

The experiences of patients with Human Immunodeficiency Virus (HIV) and  
Tuberculosis (TB) co-infection in Rundu, Namibia.

By

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**RESEARCH ETHICS COMMITTEE**

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I would like to take this opportunity to firstly, thank The Living God for His provision in terms of the financial as well as the emotional and spiritual dimensions associated with the completion of this study. Glory be to Him.

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## ABSTRACT

**Candidate:** Hazvinei Mlambo

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Namibia is one of the countries in Southern Africa which is hardest hit by the double burden of HIV and TB. Namibian national data shows that, although 50% of all TB patients in 2011 were HIV positive, there was an unintegrated approach in the management of these two diseases (Seeling, Mavhunga, Thomas, Adelberger & Ulrichs, 2014:269).

It is against this background that this study was conducted. The goal of the study was to explore and describe the experiences of patients with HIV and TB co-infection in Rundu, Namibia. A qualitative research approach was utilised in this study. The researcher draws attention to the experiences of co-infected patients by employing a phenomenological design which allowed patients to reminisce on their lived experiences. The study was therefore exploratory and descriptive in scope. Unstructured one-on-one interviews were used to collect data.

The findings reveal the presence of structural deficiencies in the management framework for co-infected patients. For instance, the multi-disciplinary team (MDT) was not well-co-ordinated and there was no integration of HIV and TB services. Consequently, patients experienced a sense of being neglected by health care professionals and noted that their interests as patients were, to a certain extent, ignored. Participants preferred to be treated in the context of their home environment by means of home based care (HBC). Most participants bemoaned the existence of stigma both at community level and in health care settings. A range of psychosocial experiences were also described.

As a consequence of this study, general recommendations were put forward and these included the need for the Ministry of Health and Social Services (MoHSS) to expedite

the integration of HIV and TB services in Namibia, particularly in relation to patients getting HIV and TB services under one roof. It was also noted that for co-infected patients to be holistically managed, there is a need to strengthen HBC as a strategy of managing patients to guarantee the involvement of family members in keeping with the biopsychosocial perspective (BPS), the theoretical framework for this study.

While the goal and objectives of this study were generally met, the researcher stressed the need for future research to explore the feasibility of HBC as a strategy for managing HIV and TB co-infected patients before the Government of the Republic of Namibia could incorporate the strategy in policy.

#### **LIST OF KEY TERMS:**

Co-infection

Experiences

Tuberculosis (TB)

Human Immunodeficiency Virus (HIV)

Patients

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## CHAPTER ONE

### GENERAL INTRODUCTION AND ORIENTATION TO THE STUDY

#### 1.1 Introduction

The *Southern African HIV and AIDS Information Dissemination Service* (SAFAIDS) (2008:4) indicates that the current trend in the field of human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS) is that most governments and organisations are only focusing on HIV and not on HIV and tuberculosis (TB) co-infection. The problem with this approach is that it disparages the magnitude of HIV and TB co-infection. Statistics show that the problem of HIV and TB co-infection is rising. In Africa for instance, the World Health Organization (WHO) (2013:71) reports that 43% of TB patients have a positive HIV test result. Narrowing down to Namibia, of the 11,145 documented TB patients 42% (4688) are co-infected with HIV (MoHSS, 2012:14). The majority (1,135) of the co-infected patients are youth aged between 25 and 44 years, meaning that the most productive age group is primarily affected by HIV and TB co-infection. This has significant implications for the overall development of Namibia (MoHSS, 2012:15). The percentage of TB patients found to be HIV positive in the 28 African countries in the list of 41 priority countries ranged from 10% in Ethiopia and Angola, to 77% in Swaziland (WHO, 2013:71). In America, WHO (2013:71) notes that the percentage of TB patients with a documented HIV test result who were found to be HIV positive was 16%, whereas in the Eastern Mediterranean, Europe, South East Asia and Western Pacific regions, less than 10% of TB patients with a documented HIV test result were HIV positive. The global average across all regions was 20%, and 21% among the 41 high TB/HIV burden countries (WHO, 2013:71).

The above statistics confirm the assertion that HIV and TB are diseases related to poverty because the highest rates of co-infection are in the underdeveloped regions in Africa whereas in the developed European and Western Pacific regions, co-infection rates are reported to be as low as 10% (SAFAIDS, 2008:3). HIV and TB are also intricately linked to malnutrition, unemployment, alcoholism, illegal drug abuse, poverty and homelessness all of which are rampant in the African region. The direct and indirect costs of illness due to TB and HIV are enormous. These are estimated to

be more than 30% of the annual household income in developing countries, thus having a catastrophic impact on the economy in the developing world (SAFAIDS, 2008:3).

In light of the above statistics it is evident that TB infection supports HIV replication and dissemination and that there is a mutual interaction between HIV and TB infection (Toossi, 2003:1146). In other words, HIV infection predisposes to the development of active TB and, on the other hand, the course of HIV-related immunodeficiency is worsened by active TB infection (Toossi, 2003:1146). This study focused on patients with HIV and TB co-infection in Rundu, Namibia because of the realisation by the researcher that these two diseases have a negative impact on each other as shown above.

It is against this background that the study was conducted. As opposed to taking HIV and TB as separate entities, the study focused on patients with HIV and TB co-infection as the unit of analysis in order to understand the burden of co-infection from the standpoint of the co-infected patients themselves.

The study was conducted in Rundu, Namibia and the participants were recruited from the Rundu Intermediate Referral Hospital which draws its patients from all over the Okavango Region.

### **Key concepts in the study**

- **Co-infection:** Co-infection is defined as “a simultaneous infection of a cell or organism by separate pathogens” (*Mosby’s Dictionary of Medicine, Nursing & Health Professions* (MDMNHPP), 2013:394). In this study therefore HIV and TB co-infection means that the patient is infected with HIV and TB at the same time.
- **Experiences:** According to the *Webster’s Reference Library Concise Edition English Dictionary* (2012:114), experiences refer to “a state of being affected from without as by events.” In this study experiences refers to what co-infected patients went through as a result of their diagnosis, the meaning they ascribe to it and how their lives changed after they became sick.
- **TB:** This refers to “a chronic granulomatous infection caused by an acid-fast bacillus, mycobacterium tuberculosis” (MDMNHPP, 2013:1824). Transmission is

usually through the inhalation or ingestion of infected droplets (MDMNHP, 2013:1824) and it is characterised by the formation of nodular lesions or tubercles in the tissues (*Oxford Concise Colour Medical Dictionary* (OCCMD), 2010:753).

- **HIV:** This refers to “a retrovirus that causes AIDS and infects helper T cells of the immune system and causes infection with an incubation period that averages 10 years” (MDMNHP, 2013:857). There are two varieties of HIV, namely HIV-1 and HIV-2 and the latter is most common in Africa (OCCMD, 2010:344).

## 1.2 Rationale and problem statement

This research was motivated by a practical concern to explore the life world of patients co-infected with HIV and TB. SAFAIDS (2008:4) points out that the current trend is that organisations and most governments are focusing on HIV, and not TB or co-infection. This approach tends to disparage the magnitude of the problem of being co-infected with two loathed diseases of HIV and TB. Moreover, there are disappointingly few studies that describe TB treatment experiences for high HIV prevalence settings or among co-infected patients (Mills, Nachega, Bangsberg, Singh, Rachlis, Wu, Wilson, Buchan, Gill & Cooper, 2007:23). In Namibia in particular, no research has been conducted directly exploring the experiences of HIV and TB co-infected patients (Seeling et al., 2014:269). Moreover, it does not necessarily follow that the results from other countries will be replicated in the Namibian context due to social, economic and cultural differences.

