matilda clearly indicated that there needed to be more staff:

> *Matilda (PN): They should get more staff. The way it is now, if a TB patient is an inpatient and the doctor or the sister pick up a social problem, they will refer the patient to the social worker. Especially when there are placement issues or caring issues, then the social worker will come into place and see to that. The staff in the ward say they do not have the time to sit down with the patients or to speak with the patients.*

Matilda continued to explain the reasons for needing more staff by describing her work situation on the particular day of the interview. She indicated the willingness to actually have to be involved in the process of doing education and even a follow-up of patients when they are discharged from the hospital.

> *Matilda (PN): Yeah, I am the only one, and then I have a staff nurse and I have two nurses on my shift and then I've got someone from another ward, a student. It is impossible to do all that, you know. But it would have been nice to actually do something, to have direct contact with the clinic to tell them, 'Let me know if this person comes because I discharged this person'. Then tomorrow I have three people. These are names of the people that must be followed up by you, so and so a day. If the person doesn't come, let me know'. And they have home-based carers go check where the person is, if I have the address, maybe – you know, stuff like that? That is what I think … maybe it can be done.*

Matilda commented on the work of other HCWs, such as the doctor, who could be involved in patient education as well as follow-up, but maintained there was shortage of staff all-round. Nonetheless, she thought the use of TB counsellors could be of great help, even more than doctors, to speak to patients. This is a similar thought to Dr Bayley's at Hospital 2, who passionately explained the use of TB counsellors in the hospital. Matilda continued:

> *Matilda (PN): We could do more on that, but our staff are worked off their feet. We have counts on the numbers of doctors as well. They are not sitting and spending time talking [to patients], which they should, but actually I feel there are people who do that better than doctors do, so they should do it because we don't have any other staff, but in my ideal world I would have TB counsellors. The biggest task for me, as it was said on World TB day is "to search, diagnose and treat". The problem I see here is that we try to do that as quickly as possible. And we try to get TB patients on treatment as quickly as possible. Not often, but it happens.*

The last sentence here denoted that even though there was the desire to educate patients more about TB and also be possibly involved in the follow-up to the clinic, the main focus was to make sure there was a way to identify patients with TB and start treatment as quickly as possible. As a result of these constraints, HCWs in the hospital embarked on more of a disease-focused approach rather than a patient-centred approach. This affects the two components of PCC explored in this chapter.

The burden of TB and emotional labour

In spite of the workload constraints as a result of the huge burden of TB, HCWs endeavour to provide other forms of care and respect to patients. In their interviews, they also expressed deep emotions as they described their work and the dire lack of support and poor living conditions of the patients. Amidst being short-staffed and having a huge workload, HCWs, especially nurses, provide some good services to patients. In addition to patients' responses, during observations I noticed that these good services included nurses attending to their daily routines, such as giving medication timeously to the patients and making sure they were comfortable. There are set times patients took their drugs and then visitors such as family members and researchers were asked to leave the wards. There are the desire and evident efforts from some HCWs to give more to patients, but the workload made it virtually impossible to do so. From personal experience in the hospital workplace and through observation during fieldwork, HCWs were always frantically busy in the wards attending to one patient after another. The patients recognised these efforts as well.

Fezeka, aged 49, lived in Khayelitsha. She was married, with three children. Fezeka had obtained a Grade 6 education, but she was unemployed. Fezeka had a quiet disposition. Her responses were brief, but very precise and clear.

> *Idriss: Describe the services you receive at this hospital.*
>
> *Fezeka: The services here are very good. They are treating us well, getting our treatment on time. It's not like 'no, you have to wait'. Yeah, it's good, like I'm relaxed. I'm keeping calm.*

Ndiliswa, aged 43, was one of the MDR-TB patients I followed up to her home and clinic. She was married, with four children. Ndiliswa also had a calm disposition, similar to Fezeka. She also confirmed that the service was good, although she did not dwell on which aspect of the service she thought was good. To quote Ndiliswa: *Yes, it is alright.*

In the interview with Matilda, as she described her daily routine she expressed strong feelings about the lack of any support base (family) for the patients, lack of resources and their inability to follow through with their treatment as a result of these problems. Matilda even related to the patients by referring to them as "our poverty-stricken people", which was very profound as she basically identified the patients as one of their own.

> *Matilda (PN): I think in Ward D10 it happens that the sister [Head Nurse] selects a family member and establishes a support base, and explains to them. It is difficult when there is no support base for the patient. And also (for) these patients with no fixed abode it is very difficult, and (for) patients that have been estranged from their families….They are lowly educated people living under difficult circumstances that has no tomorrow….Now they are ill, both with pulmonary TB and HIV/AIDS. And it is difficult for family members to accept them if their circumstances are also dire, but in the wards I know they do establish a support system if there are families that are supportive. We also find patients ... there are few step-down facilities that they don't want to go to …*

Matilda expressed that for some patients 'have got no tomorrow'. When I asked what that meant she responded:

> *Matilda (PN): There is no hope for them. They don't see a year ahead, like this patient said 'I can rather die'. They don't see a future for themselves. Now it is different because TB attacks anyone and anybody, but it is still our poverty-stricken people. And it is difficult.*

Matilda's explanation showed some level of emotional strains attached to her work. Her calling the patients as "our poverty-stricken" people showed some level of empathy and desire to see the patients get better. Following the burden of TB and how HCWs negotiated their tasks and desire, patients benefited from the emotional labour displayed by the HCWs, especially nurses in the hospital. Many patients, except one, expressed being treated very well. In other words, amidst these challenges expressed, some patients maintained receiving good services at the hospitals.

Cultural and linguistic challenges

In spite of the limited education (or none at all) happening at the hospital, patients do receive information about their diagnosis, as mentioned above. Being informed about one's diagnosis is not the same as receiving education about a particular disease. The theme of cultural and linguistic challenges is not as apparent as one would imagine it to be because when HCWs mention a "cultural" challenge it is uncertain if they were thinking of how the patients perceive their treatment or how they (the HCWs) perceive what the patients think about their treatment. Nonetheless, there were cultural and linguistic challenges that were noted in the HWCs' responses. Dr Bayley's explanation of her role resonated with the response about insufficient time to do patient education, but interestingly, she mentioned that because patients were living in Khayelitsha, which has a high burden of TB, this did not mean everybody in the community knew about TB. She highlighted cultural issues that needed to be understood.

> *Idriss: Does your role involve educating patients?*
>
> *Dr Bayley (MD): No, it doesn't. My role doesn't. I often would say a little bit to patients. The problem really is, for the doctors, they don't really have time to sit down and discuss in great detail. I also think there is a great assumption that everybody in Khayelitsha knows about TB because it is so common … And also there are a lot of cultural issues around TB. In my previous hospital we employed counsellors for TB – they would go to all the patients on TB treatment in the ward.*

Here Dr Bayley compared what was working well in the previous hospital she was working at with the procedure at her present hospital. She continued to explain what the possible "cultural issues" were and what the process would mean to have a deeper cultural understanding of the needs of the patients.

> *Dr Bayley (MD): They said the literal translation of TB is 'disease of the pype' [Afrikaans translation of "tubes", i.e tuberculosis] which doesn't make sense and when they say to patients, 'What do you mean, disease of the pype?' They don't understand it either, so it's cultural… I think there can be many misconceptions … one of the things that our counsellors also discovered, was that patients were busy comparing their treatment … this was the old days when people on repeat TB treatment had injections as well for the first two months .. she would find that the patients would say 'I have five tablets a day and an injection, but she only has three tablets a day, so therefore I am only going to take three of my tablets and I am not going to take the injection because you are punishing me. You are making it worse for me'.*

One of the key issues here is about how patients "compared their treatment". The HCW might think that they have responded to one patient with a unique medical condition, for example, drug-susceptible TB versus MDR-TB, but some patients would imagine it not to be different because all of them have TB. Hence patients would make a decision either to take their treatment in a similar way to someone that they knew had TB, or believed that they were being "punished". Dr Bayley might be looking at what the patients bring into the clinical space about what a treatment should be. Therefore, one cannot simply address this perception by just rolling out treatment. According to her, there should be experienced counsellors to attend to such "cultural issues". It must be noted that most of the doctors and nurses were middle-class workers and also who mostly could not speak the languages of the patients. All of the patients that doctors had to treat were from the working-class group. They mostly also spoke a different language. Dr Bayley continued to stress the essential need for such an educational structure to address these misunderstandings.

> *Dr Bayley (MD): They wouldn't wait for us to ask them. They wouldn't only see the newly diagnosed patients, they would see anybody because if you are on TB treatment and you are coming to hospital, you should be getting better. So coming to hospital while you are on TB treatment is a red flag that things are not going well. So they would find the patients because it meant they were in control. They find the patients and sit down and talk to them, and make sure that they know what TB was all about.*

On the other hand, as mentioned above, teaching of patients in hospitals and clinics is also influenced by an understanding of HCWs' roles and tasks. It appeared that there were cultural challenges to engaging with the patients and being sure that they understood what was communicated to them. According Dr Bayley, if there were no trained counsellors, it would be a continuing challenge to engage with patients. This is a similar response to Joan's answer about HIV counsellors in hospitals. These counsellors are not necessarily nurses or doctors, but personnel trained to teach or counsel patients before they leave the hospital, as is done for patients with HIV.

At this stage, I reflected on the earlier point made about cultural and linguistic challenges because it is was not certain if the patients would express similar patterns at home as at the clinics regarding what they thought about their treatment. This will be explored in Chapter 6. However, at this stage in exploring PCC, it seems clear that hospitals should focus more on what the patients understand about their treatment rather than only a focus on medical delivery. Dr Bayley continued to clarify how patients are sometimes confused about their treatment by giving instances where some patients were comparing their treatment plans, but without knowing the different levels and complexities of the disease. My initial thought was that this perceptions of patients might have been influenced by either improper information or dearth of proper understanding of the information given, but Dr Bayley stressed it was also a lack of understanding on the part of the HCWs because the of challenges of language and culture. Hence, the training of HCWs to understand how to teach patients in this regard becomes more essential. She continued to say:

> *Dr Bayley (MD): I want what she has [patients comparing their treatment], not understanding the difference was the patients' weight-because it is weight-based… also then we were giving injections for recurrent TB so that is something we would not have known. And patients would speak to counsellors a lot more regularly than they would speak to doctors as well and tell them these things because of language and because of culture.*

Dr Bayley did not highlight the kind of training counsellors should have in the hospitals, for example whether they should have characteristics that patients could relate to, such as speaking the same language, or what forms of training they should have in order to carry out training or/and counselling of patients. Dr Bayley was drawing on a system (where counsellors were used to counsel patients) that seemed to work well in a former hospital. Nonetheless, a closer engagement with patients by trained and culturally and linguistically attuned personnel would facilitate PCC.

Linguistic challenges were also highlighted by Dr Bayley. This problem was also expressed by Dr Alice, a Medical Officer (MO) who reported that some patients were not given correct information about their diagnosis. In these cases, there was a possibility that the doctor or nurse might have given a wrong diagnosis, but there was also evidence of linguistic challenges where sometimes the inability to speak the language of the patient was the root of the problem.

> *Dr Alice (MO): For example, some patients are lied to, which is a bit odd. So I have had some patients who have been told that they have TB, when they actually have HIV, that kind of thing. I don't know anybody will lie to a patient about having MDR-TB though, because it is quite an intensive counselling process – it is a different registration process, different medications, but that's where the confusion might have come in. A lot of us don't speak Xhosa [the local African language], so I am trying to counsel somebody from a non-native language. It is difficult because my home language is English, your home language is Xhosa. Sometimes it also can get lost in translation because my Xhosa is not particularly good, their English is not particularly good, so there can be confusion in terms of that.*

This theme of cultural and linguistic challenges is also related to patients' perception of TB diagnosis and cure. Hence it is not only about limited education, but also learning the cultural and linguistic skills to handle education of patients diagnosed with TB. Linguistic challenges could not be too difficult to explain from the statements of the participants as these are the different languages that patients and health providers speak. Cultural challenges on the other hand, might be a bit tricky to explain in the way it was used by certain particpants. For example, Dr Bayley explained that patients “would speak to counselors more regularly than doctors…because of language and culture”. This statement may not only point to the same language spoken by the counsellors but also the differences in status or classes between the doctor/nurse and the patients. The patients may not understand the different regimens, but could get clarification from someone they could relate to better.

Furthermore, there are interpreters in health centres who may speak the languages of the patients. However, there are other forms of cultural challenge, which an explanation in one’s language does not mean a patient would clearly understand what was being communicated and know how to respond to treatment. Hence to have better PCC may require training of counsellors that should include having an understanding of how the patients perceive their treatment, and strategies that could be explored together (between the HCWs and the patients) even before discharge planning.

Patients’ knowledge of TB prior to hospitalisation

PCC is not necessarily dependent on what patients know about their diagnosis or treatment before hospitalisation, but patients’ prior knowledge of TB could contribute to a better understanding of the disease during the hospital experience. This may minimise any confusion before leaving the hospital. In such a situation PCC becomes strengthened because one of the components is for patients to understand the ramifications of their diagnosis as well as treatment. Prior to hospitalisation responses from patients showed that there was little or no knowledge about TB. This did not mean that the patients may not have had any idea about TB. However, most of them did not clearly associate their hospitalisation with their diagnosis or type of TB. I asked them in interviews to share their experiences of their diagnosis with TB at the hospital. One of the probing questions under this main question was for them to explain their knowledge of TB. Two patients highlighted how TB was transmitted and showed a fair knowledge of the different kinds of TB that they had heard of either from TV or from clinic or social settings.

Buhle was a 29-year-old married woman who had completed Grade 12 and had no children. Her disposition was vibrant and energetic as she was responding well to treatment as compared to most of the patients interviewed at the hospital. She looked happy as she expressed having good family support, evidenced by her family's frequent visits to her, bringing food and spending time with her at the hospital. In spite of a better general education than the average level of patients interviewed, she did not have better knowledge of TB prior to admission at the hospital.

> *Idriss: Explain what you know about TB.*
>
> *Buhle: I don't know whether it is the treatment or it's my body. I don't know anything about TB.*

Buhle was trying to understand whether the treatment she was receiving was causing her to feel uncomfortable or it was just something normal happening with her body that did not have to do with TB medication. The main issue was she did not know anything about TB. Buhle was also not sure what was wrong with her. Other patients expressed similar situations regarding knowledge of TB. One of these was Bongani, a 31 -year-old male.

> *Bongani: I don't know. I am confused. I know nothing about TB. It is the first time I have ever had TB. I always say I don't want to have TB. I was always afraid to have TB. It is the first time in my age I have had TB. I am afraid of TB.*

Bongani stated that he was "confused" and "afraid" of TB, which showed that he might not know enough about TB to explain to someone else what it meant because he was confused. Most importantly, he was "afraid" of it, which signified that he would have heard about how fatal TB could be even though he might not be able to explain exactly what would cause the problem. Aphiwe's explanation was different.

> *Idriss: Explain what you know about TB.*
>
> *Aphiwe: No, but I was asking the doctor, which TB I got, MDR or XDR? What I know about TB is like… for spreading TB is not a mistake in our local places. People are smoking. So when we are youngsters we are sharing the cigarette and the drugs, tik*[11]*, something like that. That way we are using one container to pour something like powder you see? I am going to smoke it finish. Have you watched when they smoke dagga with that bottle? It is a mistake to spread TB. The difficult thing is just to spit out and to cover that saliva because it can spread still when you spit out. For TB you cannot just spit out like that. You must cover it*

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[11] Tik is slang for crystal methamphetamine. It is normally smoked using a tube or a straw in a light-bulb

Aphiwe initially said he did not know about TB, but he later gave an interesting reflection on the spread of TB, which was more detailed, linking it to some behavioural traits in the community. When probed where he got this information from, he replied:

> *Aphiwe: I did learn at the local clinic when I was growing, I grew up with asthma. I was using that thing [tik] …Hey, I didn't have a nice life.*

Some patients attended clinics for different reasons prior to their hospitalisation. It is not uncommon to hear about TB because there are posters and discussions about TB at the clinics. Patients who may not have had a similar experience to Aphiwe would be far less knowledgeable about TB. Aphiwe and Buhle lived in Khayelitsha. There could be instances where if someone were to attend clinics they would have access to information about TB (as in Aphiwe's case) as compared to patients who might not have been attending clinics, albeit in different medical conditions. Buhle did not actually express why she did not have knowledge of TB, but she might have had some knowledge about TB had she visited clinics as Aphiwe did.

Patients may not be oblivious of the dangers of TB, as expressed by Bongani who said he was "afraid" of TB. Aphiwe gave detailed information about the spread of TB. However, being concerned about the kind of TB he had opened up areas of deficit. These areas of deficit may be linked to crucial phases of TB treatment, different regimens and side effects that may need some indepth explanantion or clarification. Lack of adequate knowledge may not mean that patients would not attend clinics for continuation of treatment, but thorough counselling at hospitals may be an important aspect if patients are to understand the kind of disease that they have and how it can impact their lives.

PRELIMINARY DISCUSSION OF FINDINGS

The literature explained PHC being the cornerstone of health policy, including TB in South Africa (Coovadia et al., 2009: 828) following treatment strategies of either DOTS or SAT (Pasipanodya & Gumbo, 2013; Das et al., 2014). However patients are sometimes diagnosed with TB at the hospital. Hence, patient education at hospitals and responding to patients' needs and feelings are important. PCC measures need to be clearly embedded in policy for hospital staff to implement them. To understand the wider contexts of the way HCWs interpret their roles in regard to patient education, limited staff and HCWs' capacity in the health sector comes to the fore (Kapp, 2009; SANAC:2006). Policy makers from the WCDOH commented on the essence of TB education, drawing what should be happening according to the WHO protocol. One would expect that policy makers to comment on the workload and time constraints expressed by hospital staff that would affect them doing TB education. What was clear from policy makers' discussions was that there was a policy and implementation gap. This is not uncommon in certain sectors in South Africa, including the health sector (Coovadia et al., 2009; Shelmardine, 2011). The extensive discussions with Dr Bayley suggest that there needs to be patient education or counselling of TB at the hospital. This suggestion does not consider not having patient education on TB because of workload, but rather it is suggestion for it to be embedded in hospital protocol with trained counsellors to execute it.

Bianca's expression of helplessness transcends simply language problems (Sissolak, Marais & Mehtar, 2011) in communicating information to patients. Neither is it based on an imposition of knowledge power exerted over patients by HCWs (Shelmadine, 2011; Foucault, 2003; Gastaldo & Homes, 1999), without much engagement with patients to understand these fears and anxieties. Researchers have highlighted communication challenges due to linguistic and cultural differences between HCWs and patients, as also noted in the literature (Shelmadine, 2011; Sissolak, Marais & Mehtar, 2011). Communication problems are not only about the linguistic challenges between HCWs and patients, which can lead to patients' inability to understand what is being said. They also are about how patients perceive their treatment. For example, patients comparing the amount of pills without knowing the weight differences transcends beyond linguistic challenges. PCC also involves training HCWs to understand the patients' perceptions of their treatment and ways to prevent confusion about their treatment. This is a crucial element that goes beyond the state of health of the patient. It should include the patient's ability to grasp and interpret information given to them and also be clear about what happens after discharge from the hospital. Stewart (2001) asserted that it is essential to understand what patients think about the space in which they find themselves to receive medical care.

Khayelitsha had a higher number of patients diagnosed with TB compared to other areas in the Western Cape (Cox et al., 2010; SANAC, 2011) but patients living in that community had different knowledge of the disease. Adequate knowledge of TB may have a significant role to play in enhancing a better health-seeking behaviour. It is noted in the literature that there is an association between peoples' access to social amenities – including health services and health education – and their health status (Engels, 1995, Farmer, 1996; Coovadia et al., 2009; WHO, 2015). On the other hand, Edginton et al., (2005) and Khan et al, (2006) identified an essential aspect on CoC of TB that links to PCC because having a general knowledge of TB is not the same as having an education focused on one's particular illness. Some knowledge that patients have about TB can be linked to the way they access healthcare and the manner in which they are retained in care. Salaniponi et al (2000) expressed that even though most patients accessed the hospital for treatment of TB about 30% of them sought alternative treatment. These authors asserted that seeking help from unorthodox places was because of limited schooling and little or no awareness of other people who had been infected with TB. Even though the patients in my study who accessed care in the hospital may have demonstrated some knowledge of the workings of conventional treatment strategies, it did not mean they had sufficient information about the disease. Hence, patient knowledge of TB is crucial and should be embedded as a part of the infrastructural development in the health system, as suggested by Epstein and Street (2011). This infrastructural development also acknowledges patients' needs and feelings as maintained by Jardien-Badoo, van Booyen and Ricks (2016) and O'Donnell et al. (2016).Salaniponi et al (2000) recommended an expansion of TB education about TB in"unorthodox" places, especially in the area of TB diagnosis and its side effects when people experienced signs of TB infection.

The concept of the social determinants of health (SDH) draws our attention to the health problems faced by the patients prior to admission at the hospital. It also informs us about patients' living and financial situations that may affect CoC, which will be discussed in Chapter 6. However, at this stage of the patients' treatment journey, a structured educational programme at the hospital could at least bridge a knowledge gap, to clarify some misconceptions or low or no knowledge of TB among patients.

The impact of responding to many sick people with few helping hands takes its toll on the HCWs in the hospital, as has been mentioned by several authors (Breier, Wildschut & Mgqdozana, 2009; Hall 2004:30; von Holdt and Murphy, 2007). Staff shortages continue to be an ongoing problem in South Africa's health sector. The need to have more staff in hospitals to do counselling with patients diagnosed with TB is still essential. In addition, it may be helpful if there is transformation of the education programme. There could be access to medical education programmes where there is emphasis on language learning in medical and health professions training. Despite the fact that cultural issues go beyond simply language, what is also needed is a workforce that can speak peoples' first language, and who share the same or similar culture.

CONCLUSION

In this chapter I have described and analysed the patients and HCWs' experiences of treatment at the hospital. I drew on PCC as a theoretical framework/model of treatment that puts the patient at the centre. Two of the core elements of PCC, patient TB education and engaging with their needs and feelings, greatly influence CoC. The chapter discussed and analysed the ways the hospitals have achieved—or did not achieve—PCC for a better CoC. It was noted that many patients either did not have knowledge of TB or had a limited knowledge of how TB was transmitted prior to hospitalisation. There has been no adequate TB health education. The activities at the hospitals have been more disease-focused than patient-focused. Hence patients' needs and feelings have not been adequately explored. These problems contributed to some patients feeling hopeless. The reasons given in this study for these lapses in PCC are the huge workload of HCWs, the high burden of TB, the cultural and linguistic challenges, and patients' limited knowledge of TB prior to hospitalisation. As a result of work load, nurses and doctors did not embark on a structured and consistent education programme of patients, which is one element of PCC. There is also communication breakdown between staff and patients, which is seen through cultural and linguistic challenges.

Patient-centred care (PCC) is very important in CoC as it brings the patient to the fore regarding what matters to them as they start their treatment journey. It is more crucial when patients diagnosed with MDR-TB will be embarking on a protracted treatment journey between six months to 18/24 months of different kinds of treatment. The hopelessness that emerged when the patients accessed medical care in the hospitals was as a result of many problems including constraints of time and workload that affected the focus on patients' needs and feelings. Having an adequate and trained staff, a better response to cultural and linguistic challenges may enhance PCC. As mentioned above, there could be interpreters and counsellors who would be employed to help patients understand their treatment plan better. Unless these kinds of problems are addressed, CoC for TB patients will continue to be poor.

CHAPTER FIVE:

PATIENTS' EXPERIENCES OF DISCHARGE PLANNING AND LINKAGES TO PRIMARY HEALTH CARE CLINICS

INTRODUCTION

This chapter covered patients' experiences of discharge planning and the coordination between the hospital and the clinics. The discharge process raised several issues related to the third aspect of patient-centred care (PCC), which was shared decision-making (Barry & Edgman-Levitan, 2012; Epstein & Street 2011; Little et al., 2001; Stewart, 2001). Most importantly, it raised concerns regarding the partnership between the healthcare worker (HCW) and the patients in the discharge system itself and the role patients play in the coordination between the hospital and the clinics. The first part of the chapter reviewed the role the patients play in discharge planning (or lack thereof). This review included how the patients described their needs as they prepared to leave the hospital. Many patients were not consulted about their concerns, anxieties and needs that should be considered, which could ensure better CoC. As was expressed in the previous chapter, there were lapses in PCC because of the workload and constraints of insufficient time experienced by HCWs. Nonetheless, I argued that the referral system being diseased-focused rather than patient-focused also did not consider patients as partners in their treatment plan before leaving the hospital. The second part of the chapter examined how the patients were also positioned in the coordination between the hospital and the clinic regarding CoC. One of the key aspects of CoC is that of well-coordinated transfer of information between the two health centres (Dudley et al., 2018; Gordon & Krauthoefer, 2007). In this section I discussed not only the insufficient collaboration between the hospital and the clinic, but also raised the question of what role the patients played in this collaboration as well. Patients were being referred from one health centre to the other with no clarity on what lied ahead of them, including the concerns raised about their diagnosis and treatment. Many patients expressed the feeling that their life outside the hospital should be taken into consideration. Policy makers, however, framed patients' involvement in decision making as crucial. I drew on Foucault's (2003) analysis of the 'medical gaze' and social determinants of health (SDH) in this section.

I argued that the patient has not been a partner in their treatment journey. The discharge system and coordination between the hospital and the clinic that I explained can be understood as a result of the impact of the “medical gaze”. This is so because the patients appeared to be passive partners in their own treatment journey. I drew on SDH to make sense of the perceptions of HCWs about what influences patients’ CoC. Even though patients were expected to display agency in taking charge of their own health, they were constrained by many socio-economic circumstances.

PATIENTS’ EXPERIENCES OF DISCHARGE PLANNING AND THEIR NEEDS

Discharge planning and patients’ involvement in the planning

It was helpful to understand what happened before patients were discharged from the hospital. From the way the HCWs described their roles, we understood that the patients only received discharge letters with minimal or no contribution to the process of discharge planning. I asked the HCWs at Hospital 1 to describe their roles regarding treating TB patients leading to their discharge from hospital.

> *Idriss: Please describe your roles in treating TB patients.*
>
> *Matilda (Professional Nurse (PN)): I go and see patients – when we get results of positive TB, I go and see the patients. And specifically check whether they are in the wards. Does the staff know? And then we complete the TB surveillance form to see where the patient has been admitted from, is there any co-morbidities, We give education to the staff about the specific patient and do they know how to wear the correct N95 respirator, and if no, we show them. We don’t always speak to the patients, but at times we will speak to the patients if they know about the results. The doctor gives the results. If not, we will briefly explain if the patient have got a direct smear result and explain to the patient that TB can be cured and the type of TB that they had and they need to take the treatment the months as they are prescribed.*

According to Matilda’s explanation above, after the patient has been diagnosed with TB they do the normal checks, including a check where the patient is admitted and checked for any co-morbidities. Staff are informed how to secure themselves around the patient, and lastly, a brief explanation is given to the patient of what the result meant and that they should continue with the prescribed treatment. What happens after these initial interactions with the patients is continuous treatment with the drugs until the time the patient is ready to leave the hospital. I asked Matilda what happens afterwards.

> *Idriss: So what happens leading to discharge?*
>
> *Matilda (PN): This card* [Matilda pointed to one of the cards on her desk] *is supposed to be given to the newly diagnosed TB patients currently in the [Internal Medicine] module … So, to start the treatment and even sputum result and so when they go out, they go out with this card. The sister can carry on with the treatment. If is a known TB case from outside, the sisters and nurses are also supposed to ask them about the card, so we can tick off to carry on the treatment, so when they go out the clinic sister knows because we get the TB patients that are very ill, with all the complications. So sometimes it means 'your TB treatment is being stopped for liver or kidney problems' so that they can draw a line and say stop and when doctor resumes the regime again it will just make it so much easier.*
>
> *Idriss: So the patient only gets a letter?*
>
> *Matilda (PN): Idriss, again, just to ensure that the patient has his discharge letter, his medication that he should get for five days and he/she should know exactly where to go, exactly where to go, because there are too many clinics in Eerste River. The doctor can't say Eerste River clinic, find out exactly where is the nearest clinic to where they stay and that should happen when they are admitted already.*

At this point I realised that there were minimal or no roles the patients play in the treatment leading to their discharge from hospital. Another nurse, Alice, in Hospital 1, explained that there were virtually no contacts with the patients after they had initially been treated and were waiting for discharge. After explaining a similar work role to Matilda's, Alice gave reasons for this minimal contact with the patients.

> *Idriss: Please explain your roles in treating patients with TB at the hospital.*
>
> *Alice (PN): My role is to make (sure) that all patients, those who are normal TB, we put six in a bedroom that are on treatment. Those with MDR-TB we put them in single rooms and put them at the back. They have their own bathrooms and toilets. They are isolated and they can't come out of their rooms, but it is not nice (for) them being alone there at the back and they hate it, but if a person (a nurse or a doctor) goes in there to explain to them they do not stay there all the time*

> *because that is what happens. Especially my nurses they are scared of TB. I tell them, 'Go into the rooms, go speak to the patients. You don't have to go in for half an hour'. Because I go into the rooms and I speak to the patients and they say, 'Sister, you are the only one that comes to speak to us'. I told the nurses, 'We are two years here already, more than two years and none of us ever got TB. So don't look at the doctors, just do it'. They just look through the window in the door and they turn away. And when I go into the rooms they (the patients) have this complaint and that complaint*.

The patients did not participate in the processes of discharge planning because there were seldom contacts between them and HCWs after the initial treatment initiation. Nurse Alice provided brief explanations as to why HCWs could not spend more time with the patients, especially patients with MDR-TB. According to Nurse Alice, the nurses and doctors were afraid to go close to the patients.

> *Idriss: You said the patients complained?*
>
> *Alice (Professional Nurse): Yes, because the doctors don't go in there and ask them what's wrong, they (the doctors) are scared of TB. This is a very safe ward, so that's why some of the patients feel 'I don't want to be here', because they think they have a thing that you are going to catch because you never come into the room, even to come say hello. So we put them at the back in single rooms where they have their own toilets and bathroom. And then we refer them to (another Hospital).*

This discharge planning system is similar to what happens at Hospital 2, where on diagnosis of the patient, the nurses do the placement of the patients based on this diagnosis. From the doctors' perspective there, the patient is treated, but there was also no explanation about the patients' involvement in the discharge planning process.