For instance, Isaakidis et al. (2013:1) carried out a study on patients co-infected with HIV and TB in a clinic in Mumbai, India and found out that by the time patients and their families initiated treatment for co-infection, their financial and emotional resources were often depleted. Side effects of the drugs were reported to be severe and debilitating, and patients expressed the burden of care and stigma on the social and financial viability of the household (Isaakidis et al., 2013:1; Sharma, Mohan & Khadiravan, 2005:559). Skin rash, gastrointestinal disturbances and drug-induced hepatotoxicity were among the most reported side effects (Sharma et al., 2005:559). Family caregivers were crucial in maintaining the mental and physical health of patients, but reported high levels of fatigue and stress. Barriers to adherence were to

a large extent social, rather than medical (Isaakidis et al., 2013:1). Treatment adverse events, pill burden, rigidity of directly observed therapy (DOT), psychosocial support and interaction with health personnel posed major challenges to adherence for concomitant anti-TB and antiretroviral treatments (Munroe, Lewis, Smith, Engel, Fretheim & Volmink, 2007:1236, 1239).

Moreover, Isaakidis et al. (2013:5) identified that patients felt embarrassed and had a sense of loss of respect by having to take DOT at the clinic. Patients' households were socially and financially affected by the burden of disease. Patients described side effects of the drugs as being worse than the disease itself and detailed the heavy social and financial burden of prolonged treatment for two highly stigmatised diseases. Therefore, stigma associated with TB emerged as an important barrier to treatment seeking and adherence (Isaakidis et al., 2013:5).

It is important to note that these studies were all done outside Namibia and that Seeling et al. (2014:269) report a dearth of knowledge in HIV and TB co-infection in Namibia. This particular qualitative study was conducted in light of the need to appropriately respond to the challenges faced by HIV and TB co-infected patients in Namibia. The study was also useful for determining the nature and scope of the problems faced by patients with HIV and TB co-infection. The study findings may inform appropriate programmes of intervention to respond to the needs of HIV and TB co-infected patients in Namibia.

The core research question for this study was: **What are the experiences of patients with HIV and TB co-infection in Rundu, Namibia?**

### **1.3 Goal and objectives**

The following are the goal and objectives of the study:

#### **1.3.1 Goal**

This research sought to explore and describe the experiences of patients with HIV and TB co-infection in Rundu, Namibia.

#### **1.3.2 Objectives**

- To describe the phenomenon of HIV and TB co-infection.

- To explore the impact of HIV and TB on the daily functioning of persons who are co-infected.
- To determine the biopsychosocial challenges of patients affected by HIV and TB co-infection and treatment.
- To devise strategies for social work intervention with HIV and TB co-infected persons.

#### **1.4 Overview of research design and methodology**

This study utilised a qualitative research approach which enabled the researcher to explore the life world of HIV and TB co-infected patients by listening to the accounts of their personal experiences (Rubin & Babbie, 2011:437). This applied study sought to provide recommendations in relation to the management of co-infected patients, as well as to devise strategies for social work intervention with them. The researcher utilised a phenomenological research design by examining human experiences through the descriptions that were provided by the participants (Fouché & Schurink, 2011:316; Brink, 2006:113). A phenomenological research design was preferred because it enabled participants to describe the hidden emotions associated with HIV and TB co-infection (Brink, 2006:113). The study population consisted of all TB and HIV co-infected patients at the TB ward in an Intermediate Referral Hospital in Namibia. Since the researcher managed to compile a list of all HIV co-infected patients in the hospital, based on the data from the admission records, a probability systematic sampling technique was deemed to be the most suitable sampling method due to the randomisation element that is embedded in it (Strydom, 2011:228). Unstructured one-on-one interviews were used to collect data from participants and the interviews were tape recorded with the permission of the participants. For data analysis, the researcher utilised the five steps of data analysis as put forward by Creswell (2009:126-129). A more detailed outline of the research methodology is presented in chapter three, subsections 3.2-3.6. The ethical considerations for the study are discussed in chapter three, section 3.7.

#### **1.5 Limitations of the study**

Even though the objectives of this research were met, the researcher was cognisant of the following limitations:

- This research did not separate Multi Drug Resistant-TB (MDR-TB) and Extensively Drug Resistant-TB (XDR-TB) patients from drug-susceptible TB patients. It would have been better if these patients were separated because it is obvious that their treatment regimens are quite different and thus could also be affected by their treatment experiences differently. However, due to the time limit, this research did not focus on co-infection with any one form of TB. Future research could therefore overcome this limitation by focusing on co-infection with either drug susceptible TB, MDR-TB or XDR-TB.
- Some of the participants did not understand English and hence had to be interviewed in their vernacular Rukwangali language through a translator. Transcription of interviews for these participants was also done with the assistance of the same translator. It is possible that important and rich meanings of data could have been lost through the translation process.
- Although the researcher utilised a systematic sampling technique to identify participants for this study, nine out of the ten participants ended up being females. This may mean that the findings of this study could also have been influenced by the gender-bias of the sample.

## **1.6 Outline of the mini-dissertation**

The research report is composed of four chapters.

Chapter one introduces the study, explains the rationale for conducting the study as well as the problem statement. Goals and objectives of the study are also presented in this chapter. The chapter also gives a brief overview of the research methodology that was used as well as the study limitations.

Chapter two presents the review of literature related to the experiences of patients with HIV and TB co-infection including the theoretical frameworks that informed the study, namely the ecological systems perspective and the biopsychosocial perspective. Furthermore, the chapter discusses HIV and TB co-infection within a global, African and Namibian context and presents previous findings in the area of HIV and TB co-infection.

Chapter three discusses the research methodology in more detail and explains the ethical considerations which governed the research. Moreover, the chapter presents

findings using themes and sub-themes generated from the study, quotes from the interviews, as well as literature to substantiate the findings. These findings are also discussed in light of the ecological systems and biopsychosocial theoretical frameworks.

Chapter four is the last chapter of this research report. It evaluates the extent to which the research objectives were met. Key findings are summarised and conclusions and recommendations are given.

Having outlined the contents of the research chapters, the next chapter will focus on the literature study.

## **CHAPTER TWO**

### **HIV AND AIDS AND TB CO-INFECTION: A BIOPSYCHOSOCIAL PERSPECTIVE**

#### **2.1 Introduction**

According to Gardezi et al. (2008:718) social, structural and cultural contexts determine how patients respond to, and experience their diagnosis. Although some studies (Daftary, Padayatch & O'Donnell, 2014:1110; Rodlach, Dlodlo & Hwalima, 2012:110) discussed co-infection experiences for HIV and TB patients, there is a paucity of studies exploring experiences from the perspective of Namibian patients. This particular study was motivated by the need to bridge that gap.