> *Idriss: How long do you wait to get the result of a diagnosis of a particular patient?*
>
> *Dr Bayley (MD): So you get your clinical signs if there are suspicions of TB or a test for TB. If we send the sputum in two days to the GeneXpert* [TB diagnostic test]*, we get [it] in the next day or two. If they are HIV positive we will wait for the GeneXpert before we start them on treatment.*
>
> *Idriss: So in the meantime, what happens to that particular patient?*

> *Dr Bayley (MD): If they come in with signs of antibodies, we suspect TB, we treat them with antibiotics. For example, if they come in with hemoptysis, that is the coughing of blood, we initially treat them with antibiotics; first that is to sort out the hemoptysis, but at the same time test for TB.*
>
> *Idriss: They are not put in isolation yet?*
>
> *Dr Bayley (MD): If we have a sound suspicion, if they are HIV+, especially if they have previous TB before, if they defaulted TB treatment before, so immediately you will say suspicions of TB then they will already try and send the patient to D10 or isolation wards.*
>
> *Idriss: What happens before discharge?*
>
> *Dr Bayley MD): When we discharge patients we obviously give them a form and there is also a specific TB referral form, so this is now in the case of normal TB. We usually issue the first two weeks in the first month of therapy and I must admit from there, from the clinic we don't follow up. It becomes the responsibility of the clinic, but usually they do keep an eye, but that's what they should be doing. Obviously for the in-patient admission like MDR, etc., there are doctors there to follow the patients up. You are talking about home-based carers, that's only the sisters that will [do follow-up], they will usually refer to the doctor if they think the patient needs more attention. And the doctor will discuss the medication on a monthly basis. So that's how it really works.*

In both hospitals, the roles of the HCWs in treating patients leading to discharge planning (or lack of thereof) did not include what the patients brought into this clinical space. It is noteworthy that from the descriptions of the work of the HCWs, what is not being said also stood out. Patients were not consulted about what their understanding of the discharge process. Patients are diagnosed, treated, given information about their diagnosis and told that they had to be discharged. It is then the responsibility of the patients to find the clinic they are being referred to continue with the treatment. A detailed connection or coordination between the hospital and the clinic will be discussed below. At this stage it is important to record the responses of the patients with regard to their roles in the discharge planning.

From my observations and conversations, I concluded that in these hospital sites discharge plans were not discussed with patients and families and they received insufficient information about what would happen when they were discharged. The patients and families neither had sufficient information nor engaged in discussion with the doctors or nurses regarding their discharge from hospital. Therefore, they had minimal or no role to play in the decision-making processes around their treatment plan. In this way an opportunity for enhancing patient-centered care (PCC) was lost.

> *Idriss: Do you play any role in the discharge planning?*
>
> *Buhle: They have not told me anything …*
>
> *Aphiwe: I am just listening to them. I do what I have to … they just give you the letter and tell you to take the letter to the local clinic so that they can know that you are coming from the hospital.*
>
> *Morne: No. The doctor told me yesterday that maybe they will send me to another hospital for recovery. It's a TB hospital. They send something there, but it never comes here [to Hospital 1]. They will wait and see when it comes, then they are gonna go to the doctor.*
>
> *Bianca: The sister asked me if I wanted to go home because they can't do anything here for me. So, if I want to go home … what is the use of lying here? They can't do anything…*

One of the patients, Themba, a 29-year-old man who resides in Khayelitsha, told me that he knew when he was going to be discharged. I then asked if his family knew he was coming home and if he would receive support from them.

> *Idriss: Did your family know you would be coming home?*
>
> *Themba: No. I don't have family as such because it's only my aunty, my sister, my cousin. Yeah, she knows, but we don't have much, even my trousers is taken* here [trousers were stolen at hospital]. *I don't know, but I will be at home. God will provide.*

Some patients immediately mentioned their home circumstances alongside not knowing much about what the discharge planning entailed. From this point I became aware that more of the expressions of their needs at home are discussed, which are highlighted below. By simply asking the patients what they knew about the discharge processes could have revealed their needs and hence encouraged some level of participation by the patients.

Patients' needs in preparation for discharge

One of the areas worth considering in discharge planning is not only the connection of the patient to the clinic, but also an understanding of their home circumstances. There are social workers in the hospitals whose main role is to make sure that patients have transportation to go home, and are able to locate their family's addresses and get subsequent help from families. I investigated the support the patients had at home and their needs as they prepared to be discharged from the hospital.

> *Idriss: Tell me about any support you may receive at home after discharge from hospital.*
>
> *Kaitlin: There are many things I need to make right in my house. I need to go home. I was so full of depression.*
>
> *Bianca: I don't have money to go home. It is for transportation to go home. My family doesn't know that I am here. And I don't have any contact numbers*.
>
> *Kaitlin: It is too far from there to here, from Khayelitsha to here. They [her family] don't have money. They don't even have money to buy food … When I go back I will sell my house because my problems are too heavy. My children are not working. I have a Wendy house [a small shed] for me and my children. I want the older children to leave … I must do it myself … That's why I told you that when I finish with my treatment I am going to sell my house because I have nothing … No one anymore [crying] … Since I am here no one has come to visit me …. Last night I asked God to come take me. I feel so depressed, I feel so … I don't know how to say it. I feel alone [still crying]. I can't sleep in the night. I can leave the cigarette, but not so quickly. A lady is the one that supports me. She gives me anything I ask* [coughing] *because I help her legs, I put her legs up and she gives me juice. I have no one in my life.*

Kaitlin's interview was one of the most difficult interviews I conducted at the hospital. She was very depressed and as highlighted in her response, she hoped God would take her life. She cried half-way through the interview. Discussion of my response to this and other similar cases can be found in the Methodology section under ethics. Kaitlin's immediate concern was her family and income situation. The issue of clinic attendance or continuing treatment after discharge from hospital was the least of her worries. She displayed not only lack of involvement in discharge planning, which would have given her the opportunity to express her immediate needs, but also anxiety about what would become of her financial status and family support after discharge from hospital. Themba expressed a similar situation regarding his basic needs at home and even made a request of support from the government.

> *Idriss: Tell me about any support you have at home.*
>
> *Themba: But I want them to first see how I live before they give me something. It is important to see the way that you are … I need support from government that you can see the way I live, the way I stay because it is so important where I stay. If I can fix the way I stay first, you can support me about money until this treatment finish. After that I will say I can carry on and see. Because when I have power I can be able to work.*

Themba believed that his "power" [strength] could be restored when his needs at home are met. (Themba's home situation will be discussed in Chapter Six). He juxtaposed treatment with basic support, which is not necessarily money, but housing and food.

Joan (WcDoH) was well aware of the needs of patients, but most importantly expressed the partnership role that patients should play as they articulated these needs. Patients must be given the opportunity to make an input in their lives as they would be taking the treatment.

> *Joan (WCDoH): We are addressing what we think they must need. You see what I am getting at? So for TB patients, for TB specific, I ask the question, if I am diagnosed with cancer and my chemo is tablets and I must take the tablets daily, they send me home with my tablets … .Why is it our disease to protect? As much as we blame patients for not taking responsibility we are not allowing them the space to take responsibility. We assume they need more information about the disease. I want to go as bold as saying NO, they need more information about their challenges. Their challenge is they don't have food to eat.*

To know patients' challenges you should be able to engage with them. We learn from the responses from the HCWs in both hospitals that there are certain things that worked well in treating patients diagnosed with TB. This system follows from the protocol of treating the patients, but also makes sure to prevent its transmission to other patients and HCWs. However, even though this system worked well it still emphasised a disease-focused approach discussed in the previous chapter. Responses from policy makers and the patients re-echoed the importance of considering patients' input in discharge planning because they would be expected to report to the next health centre and carry out the treatment. The patients articulated their needs as they prepare to be discharged from hospital. There is a structure at the hospitals to respond to some of the needs of the patients, such as transportation or regarding their family support. The social workers in the hospitals play this role of providing transportation to patients and also try to locate patients' families. Nonetheless, I argue in this chapter that the discharge planning did not consider the patients as partners where the patients' input into their own discharge process were needed. It is interesting to note that even though the HCWs discuss that patients' agency is necessary to continue with their treatment from the hospital, most of their responses are linked to the socio-economic constraints the patients faced. These barriers to agency are teased out from the responses of HCWs. This shows the relevance of the barriers to patients' agency that are worth exploring before patients leave the hospital. These are discussed in the next section.

BARRIERS TO PATIENTS' AGENCY

Following from an understanding of the needs articulated by the patients, the HCWs discussed extensively the agency of the patients. What is of special interest here is that the agency of the patients is discussed alongside the constraints that limit it. These constraints include poverty or the social class in which the patients found themselves, experiences of stigma, and lack of TB education pertaining to discharge. Portia (Professional Nurse/PN) at Hospital 1 explained about patients' problems. Responding to the question about the role the patients play in the discharge process, Portia said:

> *Idriss: What role do patients play in discharge planning?*
>
> *Portia (PN): Lots of our patients need to be referred to the social worker. That's the first thing. Most of them ask for the social grant or dietician. Most of them are thin, undernourished, so we refer them to the dietician, speak to the family, if the family comes and asks. The TB patients can all get grants while they are on treatment for six months. And most of our people are poor. Most of the TB patients are poor. Most of them qualify for grants for six months. And the people don't*

> *want to go to [TB hospitals][12]. They don't want to go there, they will rather go back to the same circumstances they came from; not having food. They prefer that.*

For Portia, sometimes the better option is to send patients to TB hospitals and clinics that provide more intensive treatment since they also provide other kinds of support, such as giving them food. Intensive care is given mostly to patients with MDR-TB who would be hospitalised for six months receiving TB medication. After six months they will be discharged to continue treatment. However, some patients would go home and choose to go hungry. She indicated that some of the patients thought they were being "locked up".

> *Portia (PN): I don't really know what is happening there [at these hospitals/clinics that are meant to give more intensive treatment to patients diagnosed with TB] and I haven't been there myself, but a lot of people told me it is nice there, but the people actually told me it is better than* [other hospitals], *but I don't personally know how it is there. But I think the people* [the patients] *think when they go there they are going to be locked up for three months or six months. And no one wants to be locked up. Maybe they are scared of that.*

Portia had mentioned earlier that patients with known social problems were referred to the social worker. She added that the social worker also links up with the family members of these patients. Linda, a Social Worker (SW), expressed the dire situation that the patients diagnosed with TB are in, including the lack of adequate education and the use of drugs, which was also mentioned in the previous chapter. The focus here is education during discharge planning. Alice (PN) also highlighted patients' non-attendance at clinics due to the use of drugs, but interestingly also linked these problems with social conditions that the patients are faced with.

> *Idriss: Could you explain the reasons some patients do not attend the clinics after discharge from hospital?*
>
> *Alice (PN): Most of our patients are defaulter, neh? ["Neh" is an expression that means "you know?"]. Most of them, we do get new ones, but most of them are defaulters. So then the social*

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[12] There are some TB hospitals where some DR-TB patients are referred to get intensive treatment and monitoring from HCWs. DR-TB patients often stay in these hospitals for six months, a time when they are on daily vaccination of TB medication.

> *workers come and contact the family and see how the support structures are at home. Then most of the time the patients are referred to [other hospitals] where they get their tablets on time, where they get food. Yeah, mostly because of the drugs. Most of them are "tik" users. They drink a lot. Most of them don't have a place to stay. They sleep outside. They don't have money. Some of the patients are sick at home; they can't go to the clinic.*

Alice indicated that even though patients are "defaulters", their actions are juxtaposed with the immediate structural factors at home, including family support (or lack of), scarce food, and little or no money. Socio-economic class was another factor that health professionals raised in explaining why some patients may not seek care early, or follow-up with care after discharge.

> *Idriss: Please explain to me your experiences working with patients diagnosed with TB.*
>
> *Linda (SW): What I know and from what I have seen, we often get educated on it, so not about the medical treatment as much, but the fact that, for example if I look at peoples' social circumstances, you can kind of expect something like TB if you look at the way they live. And because I work in the ward, you can just see from the cases in the ward you can just link poverty with most of them. Look at people's living arrangements – you get a lot of TB in poorer communities. Yes, from what I have seen. I think the more high socio-economic class, with better education, we don't get to see them, and if they are admitted maybe in private hospitals or they treat themselves at home, but here you see them. They are at the weakest, very, very sick, maybe at the lowest point, and the saddest thing is there are day hospitals, there are clinics, they should have gone earlier. So when they come here, it is like damage control.*

Linda did not only express socio-economic problems that were confirmed by the other HCWs, she mentioned the relationship between social class, poverty and sick patients with TB. Further, she highlighted the flip side, which is that people from higher socio-economic classes have access to better health services. Linda also confirmed the lack of time HCWs have to educate patients; however, she also highlighted the importance of knowing the 'whole history' of the patients for a more detailed counselling of the patients.

> *Linda (SW): I think to some extent doctors, don't necessarily have that time to make a person sit and explain to him what causes TB or how it spreads or investigate and hear from the patient – 'When did you start feeling sick? What were your symptoms? Anybody else that you know that you could have been in contact with?' So they skip that whole history. They need assistance. If they are living by themselves we can't send them home. That is why we send them to [other hospitals that provide admissions] just for them to get better. Some of them live on the streets. They don't have houses to go to. We also send them [to these hospitals]. Unfortunately, sometimes they have been sent back to the streets. We have tried to send them to shelters, they refuse.*

Linda (SW) that dealt with patients that have known social and/or economic problems, confirmed that the hospitals provide transportation for the patient to go home or to another facility where patients would be hospitalised for a longer period. In other words, apart from referrals to another facility with monetary assistance for transportation, there were no actions taken at the hospital to address the problems described by the patients for not wanting to go to a particular referral hospital. In addition, there were no measures to address why patients may refuse to go to another facility or what structured measures could be taken if family members were not around who could give support to the patient after discharge. Consequently, if a patient refuses to go for in-patient TB treatment, they were "sent back to the streets".

Most importantly, Linda confirmed that the doctors did not consider the "history" of the patients, even less to speak of partnering with them. The questions suggested by Linda may encourage a partnership model of discharge planning. These questions may include: "Why do you (the patients) think you would be locked up at the other hospital? What ways do you think this can be better addressed? Which is the best place you can be referred to that will help you continue with your treatment? Would you mind us exploring other options if your family may not be the best place for you to stay after discharge?

In continuing to explore the perceptions of other HCWs regarding the reasons for patients' non-attendance at clinics and non-adherence to treatment, the predominant theme is still patients' lack of agency in taking charge of their health. Yet again, HCWs also tied lack of agency to social determinants, such as stigma. Portia's (PN) response similarly highlighted homelessness, family problems, stigma and lack of adequate counselling. In addition, some patients' immediate problems were caused by drug abuse that could limit their attendance at clinics after discharge. These were discussed alongside other structural constraints, including poverty, homelessness, stigma and lack of TB education.

> *Idriss: Could you explain the reasons some patients do not attend the clinics after discharge from hospital?*
>
> *Portia (PN): A lot of our patients are actually abusing substances or maybe they don't have a fix abode, say they are homeless, or staying in the streets, that's also where they are susceptible of contracting TB … Social, economic, transport as well is a big problem, taxi fare, etc. Also these other social problems like substance abuse and issues in the family, etc,, if there are side-effects to the drugs they should be counseled, they can change the medication. There may be stigma attached that they don't want anyone to know. Or just a lack of insight. Maybe they were not counselled enough.*

Another interesting trajectory with regards to patients' non-attendance to clinic was some patients thinking that they were young and healthy, and so, being treated for such a long time did not seem realistic. Mandy, a PN at Hospital 2, started by identifying what enabled the patients to attend the clinics in the first place and highlighted some interesting, yet contradictory statements in the area of TB education. She spoke about the patients receiving education (within discharge planning), but again mentioned that there were failures in educating the patients. This response once again confirmed patients' lack of agency, but this was embedded in many structural factors both at the health centres and their homes.

> *Mandy (PN): I think most patients do turn up though because they do realise that they have been sick. They have come into hospital. They know that there is something wrong with them. I think there is pretty decent education going on about TB treatment is for six months and they need to take their medicine. So for the most part, patients do go to their clinics and they do go to TB rooms and continue their treatments. I have had some patients who feel better and they have stopped though. That's a failure more on the system of education … yeah. It is also difficult to tell a young healthy person that they are sick and they need to on treatment for such a long time. They often can't ratify the thought that they are young and healthy and that they have got chronic illnesses*

According to Mandy, some patients would be thinking that they were healthy and strong so they would not believe that they needed to be treated for that long. In as much as it is an individual's responsibility to follow through with their treatment, this perception – due to limited knowledge of the disease as well problems that affect PCC already discussed – it may subsequently affect CoC.

DISCHARGE SYSTEM: SHARING INFORMATION BETWEEN HOSPITAL AND CLINIC

In the previous sections I have discussed how the patients have not been consulted in the discharge planning process. In search of a clearer picture of what influences CoC from the hospital, I asked the HCWs of their perceptions on this matter. The discharge planning (or lapses therein) is not the only factor to consider. HCWs explained that patients' agency is required in continuing with their treatment. However, patients' agency in continuing with their treatment is limited by many socio-economic factors, as discussed in the previous section. In this section I continue to discuss the discharge system, with particular reference to the linkages to clinics. I also explore the role of the patients when they are eventually referred to clinics and hospitals. I argue that not only is there insufficient collaboration between the hospital and the clinic, but I also question the role of the patients in this kind of collaboration.

HCW-Patient Partnership

From the planning phase to actually leaving the hospital, patients mostly receive instructions from HCWs, as already mentioned in this chapter. Joan (WCDoH) commented on the patients' involvement in the discharge planning, that not much attention is given to what the patients had to say regarding their own situation. Hence, patients' partnership is not valued.

> *Idriss: What is your understanding about the discharge planning at the hospital?*
>
> *Joan (WCDoH): Around the management of the TB patient, it's almost as if the patient is not as important as me reporting the number of tablets that I have given out. You know? ... Yeah, nothing has changed. So that patient still does not have food security. And it is not the person alone. You must see that patient in the context of his family responsibilities. And if he doesn't have food security, his family doesn't have food security. And he would make the choice [to attend the clinics and take their medication], maybe not for him, but he would make the choice for his children. So that is what we need to address.*

Again, in addressing the needs of patients, it is important that an interaction with the patients is held where they (the patients) can articulate what may work for them. In describing the discharge system and how the patients were involved, the HCWs referred to the discharge letter that they gave to patients. This referral letter should be taken to the clinic. Hence, the HCWs confirmed that the interaction with the patients was basically to treat the patients in the hospital and eventually referred them using the discharge letters. Therefore, as also indicated above, the patient's role was basically to receive information and move to the next level of care.

> *Idriss: Tell me the role the patients play in discharge.*
>
> *Alice (PN): When we discharge patients we obviously give them a form and there is also a specific TB referral form so this is now in the case of normal TB. We usually issue the first two weeks in the first month of therapy and I must admit from there … From the clinic we don't follow up. It becomes the responsibility of the clinic, but we usually do keep an eye, but that's what they should be doing.*

Alice did not only speak about the discharge letter that was given to the patients, but also commented on follow-up that should only happen at clinics. This response was not different from HCWs at Hospital 2.

> *Christopher (Medical Officer/MO): From our side, if the patient is here and we have done the samples, then they are always discharged with a letter and the MDR patients are always counselled about their diagnosis and the counsellor comes and sees them. They don't get pushed into the community with no information, no background. We do provide them with a letter for themselves and a letter for the clinic. So they go there and follow-up their results and continue with their treatment.*

The policy makers, Joan and Edwina, put some of the responses regarding policies and implementation in the context of PCC. According to Joan, one policy-driven activity is that of screening each patient for TB, followed by education about the disease. Screening is only part of a complete job. Spending time with patients will give them their own space to be actively involved in their treatment journey.

> *Idriss: What do you think can be done to ensure better continuity of care for patients with TB?*

> *Joan (WCDoH): I think every time when you speak to a patient about TB … and what we have now with this very ambitious 1990 target [WHO target], our target is to screen every person coming to the PHC facilities, screen for TB. When you screen for TB, don't ask the patient 'Have you got TB symptoms?' – that is an opportunity to educate the patient about the disease because asking him, whether he's got symptoms is not doing anything in terms of prevention. So we must, every time we speak to patients … and we create the opportunities to speak to patients about TB or at least, then we must ask … and then we can ask the question. 'If you should be diagnosed with TB, do you think you can come, really come every day or really drink tablets for six months every day?' Get the feel of six months treatment without stopping, from even people who do not have TB at that stage. And the other thing is asking the question and giving patient time to think about 'what the hell are they asking me now?' And you will find people will … there will be things that you don't think about and even personal experiences.*

Joan explained that the ideal situation for a patient to continue with their treatment was not so much in provision of drugs, but also in their understanding of what it really meant to take the treatment in six months. Therefore, there must be time spent with the patients that will empower them in decision making – in the process, establish whether the most important aspect of PCC is to ask how the patients feel about all this information given to them. Firstly, receiving a diagnosis that one does not have much understanding of, is problematic. Secondly, not being able to understand what the treatment procedure means, on the verge of leaving the hospital, may be a bigger concern; considering the living conditions of the patients.

Transferring/Sharing Information between Hospital and PHC clinics

Poor linkages to PHC for continuity of care

The referral document was the only piece of documentation that linked the hospital to PHC for patients diagnosed with drug-susceptible TB. At Hospital 1 they started with the discharge letter that included the details of the patients' diagnosis and the length of their treatment. At some point there was the introduction of a card with more pieces of information about the patients. Before an exploration of the linkages between the hospital and the clinic, it is important we look at components of the patients' card and the discharge letter.

> *Idriss: So when do you use this card, is it when you have been newly diagnosed here or when you are leaving the hospital?*
>
> *Matilda: This card is supposed to be given to the newly diagnosed TB patients. So, to start the treatment, and even sputum result and so when they go out, they go out with this card, the sister can carry on with the treatment. If it is a known TB case from outside, the sisters and nurses are also supposed to ask them about the card so we can tick off to carry on the treatment so when they go out the clinic sister knows because we get the TB patients that are very ill, with all the complications. So sometimes it means their TB treatment is being stopped for liver or kidney problems so that they can draw a line and say stop and when doctor resumes the regime again, it will just make it some much easier.*
>
> *Idriss: It will make it easier for proper documentation?*
>
> *Matilda: Proper documentation and ensuring proper continuation of the optimal care because sometimes the doctor changes the regime also here in the hospital.*

Patients used to be given a card, which is like a checklist of activities performed with the patients, which may include change of medication. Unfortunately, the card system failed. It was not clear at what point the card system failed or why. The referral letter remained. The doctor prepared this letter and the nurses gave the letter to the patient upon discharge. The information in the letter spoke only to the medical diagnosis, which denoted a weak linkage to another health facility considering the 'complexities' of the patients. I explored this linkage between the hospital and the clinic regarding the referral letter.

> *Idriss: What is the linkage to treatment of patients with TB between the hospital and clinic?*
>
> *Matilda: What is working well now, in the Internal Medicine module they have the electronic content management so the doctors on discharge complete that form and that's fully detailed. The report of the stay of the patient in the hospital, so if the patient goes with that referral form to the clinic the sister has the big picture, the complete picture. So that is working now … We have certain papers that need to be filled in. We have a blue, green card I think or blue card where we tick off the patients' TB meds every day, but we do not get to that. Most of the staff here know*

> *about it, but it just phased out. We don't do it anymore … But we only work with the discharge letter that the patient is referred to, let's say [some clinics in the Western Cape]. We give the patient that discharge letter with the medication for five or seven days. When I am working I explain to the patients 'go to the clinic before your medication is up', then you give them the letter, 'then you continue with your medication.'*

It was not clear from the reasons given, why filling in the checklist and the other relevant documents just "phased out". However, Matilda explained what an ideal model regarding the link between the hospital and clinic would be to address these challenges.

> *Matilda (PN): A good model would be, if budget and human resources allow it, a good system in my opinion should be all TB cases that are being discharged [at Hospital 1], those come to a central point in the hospital where it can be dispersed, so outside people will have one office to send their acknowledgement of the TB patient forms back because now it is all over the hospital. We have seen TB in every module in our hospital. If that can be done it will be marvellous.*

I asked for further clarification on this proposed model. I wanted to know if the practices at present motivated this model and how all cases of TB should go to one particular point where tracking of all patients would start.

> *Idriss: Do you mean all the patients should be directed to one particular place in the hospital before they are discharged?*
>
> *Matilda (PN): Yes. When they leave the hospital, they get their discharge form, we at the Internal Medicine module at least get those discharges, for that we can put the tracking system in place, but it is not so much all over the hospital [meaning there were measures tested in the Internal Medicine to examine its effectiveness before implementing them throughout the whole hospital. One of these measures was to issue the patient with a checklist card to show the treatment that had been rolled out to the patient.]*

I probed further, asking how feasible this model would be. She replied by drawing on present practices. It seemed that, based on the poor CoC among patients, there was the introduction of the card system, which as mentioned above, did not work well.

> *Idriss: How feasible do you think this model will be?*
>
> *Matilda: (PN) IPC [Infection Prevention & Control is the unit at Hospital 1 that designs infection control methods for the hospital] receives that form. IPC sends it to the coordinators outside, but if IPC does not receive it we cannot. But very particular now since we have this Data Capturer Clerk, we will note when the patient has been discharged and where to. [She showed me copy of a patient's document]. For instance, here this patient was discharged; ok, so he will have follow-up. He went to* [one of the clinics in the Western Cape]. *He didn't go to a clinic now, but went to [another hospital]. I will write now to the clerk where the patient should be followed up, ok? All the patients that you see on the ECM [an electronic register], I will say to her, 'Alright, these patients will be followed at* X/Y clinic. So these forms you scan and send to [a particular clinic in the Western Cape]. *If it is a rural place, let's say* [a rural hospital]*, this is the person that you scan the forms to.'*
>
> *Idriss: Ok, so from this point, who would do the follow-up?*
>
> *Matilda. That is now not been done yet and that communication has not been established how we will know. The only way that we will know (is) to go back on the system and check. Did the patient arrive? Because we will see, oh well here the five months sputum should be done now. Did the patient go to the clinic or not? So that link from outside to needs to be established.*

Portia recounted a similar problem about poor linkage between the hospital and the clinic in the sense of not knowing what actually goes on in the clinic once the patient leaves the hospital.

> *Portia (PN): I don't know how they issue the medications by the clinics, if the patients must go every day or if they also give a week's medication, I don't know. I don't hear anything again from that people. When they come in again, then I know they defaulted, but sometimes people from outside, like a clinic, this sister and this sister will phone me and say, 'Sister [Head Nurse], this person pitched up here without his letter' or this sister pitched up here again or we send that patient back to you', but I don't really know what happens to them when they go out of here.*

There were similar experiences among HCWs in Hospital 2. The problem is not only experienced by nurses, but doctors as well. There are also concerns raised about the practices of some HCWs in implementing measures that may facilitate this linkage between the hospital and the clinic.

> *Idriss: Explain your knowledge of the linkage between the hospital and the clinic*
>
> *Dr Bayley (MD): You can set up a system, but then nobody does anything about it, it doesn't happen because if you are referring patients for home-based care, a form needs to be filled out. I'm worried that unless we keep saying to our doctors that you must do this, it obviously won't get done, but I don't know how often things go well or go badly, so that information needs to be collected*

Christopher (Medical Officer/MO), on the other hand, not only mentioned that there was nothing they could do with patients who left the hospital, but also thought that the responsibilities of follow-up should lie with the family.

> *Christopher (MO): Yeah, that can be a problem. We trust on families to ensure the patients get followed up. We of course give all patients who get discharged, especially from Internal Medicine – we give them a letter for the clinic. We trust that letter (will) be seen by a medical officer or doctor at the clinic. But we can't contact the clinic about every single patient that is diagnosed with TB I think, but we always try to talk to family members to say, this is what is happening, get permission from the patient, because it is important to have some treatment support*

Karabo (PN) also confirmed the problem of linkage, but also drew an association between the inabilities to do any form of follow-up to that of the workload that they already had.

> *Idriss: What are some of the reasons for not doing follow-up with patients?*
>
> *Karabo (PN): I think it depends on which facilities you are at because you have different work load, so it depends mostly on time. Do you have time to do that, to trace it back? I don't want to say make it a policy and then it is setting stone … It does take a long time sometimes to get hold of it.*

> *There is one of the patients now that I have tried yesterday and today and I can't get hold of the clinic. So it takes a lot of time. Somebody will have to sit on the phone and try and find out.*

The aspects of workload of HCWs and time constraints have been explained in the previous chapter, and also featured in discharge planning. Lina (PN) at Hospital 2 responded to the question of the link between the hospital and clinic by affirming the lack of adequate linkage, although she also commented on the patients' responsibility to turn up at the clinic.

> *Lina (PN): Most of the time we actually don't often collaborate. It is more of a patient needing to go the clinic themselves. So we won't call that a patient is coming to them unless it is a DR-TB patient. Otherwise every clinic should have a TB section. So it is just up to the patient to go to their local clinic within a week. Otherwise we give them a week supply of medication and tell them to go the clinic within a week with their letters so they can continue treatment there.*

The responses above show the inadequate linkages between the hospital and the clinic. The conversations also show that the patients are involved in the process as recipient of discharge information, but their input regarding their concerns about the discharge process has not been adequately addressed. Further, there were patients' concerns regarding going to another facility, which might have the propensity to affect CoC. Exploring patients' fears and concerns, which is an integral part of PCC, and subsequently enhances CoC, has not been suitably explored by the hospital.

Dysfunctional Parts of the System

HCWs pointed to a number of other design elements of the linking process that needed improvement. Through their suggestions (and their complaints) they also pointed to dysfunctional parts of the system. One interesting observation was a complaint that more resources were being used for the HIV/AIDS programme compared to that of TB.

> *Idriss: What do you think can be done to ensure better continuity of care for patients with TB?*
>
> *Matilda (PN): When I worked at the TB programme, it was a vertical programme from the National Department of Health with all the materials and all the documentations and so on. And when AIDS*

> *came on board we were scared that the AIDS programme will just swallow the TB programme because it was this co-morbidity – HIV/TB, TB/HIV, and it happened – hey, because in my opinion more money goes to HIV/AIDS programme than the TB programme. I might be wrong, but that is just my perception.*

The experiences of Matilda could be explained in terms of the focus on HIV counselling, resonating with the response of Dr Bayley about counsellors of HIV patients being more structured compared to TB at the hospital. Hence, the policies emphasise the co-morbidity of HIV and TB, but the activities on the ground in the area of mitigation are skewed in the favour of HIV response. Matilda also stated that there were two authorities delivering healthcare, but there was not much coordination between these two authorities, the City of Cape Town and the WCDoH in the province. It is worthy of note that some clinics are under the Western Cape Province while most of the others are under the City of Cape Town. Matilda's thoughts are that if these two different types of clinics can coordinate better it may help in patients' CoC. Having served for many years in the health sector, she thought this was a policy problem that needed to be addressed to ensure better coordinated treatment procedures in the WCDoH provincial and City of Cape Town facilities.

> *Matilda (PN): And also in a metro area where we still have two different authorities that deliver healthcare, City of Cape Town and Provincial Government. The people don't get the optimal treatment because do they get ARVs at Provincial Government? Do they get TB drugs at City of Cape Town clinic? Or do they get both at one clinic? Or do they need to go to more than one facility to get the treatment?*

Portia commented further on the sound policies for health treatment, but she thought that it will be more helpful if there was another layer of institutional help from schools as well as better implementation of TB policies.

> *Portia (PN): As far as TB policies are concerned, the policies are all sound. They are just not implemented properly and we need to find some middle management level rather than from policy making. Maybe it is somewhere in-between. From what I have seen the policies are sound. Perhaps*

> *schools, I know my children are a great … ah, you are not wearing your safety belt…You know perhaps focusing on schools in understanding … It is something any community leader can do. It is not something that can be done from the government Eiffel Tower*

Portia maintained that better coordination from the education sector could facilitate better attendance for TB treatment. This means that there should be more teaching about TB in schools. However, it may not be far from accurate to say better coordination between the main health authorities should set the pace for more coordination between institutions, such as schools.

There were also issues that included uncoordinated authorities between staff themselves in different health centres. Dr Lina (Medical Officer/OM) commented on what should inform proper coordination, including roles and tasks when working with patients diagnosed with TB.