This chapter reviews literature pertaining to HIV and TB co-infection. It starts by discussing the ecological systems perspective and the BPS perspective, the theoretical frameworks for this study. Thereafter, the debate on the involuntary treatment of and management of co-infected patients is explored. In this thrust, public health issues and the human rights issues affecting co-infected patients are highlighted. The implications of the human rights debate to social work practice are presented. The chapter also conceptualises and discusses stigma as it affects co-infected patients. Regional and Namibian perspectives of barriers to HIV and TB treatment are also presented. Post-traumatic stress disorder (PTSD) in co-infected patients is then explored, as well as a discussion on their daily functioning. The chapter then explores spirituality issues and HBC as strategies for managing co-infected patients. Lastly, the continuum of care and multi-disciplinary teams are discussed.

#### **2.2 Theoretical framework**

The study was informed by the biopsychosocial perspective as embedded in Bronfenbrenner (1979)'s ecological systems framework.

##### **2.2.1 Ecological systems perspective**

The ecological systems perspective holds that interaction between the developing person and the environment is pivotal and "the developing person is an active participant who changes, restructures and finds a mutual accommodation with their environment" (Nash, Robyn & O'Donogue, 2005:37). For Bronfenbrenner (1979) the ecology of human development was based in a concentric arrangement of systems,

which he categorised as the micro-system, meso-system, exo-system and macro-system (Nash et al., 2005:37). This perspective is appropriate in this study in that it helps in identifying the various levels at which patients with HIV and TB co-infection face challenges or receive help. For instance, a strong commitment at micro level by the family members as treatment supporters and caregivers is paramount to treatment and recovery, as well as psycho-social well-being of the patient. The ecological systems perspective encourages practitioners to adopt a broad focus, examining not only the individual patient, but the patient's interactions with family members, co-workers and even the physical environment of buildings, parks and other structures (Dinitto & McNeece, 1997:58).

Whereas the biomedical model focuses on the sick individual as opposed to taking the individual in his or her social context, the ecological systems perspective highlights the larger, complex picture of interaction within a community and does not focus on the patient in isolation (Gehlert & Browne, 2012:21). The ecological systems perspective provides the basis upon which patients with HIV and TB co-infection could be holistically managed and their behaviour understood. Hence, the ecological systems perspective may help social workers to analyse the macro environment in which policies for management of HIV and TB co-infected patients are formulated.

## **2.2.2 Biopsychosocial approach**

Proposed by Engel in 1977, the BPS approach addresses “the biological, social, environmental, psychological and behavioural aspects of illness” (Gehlert & Browne, 2012:20). It also enables the exploration of all the systems that affect the patient by expanding on the traditional medical model of health care that focuses primarily on the biological basis of disease (Gehlert & Browne, 2012:20). The medical model has been criticised for being preoccupied with direct observations of the human body, as well as for focusing mainly on scientifically verifiable aspects of health (Hewa, 1994:117). Edozien (2015:900) refers to the medical model as a biomedical model and notes that it gives precedence to biology and does not pay attention to the psychological and social aspects of health. In the process, social, psychological and environmental factors on health and illness are overlooked. The BPS approach is relevant to this study as it enables the assessment of the psychosocial aspects of TB and HIV co-infection. The BPS approach, “combines biological, psychological and social factors,

rather than relying only on biological factors, in understanding health and illness” (Edozien, 2015:900). In other words, this approach gives attention to the social context of health and illness and how it affects the biological aspects of disease. For instance, a patient who does not have health insurance, transport money to the health facility or money to buy nutritional supplements and special dietary requirements may fail to adhere to treatment (Gehlert & Browne, 2012:21). Adherence is an important component for the success of both HIV and TB treatment. Edozien (2015:902) argues that when using the BPS approach, focus should shift from mere disease prevention and treatment, to health promotion. In the context of the BPS perspective, there is need for an overhaul of the curriculum for undergraduate and postgraduate medical and other health professional students to include not only biological, but also the psychological and social components of health and illness (Edozien, 2015:902). By expanding focus to the social networks and cultural contexts of patients, and thereby enabling a holistic approach to patient management, the BPS approach borrows from the ecological systems perspective as put forward by Bronfenbrenner (1979). It is for this reason that the BPS approach was utilised to provide the theoretical underpinning for this study.

### **2.3 Overview of TB and HIV**

The researcher is of the view that it is important to understand the history behind TB and HIV in terms of their development in order to have a good appreciation of their present dynamics in how they pose a public health problem. In this sub-section, the history of TB and HIV are discussed separately. Thereafter commonalities between these two diseases are drawn.

#### **2.3.1 TB**

TB is one of medicine’s oldest plagues (Bartlett, 2007:S124). Robert Koch discovered the tubercle bacillus in 1882. He did culture, staining and experimental studies in animals in order to draw some conclusions relating to the bacilli (Bartlett, 2007:S125). The discovery of streptomycin in 1943 provided the springboard for successful treatment of TB infected patients (Bartlett, 2007:S125).

In terms of curability, Bartlett (2007:S124) notes that TB has been curable for 40 years and on average a single patient can now be cured for as little as US\$16 per patient.

Nevertheless, it has been estimated that 30% of the global population is infected and that a new infection occurs every second. Even more disturbing is the fact that globally, approximately 1.7 million deaths occur due to TB every year (Bartlett, 2007:S124).

### **2.3.2 HIV**

The supposedly causative agent was discovered in 1983 and zidovudine received approval as the first effective antiretroviral agent in 1987 (Bartlett, 2007:S124). Since then, extra-ordinary achievements have been made in the treatment of HIV/AIDS courtesy of the introduction of highly active antiretroviral therapy (HAART) in 1996. However, in spite of such progress, about 39.5 million people globally, are living with HIV infection (Bartlett, 2007:S124; Friedland, Churchyard & Nardell, 2007:S51). In 2006 alone, 4.3 million new infections and 2.9 million deaths directly related to HIV/AIDS were recorded worldwide (Bartlett, 2007:S124).

### **2.3.3 HIV and TB common characteristics**

Bartlett (2007:S124) believes that the intersection of TB and HIV is a dangerous combination and points out that:

- Both diseases are concentrated in areas of poverty where there are minimal resources for diagnosing, treatment and infection control.
- Both diseases represent major public health failures, despite the great achievement in treatment that have been made.
- The diseases are linked by biology: depending on geographical area, the approximately 40 million people living with HIV infection are 6-50 times more likely to develop active TB than are people living without infection.
- These epidemics are a particularly noxious combination because each epidemic accelerates the other.

Bartlett (2007:S124) takes the emergence of MDR-TB as testimony of the evils of the combination of HIV and TB and cites the following cases as evidence:

- The MDR-TB outbreak that occurred in New York City in the early 1990s.
- The MDR-TB epidemic in Tomsk Oblast in Russia.

- The outbreak of XDR-TB in KwaZulu Natal in South Africa.

Bartlett (2007:S125) notes of these three cases:

The emergence of MDR-TB and XDR-TB has been described as a reflection of weaknesses in TB management, with an urgent need existing for effective disease control and health care infrastructure, including the use of culture sensitivity testing, and strict supervision of therapy. It is also a reflection of the convergence of the TB and HIV infection epidemics and the likely transmission of MDR-TB and XDR-TB to an enlarging pool of HIV infected and immunocompromised individuals.

The implication from the picture presented by Bartlett (2007) above is that of a world under siege by HIV and TB co-infection. This is because the cure rate of TB alone for instance, has been shown to be very high in the absence of HIV (Converse, 2000:149). It is therefore safe to say that the greatest threat does not lie in HIV alone or TB alone but in their synergy.

### **2.3.4 Preferential adherence to ART over TB medicines**

Taking TB and HIV as separate entities may also have implications when it comes to patient adherence to treatment, as reported in a South African study by Daftary, Padayatch and O'Donnell (2014:1107). In the mentioned study, participants expressed a preference for ART over MDR-TB treatment. The participants cited greater tolerability, lower pill burden and a commitment to ART as the reason for such preference (Daftary et al., 2014:1107).

Preferential adherence may have been due to the fact that much emphasis is placed on HIV and not TB or HIV and TB co-infection. One female participant in a study of Daftary et al. (2014:1110) was quoted as saying:

“If I can dodge, I can dodge TB. I can take for HIV; even if I can take them my whole life I don't have a problem. But for TB, no, I can dodge them if I can be given a chance...there are many injections, lots of tablets, they are bitter, they are sour. It's all mixed here; it's something you don't know. But HIV, you just get three, maybe once daily.”

Such a scenario can possibly stem from the naivety on the part of patients which could be attributed to separatist approaches in the management of HIV and TB. On another note, preferential treatment could be a way of dealing with the feelings of being

overwhelmed by the amount of tablets patients with HIV and TB co-infection have to endure. Daftary et al. (2014:1107) revealed in their study some of the extremes as far as what HIV and TB co-infected patients go through in their everyday lives, as well as the psycho-social implications of an HIV and TB co-infection diagnosis. It is in this context therefore, that this study sought to explore and describe the experiences of patients pertaining to HIV and TB co-infection.

## **2.4 Tuberculosis in the context of this study**

As mentioned earlier, this study was not confined to any one form of TB. All the three forms of TB were considered and these will be discussed in the following sub-sections.

### **2.4.1 Forms of TB**

With regard to HIV and TB co-infection it is important to note that literature refers to three forms of TB, namely TB that is susceptible to drugs (Wells, Cegielski, Nelson, Laserson, Holtz, Finlay, Castro & Weyer, 2007:S86), MDR-TB, as well as XDR-TB (Koenig, 2008:894).

#### **2.4.1.1 Drug Susceptible TB**

As noted by Wells et al. (2007:S86), drug susceptible TB refers to a type of TB that is susceptible to all of the standard TB drugs like isoniazid, rifampicin pyrazinamide and ethambutol.

#### **2.4.1.2 MDR-TB**

According to Koenig (2008:894) MDR-TB first gathered widespread attention in the 1990s when researchers around the world began identifying a substantial number of cases that were resistant to at least two of the four standard drugs used to treat TB. Wells et al. (2007:S86) note that these drugs are isoniazid and rifampicin. Moreover, the treatment period for MDR-TB is said to be two years as compared to 6-8 months required for drug susceptible TB (Wells et al., 2007:S86; Koenig, 2008:894). In addition, MDR-TB treatment requires the use of 'second line' drugs which are more toxic and prohibitively more expensive (Wells et al., 2007:S86).

MDR-TB cases tend to be concentrated in regions where inadequate health care services make it harder to ensure that patients can follow the length of drug regimen

(Koenig, 2008:894). Failure to adhere to treatment gives the TB bacteria the chance to mutate and to evade the drugs, thereby leading to resistance (Koenig, 2008:895).

### 2.4.1.3 XDR-TB

XDR-TB is a strain of TB which is resistant to almost all known TB drugs (Koenig, 2008:894). This strain is “resistant to at least rifampicin and isoniazid (MDR-TB), in addition to any fluoroquinolone, and to at least one of the three injectable drugs used in anti-TB treatment” (Boggio, Zignol, Jaramillo, Nunn, Pinet & Raviglione, 2008:121). These injectables are capreomycin, kanamycin and amikacin. In South Africa such TB strains were first detected in 2005-2006 in the poor, mainly Zulu community of Tugela Ferry in KwaZulu Natal Province of South Africa and nearly all the victims were also co-infected with HIV (Bartlett, 2007:S124,S125). Koenig (2008:894) alludes to the alarming fatality rates of XDR-TB at Tugela Ferry noting that of the 53 patients co-infected with XDR-TB and HIV, 52 of them had died within sixteen days after being tested for TB.

## 2.5 TB/HIV indicators in Namibia

Table 2.1 below gives a summary of the major TB and HIV indicators in Namibia from the year 2007 to 2011.

**Table 2.1: Summary of major TB/HIV indicators in Namibia, 2007-2011**

Indicator	2007	2008	2009	2010	2011
No. of notified cases of all forms of TB	15 244	13 737	13 332	12 625	11 937
TB case notification rate for all forms of TB per 100 000	722	665	634	589	556
TB cases with known HIV status (as percentage of all notified TB cases)	8 186 (54%)	9 188 (67%)	9 849 (74%)	9 534 (76%)	10 039 (84%)
TB patients with known HIV status who are HIV-positive (as percentage of all TB patients with known HIV status)	4 358 (59%)	5 425 (59%)	5 676 (58%)	5 227 (55%)	4 980 (50%)
HIV positive TB patients on ART (As percentage of all TB patients with known positive HIV status)	749 (17%)	2 019 (37%)	1 995 (35%)	2 294 (43%)	2 700 (54%)

Source: MoHSS (2012) cited in Seeling et al. (2014: 269).

Since 50 % of all TB patients in Namibia are HIV positive (as depicted in table 2.1 above), the MoHSS (2006:94) emphasises the need for joint TB/HIV planning in order to benefit the co-infected patient in terms of positive treatment experiences. Currently TB and HIV programmes in Namibia are set up as independent entities (Seeling et al., 2014:269). The rationale behind the need for co-ordinated management of HIV and TB programmes in Namibia is discussed later in section 2.6.2. There is, however, need to pay attention to international statutes with regard to management of HIV and TB patients if the rights of these patients are to be respected (Boggio et al., 2008:122).

## **2.6 The integration of HIV and TB services**

Heunis, Woulters and Kigozi (2012:344) point out the existence of independent and disconnected TB and HIV services that negate patients' preference for an integrated service and result in wastage of scarce health resources and an increased burden on patients' time and finances. WHO (2013:68) concurs with Heunis et al. (2012:344) and points out that there is need for collaborative TB/HIV activities. These collaborative activities include establishing and strengthening coordination mechanisms for delivering integrated TB and HIV services, testing TB patients for HIV, providing HIV prevention services for TB patients, integrating, intensifying TB case finding among people living with HIV and controlling the spread of TB infection in health care congregate settings (WHO, 2013:68). SAFAIDS (2008:3) notes the need for a 'one stop' approach to addressing co-infection whereby patients receive TB and HIV care and/or treatment under one roof. Integrating Anti-Retroviral Therapy (ART) and DOT will promote efficient usage of health workers' time and a more navigable experience for patients. Integrating ART and DOT will ultimately ensure improved TB treatment and completion rates as well as MDR-TB prevention (Heunis et al., 2012:344). The lack of integrated policy by most governments, especially in developing countries, has led to inadequate responses to the 'cursed duet' of HIV and TB co-infection at various levels (SAFAIDS, 2008:4).