> *Idriss: What do you think can be done to ensure better continuity of care for patients with TB?*
>
> *Dr Lina (OM): I think to have all of this, for all of this to be done is to make sure that all of this gets written down in black and white; it might make a difference. I am not saying it shouldn't happen at the hospital, it should if we can. If we can't, we ask the clinic to do so. I think if it can be put down in black and white what needs to happen for all patients, if there is a tick list that can be followed, I think that can be great. The problem is that in the healthcare profession there are also other tick lists to go through and to give that extra work to healthcare workers it can be a little difficult, but we try, yeah …*

Dr Lina thought it would be much better that there were clear roles given to staff in hospitals and clinics. Edwina (WCDoH) pushed the discussion further by confirming the apparent gap between the hospital and the PHC clinics. Nonetheless, she was hopeful about the upcoming policy [TB policy] regarding better services to patients diagnosed with TB at the hospital. She firstly mentioned the issue of follow-up with DR-TB patients, which was a specific area of her work.

> *Idriss: What do you think can be done to ensure better continuity of care for patients with TB?*
>
> *Edwina (WCDoH): I am excited about it because we realise there were these gaps. With DR-TB it is*

> *easier to follow up because the cohort is smaller, and in addition to that, we are getting our sputum results of every person that has been tested positive for DR-TB – so it goes out to the sub-districts, it goes out to the coordinators. So whether you are tested at [a tertiary hospital in the Western Cape] or wherever, we will get that result. So our initiation with the DR-TB is 80%+, which I think is not bad. Our challenge is with patients that die without starting treatment. And that is a major case at the hospital because when they end up at the tertiary hospital they are very, very sick, but we want to strengthen that relationship even for sensitive TB.*

She went on to describe the relationship that has existed with some researchers that have been focusing on children discharged from the hospital.

> *Edwina: We have been working with the [a university in the Western Cape] to compile this. We have sent it for various communications. It is coming out today to say this is it. We are working with [Mikhail] because we have realised even with children as well, the children have been diagnosed and treated … we do not register the patients. We don't even know the children that were diagnosed with TB … I can say for DR-TB as well, because it is not sputum that have been done because if it is sputum that has been done, we'll get the results, it will filter to the facilities, but if it is a child or if it is extra-pulmonary TB the gap exist, but we are going to tighten that gap with the new SOP that is coming out. If I can table it on Monday, because my deadline is Monday … if people are not, because we are sitting with the 'B' group, if people are not happy with it, we will have relook at it* [laughs], *I want it to be enforced and approved.*

Edwina identifies that there were gaps on patients' CoC. She also mentioned that this is more crucial when children are also affected. She was hopeful that the new policy would bridge this gap of following-up patients upon discharge from hospital. The policy is in the pilot phase and hopefully might address some of the challenges being faced presently. In all the sections discussed above, the patients' treatment journey has been predetermined by the HCWs. The patients have been passive players in their treatment leading to discharge.

The main thrust of this study is finding the linkage between the hospital and the clinic. One of the key processes of this linkage is the discharge planning, understanding patients' needs as they prepare to leave the hospital and deciding how they can be involved in the whole process. The HCWs' knowledge on the way discharge planning should be carried out effectively left the patients powerless in this regard. Patients were seen in the health system through a "medical gaze" (Foucault 2003) that drew the attention of health professionals to the sick body and pharmacological treatment at the expense of focusing on the person as a whole. The "gaze" strips the individual of his or her individuality (Foucault 2003:65). Patients' "complexities" (Gastaldo & Homes, 1999:236) and "life issues" (Stewart, 2001: 445) get overlooked unless time is found to converse with patients. Using Foucault's analysis (considering the differences of French medical structure at the time from the present) I argue that patients do not have a role in discharge planning. Patients are treated and referred to the next level of care is a continuation of observing and providing medication to the patients. The patients have much to say about their home circumstances, which gives an indication of the most important area of their lives. The patients themselves are in a better position to not only express these "complexities" and "life issues", but also to be able to contribute to their own treatment journey. I suggest that the hospital should be mindful of the socio-economic problems that patients had that might have fuelled the health problem. The hospital could only refer the patient to the social worker for assessment before discharge. However, the social workers were not totally capable or empowered to respond to some of the problems. They basically provide transportation to the patients and only engage with families if they are around or if the families ask questions. Furthermore the HCWs confirmed the dire socio-economic needs of the patients. According to Joan, patients should be allowed the "responsibility" to be actively involved in their treatment, but the present medical structure does not afford them that opportunity to do so. This affects the third aspect of PCC, which is allowing the patients to make an input in their treatment plan.

The counseling of DR-TB patients is also highlighted, which makes the discourse of patient education at hospitals more crucial. It is understandable that patients with DR-TB compared to Drug-susceptible TB (DS-TB) should be counseled based on the severity of the disease. Many authors (Cox et al., 2010; Dheda et al., 2010; Streicher et al., 2012) have explored that it is very essential to provide extra care for patients diagnosed with DR-TB to DS-TB. However, the roles of patients in both cases (DR-TB and DS-TB) should be considered in discharge planning because one of the problems of DR-TB is incomplete treatment, which is sometimes due to non-attendance at clinics and also non-adherence to treatment. This is noted in the literature (Chaisson & Martinson, 2008; Cox et al., 2010; Dheda et al., 2010). In addition, the socio-economic constraints faced by the patients were clearly expressed by both patients and HCWs, including policy makers. The context of poverty and lack of participation seen through powerlessness by patients in discharge planning were discussed as themes that featured significantly in the hospital. Joan, one of the policy makers, commented about "patient's needs", but also how patients are not active players in decision-making in the hospital regarding issues that will directly affect their health. Hence, on one hand the system makes people powerless, but also people are powerless in the face of the huge material insecurity they live in and the family situations they are a part of. Patients' agency to continue with their own treatment was widely discussed by HCWs, but it was clearly noted that there were many socio-economic barriers that militated against this agency. How patients' socio-economic life influences their attendance at clinics will be explored in the next chapter.

The public-private sector disparity and imbalances in managing one's health in different social classes in South Africa and the focus on public PHC (Schaay, Sanders & Kruger, 2011; Lewin et al., 2008) feature in Linda's statements. She mentioned that patients may receive better care in private hospitals, but the patients who accessed public hospitals are mostly from poorer backgrounds. Joan made the point that the "complexities" of the patient include not only about treatment of the disease but also family responsibilities. This theme can be compared to adherence to TB treatment as well. These complexities of the patients' treatment will be more apparent if the patient does not have or will refuse to go to any other place to get TB drugs. Joan goes on to make a statement, regarding TB treatment linking it to food security, which is the main challenge facing patients that have been neglected. The literature reveals that even though individuals are responsible for making choices including to lead healthy lives, some of these choices are made in particular contexts (Abebe et al., 2010; Noar & Zimmerman, 2005; Mackian, Bedri & Lovel, 2004). The health sector in itself is positioned as a structure that either enhances or limits the choices that individuals make. In the HCWs' responses, the patients displayed lack of agency, but this agency is often greatly constrained by structural factors (Bradshaw et al., 2006; Sanders et al., 2009; Sinanovich., et al., 2003).

Shared decision-making, which is one core tenets of PCC affects CoC. Furthermore, CoC can be enhanced by good collaboration and coordination between health centres to the benefit of the patients. Availability of information about patients is, of course, a crucial component. However, there is also an interpersonal relationship that should develop with HCWs, to enhance "a sense of trust and sense of responsibility" by the patient and the HCW (Hjortdahl & Laerum, 1992:137). Gordon & Krauthoefer (2007:937) also argued that to enhance CoC there must be "clear notifications, referrals and follow-ups" between the hospital and the clinic. They warn that limited coordination and inadequate transfer of information or communication between health centres and health care professionals can lead to "patient and family dissatisfaction…and increased cost" (Gordon & Krauthoefer 2007: 937). Furthermore, patients' knowledge and experiences of what the system entails can facilitate this continuation of treatment in their preparation to leave the hospital. This was not the case in the hospitals.

It has been discussed above that some patients think that the treatment received at the hospital was sufficient and they are healthy enough to continue with their normal life (Gebremariam, Bjune & Frich, 2010). As I continue to argue in this chapter, the patients' individuality including socio-economic life situations are not prioritized in the healthcare they receive. The main concern for HCWs is for patients to get access to the next level of care. Within PCC, and proper CoC, the production of a discharge letter may only be part of the solution when it comes to a successful health outcome. HCW-patient interaction should be used as a moment of opportunity to speak to the patients. There should be at least an awareness of socio-economic constraints of patients alongside treatment plans (Engels, 1995; Farmer, 1996; Coovadia et al., 2009; Sanders, 2009). Otherwise, patients will be treated in the hospitals and the clinics and go back to the same conditions that may have caused the problem in the first place.

CONCLUSION

This chapter examinedthe discharge planning process at the hospital. The third aspect of PCC, which is decision making/shared mitigation strategies, has been explored. Drawing on Foucault's analysis of the "medical gaze" and SDH, I argued that the patients have not been a partner in their treatment journey. There has also been poor collaboration between health centres, where patients move from one health centre to another with not enough clarity on what lies outside the hospital. PCC requires a process where patients are an integral part of the processes of treatment, in which listening to their fears and concerns before leaving the hospital is essential. The patients should be able to explore ways that will enhance better CoC. Furthermore, there could be ways to find a shared solution for a better health outcome. SDH as well as patients' lack of agency give us an indication that patients were much more concerned about living conditions and family life equally, much more than even their medical condition.

Also, on the bigger structural end of the situation there was still a medical structure that saw the patients at the receiving end of scientific information. Their only choice for continuing with treatment was to report to the next level of care until they were cured. There wee some observations by HCWs on what would enhance CoC, including a parallel response to HIV/AIDS and TB and strengthening coordination between hospital and PHC clinics – but the patients' perspectives and contributions were still not part of this imagined solution. Although policy makers mentioned the aspect of shared responsibility and allowing patients to be part of the healing process, the literature and findings in the previous chapter have confirmed insufficient staff and time constraints that continued to be a serious challenge in the health sector in South Africa. These problems also featured in discharge planning. PCC encourages an approach where patients should be given the space to express their needs. They should be able to describe their socio-economic and cultural circumstances. Supported by governmental and non-governmental organisations, the hospital should be more proactive in addressing the circumstances. They should incorporate patients' own contributions. The patients are concerned about improvement of their health, but they are not oblivious to the socio-economic conditions of their lives. The lived experiences of the ten patients who were followed-up to their homes and clinics wereexplored in the next chapter. It showed the complex circumstances that caused them to attend the clinics for continued treatment or stopped attending the clinic during the course of their treatment.

CHAPTER SIX: PATIENTS, FAMILIES AND HCWS EXPERIENCES OF TREATMENT AFTER DISCHARGE FROM HOSPITAL

INTRODUCTION

This chapter described and analysed patients' experiences and perceptions of treatment after discharge from hospital with special attention paid to their home and family circumstances. Conducting follow-up interviews in patients' homes was important to this study as this allowed better understanding and contextualising of patients' perspectives. Being in the intimate space of the home enabled me to observe first-hand some of the difficult living conditions and troubles with family support patients had described in their hospital interviews. It created an opportunity to explore these in greater depth. This study brought to the fore the experiences of patients in both clinical and their living conditions in order to get a better understanding of what influences CoC (based on these dual experiences of patients). Both aspects are crucial elements to explore in the patients' journey in CoC.

In this chapter the experiences of healthcare workers (HCWs) treating patients in clinics were also described and analysed. HCWs at clinics also did not only roll out treatment, but offered education and counselling to patients and did home visits. It is argued in this thesis that influences of CoC involved not only interaction with HCWs at hospital and collaboration and transfer of information between the hospital and the clinic, but also patients' home situation and family support. Throughout this chapter I pointed out that social determinants of health (SDH) were at play when trying to understand why some patients either attened the clinics or stopped attending the clinics. These were also seen in some of the responses during their treatment at the hospital, including discharge planning. Failures in patient-centred care (PCC) still linger on in many aspects of patients' lives. Foucault's 'medigal gaze" was also seen in the way nurses operated in a medical structure that objectified patients. The first part of this chapter described the environments in which the patients resided. It continued with identifying the numbers that attended the clinic after discharge and reasons provided for attending or not attending the clinic during their treatment plan. The second part of this chapter presented some of the reasons for, and factors influencing, non-attendance from the patients and families' perspectives. This part of the chapter highlighted how the failures of PCC continued right through to the clinic; more specifically how the hospital took note of estranged family relationships. The third part of the chapter presented HCWs' perspectives on what influences attendance or non-attendance at clinics. This third part juxtaposed the impact of a lack of PCC and the socio-economic aspects of the patients' lives and how that affected CoC.

I argued in this chapter that problems with CoC caused by a continued lack of PCC were compounded by patients' socio-economic circumstances. The HCWs in the clinics, just as those in tertiary and district care, spoke of lack of adequate education and collaboration between the hospital and clinic. In addition, the patients followed through to their homes expressed confusion about their diagnosis and being too scared to attend clinics about the disease despite TB counselling at the clinic. Some of them also expressed lack of resources, abuse and stigma at home by family members. On the other hand, the patients who continued consistently with their treatment at the clinics said that they had internal motivation to do so –these patients also had better financial standing and family support.

SOCIO-ECONOMIC CIRCUMSTANCES OF PATIENTS

Ten patients were followed up to Khayelitsha and Langa, known as "townships" (See Chapter One). I observed that some houses were well-structured, meaning they were made of brick, had well-fitted roofs, were nicely painted and had a fairly big space for children to play or to park vehicles. Some of these homes had television sets, radios, heaters, running water supply and good sanitary system, for example a flushing toilet. However, what was common in some of these well-structured homes was that many people resided in them. For example, a two-bedroom house that could normally house a nuclear family comprising father, mother and one or two children, may also house extended families of aunts, cousins and nephews. Some of the residents may sleep in garages and other smaller units on the same plot. Conversely, there were many precarious houses, called 'shacks', made of some discarded items or scrap materials such as timber and metal sheets, which can be acquired at no cost. Sometimes metal sheets are purchased as materials used to construct these houses are not always made of materials that are thrown away. Some of these houses barely had a proper chair to sit in. These houses were also not only overcrowded, but also lacked running water, better sanitary systems or flushing toilets inside the house and heating facilities to keep residents warm.

The townships where my participants resided had at least one public clinic and a fairly big shopping centre, mostly within walking distances from their homes. Khayelitsha actually has several public clinics and many private general practices. There were also local food outlets and open areas where people sold a variety of foods and beverages. Generally, the clearing of debris and waste disposal in some residential areas were not always done as more piles of waste could be seen in some sections than others. Some smaller roads leading to main roads were not well constructed compared to main roads in the townships. Cars had to travel carefully in order to navigate to desired areas by a given time. Electricity was available in most parts of the neighbourhoods, apart from those who could not afford to buy 'prepaid'[13] electricity at one time or another and would connect informally. The available electricity was evidenced by the sound of a different blend of local and international genres of music in the streets and some neighbourhoods. The signage of buildings and streets was clear enough to find one's way using a GPS, although it was more difficult to locate specific houses. There were problems with the numbering system of houses because there were often multiple homes on one plot. This brief description of the homes and nearby environments is quite similar to other documented experiences of life in the townships (Final Draft, HRC Area Case Report, 2003; Muchapondwa, 2007; Puoane et al., 2005). Problems of poverty and inequality as well as high crime rates (Ohuabunwa, et al., 2015) plagued the daily living of many people in Khayelitsha.

Langa is not significantly different in terms of living conditions described above. However, even though both communities are part of the City of Cape Town, known as Cape Flats (Regional Development Profile, City of Cape Town, 2013), Langa is situated much closer to the suburbs and city centre (see Chapter One) than Khayelitsha. Also, Langa has a population about 10 times smaller than Khayelitsha. The experiences of people living in the townships contrasted vastly to areas known as 'suburbs' in other parts of Cape Town.

The five different clinics[14] that the patients attended had very similar structural and physical profiles. They were brick-walled clinics, with flushing toilets, staff offices, changing rooms and counselling rooms. The staff members range from at least one doctor seeing patients with TB, one TB counsellor, a few community

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[13] Prepaid is an electricity provision system where people subscribers buy the amount of electricity they need at a given time.

[14] Note that one patient attended a clinic in another township, but resided in Langa.

health workers (CHWs) who visited patients diagnosed with TB in their homes, and a number of nurses. There were always designated nurses who worked with patients with TB. In some clinics, a collection of HCWs – nurses, doctors, TB counsellors and CHWs – worked as a team, where they met weekly to discuss activities relating to patients with TB.

Based on my observations, one of the problems at the clinic was overcrowding, especially in the morning hours from 6am to 11am. The numbers of patients, initially about 200, waiting to be attended to gradually dwindle between 12 and 2 pm. Everyone accessing the clinic was advised to put on a surgical mask. This not an N95 mask (See Chapter Three), but a fragile mask made of a lighter material, so it did not fit as well and was not as comfortable as the N95 one. Some people wore the mask and some did not. In other words, from my observation, if one chose not to wear a mask, no one would insist one did. I observed that in all the clinics there were limited staff attending to large numbers of patients. This was evident from the length of time it would take for a patient to be seen by a nurse or doctor. Many patients would come very early (as early as 5:00 am), in order to be treated at the clinic. Staff shortage has been a recurring theme in the health system, which the literature has discussed (Breier, Wildschut & Mgqdozana, 2009; Hall, 2004) as well as experiences of HCWs at the hospitals.

PATIENT PERSPECTIVES ON FACTORS INFLUENCING CLINIC ATTENDANCE

Once again, in theory, patients diagnosed with TB while hospitalised were meant to be discharged with a week’s worth of drugs (Department of Health, 2004; Dudley et al., 2018); Marais, Kallon & Dudley., Forthcoming). They were meant to have had the length of their treatment explained to them, been given a referral letter and been told to go to their local clinic before their medication ran out in order to get their next supply. The DOTS system, as explained in Chapter One, required each patient to attend the clinics five days in a week for the first eight or 12 weeks. After this period, the patients were expected to attend three days in a week until the treatment is completed (Karumbi & Garner, 2015). In some cases, as would be seen in the responses of the participants, some of patients receiveddrugs for one month as they were discharged from the hospital. In addition, when they started their treatment at the clinic, they should continue to attend daily. After the first eight weeks, they should attend the clinic every third day. In some cases, depending on patients’ adherence to treatment, they would attend the clinic once every month to collect their TB pills.

Of the ten patients with whom I conducted home interviews, nine attended the clinic at the expected time, which was after one week of TB pills given to them. One patient attended the clinic three days after her TB pills were finished because she was feeling sick. Most importantly, four of the patients stopped attending their clinics during the course of first four to 24 weeks of treatment, five of the patients attended consistently, one passed on. It must be noted that even though some of the patients did not mention the exact date they stopped their treatment, I was able to estimate it at between the first four to 20 weeks. I conducted the second interviews after one month and the third interview after 20 weeks, which was closer to their completion date. The two MDR-TB patients' treatment was ongoing, but I secured the information of treatment completion of all patients from HCWs at the clinics. The patients that stopped attending the clinic during the course of their treatment and those who attended consistently expressed their reasons for not doing so, wweredescribed and analysed below. In addition, as mentioned above, the experiences of HCWs in the clinics as well as families who assisted the patients were described and analysed. The patient's referral hospitals and clinics, attendance or non-attendance and treatment completion are listed in Table 3: Patients' description of clinic attendance/non-attendance and completion of treatment.

Table 3: Patients' description of clinic attendance/non-attendance and completion of treatment

Patient's Pseudonym	Hospital referred from	Referral clinic and location	Attendance at clinic after discharge[15]	Stopped attendance (between 4 – 20 weeks)	Attended till completion of treatment	Completed treatment
Aphiwe	Hospital 1	Clinic 1	Yes	Yes	No	No
Babalwa	Hospital 2	Clinic 3	Yes	No	Yes	Yes
Bianca	Hospital 1	Clinic 6[16]	No	N/A	N/A	N/A
Buhle	Hospital 1	Clinic 5	Yes	No	Yes	Yes
Fezeka	Hospital 1	Clinic 2	Yes	Yes	No	No
Nandipha	Hospital 1	Clinic 1	Yes	No	Yes	Yes
Ndiliswa	Hospital 1	Clinic 2	Yes	Yes	No	No
Thandiwe	Hospital 2	Clinic 2	Yes	Yes	No	No
Themba	Hospital 2	Clinic 3	Yes	No	Yes	Yes
Zintle	Hospital 2	Clinic 5	Yes	No	Yes	Yes

Scared and confused in accessing care

Fezeka, aged 49, lived in Khayelitsha, and was married, with three children. She had obtained a Grade Six education, but she was unemployed. As briefly explained in Chapter Four, Fezeka had a quiet disposition. She lived in a two-bedroomed house with her mother, daughter, two granddaughters, her aunt and cousin. Her brother lived in another house in the suburbs. We sat in the lounge on three white plastic chairs, with a small dining table a few metres from where we were sitting. The house was fairly well ventilated, because I could feel the air coming through the window, although her house was virtually attached to her neighbour's. There was some space in between the houses, though – big enough for someone to walk between the houses. Fezeka quickly lamented being unemployed because of her illness. She had lost her job because she became sick with TB. Also importantly, as she expressed lack of income

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[15] A reminder that patients are given 7 days TB pills, which they are expected to take at home after discharge. They are expected to report at the clinic before the treatment is finished.

[16] Bianca did not attend Clinic 6 that she was referred to. She passed away before attending the clinic. As a result of this I did not interview healthcare workers at this particular clinic. Therefore, it was omitted from the list of clinics I visited.

at present (she had been employed prior to discharge), she explained her feelings when taking the medication after discharge and her anxiety about continuing to go to the clinic.

> *Idriss: How have you been feeling?*
>
> *Fezeka: I am feeling better … though I am not working now because of my illness ... but sometimes you get pain, like vomiting.*
>
> *Idriss: Have they changed your medication recently because of that?*
>
> *Fezeka: Yes, that one is fine now. It doesn't make me feel like vomiting. And then I try to eat.*
>
> *Idriss: Tell me about your knowledge of TB now as compared to before when you were in hospital.*
>
> *Fezeka: No one talks about TB. They just give you your tablet and you go home. I started going every day to the clinic. On Friday, they give you for Saturday and Sunday.*
>
> *Idriss: So you were going there every day?*
>
> *Fezeka: Yeah, every day. No, now they give me monthly.*
>
> *Idriss: Do you take your medication daily?*
>
> *Fezeka: Yes, I do. If you do not take it, the TB will come back. I get more support from the hospital.*
>
> *Idriss: What makes you say that?*
>
> *Fezeka: Because always the nurses [*at the clinic*] will give me the tablets and everything and say you must eat now and take the tablets. The tablets caused the death of my daughter.*

At this moment I was trying to make sense of Fezeka's statement regarding getting "more support from the hospital" and that "the tablets caused the death of my daughter". I probed this issue a little bit further. It must be noted, as it was with the patients I interviewed in their homes, that this was my third interview with Fezeka. I had interviewed her once at the hospital and twice in her home. One of the interviews at home was done about a month after discharge and another interview during completion of her treatment. It was during the third interview at home that she felt at ease enough to reveal some intense apprehension and anxiety of the way she was treated at the clinic she was attending.

> *Idriss: So how do you feel when you have to take the same treatment that you say caused the death of your daughter?*
>
> *Fezeka: I didn't feel good. I am always vomiting. I am not eating. Another doctor take me to another clinic by [*Hospital 2]*. And they told me that my liver is damaged. I told my brother. He was so upset, I was also upset. He wanted to go to the doctor* [at Clinic 3] *asking why he gave me the tablet because my liver was damaged. I am scared. I am so scared.*
>
> *Idriss: What did you do after this?*
>
> *Fezeka: I stopped going there and stopped taking the drugs at some point.* [Fezeka did not explain the exact time that she stopped taking the treatment, but it was between four to 20 weeks because I conducted my last set of interviews in the fifth month of treatment].
>
> *Idriss: Did you stop going to the clinic to receive the drugs at that time you were scared?*
>
> *Fezeka: Yes. I went to that doctor on Monday and asked him, why didn't you tell me that my liver was damaged? He said, No, it is not me, it was the nurse who gave you the tablets. Why didn't you tell me?*

Fazeka and others described defining moments in their engagements with HCWs in the hospitals as well as the clinics. Generally they recounted feeling much better after discharge, but an understanding of the information regarding their treatment including side effects and/or different adaptability to the same treatment seems to be a problem. Fezeka's aunt and daughter confirmed that she did stop taking her medication at home. Fezeka's aunt, Phumi, who was interviewed separately and at a different time, said:

> *Phumi: Sometimes the patient hides the information from the family … she stopped taking the medication. She thinks she is feeling well now and she can stop taking her medication.*

Phumi's story did not include Fezeka being scared to attend the clinic and continue taking the drugs. It only affirmed that she did stop taking her treatment. What is interesting, though, is that Phumi's statement is similar to one that a HCW made at the hospital, that some patients stopped going to the clinic because they thought they had been cured.

Aphiwe, a 28-year-old, lived with his mother in Khayelitsha, not too far from the clinic. He had attained a Grade 10 education and was unemployed (See Chapter Four). Aphiwe's home was much smaller, compared to Fezeka's. He and his mother lived in a one-bedroomed "shack" with little ventilation or light as it was also squeezed between other shacks. The living home had few sofas. The windows were opened though that had some air flowing into the living room. Aphiwe's story highlights other reasons for not attending the clinic and stopping treatment. He was more "confused" about his care than being "scared", based on the information given to him about his diagnosis. From my first encounter with him at the hospital. Aphiwe's facial expressions were never pleasant. He also looked pale and emaciated. He was very concerned about his diagnosis and was not satisfied with the knowledge he had received regarding his sickness as a whole.

> *Idriss: Tell me how you are feeling since your discharge from hospital.*
>
> *Aphiwe: I have not been feeling well.*
>
> *Idriss: What has been the problem?*
>
> *Aphiwe: Because I stopped taking the treatment*

I was a bit surprised by Aphiwe's immediate response as that was the first set of questions I asked in my second interview with him. It appeared he wanted to explain that he had tangible reasons for doing so. I probed further as to why he discontinued the treatment.

> *Idriss: Were you told that you had to take the drugs for six months?*
>
> *Aphiwe: They* [at the clinic] *did, but I have not been going there.*
>
> *Idriss: Then what makes you stop taking the treatment?*
>
> *Aphiwe: Yeah, I didn't understand it. I am getting weaker again.*
>
> *Idriss: OK, you didn't have enough understanding of what, the treatment?*
>
> *Aphiwe: The doctor that I met* [in Hospital 2] *did not tell me, but at* [Clinic 4) *I did ask them, 'Doctor which TB are you treating?' She told me that it was a normal TB. As the time goes after they discharge me there* [Hospital 2] *I came back again for the treatment, now the story changed they told me that it is a TB that is close to MDR, but it is not MDR. That is where I started to be confused*

> *… I am not on MDR treatment and they are stopping me to take the treatment I get from the clinic when I am there [*at Hospital 2*]. They are giving me another treatment. And when they send me to the clinic they are also stopping me to take that treatment [*the treatment received from Hospital 2]. *They are giving me another one. So, I don't know … I am confused.*

The cases of Fezeka and Aphiwe being scared and confused respectively were based on the interaction they had with HCWs, both in the hospitals and clinics. Also, they responded to questions based on the kinds of information given to them. For example, Aphiwe mentioned that he was concerned about what kind of TB he had from his hospital experience. This anxiety continued and led to confusion. An engagement to understand Aphiwe and Fezeka's concerns could have reduced this confusion. The problem of not spending time with patients to understand their concerns, fears and anxiety continued after discharge. Hence, clinics, just as hospitals, did not seem to bridge this gap in PCC. Fezeka was understandably concerned about the drugs given to her because she blamed these for the death of her daughter. The way Fezeka internalised the treatment given to her daughter was a problem. Nonetheless, an exploration of her fears and anxieties, coupled with proper counselling in the hospital and clinic, may have clarified some misconceptions about the treatment. The patients' expressions seemed to trigger doubts and lack of trust. This has the propensity to affect CoC. Aphiwe and Fezeka seemed to have distrusted the health system because of the mixed messages as well as a failure to explain what may have caused a fatal side-effect or about something else that caused the death of Fezeka's daughter. As a result of these problems, both patients stopped attending the clinic for continued treatment.

PCC would have first involved being clear with Aphiwe about his diagnosis and taking the time to listen and respond to his fears and anxieties. This engagement should have been continued in the clinic, and could have prevented any confusion. One of the tenets of PCC is to treat all patients on a case-by-case basis. Other patients did not express a great desire to know what was really wrong with them. This was not the case with Aphiwe. He expressed concern about his diagnosis from the hospital right through to the clinic. According to him, his response to the demands of attendance greatly depended on knowing what kind of TB he had. Secondly, when he was eventually told it was not really MDR-TB, but "something close to MDR-TB", he became more confused. There was not much time spent on understanding what was going on in the head of Aphiwe. The interpretation of Aphiwe staying away from the clinic may be considered as a case of ‘defaulting’, as he himself said earlier, but labelling him a ‘defaulter’ obscures the fact that there were opportunities to take his fears and anxieties seriously that were missed and these may have helped him to attend the clinic and continue with the treatment.

Poor partnership in discharge planning and estranged family relationships

The previous chapter described how patients were not involved as partners in discharge planning. In discussing their plans for going home, it became clear that not all patients had a good relationship with their families. Hence, the discharge process failing to adequately understand that patients’ home situations compounded the existing rifts between patients and their family members. Examples of this are provided in the participants’ responses. In some instances, patients having to stay in the homes of family members with whom they did not have good relationships also caused tension, especially if family members were afraid of contracting TB themselves. Even though there were lapses in PCC from the hospital through to the clinic, these intermingled with the family problems of the patients created severe stress in the patients. Bianca was the only patient I interviewed in a suburban area (this one being Parow), where she stayed briefly with her mother, Cheryl. The home was a one-bedroomed flat in tall complex with not much ventilation, overlooking the mid-town district. Even though the building was tall, and ideally could have far more air flowing through it, it was surrounded by other buildings that were too close. The flat had one small window. The area could be considered a middle-class environment, but there were many working-class people in the neighbourhood, such as Bianca’s mother. The apartment had comfortable furniture but no television or radio. Cheryl, who was interviewed separately from her daughter, complained of dealing with an issue she was not prepared to handle.