The next section presents a model of HIV and TB integration as per WHO standards and guidelines as presented by Hausner, Kulsharova, Seledtsor, Khodakevich and Deryabina (2007:149). Furthermore, as this study was conducted in Namibia, a brief discussion of how Namibia is attempting to integrate HIV and TB treatment services will be provided.

### **2.6.1 HIV and TB integration model: The case of Uzbekistan, Tajikistan and Kyrgyzstan**

An interesting model of HIV and TB integration of services in Uzbekistan, Tajikistan and Kyrgyzstan is discussed by Hausner et al, (2007:149). In this model, patients living in the aforesaid geographical areas were being managed and treated appropriately for TB and HIV co-infections. New patient registration forms and an electronic surveillance database were used to monitor patients flow and outcomes. In order to detect TB early and thereby increase the chances of a complete cure, all newly diagnosed HIV-infected individuals were immediately referred to screening for TB by chest x-ray followed by repeat screening once every year. Patients who discharged sputum were promptly tested for Acid Fast Bacilli (AFB). HIV-infected individuals who were diagnosed with active TB were registered and treated in TB facilities.

All TB patients received special consultations on HIV prevention measures. TB patients were referred for HIV screening, based on special clinical and social indications such as behavioural risk factors and underwent voluntary counselling and testing (VCT). TB patients who tested positive for HIV were examined within a week by an AIDS specialist. Decisions regarding whether to start or delay antiretroviral therapy (ART) were made jointly by AIDS and TB specialists based on World Health Organization (WHO) approaches, and taking into account potential interactions between ART and TB treatment. If ART was prescribed, it was managed in TB hospitals for in-patients, in ambulatory TB facilities during the continuation phase of TB treatment, in AIDS centres, or in polyclinics, depending on what was convenient for the patient.

As per the WHO recommendations, all HIV and TB co-infected patients were prescribed cotrimoxazole preventive treatment (CPT), so as to prevent other opportunistic infections. Upon completion of treatment, the decision on whether or not to continue CPT was made by an AIDS specialist.

Newly detected HIV-infected individuals, for whom active TB was excluded by clinical, laboratory and x-ray examinations, were prescribed with isoniazid preventive therapy (IPT) for six months duration, in order to prevent the development of active TB. Prescription of IPT was made by TB specialists and was managed by AIDS centres, primary care facilities or TB facilities.

In ministries of health in all three countries, participated very actively in the development and implementation of the TB/HIV collaborative models. Moreover, in all these countries government orders and approvals were signed, approving the continuation of the activities and training as well as scaling up of these models.

### **2.6.2 Integration of HIV and TB services in Namibia**

The case study discussed above presents WHO recommendations for an ideal model for HIV and TB treatment collaboration. However, huge investments in terms of human and capital resources are required for the model to work effectively. For instance, AIDS specialists were used to examine patients who tested positive for HIV within a week. Such specialists are scarce in resource constrained settings like Namibia (Seeling et al., 2014:268) making it problematic to implement the model effectively in Namibia.

MoHSS (2006:94) however, realises the need to adopt such a model to effectively render services to HIV and TB co-infected patients in Namibia. The following points provide the rationale behind the need for co-ordinated management (MoHSS, 2006:94, 95):

- **Joint resource mobilisation:** Financial and human resources need to be made available at all levels, in order to achieve the TB and HIV mid-term plan targets.
- **Capacity building including training:** Joint capacity building includes training of health care workers in both TB and HIV.
- **TB/HIV communication and mobilisation:** Advocacy targeted at influencing policy, programme implementation and resource mobilisation is important. Two way communication between the programmes and the general public that creates awareness and informs about TB/HIV is crucial for ensuring that patients with HIV and TB co-infection seek out and avail themselves of the services. Social mobilisation that generates public will and secures broad consensus and social commitment among all stakeholders, is crucial in reducing stigma, thus mitigating and preventing TB and HIV, as well as encouraging participation in collaborative TB/HIV activities.
- **Enhancing community involvement in collaborative TB/HIV activities:** Through support groups for people living with HIV and community based

organisations, TB prevention and care can be integrated with HIV/AIDS prevention, care and support. Communities can be mobilised to advocate for resources and help implement collaborative TB activities.

- **Operational research:** It informs global and national policy and strategy development, taking account of cultural, geographical and resource diversity.

The value of community involvement in the management of patients with HIV and TB co-infection is emphasised in the above discussion. It should be noted that the above discussion clearly shows that there is no coordinated integration of HIV and TB services in Namibia (Seeling et al., 2014:268) to the magnitude shown in the discussed model (see sub-section 2.6.1 above). The MoHSS, however, realises that without the active participation of communities in management of co-infected patients, chances are that initiatives may not be holistic and may fail to address the needs of the patients. It is because of this realisation that the MoHSS (2006:94) recommends the need for Namibia to work towards the integration of services in as far as HIV and TB treatment and management are concerned.

## **2.7 Involuntary treatment and management of TB patients**

The debate on the importance of treatment supervision for basic TB control and management has evoked the sensitive issues of involuntary treatment including compulsory medical examination, compulsory isolation or detention of infected patients (Boggio et al., 2008:122). International law, however, permits involuntary treatment on the basis of public health and is viewed as enough grounds for limiting certain individual rights (Boggio et al., 2008:122).

### **2.7.1 Public health and human rights law**

Human rights are protected under international law, regional systems and by national constitutions and are packaged in the Universal Declaration of Human Rights which was adopted in 1948 by the General Assembly of the United Nations as basic human rights (Boggio et al., 2008:122). According to Boggio et al. (2008:122) the basic principles on the Universal Declaration of Human Rights are reflected in countless international legal instruments as well as in regional and national legal frameworks. Other international legal instruments include International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural

Rights (Boggio et al., 2008:122). The latter covenant for instance implores state parties who are signatories to it to recognise the right of everyone to enjoy the highest attainable standards of physical and mental health. Namibia is a signatory to both the Covenant on Civil and Political Rights and the Covenant on Economic, Social and Cultural Rights. Boggio et al. (2008:122) further alludes to the need to limit individual human rights on considerations of protecting public health.

### **2.7.2 The Siracusa principles**

The Siracusa principles hold that “measures restricting human rights should be legal, non-arbitrary, non-discriminatory, proportionate, necessary, the least restrictive means that are reasonably available under the circumstances, and based on sound science”. Specifically, for a restriction of human rights to be considered legitimate, a government has to address the following five criteria listed by Boggio et al. (2008:122):

- The restriction is provided for and carried out in accordance with the law.
- The restriction is in the interest of a legitimate objective of general interest.
- The restriction is strictly necessary in a democratic society to achieve the objective.
- There are no less intrusive and restrictive means available to reach the same objective.
- The restriction is based on scientific evidence and not drafted or imposed arbitrarily - that is in an unreasonable or otherwise discriminatory manner.

Figure 2.1 below gives an illustration of a typical medical ward where HIV and TB co-infected patients are managed:



**Figure 2.1: Heavily secured ward for HIV and TB co-infected patients**

Justifying involuntary confinement of specific patients is always controversial because it represents a significant deprivation of an individual's freedom of movement and runs the risk of resulting in limiting other civil liberties like privacy, non-discrimination and freedom from arbitrary detention (Boggio et al., 2008:123). Boggio et al. (2008:125) further argue that compulsory diagnosis and treatment violate the right to non-consensual bodily invasion, which is the cornerstone of the informed consent doctrine. In addition, authority to confine TB patients does not necessarily imply authority to treat or monitor their health (Boggio et al., 2008:125).

### **2.7.3 Implications for social work practice: The human rights approach**

It is therefore clear from the above discussion that HIV and TB co-infection challenges social workers to push back the frontiers of human rights violations particularly pertaining to HIV and TB co-infected patients. One way of doing this is by adopting the human rights approach to intervention. According to Chopra and Ford (2005:384), "health promotion interventions... need to integrate a human rights-based approach into strategic and effective action plans within the existing resource constraints."

Utilising the human rights approach, Chopra and Ford (2005:384) note that community participation and engagement are indispensable if programmes focused on HIV and TB patients are to be successful. This implies that the traditional public health activities like supplying condoms and health messages for safe sex, for instance, should be complemented with approaches that treat HIV transmission and prevention and social issues such as tackling stigma, power networks and kinship systems (Campbell &

Mzaidume, 2002:230). A human rights based approach should empower people to have access to basic resources needed to live a dignified life. In this context poverty “...is not only a lack of income or economic and material resources; it is an infringement on human dignity and also on human rights” (Strauss & Horsten, 2013:341). Chopra and Ford (2005:384) identify five approaches to scaling up health promotion interventions. These include; the blue print, explosion, additive, biological and human rights approaches.

### **2.7.3.1 The blue print approach**

According to the blue print approach, experts or technocrats select successful interventions from local or international experience. Outsiders design all action plans based upon log frameworks, targets and regulations and success depends on tight supervision and incentives (Chopra & Ford, 2005:384).

### **2.7.3.2 The explosion approach**

Within the explosion approach, interventions are selected as national or global priorities and a bureaucratic management system is used to guarantee success. However, the problem with this approach is that it ignores local priorities. Although this approach may strengthen the local system in the short term, it may fail to succeed in the long run due to the fact that it ignores local priorities (Chopra & Ford, 2005:384).

### **2.7.3.3 The additive approach**

The additive approach is “bottom-up and culturally adapted” in scope in the sense that it is implemented from the grassroots (Chopra & Ford, 2005:384). It is normally employed and bankrolled by outside non-governmental organisations with hopes of eventually weaning the community. The main problem with this approach is that communities tend to develop dependency and may be too slow to eventually fit into the national system (Chopra & Ford, 2005:384).

### **2.7.3.4 The biological approach**

The linchpin of the biological approach is the identification of existing successful community projects which demonstrate self-reliance and empowerment (Chopra & Ford, 2005:384). Communities are encouraged to be building blocks in initiatives for socio-economic development at a national scale. The role of external agencies is to

establish an enabling environment as well as empowering the communities and facilitating the sharing of experiences (Chopra & Ford, 2005:384).

### **2.7.3.5 The human rights approach**

According to Chopra and Ford (2005:386), the human rights approach is championed by the United Nations Children's Fund's human rights based approach to programming (HRBAP). In this approach, health promotion is acknowledged as an ongoing activity within a community. Furthermore, community campaigns do not fit in human rights approaches as long as they constitute once off initiatives by technocrats from the outside (Chopra & Ford, 2005:386). Human rights approaches are premised within the following reasoning:

People communicate constantly as they make daily decisions, explore strategies for surviving and coping, discuss norms and standards to apply in their communities, absorb and apply new information and experience and affirm themselves. This ongoing communication reflects existing power relationships and can therefore either support or constrain people's choices (Castelloe & Watson, 1999 cited in Chopra & Ford, 2005:386).

The researcher found these models worth of consideration by social workers especially those practising in the Namibian context in the sense that the violation of human rights for TB and HIV co-infected patients does not start at the time when they are co-infected, but before they get sick. The ecological systems perspective (see theoretical framework in section 2.2) demonstrates that the macro-system is very influential in determining patient dynamics. It is therefore important when it comes to HIV and TB co-infected patients for social workers to realise that they have to positively influence macro systems like communities at large, so that the problem of HIV and TB co-infection can be adequately addressed. One way of doing this is to advocate for preventative approaches that empower communities to take ownership of public health initiatives. At the present moment, social work practice in Namibia has a curative and remedial thrust (MoHSS, 2010:1), although attempts are underway to migrate to a developmental approach which has emphasis on prevention and the empowerment of communities. The researcher believes that only within the context of developmental

social work can communities be fully empowered to deal with the synergistic effects of HIV and TB.

## 2.8 Stigma and discrimination

According to Goffman (1963:3) stigma is “an attribute that is deeply discrediting, or an attribute that makes a person different from others in the category of persons available for him to be, and of a less desirable kind – in the extreme, a dangerous or weak.” Figure 2.2 below provides a visual illustration of the concept of stigma as it affects patients with HIV and its associated complications. The image co-relates with the definition of stigma as given by Goffman (1963:3) in that it depicts that stigma is a shameful practice which provokes pain and suffering to those at which it is directed, in this case HIV and TB co-infected patients.



**Figure 2.2: Stigma in HIV and TB co-infected patients**

According to Williams (2014:149), the society determines and shapes the individual's views about social phenomena. The perception of the society or community therefore determines the extent to which an attribute is stigmatised. In other words stigma is socially constructed (Williams, 2014:149).

A survey of over 1000 HIV positive participants in Cape Town, South Africa conducted by Simbayi, Kalichman, Strebel, Cloete, Henda and Mqeketo (2007) found that 40% of participants had experienced discrimination resulting from HIV/AIDS related (HAR) stigma. A similar study by Kohi, Makoe, Chirwa, Holzemer, Phetlhu, Uys, Naidoo, Dlamini & Greef, (2006) supports the blatant prevalence of HAR stigma. The net effect of the stigma according to Williams (2014:146) is to impede the ability of health services such as counselling and testing to prevent new infections and to discourage HIV-positive individuals from accessing treatment.

Gebrekrstos, Lurie, Mthethwa and Abdool Karim (2009:2) provide interesting scenarios in which patients took advantage of their HIV and TB co-infection status to evade HIV stigma in their communities. Patients in the aforementioned study would tell people that the HIV and TB medications they were taking were just TB medications only. Gebrekristos et al. (2009:3) however note that this method of evading HIV stigma exposed the participants to unsafe sexual practices with their partners. Though participants understood the importance of disclosing their actual status to their partners, they did not do so due to fear of being rejected (Gebrekristos et al., 2009:3). Integrated HIV and TB services should, however, contribute to the reduction of stigma if such a model takes into account the involvement of all systems affecting the patient (Norman, Chopra & Kadiyala, 2007). Chileshe and Bond (2010:57) in their study of HIV and TB co-infected patients in Zambia refer to a new stigma that has emerged—namely ‘TB/HIV’ stigma. As TB and HIV stigma were experienced by all seven co-infected HIV and TB participants in the mentioned study, it resulted in limited disclosure patterns that made it hard and sometimes impossible for participants to access ART. Moreover, the TB and HIV stigma enhanced participants’ denial of their HIV status, fear of HIV testing and, in one case, the participant preferred witchcraft and faith healing to receiving treatment at a health care facility (Chileshe & Bond, 2010:57).