Bianca had not been living with her mother for the past four years, but had been staying with her grandmother in Bishop Lavis, a comparatively poorer community. Cheryl only found out about Bianca’s illness when she was contacted by a work colleague to say Bianca had been discharged from hospital. Cheryl lamented that she did not understand why the hospital had discharged her daughter without trying to get in touch with her first. Bianca had not started going to the clinic yet, even though she had been discharged for about three weeks to a month. She been told to continue taking her ARVs and TB pills given to her by the hospital. This was my second interview with her. Bianca told me she was doing fine, but her facial expressions did not show that. She looked sad, pale and emaciated, similar to Aphiwe's appearance. She was one of the patients who articulated a sense of hopelessness before her discharge from hospital. and the home situation compounded her predicament. There was a clear lack of affection between Bianca and Cheryl, who explained their strained relationship:

> *Idriss: How is Bianca coping with the treatment* [drugs given to her at the hospital*]?*
>
> *Cheryl: It was only on Friday when they* [Bianca's aunt] *came … I don't have contact with my daughter. She is not part of my life anymore because they are grown-ups, they are adults. It is just now when she came.* [Cheryl explained this in an unpleasant tone. Her voice sounded hoarse]
>
> *Idriss: In other words, she was not living with you?*
>
> *Cheryl: Friday was when she came here. Now you understand my inconvenience?*
>
> *Idriss: Yes, I understand. You mentioned earlier* [on the phone. Cheryl contacted me before and complained before I came to interview them] *about the hospital not informing her about when she would be discharged or where she would be going.*
>
> *Cheryl: Or even the people, because remember on record they have got addresses, they* [the hospital] *have got everything written on the paper. Even if they don't have the phone number, they do have the addresses before they send them to someone. This is just my point of view.*
>
> *Idriss: Explain to me how she came here.*
>
> *Cheryl: She was at* [a resource-poor community in the southern part of Cape Town]. *That was the address she gave to the hospital, but my mom sold the house so she told me that she went to my aunty and my aunty phoned me because she can't stay there. And obviously, where must she go? So I have to take her in.*

Cheryl had mentioned earlier that the hospital had their addresses, but it seemed that the hospital only had an address in the southern part of Cape Town and not hers. Nonetheless, it was interesting that Bianca left the hospital by herself, very ill. She received taxi fare from the social worker and went to her aunt's place. From observation of the condition in which I had seen Bianca in hospital, I would have thought she would be hospitalised for a longer period. She was very weak and, most importantly, not in a good emotional state regarding her illness. Based on the frequent calls I had received from Cheryl as to why

Bianca had been allowed to be discharged in such a state without any contact with the family, I had to conduct the interview earlier than I had expected (about three weeks after she was discharged). From my conversation with Bianca in the hospital ward, I knew that her family did not know she was in hospital. The hospital did not know this because she had an estranged relationship with her mother. Apart from the fact that Cheryl had not had a good relationship with Bianca, her present living conditions escalated the problem. I probed this issue further.

> *Idriss: You mentioned certain things over the phone – could you clarify some of them for me? Firstly, do you think this* [her home] *is a good place for Bianca to be treated?*
>
> *Cheryl: No.*
>
> *Idriss: What makes you say that?*
>
> *Cheryl: Because, number one, it is a bachelor flat. It is only supposed to be for one or two people, but now she is here it makes it very …* [could not find the words]. *I have to keep her here and look after her and I am at work. So at night she must sleep here because if anything happens to her and I am alone, I don't know what to do. So that is the inconvenience and I know with TB you have to have a lot of breathing space. You can see here it is not much. And at night I cannot sleep with my windows like this. So all in all, it is very inconveniencing. She collapsed twice here, but luckily we were around. What if we weren't around? And my personal life, it is being affected also because I just got married now in December last year and it is my first marriage. He* [her husband] *got one child which is nine years old. He doesn't have these experiences. So that is putting a bit of strain on my personal life also.*

After one month I got a call from Cheryl that Bianca had passed away. I consoled her over the phone. I did not do a follow-up interview, but I talked to Cheryl again on the phone, asking how she was doing. She said she was coping well. She told me she would go to be tested for TB. We did not speak of her disgruntlement about the discharge process of the hospital again.

Feeling embarrassed at clinics

Nandipha’s home was structurally in a better condition than Fezeka and Aphiwe’s. It was a nicely built cement house with a garage, a small playground for children, running water, electricity and comfortable couches in the lounge. However, it was overcrowded because it was a two-bedroomed house where Nandipha lived with her grandmother, her aunt and her husband with their two children, and her own two children as well. Nandipha slept on the couch with her two children. She recounted how she had moved to another clinic [Clinic 3] at one time during her treatment because the nurses at her first clinic used to shout at her. This behaviour made her very concerned any time she had to go to the clinic. Nandipha’s story of stopping her treatment because of being embarrassed by the nurses when she attended the clinic to receive her treatment also highlights the issue of stigma in some of the clinics, which has been a recurring problem in the community.

> *Idriss: How do you feel when that* [being embarrassed] *happens?*
>
> *Nandipha: And you have got the right support because even the first time I went to the clinic I was feeling quite weak. My legs were jiggy. I didn’t actually go to the clinic as soon as possible, but when I got there, yoh, those nurses were shouting ‘Why don’t you go to that clinic?’ I told them that a lot of people in my area are going to that clinic. You know how stigma can stay with someone and I don’t like people talking about me, saying she is also taking ARVs and … I mean that also makes you lose your concentration on what you are trying to do, but they said ‘No you cannot come here’, but I said ’What is wrong in asking for assistance in healthcare? I mean, you can go anywhere and get healthcare, why can’t I come here?*
>
> *Idriss: What happened afterwards?*
>
> *Nandipha: I had to stop because there is no taxi there. So you have to practically walk and my legs are still not fit enough, even when I walk long distances, I have to rest in-between, but when you go to* [Clinic 3] *it is like five minutes’ walk.’ You catch a taxi. Why don’t you go there?’ they were shouting. So that doctor wrote a letter to another doctor, and then she said she doesn’t have a problem because she has treated me before. And there you just get your tablets … they* [nurses at Clinic 3] *can really break somebody’s spirit, honestly.*
>
> *Idriss: How would you like to be treated at the clinic?*
>
> *Nandipha: More politeness towards people, not necessarily me, towards a lot of people because* [Clinic 3] *staff, they are quite known for the way they treat their clients. You know? My granny was offended when she went there* [Clinic 3] *the first time she was told to go and get an HIV test.*

> *She didn't like that. She was quite offended … If you know you have to go to the clinic, you will wake up cheeky in the morning because you know you will be going to some hell hole or something.*

Themba, a 29-year-old man, lived in Khayelitsha with his aunt. The house that was owned by his aunt was quite similar to Nandipha's. It was made of bricks, it was strong-roofed, nicely painted, had running-water. There were a few comfortable sofas in the lounge with some long benches to accommodate more people at a given time, as well as a television. The main house had good ventilation, as there were several windows and corridors linking to a back door. Themba did not sleep in the main house, though. He slept in what used to be a garage on the same plot because there was no space for him in the main house. Themba complained of poor ventilation and how cold it could get in winter and on rainy days. He told me that he hoped he would one day have a decent flat of his own. Themba also expressed concern about reporting to the clinic for fear of being embarrassed by the nurses. However, he said he never stopped attending the clinic because of those experiences. He was attending Clinic 3, which was not too far from where he lived. He expressed uneasiness about having to attend this clinic:

> *Idriss: How is your experience at the clinic?*
>
> *Themba: They used to be annoyed when I ask something because I have to think twice if I want to ask anything because they have different choices and they can address you in that proper manner, but as the time unfold they became nice.*
>
> *Idriss: When were they not nice?*
>
> *Themba: When I defaulted.*

Temba's use of the term 'defaulted' caught my attention again as it showed how some patients have incorporated terms associated with the 'adherence' and 'compliance' discourse in medicine. It sounded as if Themba was blaming himself for not attending the clinic at a time he was supposed to collect his medication or pills.

> *Idriss: So there was a time you did not go for your treatment?*
>
> *Themba: Yes, because it was raining. That is when they would shout at you.*

Bad weather, such as rain, can sometimes affect patients who would have to walk to the clinic to get their TB pills. Heavy rains sometimes cause floods in some areas, so it might be a concern for Themba about getting wet and cold and being unable to warm up because there are no heaters or thick blankets available. Having to walk to the clinic and wait outdoors there in the rain could be a challenge to many patients. It worsens when you do not have the facilities to dry your clothes and shoes at home.

I interviewed Themba's mother separately, as I did with most family members. The family members of these patients recounted similar patterns of being ill-treated at clinics, whether attending for themselves, or accompanying their family members. Themba's mother, Thandi, explained:

> *Thandi: There is some kind of that nature that one feel sometimes not to go to the clinic because of the attitude of some nurses. Yoh! The nurses are the ones who have the attitude that will make someone not to go to the hospital or to the clinic"*.

Some of the participants were keen to hastily suggest what they would like to see in the clinic. Thandi was no exception. She indicated what they needed to do at the clinics:

> *Thandi: If the clinics could have a proper care for the patients, even the patients themselves could have a way of getting help because of the way, the care that he gets from the clinic. And that will make him go frequently to his appointment. The care is the major part at the clinic. They are not doing enough …They shout at patients and they get very impatient at times.*

Thandi explained one key component of PCC, which is showing 'care' to the patients, which means understanding their needs and feelings about the treatment. A lot of the patients and family members had some good things to stay about the doctors in the clinics, but many bad things to say about nurses.

Domestic abuse and stigma in the home

Some of the patients experienced different forms of domestic abuse which hindered their attendance to the clinics during the course of their treatment. Family relationships were complex and involved expectations that were not always forthcoming. In my third interview with Nandipha, the issue of sexual abuse by a family member was brought to the foreground.

> *Idriss: I see that you are not looking too good as compared to the last time I saw you.*
>
> *Nandipha: I have not been feeling well lately. I have not been going to the clinic either.*
>
> *Idriss: What happened?* [She paused for a long while].
>
> *Nandipha: Hey Idriss, I don't want to cry* [she started crying anyway]. *I was too stressed, I guess, because my uncle who was living here came inside here at home and he was the one who was abusing me and everything* [continued crying], *from an early age. He was the one who made me sick. He is my grandmother's last-born son. And when he is here I am not motivated to do anything. You know I am sorry to say this, but I hate him so much because I won't be in this position if it wasn't for him, but now that he's left I am just trying to scram my life back together again.*
>
> *Idriss: Did you try and speak to a family member?*
>
> *Nandipha: My grandma knows everything, but you know how old people are. She said 'Why didn't you say anything sooner?' Because I had to break to it to her that I was taking ARVs also … because all these years I have been telling my grandma that I was taking medication for low blood sugar* [Nandipha was referring to her ARV treatment].

Ndiliswa also told me about having to cope with the abusive behaviour of her husband who stigmatized her for having MDR-TB. She lived in a fairly big house that was more spacious than the other patients mentioned above. It was a three bedroomed house, with a dining room and one toilet. Though it was not painted on the outside, it was nicely painted on the inside. Ndiliswa resided with her children (aged 12 and 10), who were much older than the other patients' children. Since she was diagnosed with MDR-TB and her treatment was extended, that had the potential to put more strain on family relationships. Ndilisiwa's situation appeared to be stigma at the home, but was also coupled with some level of confusing information received at the clinic and hospital. According to Ndiliswa, stigma at home, coupled with confusion about her treatment, affected her attendance and her continued treatment at the clinic. Ndiliswa experienced it in the home from someone she expected support from. I asked her about her family support at home.

Idriss: Have you been getting support from your family?

Ndiliswa: Yeah, Doctor [she was referring to me], *it is my first born. He's the one who takes me to the hospital, the clinic, looking after me because when I came I was so weak ….* [crying] *my daughter was very strong. Some people, if they hear MDR, they think that* [did not finish the sentence] … *I have got two kids 12, 10 years, they have got that joy that 'My mother is coming from …* [the hospital]', *(but) my husband is saying 'You must not sit close to your mother because she is going to affect you'* [crying]. *I was not feeling nice.*

Idriss: He said they must not sit close to you because you are sick?

Ndisliswa: Yes. When I was coming [at Clinic 2] *they know that this* [Ndiliswa was referring to herself] *have got MDR, but it did not affect the people.*

Idriss: Did you tell him that you were not feeling nice about this?

Ndisliswa: He is the first person that got MDR, my husband, but now I don't know why he is saying 'don't go closer to your mother'.

Idriss: Do you think it is because he is afraid that the kids might be infected?

Ndisliswa: Because my husband say [to the nurses at Hospital 2] ' *My wife takes a long time staying here and you say she has got TB, but now they say she has got MDR-TB'. Now they gave me to take the pills for the six months* [in Hospital 2]. *The medication did not work. My husband says to these guys who came here, 'It is now affecting us because they didn't give her anything after they told her to stop taking the treatment'. It is only when I came to* [Hospital 1] *is the time they said I have got MDR. When I came to* [Hospital 2] *they said you must stop this [the treatment for susceptible-TB]. So my husband says that is why he is saying it affected us … He is supporting me, but sometimes, maybe, I don't know, man.*

Idriss: Did this feeling make you stop going to the clinic to collect your drugs?

Ndisliswa: Yes. Not always.

Ndisliswa expressed being stigmatized by her husband, but the situation was not helped by her being given different information of her diagnosis at the first hospital that she attended. She explained that she was at first diagnosed with normal TB at Hospital 2. During the course of her treatment, her health did not improve. It was only when she was brought to Hospital 1 that she was told that she had MDR TB. It was then that the husband became alarmed and instructed the children to stay away from her.

Family support and socio-economic factors

One of the stand-out themes from the patients' home experiences that prompt them to attend clinics was that of good family support. It is also noted that the patients who consistently attended a clinic had better socio-economic circumstances, such as having better financial income through employment or through support from family. However, one cannot conclude that family support and income stability alone propelled these patients to attend the clinic. The theme of family support was expressed alongside patients' internal motivation to get better. Some patients recounted many different signs of positive support from family; nonetheless, there were expressions of the onus being on oneself to go to the clinic and get help.

Buhle, one among five of the patients who consistently attended the clinic, had positive things to say about family support structures at home. However, she also emphasised that her determination of becoming well again influenced her as much as family support. Buhle was employed as a salesperson at Metrorail (the railway service in Cape Town) before she was hospitalised. She resided with her husband, brother-in law and his wife and her mother. She also had the support of her sisters (who did not live in the same house). The occupants of the two-bedroomed house were her, her husband and her mother. Her in-laws stayed in another room that was separate from the main house. The lounge was fairly well furnished, with a separate kitchen and a small flushing toilet in the house. It was a bit more spacious and airy than the other residences. Buhle claimed that her family members gave her all the support she needed.

> *Idriss: Do you get support from your family?*
>
> *Buhle: Yes, a lot of support.*
>
> *Idriss: In what ways?*
>
> *Buhle: Most of the time my sister comes. As I tell you, my mother is very sick. They didn't come. They came with everything that I want; food they gave me if I want, money, if I want. They gave*

> *food at times at work, also my husband, but this week he is on night* [night shift].
>
> *Idriss: Does this help motivate you to go the clinic and take your medication?*
>
> *Buhle: Yes, but again I see many things that happened to people not taking their drugs. And then I told myself, if I take my drugs I will be better. That is my main motivation.*
>
> *Idriss: If you were to speak to other people newly diagnosed with TB, what advice would you give them?*
>
> *Buhle: First advice I will give is that they should take it* [their medication] … *You can survive it. You cannot think all people have HIV/TB. You must eat your treatment* [take your pills]. *And tell yourself that you are not sick. Don't tell yourself. 'Oh I'm sick I have HIV', no. If you think about that you are going to be dead.*

Buhle's last statement focused on actually adhering to treatment. As mentioned in Chapter One of this thesis, I did not explore adherence to treatment, but not attending the clinic to collect the drugs may lead to non-adherence, which Buhle highlighted in her response. She believed that a positive attitude that comes from oneself should be enough for you to take your treatment consistently. The family members of Buhle as well as Themba confirmed that they supported them in the best way possible and they were happy about the progress that they were making in the treatment of TB. Buhle's mom, Thandi said:

> *Thandi: We all give her hope that she will get healthy again and to encourage her to take the medication.*

Themba's mom, Saki, also indicated that she would know if he has lagging behind in taking his medication, but she would pester him to do so. Saki said:

> *Saki: Firstly, his facial appearance changes, when he doesn't eat the medication* [take his TB pills] *he will sleep the whole day. I will ask whether he has taken his medication and he will start scratching his head. And he would say, 'No I didn't take it'. And I will make sure that he wakes up and go and take his medication".*

Zintle expressed similar family support that really encouraged her to be positive about her illness and expressed the desire to get better. She lived with her mother and her son. Their house was as not big as some of the other patients', but spacious and well-furnished. It had a television set with satellite channels. The couches looked relatively new and were comfortable. Zintle was among the only patients I interviewed who had a tertiary education. Even though she said she had not been taught about TB at the hospital, she had been reading about it since she got sick. She also drew on her knowledge of many adverts on television about TB. This was my second interview with Zintle. I asked her about her support structures at home and her experiences at the clinic.

> *Idriss: I remember you told me that you missed your family when I interviewed you at the hospital. Do you still have family support at home?*
>
> *Zintle: Yes. My home is a happy home.* [Pointing to her mom and son and smiling. They were sitting about 5 metres away from us. Zintle also spoke about her happy home when I interviewed her at the hospital]. *As I told you, we are not a lot. Yeah, it's a happy home.*
>
> *Idriss: So how have you been generally?*
>
> *Zintle: For me, I thought TB was one of those simplest diseases. I didn't know when you are on treatment you have these bone pains and all of that. I thought when I was on treatment everything will be normal, like now I am not going anywhere far. Most of my friends they always come to me. I don't always go out like I used to. With the knowledge it is usual. I know that I have to take the treatment for about six months, and what else? And the side effects.*
>
> *Idriss: What is it about the side effects?*
>
> *Zintle: Painful. I just want to be OK and be done with it. I don't want to be sick at all. That is why I take my medication every day.*

She was able to cope with the side-effects because of her family's support and her strong desire to be well again. What is clear from Buhle and Zintle's experiences is that both had comparatively better socio-economic resources. One had a job and family that supported her. The other had a tertiary education and a good family support also. Although they expressed personal motivation to attend the clinics, their situations were helped by their families.

HEALTHCARE WORKERS’ PERSPECTIVES ON FACTORS INFLUENCING CLINIC ATTENDANCE

In speaking with HCWs, similarities and differences were observed between their and patients’ explanations for clinic attendance and non-attendance. As with patients, family support and personal internal motivation were considered important factors. The unique themes mentioned by HCWs that influence attendance at clinics were poor communication between the hospitals and clinics, patients’ lack of personal internal motivation, poverty and the quest for disability grants. The nurses specifically mentioned that patients’ personal motivation affected their attendance at clinics. The doctors, on the other hand, commented mostly on the poor communication between the hospitals and the clinics and the quality of medication information given before discharge. All the HCWs highlighted poverty and the quest for disability grants.

There are several themes that will be discussed under the broad headings of HCWs’ perspectives. These are: patients’ family support and personal motivation, poverty and disability grants, partial links between the clinic and the hospital (including sub-themes) and inadequate TB education at clinics. It is seen from this chapter that there are overlapping themes from the hospital and the clinics, which will be mostly highlighted in the discussion chapter.

Family support and personal motivation

Most of the clinic nurses indicated that family support and the patients’ willingness to get well are the driving forces to attend clinics for CoC. Cebisa, a Professional Nurse (PN) at Clinic 4, mentioned that wanting to get well in order to look after their family is an important motivation.

> *Cebisa: I think everything starts from each and every individual because you know what you want to achieve in life. You know you have got goals because those who are coming they will say ‘ I have to come because I have small babies at home. Then I must look after my children so I cannot manage to be sick or die while there is help’. And then the support they are getting from home.*

Conversely, according to the nurses, lack of personal motivation and drug and alcohol usage play a role when affected patients stopped attending the clinic as well as not adhering to the treatment. The patients in this study, apart from Themba, who said he had a brief drug problem, did not mention having such problems. Funeka (PN), a nurse who worked at Clinic 2, commented on this, as did Khanyi (PN), who worked at Clinic 4.

> *Funeka: You find that in this community, or that is what I find in this community, people are on drugs, especially "tik" and they just really don't care. You can talk, because we really do talk to them, you know, counsel them.*
>
> *Khanyi: Sometimes alcoholics, kids on "tik", we will keep it DOTS and we will try on a weekly basis, it depends. It is the unreliable patients we don't get on that monthly system, but we try to get working patients on it as quickly as possible, and any patient that we think is reliable will go on to monthly treatment.*

One should note here also from Khanyi's statement that some patients are given one month's TB pills if they have been responding well to treatment and are deemed 'reliable'. According to the nurses, as some demonstrated personal motivation to get better, some were constrained by lack of income and the desire for social grants from the government. This was a case of patients' needing the grant, particularly disability grant to economically sustain their families. These are expressed in the theme below.

Poverty and disability grant request

Funeka (PN), at Clinic 3, explained that because the patients did not have food, they feared losing disability grants. A disability grant of R1600 per month is given to patients who are newly diagnosed with TB for a six-month period. Those diagnosed with MDR-TB get disability grants for a longer period because their treatment obviously takes longer. However, one becomes eligible for the grant if one's health is so compromised by the disease that it renders one incapable to work. Further eligibility to get a disability grant depends on residential status. Only South African citizens, permanent residents and refugees can access these grants. These social grants become one of the sources of income for many people who live in poor areas and are sick with acute forms of TB. The eligibility to secure this grant sometimes confuses patients. This will be explained in greater detail in the responses of one of the doctors below. Funeka explained that some patients wanted disability grants because they needed food, but if that was not forthcoming, they would go to work and would not attend the clinic.

> *Funeka: Most of our clients are wanting disability grant because they don't have food in the house or they were working somewhere else. They cannot come to the clinic because they have to, on a daily basis, they need to go work out and see how much money they can get for the day to buy food or they work somewhere else where they can't come back immediately, like on a farm or something like that.*

The social workers and community health workers agreed with the points raised by the nurses. Akhona (PN,) who worked at Clinic 2, said that for accessing disability grants patients must have an identification document (ID), but some of them did not have an ID. According to the South African system, the ID is a barcoded booklet, which is a key documentation that includes a photograph and an ID number. It is used in almost every bureaucratic and governmental transaction or application. In other words, it is not simply an ID to show one's clearance to get into a building or drive a car. It is a card that enables you to get access to basic social services. As explained above, one of the requirements to access these social services is that one must prove that you are either a South African citizen or permanent resident in possession of this barcoded ID book.

> *Akhona: For the others, the problem is an ID issue, when they don't have the ID. Some will be committed to their treatment but the problem is the ID. And they felt that I would stop taking medication because I don't have food, but if they have the IDs they would benefit to apply for grants.*

Anathi, one of the CHWs, had similar response regarding patients who were co-infected with HIV. Anathi's response was a report on a question a patient had asked her. It did not suggest that patients would not attend the clinics had they not received disability grant, but it showed that patients were really concerned about losing the disability grant. She said, "*The patients ask if they can survive without the disability grant because they need the money*". This further confirmed that patients were very concerned in such a way by linking the grant to their economic survival.

Christie (MD), at Clinic 5, explained how the patients who were diagnosed with TB may access disability grants, but most importantly, highlighted that the patients were indeed very worried about losing the disability grant despite their improved health.

> *Christie*: *Basically, all of the TB patients or most, reasonably they will get a six months' grant, the time they are on TB treatment. That will stop once the TB treatment is finished. For MDR-TB patients it will go on for longer for the duration of their treatment. Beyond that it is a question of disability. Someone who's had TB, someone whose lungs are really messed up – and we can prove that with an x-ray or lung function test – they are likely to get a disability grant … They understand when you explain it, but they don't necessarily accept it, so they will try and go and work with somebody else and somebody else and somebody else. They don't need us really to start the whole thing. If they don't accept it they can go to SASSA*[17] *and apply for a disability grant and it is like a bit of a waste of their time because they are not likely to get it*.

This response points to the fact that just because patients have finished treatment, does not mean they are well enough to get a job. Also, it does take time to secure a job, especially after having been through a severe illness. It is a very difficult situation for people to be in. Engaging in exploring patients' needs and feelings could pre-empt the issue of coming off social grants and assisting patients to return to work after serious illness.

Even though patients expressed lacking financial support at home from the hospital and throughout their treatment journey, they did not report problems, such as needing disability or looking for work that may stop them from attending the clinics to collect their medication. This stance is different from what the HCWs mentioned. However, as mentioned above, from patients' responses and observing their living conditions and family support (or lack of support), these do influence CoC.

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[17] This is the South Africa Social Security Agency (SASSA) that rolls out different kinds of grants to beneficiaries in the country.

Partial links between the clinic and hospital

In Chapter Four, the HCWs emphasised that the main links between hospitals and the primary health care clinics is the discharge letter that they give to the patients. HCWs saw problems with relying on letters as the only form of communication between hospital and clinics. They also pointed to other factors which affected the links between tertiary/district and primary care. These were: inadequate communication between hospitals and clinics and inconsistent provision of medication before discharge. There was also no adequate TB education/counselling at clinics. Some of these themes resonated with what HCWs at the hospital had mentioned. These are discussed under the themes below.

Inadequate communication between the hospitals and the clinics

Many HCWs explained that the discharge letter is the main or the only manner of communication between the hospital and clinic. Thami (Professional Nurse (PN) at Clinic 1) explained what happens with the letter once a patient comes in to the clinic:

> *Thami (PN): He's* [the patient] *got his letter, we basically see whatever is written on the letter and we just take it from there. If he's started on TB treatment we just continue with all the details, we open the TB folder, we get all his contact details, we just continue. If he needs to start, he will start with us. The letters are not always very clear. Sometimes you don't know when the patient really started on TB treatment. You have to ask the patient. And sometimes the patients are not sure and sometimes, especially for the kids, they phone here if they have started, but then we'll say 'No, but this kid hasn't been here', but there is no telephone number or contact number that we can contact this person or address is not even on it, or it is not clear, it is not the right address.*

According to Thami, getting the letter was not the only issue. Sometimes it did not contain the information they needed. A Nurse Sister at Clinic 5, Ntombi (Professional Nurse (PN)), explained that they refer such cases to the doctor. According to Ntombi, all patients with missing information are sent to the doctor.

> *Ntombi (PN): Sometimes the clients start their treatment from different hospitals, but normally for us it is* [Hospital 2]. *Then they come with the letter. They come to the TB room we do all the*

> *observations, and then we send the client to the doctor. So all those clients are being managed by the doctors. It depends, some of them is normal TB like … GeneXpert or smear, but the first day the patient must first go to the doctor*

According to Ntombi's response, upon receiving the letter and after having done some "observations" they would send the patient to the doctor. These are patients with either missing information or sometimes badly written referrals that are sent to the doctor. Hence, the doctor's experiences of this activity should shed some light on this issue, which is discussed below.

Dr Lina (MD) at the Clinic 3 reported that most of the time the notes on the referral forms were clear, but there were times when they were not. However, her main concern was not necessarily a few badly-written notes on the letter, but rather that some doctors did not have adequate knowledge of some aspects of patients' diagnosis and that patients diagnosed with pulmonary TB had "no safety net" when leaving the hospital. Dr Lina's explanation reminded me of Aphiwe's complaints of having confusing messages about his treatment.

> *Dr Lina (MD)*: *From the doctor's point of view, the information that we get from Hospital 2 is of a good quality when they are typed. Sometimes in the Emergency room, we get handwritten, very brief letters. I assume that they are very busy, but a lot of those are very inadequate, particularly with the MDR patients, we can often get wrong medications because again, many, many doctors, most doctors don't know much about MDR-TB and we occasionally get people with just small mistakes, people with minor problems and they have not adjusted the medication …I think it is one of the challenges that most doctors and nurses have. If they haven't worked in the TB clinic they are fairly clueless … then a patient will default because between us and the hospital, they didn't really understand they had TB and so they would take whatever treatment they have got in hospital and we would never see them. So there is no safety net in that sense. If the patient doesn't come himself, there is no safety net.*

I asked Dr Lina what she meant about the patients having no safety net and her response referred back to the issue of poor communication.

> *Dr Lina: When the hospital is far away like* [Hospital 1], *sometimes the communication is very poor, and the information can be quite poor. Sometimes the referrals are good, sometimes they are not … in some cases, not so good information. And there is absolutely no safety net communication at all. And then it's irregular how much treatment the patient is given when they are given one week, two weeks or a month of treatment.*

This theme of poor communication leads to another related theme of inconsistent medication given upon discharge of the patients from the hospital. Most importantly, it is good to include here that there was emphasis on Dr Lina's words that "*We can often get wrong medications because again many, many doctors, most doctors don't know much about MDR-TB".* I was not sure if this was an issue pertaining to the specific doctors at the referral hospital where Dr Lina was working or it was a general feeling about the knowledge of MDR-TB of doctors in South Africa. Either way, if doctors struggle to prescribe medication for MDR-TB patients, then this could be a possible explanation for Aphiwe and Ndiliswa's confusion about their diagnosis. This could be another angle to pursue in future studies: that the inability to do proper diagnosis can cause confusion among some patients diagnosed with TB and affect CoC.

Inconsistent provision of medication before discharge

Dr Lina explained further that patients sometimes do not report to the clinic on time because of the amount of medication given to them, which is not always consistent with the other patients diagnosed with the same type of TB. This practice questions the DOTS system, which expects patients to be observed at the clinic when taking their treatment. If a patient has received a month's supply of TB pills, then this distorts the DOTS plan. This was highlighted by Dr Lina.

> *Dr Lina (MD): Now the patient is coming more than a one month later and you say 'Why didn't you come straight from the hospital' and he will say, 'No, I was given a month's treatment', which is not good for somebody who's just been diagnosed with TB – that is not good.*

Dr. Christie (MD), at Clinic 5, also commented on the "poor communication" as well as the inconsistent offering of TB medication from the hospital.

> *Dr. Christie (MD): The linkage is really not very good …. The discharge letters … are generally pretty good and fairly thorough. They sometimes have follow-up dates, depending if they need to or not. So in terms of documents and so on it, is usually alright. The problem is they rely on the patients then to come in their time. They also do silly things like go to your nearest clinic and then give them a month's treatment. And if somebody is in the first couple of months of TB treatment or the first couple of weeks they are given the medicine to swallow in the hospital and then they go home …..There is not direct communication always and that is a problem and if somebody decides not to come and they disappear to the Eastern Cape,* [Hospital 2] *won't know, we won't know. There is no way of tracing that.*

Another theme that resounded in the clinics with the responses from HCWs in the hospital was that of inadequate TB education, which also brings one of the core elements of PCC to the fore. Patient education does happen in the clinics, but there are challenges in doing this effectively.

Inadequate TB education at clinics

Dr Lina believed that it was not feasible to expect TB education (or counselling, to use the words of Dr Lina) to happen at the hospitals, because of the work load that they had to attend to, but she claimed there should be some attempts to speak to patients about TB in hospital.

> *Dr Lina (MD)*: *I think with the clinics themselves we are doing as much as we can. We are doing three counselling sessions. We are calling in relatives, community health workers are doing home visits, etc. I don't think you can expect a busy emergency centre* [at the hospital] *to be doing counselling. I just don't think so, we just need that safety net. We need to be doing that. I agree with them that the major counselling should be done here. I think when a patient has been on a hospital bed, that's different. If the patient has been in the ward for a length of time, then I do think they need to make an attempt to explain to the patients and the patients' family. Maybe they are bit lacking with that*.

Dr Lina commented that those patients who have been hospitalised should at least receive some form of counselling at the hospitals. All the patients I selected and followed-up to the clinics were hospitalised for at least one week. Some nurses reported that TB education of patients at clinics does happen. Nonetheless, sometimes they were not sure if the patients understood the information that they had been given. This is similar to views of HCWs at the hospital level. Kethiwe, a TB counsellor, informed me about the education given to patients, and noted that they were not sure if patients understood the information. Kethiwe could speak the language that the patients spoke. Nonetheless, it was not sufficient to make her sure that the information was being understood.

> *Idriss: Do you educate patients about TB?*
>
> *Kethiwe: Yes we do.*
>
> *Idriss: Please explain how this works.*
>
> *Kethiwe: We do give education. If the client is coming for the first time, then we will give the results and you will explain to the client what is happening. OK, you will take the results, this is your results, you will say it is positive, then you say what that means, what is going to happen from that day onwards, and you also explain that TB is six months' treatment, you are taking it every day. You explain all those things, you must avoid smoking, taking alcohol. Explain all that … Even though we do send, there are cases that the client come to us, the counsellors, but you can see that this client doesn't understand what is going on, then you will give education, but you will see the client doesn't know what is going on.*

Kethiwe's last sentence informed us that after going through the process of explaining to patients what TB was all about, there was doubt that they did understand what it was. According to one the features of PCC this should be a good time to allow the patient to explain what they understood and ways that their treatment could be better. Educating or counselling patients should be a time when patients should be given the space to express their concerns, fears and anxieties, which could enhance PCC. Although individual health workers may not be in a position to address the socio-economic conditions of the patients, hearing patients' concerns could help to reinforce messages about the disease and how they can continue to receive treatment.

PRELIMINARY DISCUSSION OF FINDINGS

This chapter expounded on how socio-economic circumstances influenced CoC. In addition, it revealed how patients felt confused about their treatment plan, being scared to continue, and different forms of domestic problems. Throughout this chapter I have explained and argued that SDH were prominent in explaining why some people attend the clinics or stop attending the clinics. Lapses in PCC impacted the patients' CoC as much as did their socio-economic circumstances. The literature extensively discussed the relationship between TB and poverty, both from earlier and more recent studies (Anderson, 1990; Bradshaw et al., 2006; Coovadia et al., 2008; Department of Social Development 2004; Head, 1999; Packard, 1990). It has also been recognised that poverty is still one of the major problems after a decade in the new Millennium in South Africa (Nattrass and Seekings, 2010). Most importantly, Berkman and Kawachi (2000:7) report that although poor diet can affect sick patients, being poor and having low levels of education influence "risk-related behaviours" that may even include failing to report to clinics for their medication. All of the patients reside in poor environments and many have problems with low income. The relationship between lack of income and related health problems cannot be over-emphasised (Berkman & Kawachi, 2003; Daftary & Padayatchi, 2012; Wadee et al., 2003). This is also confirmed in this thesis.

However, with regards to attendance or non-attendance at clinics, the role of the family appeared as equally significant. The literature affirmed that there were direct and indirect costs incurred by patients diagnosed with TB, especially with those with meagre incomes and unstable jobs (Khan, et al., 2000) that can impacted their attendance at clinics as well as their adherence to treatment. Families can provide support to patients diagnosed with TB at home, as mentioned by Ayisi et al. (2011), and Gebremariam, Bjune and Frich (2010). The kinds of support families normally could give to patients includes both financial (providing accommodation, food, transportation to go to the clinic and medical costs) (Khan, et al., 2000; Rajeswari, et al., 1999) and moral support, counselling, assistance in taking medication and accompanying patient to health facilities (Ayisi et al., 2011).

The patients in my study reported complex relationships with family. On the one hand, families provided financial and moral support to patients that enhanced their attendance to clinics for CoC. On the other hand, some families hindered their attendance at clinics because of stigma and abuse. It is interesting that while some literature documented stigma either in the community including some health centres (Abebe et al., 2010; Daftary, 2012), stigma is also experienced at home, which can have a negative impact on attendance at clinics for CoC. Patients' self-descriptions of being scared, confused and abused at home are not identified in the literature. Regarding the patients' being confused by treatment medication, as aforementioned, it could be a communication breakdown, but also lapses in implementing PCC (Epstein & Street, 2011; Jardien-Badoo, van Booyen and Ricks, 2016 and O'Donnell et al., 2016).

Health-seeking behaviours are a central concern in health research (Abebe et al., 2010; Noar & Zimmerman, 2005; Mackian, Bedri & Lovel, 2004; Pronyk et al., 2001). Some authors have argued that individuals' internal motivation or agency is better understood when one explores the contexts of the health service delivery that was rolled out to the agents (Noar & Zimmerman, 2005; Mackian, Bedri & Lovel, 2004). Some authors emphasise that agency has a much stronger influence on matters of health-seeking (Pronyk et al., 2001) while others believe that agency is inextricably constrained by structural factors (Abebe et al., 2010). The patients in this study demonstrated the latter, where choices of agents were made within structural factors, which could either be positive or negative. Either way the patient is impacted by structural factors. Although drug abuse (Drobniewski et al., 2005) and abuse of alcohol (Parry et al., 2002) are prevalent especially in disadvantaged environments, and can affected CoC, none of these featured among the patients in this study. This does not rule out the possibility that patients may have hidden this information. In addition, a request of disability grant that were described by the HCWs is not a new phenomenon by patients diagnosed with TB or HIV/AIDS. There have been reports that patients are always concerned about maintaining disability grants, which, if lost, can even prevent some of them from attending their clinics (Hardy & Richter, 2006). What was notable in the responses of patients and HCWs regarding what influences CoC was that there were areas where they resonated and areas where they differred. The possible reasons for these similarities and differences were discussed in the next chapter.

Being confused and scared could lead to lack of trust in the health system, which is not a new phenomenon in medical treatments as expounded by Boulware et al. (2003) and Gilson (2003). Structural factors continue to have an impact on individual's behaviour where problems of PCC are explained by staff shortages that affect effective performance (Breier, Wildschut & Mgqdozana, 2009; Hall, 2004). Addressing the problem of staff shortages through catering for more manpower could bridge the gap that affects HCWs' performances in responding to the needs and feelings of patients. This should also attract proper resource allocation, which has been established to be a problem in South Africa in the past (Travis et al., 2004). Drafting policies in areas of proper education and allocating resources to needed areas could help increase PCC. This could facilitate spending more time with patients in order to understand their treatment journey. All the patients I followed-up to their homes, in theory, should be on DOTS plan. However, there were times when it was not clear whether the patients I followed up were under DOTS or SAT. This inconsistency filtered down to one of the patients in this study. She stopped attending the clinic for domestic reasons, but no one from the clinic (under the DOTS plan) checked why she did not come to collect her treatment. These structural problems, coupled with the fact that patients themselves did not have adequate understanding of who they could receive help from, is essential. In addition, the attitudes of HCWs, especially nurses in the clinics, also was a problem. This theme about nurses verbally abusing patients and sometimes ostracizing them, has been well established in the literature (Jewkes, Abraham & Mvo, 1998; Lane et al., 2008), and seems to persist.

CONCLUSION

Chapter Six has discussed several key features of the patients' treatment journey from the perspectives of the patient, some family members and HCWs in the clinics. Patients who did not attend clinics during the course of their treatment expressed feelings of being scared, confused and being abused at home by family members, which has not been documented in the literature on CoC in the context of referral from hospitals to clinics. There were also responses from HCWs that were linked to individual responsibilities, such as drug and alcohol abuse, by some of the HCWs. Feeling scared, confused and embarrassed by improper behaviours by some nurses seem to interplay with bigger structural factors including socio-economic influences. There were reported cases of inaccurate dissemination of TB information to patients signalling part of the poor linkages between the clinics and the hospitals. The literature discussed similar improper relationships between patients and HCWs where some patients feel neglected and ostracized (Jewkes, Abraham & Mvo, 1998; Lane et al., 2008). Poverty that influenced a drive for disability grants has been a predominant theme amongst some HCWs, but not the patients. Poverty is an important concept in health studies, especially TB, which was discussed in Chapter Two. Notwithstanding these facts, poverty could be seen more relevant in the administering of the drugs itself at home, which is linked to adherence than preventing the patients from attending the clinics. Nonetheless, patients who attended the clinic had better financial income and family support.

On the other hand, positive family support and positive internal motivation propelled some patients to turn up at clinics to take their treatment. In as much there are complaints of ill-treatment by some staff members, many patients reported that their desire to get well is their greatest motivation. There was ample evidence from my own observations of the living conditions of the patients identified above that most of them were struggling financially. Nonetheless, positive family support encouraged patients to keep on pursuing better health amidst some of the problems discussed above.

CHAPTER SEVEN: DISCUSSION OF FINDINGS

INTRODUCTION

In this chapter I discussed the findings of this study. I incorporated how I was positioned as a researcher in the field and how my interactions with participants in the study may have positively or negatively affected any part the research process. I also reflected on methods applied in the study and recommend areas of further research.

PATIENTS INTERNALISATION OF DIAGNOSIS, HOSPITAL TREATMENT AND CONTINUITY OF CARE

In observing the inpatient care of patients diagnosed with TB and having conversations with hospitalised patients, it was clear that patients wanted clarity on their diagnosis, on what lay ahead and the potential benefits and problems, if any that would come with following treatment. The TB education in the clinics did little to bridge the gap between patients' understanding of their diagnosis and the medical explanations for their ill health. Patients also had certain emotional needs that were not fulfilled, particularly around expressing anxieties about their diagnosis and their impending discharge and home circumstances. Lack of education about the disease and discharge planning and limited opportunities for patients to express their anxieties are examples of a lack in patient-centeredness. Edginton et al. (2005) and Khan et al., (2006) argued that patient education is essential for achieving better CoC. In this study, patients left the hospital scared and confused and some did not follow-up at primary care clinics because of this. Therefore, in addition to factors such as the transfer of clear notification and accurate information (Gordon & Krauthoefer, 2007), fear and confusion are also important. I theorise that better PCC may enhance patients' understanding of their diagnosis, which may alleviate anxiety, fear and confusion about their disease. It may also minimise the lack of trust that some patients might have in the health system (Glison, 2003). Some patients were so confused that their responses suggested that they were losing trust in the HCWs' capacity to treat them adequately. Irrespective of all this, the impact of responding to many sick people with few helping hands affected the HCWs in the hospital, as has been mentioned by several authors (Breier, Wildschut & Mgqdozana, 2009; Hall 2004:30; von Holdt & Murphy, 2007). Staff shortages continue to be an ongoing problem in South Africa's health sector. The need to have more staff in hospitals to do counselling with patients diagnosed with TB is still essential.

While some patients demonstrated good knowledge about how TB was transmitted, understanding that hospitalisation was a consequence of having TB was less likely. Knowledge is more than just knowing one's diagnosis; it is about having focused educational or counsellng programmes for newly diagnosed patients in the hospital. The sites studied did not have clear educational programs and therefore in the words of Epstein and Street (2011), "infrastructural development" is needed to implement a targeted teaching programme. This idea was supported by Jardien-Badoo, van Booyen and Ricks (2016) and O'Donnell et al. (2016), as discussed in this thesis. Jardien-Badoo, van Booyen and Ricks (2016) drew on the South African Constitution in 2003 that stipulates each patient must be treated with respect. The patients must have access to education and each patient's needs and values must be taken into consideration. O'Donnell et al., (2016:431) emphasised that a patient-centred approach is not a "one-size-fits-all solution …. [it] depends on engaging each individual patient with tailored education/counselling …"

Patients in this study continued to express confusion, anxiety and fear after discharge and after following-up with clinics which suggests that the lack of patient-centeredness in education around TB and its treatment was as much an issue at clinics as it was in hospital. Implementing a robust patient-centred model of education in hospitals and clinics could help address these concerns. Adequate PCC could also involve training of HCWs to understand the patients' perceptions of their treatment and ways to prevent confusion about it. This is a crucial element that goes beyond just treating the disease of the patient. It may include understanding the limitations or patients' inability to grasp and interpret information given to them. It may also include being clear about what happens after discharge from the hospital. Stewart (2001) asserted that it is essential to understand what patients think about the space in which they find themselves to receive medical care. The uncertainty of what they had been dealing with from the hospital intermingled with the way they internalised the information given to them at the clinic. The experiences of the patients, for example Aphiwe and Fezeka, in both the hospital and the clinic impacted their non-attendance at clinics and subsequently did not complete their treatment.

In this study, most patients did attend their primary care clinic to continue with treatment, but some stopped attending soon afterwards. These patients who stopped attending were Aphiwe, Fezeka, Ndisliswa and Thandiwe. In patients' narratives the moment they stopped attending the clinic was characterised by a breakdown of communication. This breakdown was not only in terms of linguistic challenges, for example, staff not being able to speak the language of the patients, but inadequate interpersonal communication. 'Education' is given to patients but time and strategies are lacking for health professionals to explore how patients have understood the information given to them. Furthermore, patients were sometimes critical of the way nurses and doctors interacted with, especially in cases where they felt they were 'embarrassed' publically for going to the wrong clinic or for having stopped taking the medication. Some patients thought they were being harmed rather than being helped by medical treatment. With this in mind, the notion of linkage to care should be broadened beyond the idea of initial attendance. Linking patients from in-hospital treatment, to community-based treatment involves spending more time with patients to understand their needs and feelings.

Achieving PCC in these contexts goes beyond the individual will of health professionals. There are many factors that constrain health professionals' and health services' ability to implement PCC. One of these is high workload and time constraints (Motsoaledi, 2009; SANAC, 2006; van Holdt and Murphy, 2008). Staff numbers in the health system are insufficient for responding to the growing burden of disease. Limited exploration of patients' needs and health promotion in the context of education in the hospitals and clinics are strongly linked to staff workload and time constraints. What was clear from interviews with policy makers was that there was a policy and implementation mismatch. They wanted TB education to follow the World Health Organization protocol, but staff are too overburdened to achieve this. Such policy and implementation mismatches are common in South Africa, including the health sector (Coovadia et al., 2009; Shelmardine, 2011). Interviews with health professionals found that they believe patient education and counselling for TB at the hospital is important, but that perhaps they are not best placed to delivery this because of their overcharged workload. They did think trained TB counsellors should be employed to execute a hospital protocol for TB education.

The interesting issue here, however, is that even though time constraints and workload were reasons given that affect PCC, policy makers shied away from commenting on these as factors affecting PCC. Rather, the main reason given by policy makers was that patients were not given the responsibility to take charge their own health. The patients are not considered as partners in the treatment process. In addition, policy makers did acknowledge the fall-out of treatment by patients after leaving the hospital. One of the ways to bridge this gap was allowing patients time to think about this treatment being prescribed for them, to let them evaluate this treatment journey and have them say something about it.

Even though it is important that patients be given the opportunity to express their needs and feelings, as has been argued in this thesis, addressing staff workload is a very significant part of enabling PCC to take place. It was noted in the data that policy makers affirmed that TB education “should be done at all levels of care”, which is consistent with TB policies (SANAC, 2007; SANAC, 2011; WHO, 2010, 2015). However, the questions that remain are, who should do it and when should it be done? This was not clearly understood by HCWs in the hospitals. The HCWs never said that a lack of policy was what accounted for a lack in TB education. In fact, some of the HCWs highlighted that the policy on TB was sound. While some thought that the policy should emphasise increasing staff numbers, there seemed to be a perception that the government was doing the best it could. However, even if policy states that education must take place and specifies who should do it, PCC cannot take place if the other factors, such as workload and time constraints, are not addressed. Therefore, “infrastructural” changes should not only be in training of the staff to be more patient-centred care in their approach in the hospital and the clinic, but also in having more staff.

PATIENTS’ PARTNERSHIP IN TREATMENT AND FEELINGS OF HOPELESSNESS AND POWERLESSNESS

Patients’ expressions of hopelessness and of powerlessness are embedded not only in the failures of PCC, but in the medical system itself. HCWs work to provide better health care to patients, but conversely, may objectify the patient in delivering care (Foucault, 2003). This was seen in the dissemination of the information to patients and actions by the medical personnel. Knowledge wields power in both overt and subtle ways that can affect individual behaviour (Foucault, 2003; Gastaldo & Homes, 1999). Foucault’s ‘medical gaze’ is helpful for understanding the lack of partnership between HCWs and patients along the treatment journey as well as the feelings of hopelessness and powerlessness that arise. Hence, before leaving the hospital, the mindset of some of the patients is being mirrored by conversations of the initial contact of doctors and nurses. For example, Bianca repeated what she had heard from either a doctor or nurse that might have said there is nothing that they could do for her. Therefore, she could not continue staying at the hospital. Similarly, Aphiwe mentioned that they told him he had what was “close to MDR-

TB", but not MDR-TB. Some of the patients may have misunderstood the information given by the doctors or nurses, but did not have the opportunity to ask for clarification. Nor was provision made in the health centres to make sure that the patients really understood what has been communicated to them. HCWs embody expert knowledge of how the body works and their recommendations and explanations can encourage certain behaviours in patients. However, from my observations 'education' involved professionals delivering information to patients who were conceived as the objects of care rather than partners in the process. The information was presented as unquestionable expert knowledge. How patients internalised the information or understood what was being said to them was not part of the education of patients. The focus was on transfer of information.

Partnership in the treatment process helps to bridge this gap between producing and receiving knowledge by two different parties. Also, it is important to examine this relationship in the rolling out of treatment. For TB, the continuation of treatment is as important as the initial treatment received at the hospital or the clinic. Some patients were not visited by family members – in fact, family members had no idea that some of the patients were hospitalised. Some patients left the clinic by themselves after receiving transportation by the social worker. If start of treatment and discharge planning could have been more of a partnership, the patients may have felt capable of expressing their fears as they so easily seemed to do with me. There could be dialogue around how the treatment works and mapping out the best ways to continue with the treatment.

As a result of a medical system that did not encourage partnership with patients in the treatment journey, some of them left the hospital or the clinic with many unanswered questions. For example, some patients desired to know their treatment plan so much that during our interviews at home they were quite overwhelmed by their feelings of not understanding. Patients sometimes used the medical jargon 'defaulted' (that seemed to blame the patients for failing to adhere to the treatment). They also lacked clarity on the type of TB they were being treated for. This left some of them disturbed and expressing not only confusion about their treatment, but powerlessness to do something about it. The 'cultural' issue highlighted by some HCWs were used to explain the different interpretations that patients had of their treatment. They (HCWs) suggested having counsellors who could speak to patients in their own languages. Cultural differences could be lessened by having counsellors with similar backgrounds or languages delivering TB counselling. Speaking someone's language may help patients to understand what is being said, as I have highlighted with respect to communication breakdown in the literature (Sissolak, Marais & Mehtar, 2011). However, even if in the same language, the clinical encounter should be one of partnership and dialogue rather than a passive transfer of information from the expert to the medical subject.

A partnership with patients also implies going beyond bridging language and cultural differences. Barry and Edgman-Levitan's (2012) work is helpful here, where patients actively participating in their treatment makes the patients more decisive in their actions that are more in line with their (patients') values. Some of the nurses at the clinics believed that their work was, according to the job description, being carried out to the best of their ability. However, this appears to be health professionals spoke in a way that disrespected patients and make them feel inferior. This behaviour amplifies the objectification of patients. Some HCWs did provide emotional labour, mostly in the hospitals where some even referred to the patients as "our poverty-stricken people". This was a profound statement that showed that, despite lack of partnering with the patients, some HCWs showed genuine concern to help the patients succeed in their treatment of TB. On the other hand, patients were suspicious of the HCWs, especially community health workers who were supposed to assist patients with attending the PHC clinics to not only collect their treatment but adhere to the treatment. The patients who did not attend the clinics were not followed up by any DOTS worker. The DOTS plan may need to be revisited. It has been noted in the literature that there is often no significant difference between DOTS and SAT (Das et al., 2014; Karumbi & Garner, 2015; Pasipanodya & Gumbo, 2013). In a different way, the patients may have considered the DOTS plan as part of the monitoring system (disease-centred) of the hospital or clinic rather than a patient-centered system.

A better HCW-patient partnership may encourage a treatment process that is less of a disease-centered treatment to that of a patient-centered treatment. If patients feel they are partners treated with respect and their contributions to the treatment plan are encouraged it will mimimise patients feeling objectified and powerless. The discharge process is a crucial phase of the treatment journey of patients to consider this aspect. This is a time when they have to take action based on what they know about their diagnosis. It is also a time when families also have to understand and decide what to do next. Without a partnership engagement with patients, not only will fears, confusion and anxieties emerge irrespective of whether linguistic and cultural barriers are lessened (Shelmadine, 2011; Sissolak, Marais & Mehtar, 2011), but these feelings could shape CoC in negative ways. The manner in which HCWs communicate to patients need to be tailored in a way that patients understand what is being said. This kind of communication cannot simply be bridged by using an interpreter. Being patient-centered is also about lessening the power divide between patients and health professionals.

PATIENTS' SOCIO-ECONOMIC CIRCUMSTANCES AND FAMILY SUPPORT

The social determinants of health (SDH) are another explanatory model to make sense of patients' retention in care (Farmer, 1996). One of the sub-research questions sought to understand the home and community life of the patients. Khayelitsha has some of the highest rates of TB in the Western Cape (Cox et al., 2010; SANAC, 2011). In speaking to different patients from Khayelitsha it was clear that they all had different levels of familiarity with what TB is, how it is transmitted and how it is treated. Having adequate knowledge of TB may have a significant role to play in enhancing health-seeking behaviour, which is documented in the literature (Edginton, 2005). It is also noted that there is an association between peoples' access to social amenities – including health services and health education – and their health status (Engels, 1995, Farmer, 1996; Coovadia et al., 2009; WHO, 2015). A social determinant of health perspective helps us to understand why some populations are more at risk of ill health than others, and it helps us understand why some are more likely to be cured of illness than others. Even though a structured educational programme at the hospital could at least bridge a knowledge gap, clarifying some misconceptions among patients will not erase the socio-economic circumstances faced by the patients. The socio-economic circumstances of patients are a social determinant of health that influences whether patients follow-up at primary care facilities and continue with their treatment.

A recurring theme in my conversations with patients over the course of their treatment journey was concern about their situation at home. Some expressed needs for a job or better income, better living conditions and having food. Even though patients did not indicate stopping treatment because of these problems mentioned, those who attended the clinics had better financial standing, better education and more positive family support, including family financial support in addition to their own income. The living conditions of patients pose a serious challenge to CoC. The theme of poverty also resonated strongly among the HCWs (although in different ways, which will be explained later). Before the patients accessed the health care centres, they have been constrained by many socio-economic factors, which the HCWs lamented. The patients did not only have low levels of education, they were very sick, not only from the disease, but from lack of proper food, clothing and care. Upon discharge, this reality continued. Some patients had estranged family members, and thus a lack of proper accommodation compounded the problem. Living in townships already poses challenges owing to limited social amenities, access to employment, and crime. These direct causes of ill health may not necessarily cause patients to stop attending the clinics, as the patients themselves did not mention that, but according to the living conditions of the patients and income levels, I theorize that these socio-economic circumstances are one of the most important social determinants of health affecting CoC for the group of patients that I followed.

Beyond the problem of economic poverty was the issue of social support. Positive support propelled some patients to attend the clinics, although this was seen also alongside personal internal motivation. Indeed, families can play an invaluable role in helping patients continue with their treatment (Horter et al., 2014; Khan et al., 2000; Rajeswari et al., 1999). However, not all patients had supportive home lives and social relationships. The experience of stigma discussed widely in TB (Ayisi et al., 2011; Buregyeya et al., 2012; Daftary, 2012; Hasker et al., 2010; MØller et al., 2011), also played a role in shaping follow-up to clinics following discharge from tertiary and district hospitals. This thesis brings a problem of stigma in the home as well as domestic abuse in the context of CoC. In other words, patients' health-seeking behaviour, family's socio-economic standing and support contribute to patients' CoC.

Families are not the only source of social support, however. One of the main roles of community health workers is to provide social support to patients in the community and their homes (Ntshanga, Rustomjee & Mabaso, 2009; Obermeyer, Abbott-Klafter & Murray (2008). However, some patients mentioned that they did not get visitations from CHWs, neither were they being followed up by anyone from the hospital or the clinic other than CHWs. This included patients who were diagnosed with MDR-TB. The CHWs on their side mentioned that they would visit patients but affirmed that sometimes patients misunderstood the purpose of their visitation. The CHWs said patients thought they were "spying" on them instead of helping them. To the patients the CHWs would "spy" on them and report to the clinic that they were not taking their treatment in the way they should.

Presumably, if community health workers were following-up with patients in their home, they would have picked up some of the problems facing the patients. However, it's uncertain whether patients would feel comfortable enough sharing problems, such as domestic abuse and stigma with community health workers. Even if they did, community health workers might not have had the capacity or means to respond to these problems. Furthermore, physical or emotional abuse is a sensitive and difficult issue to handle. Doing so may require special training for community health workers other than simply monitoring patients taking their treatment. In addition, sometimes the details of what they needed to do in the community, especially when visiting patients with TB was not always available.

In the scenario discussed above, it appears that there was no clear discussion as to when to use SAT or when to apply DOTS. That is if CHWs do not follow-up with patients who stopped attending the clinics does that mean the patients are now considered to be on SAT? There are many debates around the effective use of DOTS over SAT (Das et al., 2014; Pasipanodya & Gumbo, 2013). A detailed comparison of the two goes beyond the scope of this thesis, but it is important to recognize that according to policy makers both were in use but it was not clear when one was being applied or the other, or if both were applied to one patient (e.g. switching from DOTS to SAT)

In theory, without a decisive stance on addressing the social determinants of health, the South African government may continue to face many challenges in combating TB. The upstream-downstream concept will always feature in diseases, such as TB, where treating the disease (downstream) will not fix what causes (upstream) the disease in the first place. The social determinants of health are as important in shaping who gets care, completes care and is cured, as they are in shaping who gets sick in the first place.

THE LINK BETWEEN THE HOSPITAL AND CLINIC

That there are gaps in communication between the hospital and the clinic has been noted in other studies (Edginton et al., 2005; Edginton, Wong & Hodkinson, 2006; Dudley et al., 2018; Marais, Kallon & Dudley, Forthcoming; Jacobson, 2015). In this case the central communication tool for linking hospitals and clinics is a discharge letter given to patients. However, as shown in this thesis, patients expressed confusion about the reasons for their hospitalization, their diagnosis and their treatment, so one would expect misunderstandings of the follow-up process. Patients not having the opportunity to engage in dialogue with HCWs or become active partners in the discharge process leaves little opportunity for information received to be clarified. Patients are currently the central link of communication between hospitals and clinics but they received inadequate education about TB while in hospital and even worse some started doubting the system and the medication itself, something Gilson (2003) also identified.

Some of the patients received mixed messages. For example, the messages Aphiwe received from the hospital stating that he had MDR-TB, was different from what the clinic told him. Likewise, Ndiliswa and her husband got an initial report that she got normal TB, but as she started the treatment, the information was changed to her having MDR-TB. It must be noted that these were not reported cases of non-adherence to treatment, rather it was patients trying to make sense of their diagnosis. Hence, some of the patients in the study understood that they needed to be at the clinic, but there was also a constant struggle to make sense of the mixed messages received that negatively impacted the attendance at clinics. I have already indicated above that patients' limited understanding of their diagnosis was expressed through a sense of hopelessness. In other cases, they were scared and confused, which affected their approach to treatment of TB both before leaving the hospital and during the course of their treatment.

Another problem was a lack of a structured TB education system that links both the hospital and the clinic to help patients understand in more detail what their diagnosis entailed. Simply attending the clinic for the first time following hospital discharge is not an indication of adequate patient-centered care and partnership because many did attend but stopped attending later. Though most of the participants followed in this study did attend their local clinics initially, we know from other studies that not all patients do (Edginton et al. 2005, Dudley et al., 2018 and Marais, Kallon and Dudley, Forthcoming) Currently, if patients do not turn up with the letter, there is no a consistent alternative follow-up system to act as a safety net. According to nurses and doctors, calling clinics to follow-up on whether their patients consulted to continue their treatment, took too long and was rarely done. Such follow-up was not seen as a viable option by hospital staff considering their current workload.

Furthermore, the content of the letter also demonstrated a disease-focused rather than patient-focused approach. The patients' information included in the letter was clinical information with regards the diagnosis and amount of drugs given to the patients. It did not contain information on how patients understood their illness or concerns they expressed nor any detail on the socio-economic circumstances that should be taken into account when providing additional counselling to the patient about TB. As a standard operating procedure, referral letters are not required to contain such information (Department of Health, 2004; Edginton, et al., 2005). Changing this might not influence whether patients attend or not, but it could help with CoC beyond medication and dosage. It could help HCWs in primary care target certain messages, or prompt them to ask patients certain questions to ensure continuity in education, coming to terms with, and making plans for completing treatment. It could help bring awareness to a problem that HCWs at the clinics could act upon more quickly. Currently, home visits by HCWs, especially CHWs, tend to focus on patients diagnosed with TB who also had problems with adhering to treatment. This ongoing DOTS strategy focuses on the 'problem' of defaulting after it has happened, rather than before it happens. Being proactive with patients who experience the socio-economic circumstances expected to hinder rather than support their chances of continuing treatment should be considered when revisiting the DOTS strategy.

Most of the patients were overwhelmingly concerned by not having food and money upon discharge, much more than by following through with their treatment. It was therefore clear that feelings of anxiety about lack of sufficient income, food, money and limited family support also influenced their health. There was no platform to express these socio-economic problems that the patients passionately communicated to me and my Research Assistant. The staff from the WCDOH explained that patients were worried about "food security" not only that "education of TB should happen at all levels". The problems manifested at the hospital are juxtaposed with a wider and more complex situation, for example, poverty and poor living conditions than the literature has affirmed (Cox et al., 2010; Coovadia et al., 2009; Fisher & Fisher, 2002; SANAC, 2007; Stillwaggon, 2006). The social determinants of health discussed here were observed to influence attendance and continued attendance at clinics, even though these were not always explicitly given as the reasons by patients.

It is clear at this stage of the thesis that even though many respondents highlight personal motivation or agency in health outcomes, social determinants of health feature strongly to explain some of the behavioural traits of the patients in this study. Looking at social determinants of health, from the findings in the hospital right through the patients’ journey, there is evidence of interwoven socio-economic problems that the patients feel very overwhelmed about. The group of patients I followed up at different phases of their treatment journey reiterate these perennial problems in disadvantaged communities. Even though the patients did not directly say that poverty or lack of food or income influenced their attendance at clinics, as highlighted above, it was seen that those who had better income and family support attended the clinic consistently and completed their treatment. Some patients believed that their own situation could be improved if they took ownership of their own lives. These patients believed that while family and assistance from health centres is important, one also needs the motivation to get better. The question now becomes: if the circumstances in which patients find themselves do not change, can completing treatment restore their health? In other words, patients get treated, yet they will have to go back to the same living and family conditions that might have affected their health in the first place. Also, with evidence of overcrowding in patients’ homes, with little or no information on infection prevention, family members may also be at risk. Improving CoC from diagnosis to cure involves not only implementing a patient-centered model but also one that tackles the social determinants of health.

THE PROBLEM OF STRUCTURE VS AGENCY

One of the standout themes in this study is that of patients’ agency to either attend or not attend the clinics for CoC. Patient’s agency (or choice) may be explained by their personal motivation to attend, or as a result of alcohol or drug use. Many HCWs mentioned that the patients use “tik” [drug] or consume alcohol that sometimes affect their attendance at clinics or adhere to treatment. There needs to be further discussion to explain these choices that patients make or what the HCWs suggested. Patients’ choices are made within specific contexts. Mackian et al. (2004) found that even though one of the dominant approaches of health-seeking behaviour is that of the steps individuals take as they access health facilities, there must be an understanding of the influences on these behaviours. One way in which individuals pursue better health outcomes is linked to the way the health system is organised, which this thesis has explored. Other ways which patients’ agency can be influenced are a result of certain situations, which could be their living conditions and other forms of structural constraints, such as lack of income and social support that have been established in the literature (Abebe et al., 2010; Noar & Zimmerman, 2005; Mackian, Bedri & Lovel, 2004; Pronyk et al., 2001). Some authors emphasise that individual choices have a much stronger influence on health outcomes (Pronyk et al., 2001), while others show that agency is inextricably linked with structural factors (Abebe et al., 2010). This is because individuals' choices are made within specific contexts, whether in the clinical space or home circumstances.