A study by Daftary, Padayatchi and Padilla (2007:574) shows that co-infected patients tend to disclose their TB diagnosis over an HIV diagnosis and also fail to adhere to HIV treatment due to the relatively greater stigma of an HIV diagnosis. Daftary and Padayatchi (2012:1485) postulate that the stigma of being identified at clinics and labelled with HIV discouraged adherence among some patients. In their research in KwaZulu Natal, South Africa, Daftary and Padayatch (2012:1485) unearthed selective

disclosures which were motivated by patients' need to access resources, which may have been denied had they disclosed their HIV status.

An unexpected finding in a study by Rodlach et al. (2012) on perceptions of HIV, AIDS and TB among patients on ART in Bulawayo, Zimbabwe, was the absence of references to promiscuity and stigma in their participants' responses. This is contrary to the evidence presented in similar studies (Rankin, Brennan, Schell, Laviwa & Rankin, 2005) which indicated that HIV and AIDS are often associated with promiscuity and stigma. However, this absence of references to stigma and promiscuity was explained by the fact that data was collected at clinics and not in the community where actual stigma is experienced (Rodlach et al., 2012:110).

The general trend in literature has therefore been that HIV and TB co-infected patients tend to experience stigma at various levels in their respective communities. HIV and TB stigma has, in most cases, been a hindrance to the success of HIV and TB programmes. The absence of integration of HIV and TB services in most countries discussed in the literature has meant that patients have been doubly exposed to stigma: one relating to the HIV diagnosis and the other relating to the TB diagnosis. Co-infected patients also tend to experience internal and external stigma (Uebel, Nash & Avalos, 2007:S500). With internal stigma, co-infected patients experience feelings of self-hatred, shame and self-blame due to being exposed to judgement by others. External stigma refers to perceptions, feelings or actions towards the co-infected patients from the community members. A one-stop approach to management of HIV and TB is likely to address the problem of stigma, at least in part. The next section explores the economic, social and health service barriers to HIV and TB treatment.

## **2.9 Barriers to HIV and TB treatment**

Chileshe and Bond (2010) carried out a study in Zambia with TB patients of which seven of them were co-infected with HIV. They found that the co-infected patients, in spite of the free provision of both TB treatment and ART, encountered economic, social and health service barriers when accessing treatment, as compared to those solely diagnosed with TB.

### **2.9.1 Economic barriers**

Poor economic circumstances also serve as an access barrier to HIV and TB treatment. This is evidenced by the fact that Chileshe and Bond (2010:53) report that food insecurity worsened in six of the seven households from which the HIV and TB co-infected participants were drawn. In a separate study by Grant and Parpart (2010:511) participants lost their livelihoods, assets and income and sank into debt due to the cost of transport to the health facility and their requirement for a special diet. Furthermore, HIV and TB co-infection prevented participants from contributing to household living, both during their search for a diagnosis and for at least 4 months into treatment. Five of the six households said that illness had disrupted their farming activities and made them less productive, with three recording a drop in the maize they harvested and two households recording no harvest in 2006-2007 (Chileshe & Bond, 2010:53; Grant & Parpart, 2010:511).

### **2.9.2 Social barriers**

In addition to the economic barriers, HIV and TB co-infected patients also encounter social barriers. Of the seven HIV and TB co-infected participants in the study by Chileshe and Bond (2010:53), only one managed to stay married and living in the same household with his/her spouse. The rest experienced translocation and dissolution of their marriages. In addition, some participants were found to be in denial regarding their co-infection diagnosis. Participants experienced various forms of both anticipated and enacted stigma which made it difficult for them to adhere to treatment. Furthermore, Chileshe and Bond (2010:56) note that isolation, gossip and name calling were part and parcel of the participants' daily experiences. As though this was not enough, at household level all the co-infected patients were isolated and were made to eat and sleep separately and at times not being bathed. One patient was quoted as saying:

I feel it is not the right time to tell my relatives about my HIV status. I think that when I do, they will fear and shun me. Already they are not free with the knowledge that I am a TB patient; HIV will only make it worse (Chileshe & Bond, 2010:56).

The above quote summarises the burden of social stigma earlier alluded to, as well as the general unpleasant feelings of seclusion that patients with an HIV and TB co-infection diagnosis often experience.

### **2.9.3 Health facility barriers**

Chileshe and Bond (2010:56) also identified health facility barriers such as congestion, electricity cuts, losing blood samples, faulty equipment and bureaucracy related to administrative procedures. These barriers were specific to ART clinics at that time as there was no integration of HIV and TB services in Zambia during the period when the study was conducted. This meant that these HIV and TB co-infected participants experienced stigma at both the TB and HIV clinics and were exposed to more or less the same health facility barriers as at the ART clinic. An account of one of the participants detailed how he had to be tested again for HIV and ended up giving blood samples three times. The participant narrated how his blood sample was 'lost' on the first visit and 'destroyed' on the second visit due to a power failure. The participant eventually received his results and some aspirins on his fourth visit and was finally given ART on his fifth visit (Chileshe & Bond, 2010:56).

These barriers made it difficult for patients to adhere to treatment even though the treatment was provided free of charge. It is clear from this study therefore that it is wrong to assume that because HIV and TB treatments are offered free of charge, patients will therefore adhere to the treatments. The researcher believes that HIV and TB co-infected patients need to be engaged at all levels and to be consulted regarding how they want to be managed with regard to how they access HIV and TB treatment. The next paragraph switches focus to barriers specific to the Namibian context.

## **2.10 Barriers in Namibia**

In their study of the barriers to accessing ART for HIV positive TB patients in Windhoek, Namibia, Seeling et al. (2014:270) noted the following health system, health care worker and patient/community level barriers:

### **2.10.1 Health system barriers**

Staff shortage in TB and HIV services was perceived to be the most prominent health systems barrier. This was due to the fact that a lot of nurses did not want to work in

TB wards and hence they resigned as a result, causing staff shortages. Moreover, chronic shortage of counselling space was also identified as a major barrier. Consequently, HIV counsellors resorted to using public conference rooms for their counselling sessions, thereby compromising confidentiality (Seeling et al., 2014:271). Limited coordination of TB and HIV services was also noted as a barrier even though participants did not perceive it as such. Furthermore, there were no joint training workshops or supervisory meetings for HIV and TB staff and there was a clear absence of the reconciliation of TB and HIV data (Seeling et al., 2014:271).

### **2.10.2 Health care worker level barriers**

The study by Seeling et al. (2014:271) also identified that inadequate training of healthcare workers constitutes a barrier to adherence to HIV and TB medicines by patients. One key informant in this study was quoted as saying that most nurses who work in the TB clinic were not trained in HIV treatment and management and therefore used common sense to manage the HIV aspects of their patients. The lack of training was also noted to affect the communication skills of nurses thereby compromising the professional relationship between nurses and patients (Seeling et al., 2014:271). This created a situation whereby patients felt scared of nurses and therefore would hide important historical information about their condition.