Bourgois' (1995) work is not based on health behaviour, but he investigated the lives of drug traffickers in El Barrio (Harlem, New York) in the late 1980s. His work helps us understand that individuals' agency is linked to larger forces. His work deals with critical questions regarding individuals' ability to engage in practices that may be detrimental to their immediate environment and people around them, but again delves into the lived experiences of these people by locating the structural factors that influenced such behaviours. He tackles the aspect of social marginalisation and representation (or misrepresentation) of drug dealers (Bourgois, 1995:11). In some instances, when investigating life in disadvantaged communities, there is the tendency to blame the victims for their situation or blame only the structural factors that affect them. In other words, it is the age-old dialectic relationship between agency and structure that researchers have been grappling with over time. The interesting aspect of his work is that he acknowledges that the 'either – or' debate, i.e. between either agency or structure, can be problematic. He gives the example of Lewis whose work participants behaviour in poor communities in the 1960s, was criticised in later years for being overly focused on how individuals endanger their own lives and communities. He referred to it as "the pathology of the intergenerational transmission of destructive values and behaviours among individuals within families …" (Bourgois, 1995:16). Bourgois (1995:16) claims that Lewis "fails to note how history, culture, and political-economy structures constrain the lives of the individuals".

So, Bourgois writing 30 years later, wanted to learn from this mistake of studying disadvantaged communities, especially how they make decisions in their everyday lives. Owing to this background of learning from the mistake Lewis made, Bourgois expresses that is better one reports the stories and events as they are described by the participants. Therefore, he draws on the dual and simultaneous impact of agency and structure. Thus evaluating what individuals say and do and the outcomes of those actions.

This thesis similarly presents the choices patients made within the structural contexts they find themselves in. Each time there is a response from a HCW or the patients themselves regarding attendance or non-attendance at clinic, there are either structural factors explained alongside them from the clinic spaces or the patients' home circumstances. This does not mean that patients (as agents themselves) are not capable of making choices based on personal internal motivation, as this thesis has expressed. Some of the patients maintained that they did not want to get sick again and this motivation helped them to overcome their difficult circumstances. For others, the constraints alongside the difficulties of continuing treatment (especially if co-infected with HIV) appeared insurmountable.

One of the aims of my study was to investigate patients' perceptions of what influenced them to attend or not attend the clinics. In addition to their explanations, I observed and learned about their difficult lives and could understand how they may eventually resort to acts that may jeopardize their own survival or health and the survival of their families and neighbours. In Bourgois' (1995) study, the participants resisted larger forces, which became a cultural practice in search of respect, albeit in a destructive way. The destructive ways of some patients as highlighted by HCWs fits in a similar situation where patients may act in ways that appears to be their own choice, but structural factors, such as lack of income, better living conditions and social support may influence these choices. I now turn to describe my own experiences in the research spaces.

REFLEXIVITY

Enhancing trustworthiness

I was called to do a presentation of preliminary findings to a group of doctors and nurses on one of the three-day "World TB Day Awareness Week" held in March 2017. It was organised by the Unit for Infection Prevention and Control (UIPC) at Hospital 1 and was an opportunity for me to see whether my interpretations resonated with health professionals' understandings and experiences. This session was also an opportunity for me to get feedback from a group that were working with the patients I had interviewed at the hospital.

Some nurses acknowledged the themes presented, including that of challenges that they faced regarding TB education in the hospital. Their feedback confirmed that there was insufficient time to do TB education due to the burden of disease and number of patients that they had to see in the hospital. One nurse claimed that the patients always had some reading materials but did not read them. Others indicated that nurses really need to go the extra mile to be more involved in the patients' lives, not only to treat them and send them away. She also mentioned that some patients felt ostracized or neglected because of their disease.

It was sometimes a difficult situation because any HIV-positive person has an increased risk of contracting TB, and that disclosing her own HIV status is problematic for a HCW, as it continues to be negatively sanctioned. Also, too much exposure to sick patients, especially those with MDR-TB, may increase the risk of contracting the disease. A nurse who contracted MDR-TB in the workplace gave a touching story about her journey. I was particularly touched by the video that was presented by the organisers of the conference. I was able to see how a HCW who had battled with MDR-TB and eventually passed away, was mourned by family and friends. It made me think that having more staff to help with the teaching or counselling of patients, as argued in this thesis, may not only require more funds for hiring staff, but implementing robust ways of preventing the transmission of TB and MDR-TB among staff in the hospital and clinics. This is important because when many staff are infected with TB and MDR-TB, it may cause fear among the others, who may not want to get close to the patients. They may also not want to engage with the patients to do education or in any other way to respond to their needs and feelings.

My work in the research space

In the Methods chapter, I briefly described my work in the UIPC at Hospital 1 for about two years which ended in 2012. My own work experience was mostly confined to a small air-conditioned office, shared with a former colleague. We would spend most of the day in that small office looking at hospital-acquired infections (HAIs) data and reporting on alert sites and samples sent and positive isolates of key HAIs including Methicillin-Resistant Staph Aureus (MRSA), Acinetobacter and Klebsiella species and TB. These were very important organisms to track daily to facilitate IPC in the clinical areas. Our work also included developing databases to capture these HAIs on patients and staff in wards that included Medical Specialty/Module (commonly called Internal Medicine), which is the specialty data collected for this study.

For this thesis I therefore had the advantage of drawing on my previous work experience in one of the clinical spaces included as a research site. In that work I had been around colleagues who expressed both positivity and hopelessness about their day-to-day activities. I could therefore understand and visualise the expressions of being over-burdened by huge workloads expressed by the HCWs in the hospital. So, based on my own experiences, a feeling of hopelessness was an issue not only among patients, but among HCWs as well. Some days of work at the hospital were better than others depending on how many patients were in need of care. Health care workers being infected by TB was one of the highlights of some bad days, where in meetings we would engage in questions such as who was infecting whom – the patients or hospital staff? The rise of TB, especially MDR-TB, among staff in the hospital was a serious concern. Even though my previous work did not require me to go to the wards, I got a sense of this fear expressed by nurses in our staff meetings In conducting this PhD fieldwork in the same site I had worked in close to five years before, some of the responses from HCWs brought back memories of the days I was working at Hospital 1. Fear of contracting TB and MDR-TB, patients' feeling of being neglected in isolation rooms, patients coming back to the hospital with MRD-TB after having been treated with TB, were unpleasant complaints one would hear from some of the HCWs. These were some of the issues that were unavoidably on my mind, although I tried to approach my observations and interviewing participants in the study with a fresh perspective.

With regards to Hospital 2, I never worked there, but I have been making frequent visits to meet up with either patients diagnosed with TB when they were admitted at the hospital or to meet up with other peer researchers or HCWs. Hence, my previous experience in the research spaces helped my navigation around the hospitals. It might be possible that someone outside this clinical space would have had challenges with regards to identifying key informants. In addition, a follow-up of patients diagnosed with TB, especially with MDR-TB, might have deterred some researchers because of fear of being infected with TB. In my case, with my knowledge of TB as well as working and interacting in this space, noticing first-hand the potential disastrous impact of TB, I was motivated to pursue the task and knowledgeable enough to know what precautions I could take.

Lessons learnt from methods used in the study

The methods employed here generated a rich data-set from a number of respondents with different perspectives and experiences. Having multiple interviews with each patient over the course of a year enabled me to understand the treatment journey in a different way had I only interviewed participants at the end of their expected treatment completion. I also embarked on collecting, transcribing and analysing data as data-collection occurred. This pattern of concurrent data analysis and collection was helpful in raising new questions to explore with future participants or with the same participants in the next interview. The idea to use a purposive sampling strategy worked well because it steered the study in the directions based on the research questions and aim of the study. Recruitment and follow-up were achieved without any major obstacles. The choice of doing semi-structured interview guide provided a good balance of structure and freedom for participants to delve into issues of importance to them.

The observation done in hospital strengthened the overall study. I had observed difficult situations with families and this became a topic to explore further in interviews. The relaxed atmosphere my Research Assistant and I created helped create space for patients and family members to talk. I felt that having established an interpersonal connection with participants while they were hospital, made home visits and interviews comfortable for all involved. With the help of my Research Assistant, the patients' families could express themselves in their own language. I could not speak isiXhosa fluently, but I could engage in small conversations of greetings, asking how someone was doing and saying good bye. This helped in getting started with some conversations. Some patients revealed important issues after the third interview, suggesting that trust was built up over time.

Being black/African researchers probably made me and my Research Assistant more relatable and encouraged some participants to open more so than if we were of another race or from another continent. Some of them would even speak isiXhosa to me, assuming that was also my language. I would simply reply by saying I did not speak isiXhosa well, but I was an African, and was learning how to speak isiXhosa and had been in South Africa for about 10 years now. I would say such things for the patients to feel relaxed and be able to engage with me, but also I was aware of reports of xenophobia in some townships in South

Africa. I never encountered any sort of violence or intimidation in the townships where I did the field work.

Some of the patients expressed severe health problems. Others, though they did not directly express suicidal tendencies, prayed for God to take their lives. Sometimes, under the pressure of time and the need to complete a project, a researcher can overlook these expressions of suffering. I chose to discuss some of these issues with my supervisors. On the advice of one of my supervisors, I had informed the social worker and one of the nurses about of a worrying situation. Up to Bianca's passing, I reported the situation a number of times to the Head Nurse and social worker responsible for overseeing the particular ward she was admitted to. I did this, hoping that they would respond to the problem expressed by Cheryl (Bianca's mother) and find ways to assist Cheryl and Bianca, at least with the relevant information in such circumstances. I had to do so for my own sense of responsibility and for dealing with my own emotional reactions to patients' hardships and suffering.

LIMITATIONS OF THE STUDY

Perception of my role as a researcher by patients

My Research Assistant and I communicated the aim of the research and our roles to all participants in the study. In one of the interviews, I was referred to as 'Doctor' by one of the patients. It is possible that some of the patients perceived me as a follow-up doctor to check if they would report to the clinic or take their medication as they should. During the recruitment at the hospital I told each patient that I would like to speak to them again. I took their addresses and contact numbers. This may have influenced some of them to turn up at the clinic knowing that a 'doctor' would come to check on them. This could present a limitation to the study if patients thought they were being followed or watched. Participants altering their behaviour when they thought they were being observed is not a new phenomenon in research, as explained in the methods section. Patients' perception of who I was may have propelled some of them to attend the clinics after discharge from hospital. Hence, their initial attendance may not have happened had they not thought that someone was coming to talk to them. The CHWs also highlighted how some of the patients would consider them as 'spies' for the clinics to check if they were taking their treatment.

However, this perception of a 'spy' did not prevent some of the patients from not attending the clinics. My role as a 'doctor' to some of them (even though I had explained that I was a researcher) and the fact that I spoke English may have attracted some level of respect (or even fear) from the patients and motivated them to attend their clinics. However, irrespective of this possible perception of someone, like myself, monitoring them, some of the patients still stopped attending the clinic during the course of their treatment.

Interviews during hospitalisation

Another potential limitation of this study was the lack of privacy of interviews conducted on the wards. The interviews were focused on each patient, but there were other patients in the room. The presence of other people in the room (although a few metres away) may have constrained how people responded to questions if they were not comfortable with others potentially overhearing. Similarly, (although it happened in only one occasion due to unavoidable circumstances), a patient was interviewed in the presence of her mother. This could also affect a patients' response, especially when asked about family support. This patient did, however, give a similar response about positive family support when she was interviewed alone at the hospital. There was no alternative to doing the interview at the bedside, and despite potential constraints to free expression, interviewing at the bedside also brought an important perspective to this study. Nonetheless, it is important to highlight this as a possible limitation because all patients were supposed to be interviewed individually.

AREAS OF FURTHER RESEARCH

My study focused on the initial diagnosis of TB at the hospital and not on the reasons for not attending PHC. However, it would be interesting for future research to probe further into the question of why it is patients chose to go to the hospital rather than their local clinic. One might hypothesise that stigma could lead some to deliberately bypass the primary health clinics, but there are likely to be a multitude of complex and interrelated reasons for doing so.

One of the HCWs spoke strongly about “many doctors” not having adequate knowledge of MDR-TB. Drawing on the results of the rise of MDR-TB and XDR-TB in South Africa, this could be a serious problem. This could be another angle to pursue in future studies where the inability to do proper diagnosis can cause confusion in the minds of patients and affect CoC.

Another important area to do further research is to explore patients’ understanding of how the DOTS plan work. This study did not dedicate much time on this. It appears in the study that patients’ treatment plan changed to something else, if it is not SAT. It would be worth investigating how changes and lack of clarity around why one or the other is chosen could be important in shaping CoC.

CONCLUSION

From my findings, I hypothesise that if patients were to receive patient-centered care, they could understand their treatment plan better and this could address some of the barriers to them attending clinics as planned. These barriers include confusion about the disease and a belief that the medication may cause them harm. PCC from hospital through to the clinic cannot take place if the other factors (workload and time constraints) are not addressed. Staff need not only be trained to be more patient-centred care in their approach in the hospital and the clinic, but more personnel are needed. Being ‘scared’ or ‘confused’ are factors affecting CoC that have so far not been adequately reported in the literature, and so considering these in rich detail is an important contribution of this thesis.

Foucault’s ‘medical gaze’ has been useful in this study for understanding of the lack of opportunity for patients to become partners in their treatment journey, which led to feelings of hopelessness and powerlessness. Even before patients leave the hospital, their conversations have been mirrored by conversations of the initial contact of doctors and nurses. This internalisation of their disease, as well as lack of adequate PCC in both the hospital and clinic, disempowers patients. I have argued in this thesis that a better HCWs-patient partnership may encourage a treatment process that is less disease-centered and more patient-centered.

Difficult socio-economic circumstances compound the problems patients face. Patients not only find themselves in places where there is high risk of TB spreading, but in circumstances that make it difficult to continue with treatment. Conversely, those with better financial and family support attended the clinics more consistently. The role of stigma and abuse in CoC has also been underexplored and is raised as an important issue by this study. CHWs may check on patients regarding their non-attendance at clinics or non-adherent to treatment, but this does not mean there is space, time or trust for patients to reveal issues relating to stigma or domestic abuse in the home. Even if community health workers or other health professionals know of these situations, it is unclear whether they would have the skills and resources needed to help address them.

In theory, without a commitment to addressing the social determinants of health, the South African government may continue to face many challenges in combating TB. The upstream-downstream concept brings the first question to consider: if SHD are not addressed, would PCC work well? It is unlikely this would be the case. The pathway of what causes TB to spread, and the cost of treatment, are as important as providing the support for patients to be retained in care. Another question worth asking is why, within the DOTS strategy, some patients do not attend the clinic, but they are not visited by DOTs workers. Even though this study does not look at how the DOTS system works among the patients, why patients consider CHWs as ‘spies’ would be a reason to revisit this strategy. The policy makers explained that both SAT and DOTS were being used. However, when did one apply and the other did not? Or when did both apply? This is another issue that should warrant a revisit of the DOTS plan.

CHAPTER EIGHT: CONCLUSION AND RECOMMENDATIONS

CONCLUSION

My thesis explored continuity of care (CoC) among patients diagnosed with Mycobacterium tuberculosis (TB) in tertiary and district hospitals who were referred to PHC clinics. Continuity of care (CoC) involves patients seeing a particular doctor over time (Alzari et al., 2007; Cabana & Jee, 2004; Freeman, 1984; Guillifford, Naithani & Morgan, 2006; Hjortdahl & Laerum, 1992; Mainous III et al., 2001; Saultz, 2003), but it also concerns the referral of patients from one health centre to the other (Edginton et al., 2005; Edginton, Wong & Hodkinson, 2006; Dudley et al., 2018). In this study, I conceptualised CoC as the referral of patients diagnosed with TB from the tertiary and district hospitals to PHC clinics. Only a few studies (Edginton et al., 2005; Edginton, Wong & Hodkinson, 2006; Dudley et al., 2018; Marais, Kallon & Dudley, Forthcoming; Jacobson, 2015) have tried to understand this process of referral, but the patients' perspectives of treatment in the hospitals and clinics as well as their home circumstances—and its impact of their TB treatment—have not been explored. My study explored patients' perspectives of treatment from their initial diagnosis at the hospital to their referral clinics and homes. In this way, I brought the dual experiences (clinical and home situations) of patients' treatment to the foreground. Not attending clinics for CoC as a result of being scared and confused because of lapses in PCC have not been documented in the literature on CoC. In addition, domestic abuse and stigma (Craig, et al., 2016; Daftary, 2012; Daftary, & Padayatchi, 2012) have been documented on TB/HIV care generally, but not in the home by the families of the patients. Having the understanding of patients' being abused and stigmatised at home broadens the literature in this context of patients diagnosed with TB at the hospital and referred to the clinics for CoC.

Continuity of care (CoC) is not only affected by lapses of the health system, but also by influences of patients' socio-economic circumstances. I have argued in this thesis that problems in the provision of TB services to hospital patients can be understood as failures of the services at the hospital to achieve some of the core components of PCC. Additionally, I argued that better systems for following up patients from the hospitals to clinics and their homes would provide more understanding of the challenges patients face when they have been referred from a tertiary or district hospital to continue with their treatment. Insights gained from qualitatively following patients from diagnosis to discharge and their home circumstances help to better understand the problem South Africa faces with CoC for TB treatment.

The key findings were substantial gaps in PCC in the hospitals as well as the clinics in engaging with patients' needs and feelings about their treatment and discharge to clinics. Foremost of the reasons for these lapses included the large amount of work that the HCWs had to do but had insufficient time to do it. Hence, they could not focus on patient education effectively and consistently. There were also cultural and linguistic challenges and patients' limited knowledge of TB prior to hospitalisation. The cultural challenges that HCWs faced were seen in areas where patients could not understand key aspects of their treatment based on their perception of what their treatment was. There were also linguistic challenges, where some of the HCWs could not speak the languages of the patients. Despite all these challenges, mostly high workload and time constraints militated against nurses and doctors implementing the core elements of PCC.

There was also poor collaboration between health centres, where patients move from one health centre to another without much clarity on what lies outside the hospital. There were similar reported cases in the clinics of inaccurate dissemination of TB information to patients, which reaffirmed poor linkages between the clinics and the hospitals. Patients who had not attended clinics during the course of their treatment expressed feelings of being scared and confused and being abused at home by family members. Feeling scared, confused and embarrassed by improper behaviour of some nurses were influenced by lapses in the health system. Poverty and lack of family support were among the influences on patients' non-attendance at clinics. Patients who attended the clinics consistently reported strong family support and high internal personal motivation; these regular attendees had better socio-economic standing as well.

The link between the hospital and the clinic, which is driven by the referral letter, concealed many misconceptions in the minds of the patients. Not all patients had a clear understanding of what their treatment entailed. The fact of patients initially attending their clinics does not guarantee continuous attendance. The patients drew on their experiences from both health centres that they attended. Patients did not only have inadequate education, both from the hospital and clinic, but there was not enough room for them to express their needs and feelings on issues that mattered to them. That meant that information provided to the patients at some point rendered them anxious about their diagnosis. Some were scared and confused about the treatment that they were receiving and stopped attending their clinics. Patients were also overwhelmed by lack of financial, material and family support, which hindered their attendance at clinics. Conversely, as mentioned above, those with family support and better income enabled some patients to attend their clinics consistently.

REFLECTING ON PREVIOUS CHAPTERS

In the first chapter I gave a background of how TB has been a persistent problem in the world. I provided evidence of this looking at global, regional and South African landscapes. Even though there has been a decrease in TB deaths, the numbers are still high. Focusing on South Africa, where the field research was conducted, I also gave a background to the specific research problem in the context of CoC. Bigger structural problems of TB, which were socio-economic marginalisation through apartheid policies, created some disadvantaged groups of people in the country. Most of these groups of people still bear the brunt of TB as they continue living in overcrowded and poor environments. From this background, including many administrative and health sector challenges, many cases of TB are found, mostly among predominantly black/African and Coloured populations who were disadvantaged under apartheid. Sadly, the legacy of apartheid lingered on as the patients who resided in areas where this research was done, lacked adequate housing. People also had lower income and sub-standard education.

With this wider context in mind, the immediate problem that drove this study was the knowledge of a significant number of patients diagnosed with TB who did not report at the PHC clinics where they were referred. The literature review of this problem showed that there has been evaluation of the numbers and experiences of patients not attending at their PHC clinics and also an exploration of HCW participants' experiences at the hospital (Edginton et al., 2005; Edginton, Wong & Hodkinson, 2006; Dudley et al., 2018; Marais, Kallon & Dudley, Forthcoming; Jacobson, 2015). No other study has followed-up the patients from initial diagnosis at the hospital to the PHC clinics as well as the socio-economic circumstances of the patients. The related objectives of my study included exploring patients' understanding of the diagnosis of TB, the discharge and referral process from the tertiary and district hospital to PHC clinics; exploring patients' perceptions of the link between the hospital and the clinic; exploring patients' experiences of TB treatment in clinics, communities and home; and exploring the perceptions of other stakeholders, such HCW participants, policy makers and families why some patients attend or do not attend PHC clinics for continued treatment; understanding the linkages between the tertiary and PHC clinics; and informing public health policy to improve on inconsistent attendance rates in clinics of patients diagnosed with TB.

Chapter Two reviewed a theoretical framework that aided my arrival at the argument above, which may broaden literature on CoC. Using PCC as a theoretical framework, I evaluated the interactions between the patient and the HCWs, regarding the patients' treatment in the hospital and the clinic. Three elements of PCC were explored to make sense of this interaction between the HCWs and the patients. These were engaging in patient education to understand their treatment, engaging the patients to know their needs and feelings', and partnering with them to discover better ways to implement the treatment plan. The data presented showed that there was no adequate engagement to meet the core elements of PCC.

Patient-centred care (PCC) was not the only explanatory tool used to make sense of the data. A key feature of the biomedical system, which Foucault referred to as the 'medical gaze' (Foucault, 2003), objectifies the patients. Medical personnel sometimes have subtle ways that impact on the actions of patients. Social determinants of health (SDH) also helped me to understand that socio-economic circumstances contributed significantly to the influences of CoC in the context of patients diagnosed with TB at the hospital and referred to PHC clinics. Though my study did not evaluate where the patients contracted TB, their demographics and reflections of some HCWs, coupled with my observation of their living conditions and family support structures, showed that most of them were struggling to make ends meet. The study affirmed that SDH do not only feature in the possible causes of TB, but also feature strongly in the patients' retention in care.

Chapter Three explained the research methods, which was a qualitative design, using semi-structured individual and focus group interviews in both the hospitals, clinics and patients' homes. There are high ethical implications in health research. In all phase of this study all researchers involved in this study were aware of these ethical issues and made deliberate efforts to address those using international ethical standards. My Research Assistant and I took note of what we brought to the research space and these could affect the data or the participants. We made efforts to avoid any negative effects on the participants or the health promotion services rendered to them. The semi-structured interview guideline allowed participants to engage with us developing a rich data set that we worked on. Chapters Four, Five and Six presented the data, which the theoretical framework above attempted to explain.

In Chapter Four I explored the initial contact the patients had with the health system. This does not mean that patients might not have been to the clinic for any other medical problem. However, I focused on patients newly diagnosed at the hospital and who were expected to continue with their treatment. This chapter informed us that patients received little or no education on TB. It gave me issues and ideas to probe on at home that were mentioned by patients in the hospital. Some of these issues related to their living conditions and family support at home. HCWs and patients' interactions provided evidence of a lack of PCC, which also led to feelings of hopelessness.

This came as a result of not only inadequate PCC, but also the medical system in which the HCWs are working. Emotional labour was performed by some HCWs, but on the other hand, there was also an objectification of the patients. For some patients, this interaction was a decisive moment in their treatment journey that even influenced the way they interpreted their diagnosis and acted upon the knowledge right through to the clinic. HCWs, especially doctors, have emerged to have a lot of influence and are highly respected when they interact with patients. In my study, this played out in the patients' internalisation of their diagnosis.

Chapter Five focused on the third aspect of PCC, shared decision-making, in the context of discharge planning. This was a crucial area of patients' treatment journey because they should be thinking about how to proceed from the hospital. They needed to make a decision about their attendance at clinics using the discharge letter given to them. With little knowledge of how the discharge system works, there was also no partnership with the patients to facilitate this smooth move from the hospital to the clinic. The HCWs who provide the care to them were oblivious to some of the problems faced and articulated by patients in this study.

In Chapter Six the clinic could not bridge the gap of education among patients. In addition, some of the HCWs, especially nurses, at clinics could not adequately engage with patients to understand their needs and feelings. Patients were also not treated as partners, which was evident by some of the patients complaining of being embarrassed at clinics. Hence in both centres, the inadequate education of patients played a role in patients' lack of understanding about their diagnosis.

Most importantly, this chapter explored patients' socio-economic circumstances, which did not only affect patients in the production of diseases, such as TB, but also in the retention of care. The link of socio-economic factors, such as poverty, is not new in the literature. It has been established that diseases are not only affected by clinical and health sector factors, but also intermingle with features of sick peoples' socio-economic lives, such as poverty, living conditions, and education. The patients that were examined in this study not only had low incomes, but some had poor living conditions and estranged family relationships.

Social conditions do not exist in a vacuum. These are linked to the political economy where better living conditions, including better housing, are made available to people in need by governments and other related stake holders in any country. It was established that the work of the medical practitioner may include the restoration of the health of sick patients, which may ignore the ongoing problems that caused the sickness in the first place. Even though, agency was seen as influencing the attendance of some of the patients, they were affected by social determinants of health and good family support.

Chapter Seven discusses the findings. One of the stand-out problems in the hospitals and clinics is the insufficient education of patients, which the data chapters presented. There are bigger factors at play one needs to consider relating to this problem. Firstly, it seems to be unclear in health policy about who should do education and at what point the education of patients should be done. Secondly, without addressing the shortage of staff in the health sector, it may be almost impossible to implement adequate PCC. Addressing the issue of staff shortage may not guarantee that patients will continue with their treatment after discharge from hospital, but it will, in theory, bridge a knowledge gap, which is also an important area to consider in CoC. These education programmes may warrant an "infrastructural change", not only in the structure of the teaching at the hospitals and clinics, but also in responding to the shortage of staff in health sector. It is not new knowledge that many people use the public health system that is under-resourced compared to private services in South Africa. There is rising incidence of MDR-TB and XDR-TB, which are much more expensive to treat than susceptible TB. The problems of the burden of diseases in South Africa also impose a heavy challenge on the health system. It is within this larger and immediate context that patients diagnosed with TB were not attending their clinics is a serious concern.

Forming a partnership with the patients as they treat TB may not solve the problems patients encounter in their homes, but it will offer them an opportunity to share their needs and feelings. It may also provide patients the opportunity to be part of the strategies to provide a better health outcome. The historical context in which this study was done not only gave an account of the challenges within the health system, but also of the present living conditions of the patients.

The gaps in the literature were reaffirmed, a task which my study embarked on to contribute to fill this gap. Patients' perspectives have in the past not been explored in the context of referrals from tertiary and district hospitals. These gaps include the inadequate documentation of patients' education in the hospital before discharge. Edginton et al.'s study (2005) focused on the numbers that arrived, which will not depict the lived experiences of the patients. Further, the patients that were interviewed, mentioned lack of knowledge of TB, but it was not clear if this lack of knowledge was as a result of lack of education in the hospital or clinic. In addition, it did not explain the intricacies of the interaction between the patients and the HCWs. My study has attempted to fill in this gap where we know some of the dynamics that influenced patients' lack of adequate PCC.

The link between the clinic and the hospital was not adequately documented because the patients' experiences at the hospital was not explored. Studies by Dudley et al. (2018) and Marais, Kallon and Dudley *(*Forthcoming*)* explored this link, drawing on the HCW's perspectives. An exploration of these gaps, including other related themes, uncovered data that shed more light on CoC and broadened the existing literature in this context of CoC.

I now make some recommendations for considerations. I do acknowledge that patients' experiences and perceptions of treatment in the clinical spaces and their homes can be complicated issues, which this thesis may not exhaustively explore. Therefore, the recommendations I put forward below may not be sufficient to address all of these different facets of the patients' treatment journey. Nonetheless, they may contribute towards patients' attendance at clinics for CoC after discharge from tertiary or district hospitals.

RECOMMENDATIONS

Clear policy statements on education of patients in hospitals

My study has noted that TB education is being done in clinics, although not effectively. It is also almost non-existent at hospitals. Policy documents and policy makers affirm that education of TB patients should be “done at all levels”. However, it is not clear who should do this education and at what time it should be done. My study also records the insufficient staff and workload that the HCWs face in hospitals. Some of them found the time to provide some education while many others did not do so. Although this aspect is linked to inadequate PCC, (which will be discussed later, and how it is linked to clinics as well), it did not help much to focus on treatment where patients went out “scared” and “confused” about their diagnosis.

Patients’ knowledge of TB is equally as important as the treatment they receive because they would have to implement what they learnt, at home with their families. The policy could indicate the training of counsellors in the hospital to do education. It is highly unlikely that the workload of HCWs, especially nurses and doctors, will reduce because of the rising incidence of TB (and HIV). One of the HCWs at Hospital 2 mentioned that in a former hospital she worked at, there were counsellors who would educate patients about TB. This method worked well because by the time the patients left the hospital, they had good knowledge about TB. She asserted that there was an assumption that because patients lived in areas where there was high incidence of TB, everyone knew about the disease.

A HCW at Hospital 1 indicated that there was a structured programme to educate staff. It would be essential to have a structured programme to educate patients diagnosed with TB as well. This theme was also emphasised when I presented preliminary findings at Hospital 1. Some nurses mentioned that it would be good if counsellors could help in the education of TB patients. Obviously, this will warrant having more staff. The difference is it may not be that expensive to train counsellors, as compared to nurses and doctors, to do this teaching of patients in the hospital prior to discharge.

Being proactive in patient-centred care

Some patients did not attend the clinics because of confusion about their diagnosis at some point in their treatment. The suggested education of patients proposed above should be patient-centred and not disease-focused. After identifying who should be doing the education, the focus in this area can enable patients to understand the implications of their treatment. The patients expressed confusion and anxiety in some areas of their treatment. Responding to patients' needs and feelings of treatment does not necessarily mean just dishing out information of treatment, but rather asking how they feel or what it will mean if they have to take this kind of treatment for 6 months.

Although effective PCC may depend on having more staff, as mentioned above, which could be some time before such venture materialises, designing educational strategies for patients in the hospital could be done in other ways. For example, there could be the use of a counsellor to come into the areas where all patients are admitted and give a talk about TB. It should be noted that when patients are sick, it is difficult to speak to all of them. Therefore, having patients wait a day or two before discharge could be a good strategy. Some hospitals may not have enough space to do such focused teaching. However, I think it would be better to make space for patients to have a proper understanding about their sickness before leaving the hospital. The alternative is a vicious circle where patients who were once treated would come to the hospital again, but this time with MDR-TB.

Some of the HCWs highlighted that there were also linguistic challenges. This could be addressed in two ways that could be done simultaneously. One of the ways is to train counsellors to speak the languages of the patients diagnosed with TB, as disseminating information about TB in the patient's language could help them understand that information. Even though counsellors may do the bulk of the teaching, doctors could also speak to the patients. The other way would be to get medical practitioners to learn some of the local languages that most of their patients speak. This might also reduce the cultural challenges, as it would help patients to relate to the doctors and HCWs better. This may help the patient giving feedback to the one who teaches. This patient feedback puts the HCW in a better position to know what the patient has understood or not and discover ways to pass on the information. Because the health system is overloaded with many medical cases to attend to, this proposal may be frowned on because it could be a time-consuming exercise. Nonetheless, I think it is better to spend the time and resources on developing this capacity of doctors and HCWs because it may enhance the treatment plan of patients diagnosed with TB and may reduce the lapses in preventing patients falling out of treatment.

Addressing the social determinants of health

The question posed in the discussion section about what would happen if education and PCC improved but SDHs are not adequately addressed, leads to the following recommendation, to address those SDHs. There are two ways this can be addressed. Firstly, at a broader level, which is already a plan the South African government, needs to be intensified and or implemented rigorously. People living in “shacks” in the townships need better houses and jobs. People in such communities, like the participants I followed up on, lacked better houses and jobs and did not have sufficient income. Some of the participants even made the plea that they wanted the government to come and see where they lived. Providing social grants would also help the patients – but the unfortunate side to this support is that, when patients get better, they lose this support. Such support can help alleviate the external costs of treatment, including food and transportation to the clinic.

The other way, which could be a short-term one, is that hospitals and clinics can have a specific strategy to improve dealing with patients’ needs. This may be linked to having adequate PCC, but it goes a step further, which is not only listening to the patients’ needs, but also being more proactive in responding to these needs. There are some established mechanisms to respond to social determinants of health at both health centres. These include the activities of the social workers who enquired about the social conditions in which patients resided. They also investigated patients’ family support at home and provided transport fare to patients before they were discharged from the hospital. This level of support needs to be increased. Providing transportation assistance may not be sufficient for initial relocation of patients for CoC. The case of Bianca is worth considering. In a situation where there is not enough clarity as to where the patients will be staying, more enquiries should be done before discharge takes place. Secondly, providing food parcels, warm clothes and having someone escorting some patients who are destitute, hungry, weak and homeless can also be done. This area of responding to patients’ needs should not only be left with the clinics.

At community level, the clinics had counsellors who talk to patients about their diagnosis and other related health matters. TB counsellors recounted incidents where some of the patients sometimes bypassed these counselling sessions because of the long wait at the clinics. The CHWs also help to counsel some patients at homes. The findings showed that some activities of the patients eluded them. Hence, I propose that firstly, there is a need to develop a trusting relationship with patients. Addressing SDH is not only about providing food and other material resources to the patients, as mentioned above. It should be well-organised and focused action in specific areas of the patients' lives. From the hospital right through to the clinic, there must be face-to-face interaction with the patients. Time should be spent allowing the patients to express themselves about their needs and problems that they face daily.

One of the policy makers, who has served for several years in working with patients diagnosed with TB, acknowledged this as very crucial. She also drew on her own experiences of contracting TB. She needed similar support from HCWs, not only family. Some patients were more concerned about where they lived, worried about abuse in the home, anxious about how they would be treated at the clinic. Hence being proactive means the HCW from the hospital right through to the clinic should initiate these discussions with the patients. Providing transportation to patients, for example, who lacked money to go home, similar to the case of Bianca, would not address some problems hidden in the family. Similar concerns need to be addressed simultaneously with the demands of patients to attend the clinics and roll out treatment for CoC. CHWs should also be trained to respond to issues such as domestic abuse.

Revisiting the DOTS strategy

Patients in this study stopped attending the clinics for CoC, but they claimed CHW did not check on them (during the time I interviewed the patients). CHWs stated that they did visit patients in the community. Apart from the fact that some patients may not get visits from CHWs when they stop treatment, policy makers reported that both DOTS and SAT are sometimes applied simultaneously. The question then is when would be the best time to use DOTS or SAT. In theory, SAT is used when patients are considered reliable with the treatment. However, some patients in the study were not reliable, but might have had DOTS supporters to check on them. In addition, if patients consider CHWs as 'spies', this does not denote a partnership model where patients are given the opportunity to take charge of their own health. Here, one of the policy makers indicated that TB is not disease for them "to protect". This means the patients should be considered as partners, but also be informed about things that really matter, which is their livelihood. The question comes here again, DOTS can be applied, but it will still not fix the patients' present socio-economic circumstances. The DOTS plan should not be seen as a monitoring scheme, rather a partnership model where patients develop trust in the health system. The DOTS programme should focus more on not only helping to check if patients take their medication, but also, for example, what the patients need to eat at home and how they should be protected from abusive family members. If patients realised that they are helped in such ways, they might not see the DOTS workers as spying on them, rather as helping them.

FINAL THOUGHTS

My study answered the research questions outlined in Chapter One. The study also generated some more questions that may inform further studies. One of these areas of further studies could be why patients end up in the hospital for treatment other than the clinic and how that may influence CoC. The other areas are how the improper diagnosis of TB, especially MDR, may affect patients' CoC and an investigation on patients' understanding of the DOTS plan. The area of improper diagnosis raises questions of the training of some doctors, not necessarily in South Africa, may lack the required skill in doing such diagnosis.

My study is significant because the South African Government has recognised the need for a practicable cohesive health system to achieve the goal of better health for all. PHC has been the cornerstone of health policy since the early 1990s. By exploring patients' perspectives, including home situations, this thesis has provided further understanding of the challenges patients are faced with when they have been referred from a tertiary or district hospital to their PHC clinics. It has also informed us about how services to patients can be improved to enhance better CoC. This was the objective of the study. Hence, I have added patients' socio-economic situation to the model of CoC of patients' diagnosed from the tertiary or district hospital to continue with their treatment in PHC clinics. Not attending clinics for CoC as a result of being scared and confused has not been sufficiently documented in the literature on CoC. In addition, domestic abuse and stigma (though these have been documented in the literature in other contexts), have not been documented in the context of patients diagnosed with TB at the hospital and referred to the clinics. From an understanding of these other factors responsible for continuity of TB care in my study, I have proposed some recommendations above to inform public health policy. These are to have clear policy statements on who does TB education in hospitals, be proactive in patient-centred care, address social determinants of health and revisit the DOTS plan so that patients are involved as partners not as part of a monitoring system designed by the clinic.

APPENDICES

Appendix A: Participants' informed consent form

INFORMED CONSENT FORM (ICF) (PATIENTS)[18]

The following informed consent is for some patients diagnosed with TB in the Medical Specialty at a tertiary hospital/district hospital and who will be referred to continue with treatment at a primary healthcare clinic.

TITLE OF THE RESEARCH PROJECT:

Influences on the continuity of care for patients with Mycobacterium tuberculosis referred from tertiary and district hospitals

PRINCIPAL INVESTIGATOR: Assoc. Prof. Christopher Colvin
SUPERVISORS/CO-INVESTIGATORS: Mr Idriss Ibrahim Kallon and Dr Megan Wainwright

ADDRESS: 104 Ashwood Centre, Main Road, Parklands, 7441, Cape Town

CONTACT NUMBER: 079 484 2269

This ICF has two parts:
Information Sheet (to share information about the study with you)
Certificate of Consent (for signatures if you choose to participate)

You will be given a copy of the full Informed Consent Form.

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[18] This sample consent form is for patients. Similar consent forms were given to other participants, such as healthcare workers and family members. The differences are in the reasons given for participants' involvement in the study and their responsibilities in the study. Healthcare workers were invited to participate because they either treated patients or understood about factors influencing patients' continuity of care. Policy makers were invited to participate because they understood about factors influencing continuity of care. Family members were invited to participate in the study because they assisted patients with their treatment of tuberculosis.

Part 1: Information sheet

Introduction

Tuberculosis is one of the major health problems in South Africa and elsewhere in the world today. This research study wants to investigate some patients' treatment of TB in clinics after they have been discharged from a tertiary hospital and district hospital. This research study specifically aims to explore the connections between the tertiary hospital/district hospital and the PHC clinics regarding patients' treatment for TB. The patients discharged from the hospital will be followed up for a period of time, starting from their initial diagnosis until the completion of their treatment. Patients co-infected with HIV and/or who are diagnosed with Drug-resistant will also be included in the research. The research team will also explore the perceptions of healthcare workers (HCWs) in the tertiary hospital and clinics, family members and policy makers who have worked the patients with TB regarding continuity of care.

Please take some time to read the rest of the information presented here, which will explain the details of this project. Please ask the Researcher or Research Assistant any questions about any part of this project that you do not fully understand. It is also very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part initially.

This study has been approved by the **Human Research Ethics Committee at the University of Cape Town as well as the City of Cape Town and the Western Cape Government.** The research will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

The aim of the study is to analyse factors that influence the continuity of TB care when patients move from the tertiary- or district-level hospital to the PHC clinics. The objective of this study is to contribute to our understanding of patients' experiences and perceptions of treatment of TB and how services to patients can be improved to enhance better continuity of care. If there are challenges beyond the control of patients, this study will inform healthcare policy makers and service providers to design appropriate strategies to address the challenges faced by patients treated for TB.

The potential participants will be interviewed initially at the hospital about their first experiences with and knowledge about TB and referral procedures. After discharge, these patients will be followed up and asked about their experiences at the clinics they have been referred to for continuation of their TB treatment. They will also be asked questions about their experiences with TB treatment in their homes. As mentioned, other potential participants who will be interviewed are HCWs and policy makers, all of whom may have worked with patients or understood about factors influencing continuity of care, and family members who may have assisted patients with their treatment.

Why have you been invited to participate?

You have been invited to participate in this study because you have been diagnosed with TB at a tertiary/district hospital. We would like to learn about your experiences of the treatment at the hospital and your experiences when you continue with treatment after discharge from hospital.

What will your responsibilities be?

You will be required to answer some questions about your experiences of the initial TB treatment at the hospital before you were discharged. You will also be required to answer some questions about your TB treatment at the clinic that you have been referred to as well as about taking your treatment at home.

Confidentiality and Sharing of Results

The information that you share during individual interview will be kept private. The information will not be discussed with anyone other than the researchers. All information collected will be kept safe in locked filing cabinets or offices, and on password-protected computers. If you agree to take part in the study you are asked to keep any information that is shared in the group discussions private and not to share this with anyone outside of the workshop.

We want you to know, however, that we cannot stop participants from sharing information that should be private.

When the results of the study become available, your name or discussion groups will not be mentioned in the report.

Will you benefit from taking part in this research?

You will receive payments for any transport costs if the need arises. You will receive light food and drinks refreshments during any interview. It is hoped that the study would help to improve the attendant rates at clinics after discharge from hospital. It may inform better policies and practice that will help future patients diagnosed with and treated for TB.

Are there in risks involved in your taking part in this research?

There are no identified risks involved in undertaking this study. However, if certain questions cause any emotional or psychological discomfort or strain, participants are expected not to answer any such questions. No potential participants will be encouraged to participate if they appear anxious or worried. If there is evidence of anxiety during the interview the participant will be asked if it would be better to terminate the interview or deferred to a later or more convenient time.

If you do not agree to take part, what alternatives do you have?

None. The participation is entirely voluntary and that there is no negative consequence for refusal or to withdraw from participation.

Who will have access to your medical records?

Any information collected will be treated as confidential and protected. The information collected will be used in a publication or thesis, but the identity of the participant will remain anonymous. Participants will be identified using a coding system.

What will happen in the unlikely event of some form of injury occurring as a direct result of your taking part in this research study?

There is no form of anticipated injury that will take place during this study. However, if participants express any form of emotional distress, the interview will be terminated or deferred to a later time at the participant's convenience.

Will you be paid to take part in this study and are there any costs involved?

No, you will not be paid to take part in the study, but your transport and meal costs will be covered for each study visit. There will be no costs involved for you if you do take part in the study.

Right to refuse or withdraw

You do not have to take part in this research study if you do not wish to do so, and choosing to participate will not affect you in any way. You may stop participating during the interview any time that you wish. The researchers will give you an opportunity at the end of the interview to review your comments. You can ask to change or remove parts of the information, if you do not agree with our notes or if we did not understand you correctly.

Is there anything else that you should know or do?

You can contact Mr Idriss Kallon at telephone number 079 484 2269 if you have any further queries or encounter any problems.

You can contact the Human Research Ethics Committee at UCT (021-938 9207) if you have any concerns or complaints that have not been adequately addressed by the researcher.

You will receive a copy of this information and consent form for your own records.

Part 2: Certificate of Consent

I_________________________________ have been invited to participate in this research study, which is about the linkage to care of patients with TB between the hospital and the clinic. I have read the information letter, or it has been read to me. I have had the opportunity to ask questions about the study and any questions I have been asked have been answered. I consent voluntarily to be a participant in this study.

Print Name of Participant: __________________________

Signature of Participant: ____________________________

Date: ___________________________

Day/Month/Year

If uneducated:

I have witnessed the accurate reading of the consent form to the potential participant and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Print name of witness: __________________________ **Thumbprint of participant** ☐

Signature of witness: __________________________

Date: __________________________

Day/Month/Year

Statement by the researcher/person taking consent:

I __________________________________, have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands that the information provided in these documents. I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

Print Name of Researcher/person recording the consent:_____________________________

Signature of Researcher /person recording the consent:_____________________________

Date: ________________________________

Day/Month/Year

An Informed Consent Form will ____ OR will not ____ be completed.

Declaration by Interpreter

I (name) ……………………………………………..……… declare that:

- I assisted the investigator (name) ………………………………………. to explain the information in this document to (name of participant) ……………..…………………………….. using the language medium of Afrikaans/isiXhosa.
- We encouraged him/her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her question satisfactorily answered.

Signed at (place) ....…………………. on (date) …………..…………….

.. **..**

Signature of Interpreter **Signature of witness**

A copy of this ICF has been provided to the participant

Appendix B: Participants' interview guides

Interview guide[19] for patients after diagnosis of TB at the hospital and after discharge from the hospital

Interview guide for patients after diagnosis of TB at the hospital

Introduction

- Confirm patients' consent to participate in the study. This will include confidentiality and anonymity
- Explain the research project again and those involved in the research study

Opening questions

- Please tell me the reason you were admitted to the hospital?
- What type of TB do you have?
- Have you been treated for TB previously?
- Briefly share your experiences since you were diagnosed with TB at this hospital. Probing questions if necessary:
    a. Explain what you know about TB
    b. How did you learn about TB?
    c. Do you know the kind of TB you have been diagnosed with?
    d. How do you feel when taking treatment?
    e. Tell me about your experiences of treatment at the hospital.
    f. Do you think you would get better when completing the treatment of TB?

Key questions guide

- Please tell me what you know about the discharge and the process of being referred to a clinic when you leave hospital
- Did you receive any information from the doctors or nurses? IF so, what did they tell or give you?
- Do you play any role in the discharge planning? Probing questions if necessary.
    - Explain the role you played
    - How did you learn about this role?

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[19] This guide does not include other probing questions that would emerge from participants' responses.

    - Did your family know you would be coming home?
- Describe the services you receive at this hospital
- Describe the conditions where you live
- Probing questions
    - Where do you live? (e.g. house, shack, shelter…)
    - Do you live on your own?
    - Who do you share your living space with?
    - How do you think the people you live, or know, will respond once they know that you have been diagnosed with TB?
    - Do you think your will receive support with your TB treatment from the people/family/friends you stay with?
    - Tell me about any support you may receive at home after discharge from hospital/tell me about any support you have at home
- Do you think there are any factors that might affect your ability to complete your TB treatment once you leave hospital?
        - Any factors that might prevent you from completing the TB treatment?
        - Any factors that would help you to completing the TB treatment?

Concluding questions guide

- Is there anything else important that you would like to speak about regarding your experiences of TB treatment at the hospital?
- Do you have any suggestions how to improve the TB treatment you received at the hospital?

Thank you very much for participating in this interview and for sharing your experiences and ideas with us!

Interview guide for patients after discharge from hospital

Introduction

- Remind patients' consent to participate in the study. This will include confidentiality and anonymity
- Explain the research project again and those involved in the research study

Opening questions

- How have you been doing since you were discharged from hospital?
- Tell me about your experiences of TB treatment after discharge from hospital. Probing questions:
    - How have you been feeling?
    - Explain your knowledge about TB now
    - How do you still feel when taking treatment?

Key questions

- Do you manage to take your TB medication daily as prescribed? If no, please explain how often you miss dosages.
- Are there any factors that make it difficult for you to take your TB tablets as prescribed? If so, please explain.
- Are there any factors that make it easier for you to take your TB tablets as prescribed? If so, please explain.
- Have you been attending the clinic that you have been referred to for continuation of your TB treatment? If yes, how often?
- Are there any factors that make it difficult for you to attend the clinic regularly? If so, please explain.
- Are there any factors that make it easier for you to attend the clinic regularly? Probing questions:
    - Please describe briefly what happens when you visit the clinic for TB treatment follow-up.
    - Is there anything that could be done to help you or others treated for TB to continue taking there tablets as prescribed until cured? If so, please explain
    - Is there anything that could be done to help you and others treated for TB to attend the clinic regularly for TB treatment follow-up?
- How can you describe this link between the treatment at the hospital and that of the clinic? Probing questions:

  - Do you think the communication between the hospital and the clinic works well?
  - Do you think you receive support from both health centres? Are they satisfactory?
  - Were your expectations met?

Concluding questions

- Is there anything else important that you would like to speak about regarding your experiences of TB treatment at the hospital/clinic?
- Do you have any suggestions how to improve the TB treatment you received at the hospital?

Thank you very much for participating in this interview and for sharing your experiences and ideas with us!

Interview guide[20] for health care workers (nurses and doctors) in the hospital/clinic

Introduction

- Confirm participants' consent to participate in the study. This will include confidentiality and anonymity
- Explain the research project again and those involved in the research study
- Participants' demographics and details of work (Form attached)

Opening questions guide

- Tell me about your experiences of working with patients diagnosed with TB at the hospital/clinic

  Probing questions

    - What is your specific role in treating patients diagnosed with TB?
    - Do you educate patients about TB?
    - What other kinds of support do you give to patients diagnosed with TB/referred to this clinic?
    - Does your role involve supporting and engaging with patients treated for Drug Resistant TB?
    - Are there different operating procedures for supporting people with differing diagnoses of TB – e.g. pulmonary vs non-pulmonary, drug sensitive vs MDR and XDR TB?

Key questions guide

- What is the linkage to treatment of patients with TB between the hospital and clinic? A probing question:

    Explain your knowledge of the linkage between the hospital and the clinic

- What is your perception regarding why some patients attend/do not attend clinics that they have been referred for continuing treatment for TB? A probing question:

    Could you explain the reasons some participants do not attend the clinics after discharge from hospital?

- Can any actions be taken to ensure that patients with TB arrive in PHC for continuity of TB care?

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[20] This guide does not include other probing questions that would emerge from participants' responses.

- How do you think can other key people; such as community health workers, family and policy makers; facilitate the continuity of TB care of patients following discharge from hospital? Probing question:

  What do you think can be done to ensure better continuity of care for patient diagnosed with TB?

Concluding questions guide

- Are there any other factors that you feel influence the ability of persons with TB to complete their treatment as prescribed by the hospital/clinic?
- Do you have any recommendations for supporting persons with TB to complete their treatment following discharge from hospital?

Thank you very much for participating in this interview and for sharing your experiences and ideas with us!

Interview guide[21] for Community Health Workers (CHWs)/Social Workers treating patients with TB at the hospital/clinic

Introduction

- Confirm participants' consent to participate in the study. This will include confidentiality and anonymity
- Explain the research project again and those involved in the research study
- Participants demographics and details of work (Form attached)

Opening questions guide

- **Tell me about your knowledge of TB in general**

Probing questions

  - What do you think causes TB?
  - How does TB spread?
  - Do you know of any side-effects of TB treatment?
  - Do you think the patient that you follow/assist in their treatment is coping well with the treatment?
  - How important it is for patients diagnosed with TB to continue with their treatment after discharge from the hospital?

Key questions

- Do you know how the TB discharge and referral process work in the hospital? If so, please explain briefly.
- Explain your role, if any, in the TB discharge and referral process in the hospital
- What is your perception about the link between the hospital and the clinic regarding treatment for TB patients?
- What is your understanding of the reasons why persons diagnosed with TB are referred to clinics following discharge from hospital?
- Explain your specific role towards ensuring that the patient takes his/her treatment consistently
- Explain your specific role towards ensuring that the patient attends the clinic that he/she has been referred to

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[21] This guide does not include other probing questions that would emerge from participants' responses.

- What do you think are the reasons for regular clinic attendance by TB patients following discharge from hospital?
- What do you think are the reasons for clinic attendance/non-attendance by TB patients following discharge from hospital?

  Probing questions

  - What do you think of the experiences of the patients' TB treatment at the hospital/clinic?
  - For example, is there an appointment system? Does it work?
  - If not, how long do patients wait to see nurses and/or doctors?
  - How long do they wait to pick up medicines?

Concluding questions

- Are there any other factors that you feel influence the ability of persons with TB to complete their treatment as prescribed by the hospital/clinic?
- Do you have any recommendations for supporting persons with TB to complete their treatment following discharge from hospital?

Thank you very much for participating in this interview and for sharing your experiences and ideas with us!

Interview guide[22] for policy makers from the South African Department of Health

Introduction

- Confirm participants'' consent to participate in the study. This will include confidentiality and anonymity
- Explain the research project again and those involved in the research study
- Participants' demographics and details of work (Form attached)

Opening questions guide

- Tell us about your experiences of working with patients diagnosed with TB at the hospital/clinic or your knowledge on continuity of care?

  <u>Probing questions</u>

    - What is your specific role in treating patients diagnosed with TB? Or what is your role in continuity of care? Or what do you understand about continuity of care on patients diagnosed with TB referred to clinics?
    - Does this role include educating patients (and their families) about TB?
    - What other kinds of support do you give to patients diagnosed with TB/referred to this clinic?
    - Does your role involve supporting and engaging with patients treated for Drug Resistant TB?
    - Are there different operating procedures for supporting people with differing diagnoses of TB – e.g. pulmonary vs non-pulmonary, drug sensitive vs MDR and XDR TB?

Key questions guide

- What is your perception about the link between the hospital and clinic regarding treatment of TB patients?
- What is your understanding about the discharge planning at the hospital?
- What is your perception regarding why some patients attend/do not attend clinics that they have been referred to for continuing treatment for TB?
- Can any actions be taken to ensure that patients with TB arrive in PHC for continuity of TB care?

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[22] This guide does not include other probing questions that would emerge from participants' responses.

- How do you think can other key people; such as community health workers, family and policy makers; facilitate the continuity of TB care of patients following discharge from hospital?

Concluding questions guide

- Are there any other factors that you feel influence the ability of persons with TB to complete their treatment as prescribed by the hospital/clinic?
- Do you have any recommendations for supporting persons with TB to complete their treatment following discharge from hospital?

Thank you very much for participating in this interview and for sharing your experiences and ideas with us!

Interview guide[23] for family members helping with treating patients with TB

Introduction

- Confirm participants' consent to participate in the study. This will include confidentiality and anonymity
- Explain the research project again and those involved in the research study
- Participants demographics and details of work (Form attached)

Opening questions guide

- **Tell me about your knowledge of TB in general**

<u>Probing questions</u>

  - What do you think causes TB?
  - How does TB spread?
  - Do you know of any side-effects of TB treatment?
  - Do you think the patient that you follow/assist in their treatment is coping well with the treatment?
  - How important it is for patients diagnosed with TB to continue with their treatment after discharge from the hospital?

Key questions

- Do you know how the TB discharge and referral process work in the hospital? If so, please explain briefly.
- Explain your role, if any, in the TB discharge and referral process in the hospital
- What is your perception about the link between the hospital and the clinic regarding treatment for TB patients?
- What is your understanding of the reasons why persons diagnosed with TB are referred to clinics following discharge from hospital?
- Explain your specific role towards ensuring that the patient attends the clinic that he/she has been referred to
- Explain your specific role towards ensuring that the patient takes his/her treatment consistently
- What do you think are the reasons for regular clinic attendance by TB patients following discharge from hospital?

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[23] This guide does not include other probing questions that would emerge from participants' responses.

- What do you think are the reasons for poor clinic attendance by TB patients following discharge from hospital?

  Probing questions

    - What do you think of the experiences of the patients' TB treatment at the clinic?
    - For example, is there an appointment system? Does it work?
    - If not, how long do patients wait to see nurses and/or doctors?
    - How long do they wait to pick up medicines?

Concluding questions

- Are there any other factors that you feel influence the ability of persons with TB to complete their treatment as prescribed by the hospital/clinic?
- Do you have any recommendations for supporting persons with TB to complete their treatment following discharge from hospital?

Thank you very much for participating in this interview and for sharing your experiences and ideas with us!

BIBLIOGRAPHY

Abebe G., Deribew A., Apers L., Woldemichael K., Shiffa J., Tesfaye, M., Abdissa, A., Deribie, F. et al. 2010. Knowledge, Health Seeking Behavior and Perceived Stigma towards Tuberculosis among Tuberculosis Suspects in a Rural Community in Southwest Ethiopia. *PLoS ONE* 5(10): e13339. doi:10.1371/journal.pone.0013339.

Abdool Karim, S.S., Churchyard, G.J., Abdool Karim, Q. & Lawn, S.D. 2009. HIV infection and tuberculosis in South Africa: an urgent need to escalate the public health response. *The Lancet*. 374 (9693):921-933.

Alazri, M., Heywood, P., Neal, R.D, & Leese, B. 2007. Continuity of Care. Literature review and implications. *Sultan Qaboos University Medical Journal*. 7(3):197-206.

Anderson, N. 1990. Tuberculosis and social stratification in South Africa. *Int Journal of Health Services.* 20 (1):41-165.

Aronis, K.N., Edgar, B., Lin, W., Martins, M.A.P., Paasche-Orlow, M.K & Magnani, J.W. 2017. Health Literacy and Atrial Fibrillation: Relevance and Future Directions for Patient-centred Care. *Eur Caediol*. 12 (1): 52-57. Doi:10.15420/ecr.2017:2:2.

Atlanta National Centre for HIV/AIDS et al*. 2010. Latent Tuberculosis Infection: A Guide for Primary Health Care Providers*. 2010. Centres for Disease Control and Prevention, National Centre for HIV/AIDS, Viral Hepatitis, STD and TB prevention.

Ayisi, J.G., van't Hoog, A. H., Agaya, J. A., Mchembere, W., Nyamthimba, P. O., Muhenje, O. & Marston, B.J. 2011. Care seeking and attitudes towards treatment compliance by newly enrolled tuberculosis patients in the district treatment programme in rural western Kenya: a qualitative study. *BMC Public Health.* (11):515.

Ayou, P.O., Diero, L.O., Owin-ong'or, W.D & Mwangi, A.W. 2008. Causes of Delay in Diagnosis of Pulmonary Tuberculosis in patients attending a referral hospital in Western Kenya. *East African Medical Journal*. 85(6):1-6.

Badri, M., Wilson, D. & Wood, R. 2002. Effect of highly antiretroviral therapy on incidence of tuberculosis in South Africa: a cohort study. *The Lancet.* (359):2059-2064.

Barry, M.J. & Edgman-Levitan, S. 2012. Share-decision – The pinnacle of patient-centred care. *N Eng J Med*. 366(9):170-751.

Bailey, K. 1994. *Methods of Social Research.* London: Schuster.

Bamford, L., Loveday, M. and Verkuijl, S. 2004. Tuberculosis. In P, Ijumba., C, Day and ANtuli, Eds. *South African Health Review*. *(*213-228). Durban, South Africa: Health Systems Trust.

Berkman, L.F. & Kawachi I. 2000. Historical framework for social epidemiology. In *Social Epidemiology*. L.F. Berkman & I. Kawachi, Eds. New York: Oxford University Press. 3-12.

Betancourt, J. R., Green, A. R. & Carrillo, J.E. 2002. *Cultural competence in health care: Emerging frameworks and practical approaches*. New York: The Commonwealth Fund.

Boulware, L. E., Cooper, L.A., Ratner, L.E., LaVeist, T.A. & Powe, N.R. 2003. Race and trust in the health system. *Public Health Reports*. July-August (118):358-365

Bourgois, P. 1995. *In search of respect: Selling crack in El Barrio.* Cambridge: Cambridge University Press.

Bourdieu, P. 1986. The forms of capital. In *Handbook of Theory and Research for the Sociology of Education*. J. Richardson (Ed). New York: Greenwood.

Bradshaw, D., Nannan, N., Laubscher, R., Groenewald, P., Joubert, J., Nojilana, B., Norman, R. & Pieterse, D. 2006. *South African National Burden of Disease Study 2000 Summary Report, March 2006. Estimates of Provincial Mortality*. Burden of Disease Research Unit. Medical Research Council.

Brandt, A. 1988. AIDS in Historical perspective: Four lessons from the history of sexually transmitted diseases. *AJPH*. 78(4):367-371.

Braun, L. 2002. Race, ethnicity, and health: Can genetics explain disparities? *Perspectives in Biology and Medicine.* 45(2):159-174.

Breier, M., Wlldschut, A. & Mgqdozana, T. 2009. *Nursing in a new era: The profession and education of nurses in South Africa*. Cape Town: HSRC Press.

Buregyeya, E., Nuwaha, F., Wanyenze, R.K., Mitchell, E.M.H., Criel, B. et al. 2012. Utilization of HIV and tuberculosis services by health care workers in Uganda: Implications for occupational health policies and implementation. *PLoS ONE* 7(10): e46069.
doi:10.1371/journal.pone.0046069.

Cabana, M. & Lee, S. 2004. Does Continuity of Care improve patient outcomes? *The Journal of Family Practice*. 53 (12):974-980.

Campbell, S.M, Ronald, M.O. & Beutow, S.A. 2000. Defining quality of care. *Social Science Medicine*. 51(11):1611-1625.

Chaisson, R. E & Martinson, N.A. 2008. Tuberculosis in Africa – Combating an HIV-driven crisis.
n engl j med 358.11(13):1089-1092.

Chimbindi, N., Bor, J., Newell, M., Tanser, F., Baltusen, R., Hontelez, J., DeVlas, S., Lurie, M. et al. 2015. Time and money: The true costs of health care utilization for patients receiving "free" HIV/TB care and treatment in rural KwaZulu-Natal. *J Acquire Immune Defic Syndr.* 70(2):1-8.

City of Cape Town*. Regional Development Profile..* 2013. Western Cape. South Africa: Western Cape Government Treasury. Available: https://www.westerncape.gov.za/ (10 October 2017)

Coetzee, D., Hilderbrand, K., Goemaere, E., Mathys, F. & Boelaert, M. 2004. Integrating tuberculosis and HIV care in the primary care setting in South Africa. *Tropical Medicine and International Health.* 9 (6):11-15.

Collins, K.S., Hughes, D. L., Doty, M. M., Ives, B. L. Edwards, J. N., & Tenney, K. 2002. *Diverse communities, common concerns: Assessing health care quality for minority Americans.* New York: The Commonwealth Fund.

Coovadia, H., Jewkes, R., Barron, P., Sanders, D. & McIntyre, D. 2009. The health and health system of South Africa: Historical roots of current public health. *The Lancet*. (374):817-834.

Cox, H. S., McDermid, C., Azevedo, V., Muller, O., Coetzee, D., Simpson, J., Barnard, M., Coetzee et al. 2010. Epidemic levels of drug-resistant tuberculosis (MDR and XDR-TB) in a high hiv prevalence setting in Khayelitsha. South Africa. *PLoS ONE.* 5 (11):1-8.

Craig, G.M., Daftary, A., Engel N., O'Driscoll, S. & Loannaki, A. 2016. Tuberculosis stigma as a social determinant of health: a systematic mapping review of research in low incidence countries. *International Journal of Infectious Diseases*. 26 (2017):90-100.

Cramer, J.A., Roy, A., Burrell, A., Fairchild, C.J., Fuldeore, M.J., Ollendorf, D. & A., Wong, P. K. 2007. Medication Compliance and persistence: Terminology and definitions. *International Society for Pharmacoeconomics and Outcomes Research (ISOC).* 44-47.

Crofton, J., Horne, N., Miller F. & Miller, F.J.W. 1992. *Clinical tuberculosis*. London: Macmillan.

Daftary, A. 2012. HIV and tuberculosis: The construction and management of double stigma. *Social Science and Medicine.* (74) 1512-1519.

Daftary, A. & Padayatchi, N. 2012. Social constraints to TB/HIV healthcare: Accounts from coinfected patients in South Africa. *AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV*. 24(12):1480-1486.

Daftary, A., Padayatchi, N & O'Donnell, M. 2014. Preferential adherence to antiretroviral therapy over tuberculosis treatment" A qualitative study of drug-resistant TB/HIV co-infected patients in South Africa. *Global Public Health*. 9(9): 1107-1116.

Dahlgren, G. & Whitehead, M. 2007. European strategies for tackling social inequities in health: Levelling up Part 2. Copenhagen, WHO Regional Office for Europe (Studies on Social and Economic Determinants of Population Health, No. 3).

Das, M., Isaakidis, P., Armstrong, E., Gundipudi, N.R., Babu, R.B., Qureshi, I.A., Claes, A., & Munimanchi, A.K. 2014. Directly-observed and self-administered tuberculosis treatment in a chronic, low-intensity conflict setting in India*. PloS One*. 9(3): 1-5.

Department of Social Development. 2004. *The social and economic impact of South Africa's Social Security System commissioned by the Directorate*: Pretoria: Finance and Economics.

de Vaus, D. 2002. *Surveys in social research*. St Leonards, NSW, Australia: Allen & Unwin.

De Wet, J.P. & Erasmus, Z. 2005.Towards rigour in qualitative analysis. *Qualitative Research Journal*. 5 (1):27-40

Dey, I. 1993. Managing data, creating categories, and assigning categories. In *Qualitative Data Analysis: A user-friendly guide for social scientists*. London: Routledge.

Dheda, K., Shean, K., Zumla, A., Badri, M., Streichter, E. M. Page-Shipp, L., Willcox, P., Melanie-Anne, J. et al. 2010. Early treatment outcomes and HIV status of patients with extensively drug-resistant tuberculosis in South Africa: A retrospective cohort study. *The Lancet*, 375:1798-1807.

Drobniewski, F.A., Balabanova, Y.M., Ruddy. M.C., Graham, C., Kuznetzov, S.I., Gusarova, G.I., Zakharova, S.M., Melentyeve, A.S. et al. 2005. Tuberculosis, HIV seroprevalence and intravenous drug abuse in prisoners. *Eur Respir J*. 26 (2):298–304.

Dudley L., Mukinda F., Dyers R., Marais F & Sissolak D. 2018. Mind the gap! Risk factors for poor continuity of care of TB patients discharged from a hospital in the Western Cape, South Africa. *PLoS ONE* 13(1)e0190258. https://doi.org/ 10.1371/journal.pone.0190258.

Edginton, M.E. 1999. Tuberculosis patient care decentralised to district clinics with community-based directly observed treatment in a rural district of South Africa. *Int J Tuberc Lung Dis* 3(5):445–450.

Edginton, M.E., Wong, M.L., Phofa, R., Mahlaba, D. & Hodkinson, H.J. 2005. Tubeculosis at Chris Hani Baragwanath Hosiptal: numbers of patients diagnosed and outcomes of referrals to district clinics*. Int J Tuberc Ling Dis.* 9 (4):398-402.

Edginton, M.E., Wong, M.L. & Hodkinson, H,J. 2006. An intervention to improve patient referrals to district clinics. *Int J Tuberc Lung Dis*. 10(9):1018-1022.

Engel, N., Ganesh, G., Patil, M., Yellappa, V., Pant Pai, N., Vadnais C & Pai, M. 2015. Barriers to Point of-Care Testing in India: Results from Qualitative Research across Different Settings, Users and Major Diseases. PLoS ONE 10(8): e0135112. doi:10.1371/journal.pone.0135112.

Engel, N., Davids, M., Blankvoort, N., Pai Pant, N., Dheda, K & Madhukar, P. 2015. Compounding diagnostic delays" a qualitative study of point-of-care testing in South Africa. *Tropical Medicine and International Health*. 20 (4): 493-500.

Engels F. 1995 [1844] The condition of the working class in England [extract]. In Davey B, et al. 1995. (2nd Edition), *Health and Disease: A Reader*. Buckingham: Open University Press.

Epstein, R.M. & Street, R.L. 2011. The values and value of patient-centred care. *Ann Fam Med*. 9(22):100-103.

Farmer, P. 1996. Social inequalities and emerging infectious diseases. *Emerging Infectious Diseases.* 2 (4) 259-269.

Fielding, N. & Lee, R. 1998. *Managing data in CAQDAS. Computer analysis and qualitative research*. London: Sage.

Fisher, J.D. & Fisher, W.A. 2002.The information-motivation-behavioral skills model. In R.J. DiClemente, R.A. Crosby, and M C. Kegler. Eds. *Emerging theories in health promotion practice and research: Strategies for improving public health*. San Francisco, CA: Jossey-Bass.

Foucault, M. 2003. *The birth of the clinic: The archaeology of medical perception.* London: Routledge.

Freeman, G. 1984. Continuity of care in general practice: A review and critique. *Family Practice-An International Journal*. 1(4):245-252.

Gastaldo, D, & Homes, D. 1999. Foucault and nursing: A history of the present. *Nursing Inquiry* (6):231-240.

Gebremariam, M.K., Bjune, G.A. & Frich, J.C. 2010. Barriers and facilitators of adherence to TB treatment in patients on concomitant TB and HIV treatment: a qualitative study. *BMC Public Health*. 10 (651):1-9.

Gilson, L. 2003. Trust and the development of health care as a social institution. *Social Science and Medicine* (56) 1453-1468.

Giorgi, A. (1997) The theory, practice and evaluation of the phenomenological methods as a qualitative research procedure. *Journal of Phenomenological Psychology* (28)235-260.

Glaziou, P., Sismanidis, C., Floyd, K. & Raviglione, M.C. 2015. Global epidemiology of tuberculosis*. Cold Spring Harbor Perspectives in Medicine*. 5(2):1-18.

Goffman, I. 1959. *Presentation of self in everyday life*. New York: DoubleDay Anchor Book.

Gordon, J.B. & Krauthoefer, M. L. 2007. A tertiary care-primary care partnership model for medically complex and fragile children and youth with special health needs. *Arch Pediatradolesc Med.* 161(10):937-944.

Grandey, A.A. 2000. Emotion regulation in the workplace. A new way to conceptualize emotional labor. *Journal of Occupation Health Psychology*. 5(1): 59-100. doi:10.1037/1076-8998.5.1.95.

Grone, O. & Garcio-Barbero, M. 2001. Integrated care. A position paper of the WHO European office for integrated health care services. *International Journal of Integrated Care*. (1):1568-4156.

Gulliford, M., Naithani, S. & Morgan, M. 2006. What is Continuity of Care? *J Health Serv Res Policy*. 11 (4):248-250.

Hall, E.J. 2004. Nursing attrition and the work environment in South African health facilities. Employment and Economic Policy Research*. Human Sciences Research Council*. 4:28-36.

Hardon, A. & Posel, D. 2012. Secrecy as embodied practice: beyond the confessional imperative, culture, health and sexuality. *An International Journal for Research, Intervention and Care.* 15(4):482-494. DOI: 10.1080/13691058.2012.726376.

Hardy, C., & Richter, M. 2006. Disability Grants or antiretrovirals? A quandary of people with HIV/AIDS in South Africa. *African Journal of AIDS Research* 5(1):85-96

Harper, I. 2010. Extreme condition, extreme measures? Compliance, drug resistance, and the control of tuberculosis. Anthropology & Medicine. 17: (2): 201-214. DOI:10.1080/13648470.2010.493606.

Hasker, E., Khodjikhanov, M., Sayfiddinova, S.S., Rasulova, G., Yuldashova, U., Uzakova, G., Butabekov, I., Veen, J., Van der Werf, M.J. & Lefevre, P. 2010. Why do tuberculosis patients default in Tashkent City, Uzbekistan? A qualitative study. *Int J Tuberc Lung Dis. 14(9) 1132-1139.*

Head, J. 1999. Understanding the social context of tuberculosis in Cape Town. A case study of two high prevalence suburbs. Master's Thesis, University of the Western Cape.

Henbest, J. 1989. Patient-centred care. A review of the concept. *SS Family Practice*. 10:454-463.

Hjortdahl, P. & Laerum, E. 1992. Continuity of care in general practice: Effect on patient satisfaction. *BMJ.* 304:1287-1290.

Hochschild, A.R. 1983. *The managed heart: Commercialization of human feeling*. Berkley: University of California Press.

Horter, S., Stringer, B., Reynolds, L., Shoaib, M., Kasozi, S., Casas, E.C., Veputten, M. & du Cros, P. 2014. "Home is where the patient is": A qualitative analysis of a patient-centred model of care for multi-drug resistant tuberculosis. *BMC Health Services Research*. 14(81):1-8.

Human Research Council. 2003. Final Draft, Area Case Report: Aftermaths of struggle: Government delivery in Crossroads, Cape Town after 1994. Integrated rural and regional development. Human Research Council.

Jacob, E. 1998. Clarifying qualitative research: A focus on traditions. *Educational Researcher*. 17(1) :16-24.n, K.B., Moll, A.P., Friedland, G.H. & Shenoi, S.V. 2015. Successful tuberculosis treatment among HIV/TB co-infected patients down-referred from a District Hospital to Primary Health Clinics in Rural South Africa. *Plos One*. 10(5): e0127024.doi:10.1371/ journal.prone.0127024.

Jacobson, KB, Moll AP, Friedland GH, Shenoi SV. 2015. Successful tuberculosis treatment outcomes among HIV/TB coinfected patients down-referred from a district hospital to primary health clinics in rural South Africa. PLoS ONE 10: 1–11.

Jardien-Baboo, S., Van Booyen, D., Ricks, E. 2016. Perceptions of patient-centred care at public hospitals in Nelson Mandela Bay. *Health SA Gesondheid*. 21:397-405.

Jasmer, R. M., Nahid, Payam and Hopewell, Phillip, C. 2002. Latent Tuberculosis Infection. *NEngl J Med,* 347 (23): 1860-1866

Jewkes, R., Abraham, N. & Mvo, Z. 1998. Why do nurses abuse patients? Reflections from South African obstetric services*. Social Science & Medicine*. 47 (11):1781-1795.

Kagee, A. 2008. Adherence to antiretroviral therapy in the context of the national rollout in South Africa: Defining a research agenda for psychology. *South African Journal of Psychology*, 38 (2) 413-428.

Kapp, C. 2009. Aaron Motsoaledi: South African Minister of Health. *The Lancet*. (374):776.

Karumbi, J. & Garner P. 2015. Directly observed therapy for treating tuberculosis. *Cochrane Infectious Disease Group*. DOI:10.1002/146518.CD00343.pub4.

Khan, A., Walley, J., Newell, J. & Naghma, I. 2000. Tuberculosis in Pakistan: socio-cultural constraints and opportunities in treatment. *Social Science & Medicine.* 50 (2000) 247-254.

Khan, J.A., Irfran, M., Zaki, A., Beg, M., Hussain, S.F. & Rizvi, N. 2006. Knowledge, attitude and misconceptions regarding Tuberculosis in Pakistani patients. Section of Pulmonary and Care. *J Pak Med Assoc*. 56(5):211-214.

Kitzinger, J. & Barbour, R. 1999, Introduction: The challenge and promise of focus groups, in R. Barbour and J. Kitzinger (*eds.*). *Developing Focus Group Research: Politics, Theory and Practice.* London: Sage.

Kitzinger, J. 1994. The methodology of focus groups: The importance of interaction between research participants. *Sociology of Health and Illness*, XVI. (1):103-121.

Kock, E. 2013. Tuberculosis Is a Threshold: The Making of a Social Disease in Post-Soviet Georgia. *Medical Anthropology*. 32:309-324. DOI: 10.1080/01459740.2012.751384.

Krefting, L. 1991. Rigor in qualitative research: The assessment of trustworthiness. *The American Journal of Occpational Therapy*. 45 (3):214-222.

Krieger, N. & Moss, N. 1996. Measuring social inequalities in health in the United Sates: A historical review, 1900-1950. *Int Journal of Health Sciences*, 26 (3):404-405.

Krieger, N. 2001. Theories for social epidemiology in the 21st Century: An ecosocial perspective. *International Journal of Epidemiology*. 30:668-677.

Kritzinger, F. E., den Boon, S., Verver, S., Enarson, D. A. Lombard, C.J. Borgdorff, M. W., Gie, R. P & Beyers, N. 2009. No decrease in annual risk of tuberculosis infection in endemic area in Cape Town, South Africa. *Tropical Medicine,* 14 (2):136-142.

Lane T., Mogale T., Struthers H., McIntyre, J & Kegeles S.M. 2008. “They see you as a different thing’’: The experiences of men who have sex with men with healthcare workers in South African township communities. *Sex Transm Infect*. 84(6):430–433.

Lewin, S., Lavis, J. N., Oxman, A. D., Bastias, G., Chopra, M., Ciapponi, A., Flottorp, S., Garcia Marti, S. et al. 2008. Supporting the delivery of cost-effective interventions in primary healthcare systems in low-income and middle-income countries: an overview of systematic reviews. *The Lancet*. 375:928-939.

Little, P., Everitt, H., Williamson, I., Warner, G., Moore, M., Gould, C., Ferrier, K & Payne, S. 2001. Preferences of patients for patient-centred approach to consultation in primary care: observational study. *BMJ* 322 (24):1-6.

Lönnroth, K., Castro, K.G., Chakaya, J.M., Chauhan, L.S., Floyd, K., Glaziou, P. & Raviglione, M.C. 2010. Tuberculosis control and elimination 2010–50: Cure, care, and social development. *The Lancet*. 375 (9728):1814-1829.

Lorent, N., Mugwaneza, P., Mugabekazi, M., Gasana, M., Van Bastelaere, S., Clerinx, J. & Van de Ende, J. 2008. Risk factors for delay in the diagnosis and treatment of tuberculosis at a referral hospital in Rwanda. *Int J Tuber Lung Dis*. 12(4):392-396.

Luitel, N.P., Jordans, M.J.D., Adhikari, A., Upadhaya, N., Hanlon, C., Lund, C & Komproe, I.H. 2015. Mental health care in Nepal: current situation and challenges for development of s district mental health care plan. *Conflict and Health*. 9(3): 1-11

Mackian, S., Bedri, N. & Lovel, H. Up the garden path and over the edge: Where might health-seeking behaviour take us? *Health Policy and Planning*. 19(3):137–146.

Mainous III, A.G., Baker, R., Love, M.M., Gray, D.P. & Gill, J.M. 2001. Continuity of care and trust in one's physician: Evidence from primary care in the United States and the United Kingdom. *Fam Med*. 33(1):22-7.

Marmot, M. 2005. Social determinants of health iniquities. *Lancet.* 365:1099-1104.

Marias, F., Kallon I.I. & Dudley, L. Forthcoming. *TB continuity of care experiences of healthcare staff at a hospital in the Western Cape, South Africa – A qualitative participatory* study. The Faculty of Health Sciences: University of Stellenbosch.

Mariolis, A. et al., 2008.Comparison of primary health care services between urban and rural settings after the introduction of the first urban health centre in Vyronas, Greece. *BMC Health Services Research* 8:124:10:1186/1472-6963-8-124.

Mays, N. & Pope, C. 2000. Qualitative research in health care. Assessing quality in qualitative rsearch, *BMJ*. 320:50-52.

McCormack, B., & McCane, T.V. 2006. Development of a framework for personcentred nursing. *J Adv Nurs* 56(5):472-9.

Meressa, D., Hurtado, R.M., Andrews, J.R., Diro, E., Abato, K., Daniel, T., Prasad, P., Prasad, R. et al. 2015. Achieving high treatment success for Multidrug-resistant TB in Africa: Initiation and scale-up for MDR-TB care in Ethiopia – an observational study. *Thorax*. 0(1-8). DOI:10.1136/thoraxjnl-2015-207374.

MØller, V., Erstad, I., Cramm, J. M., Nieboer, A. P., Finkenflugel, H., Radloff, S., Ndoro, T. & Kwizera, S. A. (2011) Delays in presenting for tuberculosis treatment associated with fear of learning one is HIV-positive. *African Journal of AIDS Research*. 10(1):25-36.

Miles, M. & Huberman, A. 1994. Early steps in analysis. *In Qualitative Data Analysis: An Expanded Handbook*. 50-89. Thousand Oaks: Sage.

Mills, B. 2006. *HIV illness and collaborative healing strategies in South Africa.*
Centre for Social Sciences Research. Cape Town: University of Cape Town.

Morgan, D. L. 1997. Focus Groups as Qualitative Research. Thousand Oaks: Sage.

Mosco, V. 2009. *Political Economy of Communications*. 2nd Edition. London: Sage.

Muchapondwa, E. 2010. A cost-effectiveness analysis of options for reducing pollution in Khayelitsha township, South Africa. *The Journal for Transdisciplinary Research in Southern Africa*. 6(2). 333-358.

Mudzengi, D., Sweeny, S., Hippner, P., Kufa, T., Fielding, K., Grant, A. D., Churchyard, G. & Vassalli, A. 2015. The patient costs of care for those with TB and HIV: A cross-sectional study from South Africa. *Health Policy and Planning.* 32:48-56. DOI 10.1093/heapol/CZW183.

Nattrass, N. 2004. *Trading-off income and health: AIDS and the Disability Grant in South Africa*. Centre for Social Science Research, Working Paper no. 82. University of Cape Town.

Nattrass, N. & Seekings, J. 2010. *The economy of poverty in the Twentieth Century in South Africa*. CSSR Working Paper 276. University of Cape Town.

Nelson, E.C., Dixon-Woods, M., Batalden, P.B., Homa, K., D, van Citters, A., Morgan, T.S., Eftimovska, E., Fisher, E.S., Ovretveit, J., Harrison, W., Lind, C. & Lindblad, S. 2016. Patient focused registries can improve health, care, and science. *BMJ* 354:1-6.

Nkosi, D., Janssen, S., Padanilam, X., Louw, R., Menezes, C N & Grobusch, M. 2013. Factors influencing specialist care referral of multidrug- and extensively drug-resistant tuberculosis patients in Gauteng/South Africa: a descriptive questionnaire-based study. *BMC Health Services Research*. 13 (268):1-5.

Noar, S.M. & Zimmerman, R.S. Health behavior theory and cumulative knowledge regarding health behaviors: Are we moving in the right direction? *Health Education Research* (20)3: 275-290.

Ntshanga, S.P., Rustomjee, R. & Mabaso, M.L. H. 2009. Evaluation of directly observed therapy for tuberculosis in KwaZulu-Natal, South Africa. *Trans R Soc Trop Med Hyg*. 103 (6): 571-574.

NVivo qualitative data analysis Software. 2012. QSR International Pty Ltd. Version 11.

Obermeyer, Z., Abbott-Klafter, J. & Murray.C.J.L. 2008. Has the DOTS Strategy improved case finding or treatment success? An empirical assessment. *PLoS One.* 3(3):1-8.

O'Donnell, M.R., Daftany, A., Frick, A., Hirsch-Moverman, V., Amico, K.R., Senthilingam, M., Wolf, A., Metcalfe, J.Z. et al. 2016. Re-inventing adherence: Towards a patient-centred model of care for drug-resistant tuberculosis and HIV. *Int J Tuberc Lung Dis*. 20 (4):430-434.

Ogden, K., Barr, J & Greenfield, D. 2017. Determining requirements for patient-centred care: a participatory concept mapping study. *BMC Health Services Research.* 17(780):1-11.

Ohuabunwa, E.C., Sun, J., Jubanyik, K.J. & Wallis, L.A. (2015). Electronic medical records in low to middle income countries: The case of Khayelitsha Hospital, South Africa. *African Journal of Emergency Medicine*. 2016 (6):38-43.

Onwuegbuzie, A.J. & Leech, L.N. 2007. Sample designs in qualitative research: Making the sampling process more public. *The Qualitative.* 12 (2):238-254

Parry, C.D.H., Bhana, A., Myers, B., Pluddemann, A., Flisher, A.J., Peden, M.M. & Morojele, N.K. 2002. Alcohol use in South Africa: Findings from the South African Community Epidemiology Network on Drug Use (SACENDU) Project. *Journal of Studies on Alcohol*. 63 (4):430-435.

Parsons, T. 1964. *The Social System*. New York: Free Press.

Packard, R.M. 1990. *White Plague, Black Labor: Tuberculosis and the political economy of health and disease in South Africa*. California: University of California Press.

Pasipanodya, J.G. & Gumbo, T. 2013. A Meta-analysis of self-administered vs directly observed therapy effect on microbiologic failure, relapse, and acquired drug resistance in tuberculosis patients. *Clinical Infection Diseases*. 57(1)21-31.

Pelzang, R. 2010. Time to learn: Understanding patient-centred care. *British Journal of Nursing*. 19(14):912-917.

Phillips, H. 2011. *Plague, Pox and Pandemics*. South Africa: Jacana Media.

Ponthieu, A. & Incerti, A. continuity of care for migrant populations in Southern Africa. 2016. *Refugees Survey Quarterly*. 0:1-18.

Pronyk, P.M., Makhubele, M.B., Hargreaves, J.R., Tollman, S.M. & Hausler, H.P. 2001. Assessing health-seeking behaviour among tuberculosis patients in rural South Africa. *Int J Tuberc Lung Dis* 5(7):619–627.

Punch, K.F. 2005. *Introduction to social research: Quantitative and qualitative approaches.*2nd ed. Perth, Australia: The University of Western Australia.

Rajeswari, R., Balasubramanian,R., Muniyandi, M., Geetharamani, S., Thresa, X. & Venkatesan. 1999. Socio-economic impact of tuberculosis on patients and family in India. *Int J Tuberc Lung Dis.* 3(10):869–877.

Ritchie, J. & Lewis, J. 2003. *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. London: Sage.

Salaniponi, F.M.L., Harries, A.D., Banda, H.T., Kang'ombe, C., Mphasa, N., Mwale, A., Upindi, B., Nyirenda, T.E., Banerjee, A & Boeree, M.J. 2000. Care seeking behaviour and diagnostic processes in patients with smear-positive pulmonary tuberculosis in Malawi. *INT J Tuberc Lung Dis* 4(4)327-332.

Sandelowski, M. 2000. Focus on research methods: Whatever happened to qualitative description? *Research in Nursing and Health* (23) 334-340.

Sanders, D. 1985. *The struggle for health: Medicine and the politics of underdevelopment*. London: Macmillan.

Sanders, D., Igumbor, E., Lehmann, V., Meeus, W. and Dovlo, D. 2009. Public health in Africa. In *Global Public Health a new era*. Beaglehole, R. & Bonita, R (Eds). 2nd Ed. London: Oxford University Press.

Satyanararayana, S., Subbaraman, R., Shete, P., Gore, G., Das, J., Cattamanchi, A., Mayer, K., Menzies, D., et al. 2015. Quality of tuberculosis care in India: A systematic review. *Int J Tuber Lung Dis*. 19(7):751-763.

Saultz, J.W. 2003. Defining and measuring interpersonal continuity of care. *Ann Fam Med*. (1):134-143.

Saultz, J.W & Albedaiwi, W.2004. Interpersonal continuity of care and patient satisfaction: A critical review. *Ann Fam Med*. 2:445-451.

Savett, L. A. 2002. *The human side of medicine: Learning what it's like to be a patient and what it's like to be a physician*. Westport: Auburn House.

Schaay, N., Sanders, D. & Kruger, V. 2011. *Overview of health sector reforms in South Africa*. UK: DFID Human Development Resource Centre.

Schnippel, K., Rosen, S., Shearer, K., Martinson, N., Long, L., Sanne, I. and Variava, E. 2013.Costs of inpatient treatment for multi-drug-resistant tuberculosis in South Africa. *Tropical Medicine and International Health*, 18: 109–116.doi: 10.1111/tmi.12018.

Shelmadine, S. 2011. Pathways to inhumane care: Medical culture in a South African emergency unit. PHD Thesis. University of Cape Town.

Sinanovic, E., Floyd, K., Dudley, L., Azvedo, V., Grant, R. & Maher, D. 2003. Cost and cost-effectiveness of community-based care for tuberculosis in Cape Town, South Africa. *JTubergLungDis.* 7(9):56-62.

Sissolak, D., Marais, F. & Mehtar, S. 2011. TB infection prevention and control experiences of South African nurses – a phenomenological study. *BMC Public Health*. 11 (262):1-10.

Soderbaum, F. 2004. *The political economy of regionalism. The case of Southern Africa.* New York: Palgrave Macmillan.

South African National Department of Health (SANDoH). 2004. *The South African National Tuberculosis Control Programme Practical Guidelines*. Pretoria: Department of Health.

South African National Department of Health (SANDoH). 2005. *National HIV and Syphilis antenatal Sero-prevalence Survey in South Africa 2004.* Pretoria, South Africa.

South African National Department of Health (SANDoH). 2011. *Multi-drug resistant tuberculosis. a policy framework on decentralised and deinstitutionalised management for South Africa*. Pretoria, South Africa.

South African AIDS Council. 2007. *HIV and AIDS and STI National Strategic Plan 2007-2011.* Pretoria: SANAC.

South African AIDS Council. 2011. *HIV and AIDS and STI National Strategic Plan 2012-2016.* Pretoria: SANAC.

South African AIDS Council. 2017. *Annual Report 2015/16. South African AIDS Council Trust.* Pretoria: SANAC.

South African AIDS Council. 2017. *HIV and AIDS and STI National Strategic Plan 2017-2022.* Pretoria: SANAC.

Spence, D.P., Hotchkiss, J., Williams, C.S. & Davies, P.D. 1993. Tuberculosis and poverty. *BMJ.* 307 (25):759-761.

Stats SA (Statistics South Africa). 2017. Mortality and causes of death in South Africa, 2015: Findings from death notification form. Pretoria: Statistics South Africa.

Stewart, M. Towards a definition of patient-centred care. *BMJ*. 322:444-445.

Stillwaggon, E. 2006. *AIDS and the Ecology of Poverty*. London: Oxford University Press.

Streicher, E., Muller, B., Chihota, V., Mlambo, C., Tait, M., Pillay, M., Trollip, A., Hoek, K.G.P. et al. 2012.Emergence and treatment of multidrug-resistant (MDR) and extensively drug-resistant (XDR) tuberculosis in South Africa. *Infection, Genetics and Evolution* 12:686–694.

The College and Association of Registered Nurses of Alberta. 2005. *Primary Health Care*. College and Association of Registered Nurses of Alberta. Canada: Edmonton.

Travis, P., Bennett, S., Haines, A., Pang, T., Bhutta, Z., Hyder, A. A., Pielemeier, N. R., Mills, A. & Evans, T. 2004. Overcoming health-systems constraints to achieve the Millennium Development Goal. *The Lancet*, 364:900-906.

Tuberculosis ICD Report. 2010-2015. Infection Prevention and Control. Hospital 1.

Uebel, K.E., Fairall, L.R. van Rensburg, D.H.C.J., Mollentze, W.F., Bachmann, M. O., Lewin, S., Zwarenstein, M., Colvin et al. 2011. Task shifting and integration of HIV care into primary care in South Africa: The development and content to expand treatment and care for HIV (STRETCH). *Intervention Implementation Science.* 6(86):1-11

Vijen, A.A., Schers, H.J., Schellevis, F.G. & Van den Bosch, W.J.H.M. 2012. How unique is continuity of care? A review of continuity of care and related concepts. *Family Practice*. 29 (3): 264-271.

Von Holdt, K. & Murphy, M. 2007. Public hospitals in South Africa: Stressed institutions, disempowered management. In: Buhlungu S., Daniel J., Southall R. & Lutchman J. *State of the Nation: South Africa 2007*, Cape Town: HSRC Press. 312-344.

Verver, S., Warren, R. M., Beyers, N., Richardson, M., Van der Spuy, G., Borgdorff, M.W., Enarson, D.A., Behr, M. A. et al. 2005. Rate of Reinfection Tuberculosis after Successful Treatment is Higher than Rate of New Tuberculosis. *Am j Respir Crit Care Med,* 171:1430-1435.

Wadee, H., Gilson, L., Thiede, M., Okorafor, O. & McIntyre, D. 2003. Health care inequity in South Africa and Public/Private Mix. Draft paper prepared for the RUIG/UNRISD project on Globalization, Inequality and Health. September 2003. P1-31.

Webb C. & Kevern, J. 2001. Focus groups as a research method: A critique of some aspects of their use in nursing research. *Journal of Advanced Nursing* (6):798-805

Western Cape Department of Health. 2007. *Results of the 2006 HIV antenatal provision and area survey*. Cape Town: Western Cape Department of Health

Whitehead, M., Dahlgren, G. & Gilson, L. 2001. Developing the policy response to inequities of health: A Global perspective. In challenging inequities in health care: from ethics to action. New York: Oxford University Press. 309-322.

Whitehead, M. & Dahlgren, G. 2016. Concepts and principles for tackling social iniquities in health: Levelling up Part 1. Copenhagen: WHO Regional Office for Europe. Available: http://www.euro.who.int/data/assets/pdf_file/0010/74737/E89383.pdf [13 September 2016]

WHO, 2000.*Global tuberculosis control. WHO Report*. Geneva, World Health Organisation (http://www.who.int/gtb/publications/globrep00/index.html (accessed 14 April 2014)

WHO, 2010. *Global TB control*. Geneva. World Health Organisation. Available: http://apps.who.int/iris/bitstream/10665/44425/1/9789241564069_eng.pdf [11 November 2016]

WHO, 2015. *Global Tuberculosis Report*. Geneva: World Health Organisation. Available: http://apps.who.int/iris/bitstream/10665/191102/1/9789241565059_eng.pdf [1 December 2016]

WHO, 2017. *Global Tuberculosis Report*. Geneva: World Health Organisation. Available: http://www.who.int/tb/publications/global_report/en/ [10 February 2018]

Williams, D. R. 1999. Race, socio-economic status, and health. The added effects of racism and discrimination. *Annals New York Academy of Sciences*. 896:173-188.

Williams, V. 2014. Welcome to the Cape Flats. 1996-2014. Available: http://capeflats.org.za/modules/home/townships.php (10 October 2017).

Zelnick, J.R., Seepamore, B., Daftary, A., Amico, K.R., Bhengu, X., Friedland, G., Padayatchi, N., Naidoo, K. et al., 2018. Training social workers to enhance patient-centered care for drug-resistant TB-HIV in South Africa. *Public Health Action*. 8(1): 25-27.