### **2.10.3 Barriers at the patient/community level**

Fear of stigma and discrimination was also found to constitute a barrier to HIV treatment (Seeling et al., 2014:271). Patients did not want to be seen at the HIV clinic or taking the ARVs. There were also reports of patients defaulting treatment at the behest of their Pentecostal pastors who promised them faith healing (Seeling et al., 2014:272). Other interviewees identified traditions, beliefs and social norms of different ethnic groups as barriers. One ART nurse was quoted as saying, “some races feel like this is not a disease for them; it’s a disease for other people. And even if they are sick, dying sick, they won’t be tested” (Seeling et al., 2014:272).

Seeling et al. (2014:273) recommend the need for a health worker training package in Namibia that includes communication skills, in order to assist health care workers to properly respond to gender-sensitive and culturally adapted needs of patients. In

addition, the need for TB/HIV collaborative activities was noted to be long overdue (Seeling et al., 2014:273). The discussed barriers naturally evoke emotional and psychological reactions in co-infected patients and hence the next section will briefly discuss post-traumatic stress disorder symptoms in these patients.

### 2.11 Post traumatic stress disorder symptoms in HIV and TB co-infected patients

The researcher could only identify one study (Peltzer, Naidoo, Matseke, Louw, Mchunu & Tutshana 2013:391) directly dealing with post -traumatic stress symptoms in HIV and TB co-infected patients. In the mentioned study, 29.6% of participants screened positive for PTSD. Although sample characteristics such as age, marital status, gender, alcohol abuse status and adherence rates of patients may have had an impact on the overall results, what was striking was that most patients reported co-infection as one of the most commonly prevalent traumatic event in their life (Peltzer et al., 2013:391). A summary of the findings of this study is provided in table 2.2 below:

**Table 2.2 Reported worst event by TB patients who screened positive for PTSD symptoms.**

Traumatic event	N= 1891	Percent (%)
Death of family member, partner or friend	632	33,4
Being diagnosed with HIV	257	13,6
Witnessing killing, shooting or assault of family member or other person	184	9,7
Accident, injury, disability	164	8,7
Major family problems, divorce	83	4,4
Family member, partner or friend diagnosed with HIV	81	4,3
Domestic and intimate partner violence	77	4,1
Raped (self or family member such as daughter)	73	3,9
Physical assault	65	3,4
Victim of serious crime, robbery, hijacking, shooting	61	3,2
Miscarriage, suicide of family member, suicide attempt	58	3,1
Being diagnosed with TB (second time/ third time, MDR)	43	2,3
Diagnosed with HIV and TB	37	2,0
Poverty (No shelter, no food, lost job, no job, imprisonment)	34	1,8
Natural disasters (lighting, burnt house, floods)	29	1,5
Diagnosed with other chronic illness (other than HIV; mental illness, cancer, stroke, epilepsy, child paralysed)	13	0,7

Source: Peltzer et al. (2013:393)

In the above table, 257 participants with a TB diagnosis noted that their HIV diagnosis was their worst event. Whereas, thirty seven patients pointed out that knowing the dual diagnosis of HIV and TB was their worst event. It is important to note that participants in this study could have chosen other variables such as witnessing killing, shooting or assault of family member or other person as their worst traumatic events. For the 294 participants shown in table 2.2, an HIV and/or a TB diagnosis was considered more traumatic than witnessing killing, shooting or assault of a family member or other persons for instance. Peltzer et al. (2013:394) pointed out that HIV and TB co-infection was associated with higher rates PTSD symptoms. HIV and TB co-infection also impacts on the daily functioning of patients as will be discussed in the next section.

### **2.11.1 Daily functioning of HIV and TB co-infected patients**

Andersen (2012:206) discusses the dynamics of the health of patients with HIV and TB during the course of disease and sickness. This means that HIV and TB co-infected patients may at times be critically sick and at times may drastically get better due to ARVs and TB medications. Akintola (2006:240) notes that some of the caregiving roles for HIV and TB co-infected patients in a study on HBC in South Africa were taking care of patients' oral hygiene, care of sores and wounds, changing diapers, feeding them, cleaning of vomitus, administering drugs and providing physical therapy. These roles paint a picture of the devastating effects of the synergy of HIV and TB on a patient and the impact on daily functioning. An HIV diagnosis often leads to a number of health and biochemical stressors including fatigue, increased substance use and sleep disturbances (Roger, Mignone & Kirkland, 2013:302). Roger et al. (2013:302) also note that older adults with an HIV diagnosis tend to experience depression. With regards to elderly HIV patients, Andersen (2012:302) highlights the presence of HIV-associated neurocognitive disorder (HAND), which can range from asymptomatic cognitive impairment (ANI) to minor neurocognitive disorder (MND) and HIV associated dementia. Cognitive functioning in many areas can be affected, including speed of information processing, psychomotor functioning, memory, concentration, attention, reasoning, perseveration and initiation (Vance, 2010 cited in Andersen, 2012:302). The effect of these cognitive limitations is to compromise the patient's ability to perform daily tasks and managing complex medication regimens (Mindt, Cherner, Marcotte, Moore, Bentley, Esquivel, Lopez, Grant, Heaton & HNRC Group, 2003:129).

It is clear therefore that HIV and TB co-infection severely affects the daily functioning of patients. It is a condition where patients have to rely on willing caregivers for most of their activities of daily living (ADLs). The stigma (Chileshe & Bond, 2010:56) and the infectiousness of both HIV and TB (Akintola & Hangulu, 2014:383) do not in any way help the plight of HIV and TB co-infected patients. Most patients tend to resort to spirituality as a coping mechanism when confronted with pain and suffering (Kohls et al., 2009:358). The next section explores the role of spirituality in coping with illness.

## **2.12 The role of spirituality in coping with illness**

Studies (Greyson, 2006:393; Kay & Raghavan, 2002:233) show that spirituality is a potential health resource that allows for coping in illness and distress. The concept of spirituality is defined as dealing with "...a life principle that animates and pervades a person's entire being, including the emotional, volitional, and cognitive aspects of life" (Karl, 1998:3). Spirituality can also manifest in the form of practising a specific religion and its underlining sacred rituals and habits (Karl, 1998:3). According to Chao (2002) cited in Feldstein, Grudzen, Johnson and LeBaron (2008:76) the dimension of spirituality is concerned with themes of higher being such as faithfulness, hope and gratitude. Added to this is the theme of self which has to do with self-identity, wholeness and inner peace as well as love and reconciliation. Lastly spirituality is embedded in nature and draws inspiration from the beauty of nature and creativity. Kohls and Walach (2006:126) differentiates between **spiritual experiences** and **exceptional human experiences**. **Exceptional human experiences** is the umbrella term for experiences that touch on areas outside the common sense reality of everyday world. **Spiritual experiences** are a specific sub-category comprised of experiences of a universal or comprehensive reality that need not necessarily be interpreted in a formal or traditional religious framework (Kohls et al., 2009:358). Spiritual practice can be seen as any regular activity like prayer, meditation or forms of contemplation, intended to facilitate spiritual experiences. Whilst spirituality and religion are interrelated, spirituality hinges on experiences whereas religion refers to a complex cultural and social framework that endeavours to explain and facilitate spiritual experiences (Kohls et al., 2009:358).

### **2.12.1 The relationship between spirituality and religion**

Kay and Raghavan (2002:231) state that spirituality is a broader term and is the umbrella concept under which religion is found. Religion is an arm of spirituality which “...often provides patients with specific moral guidance about a variety of medical issues and prescribe rituals that are important to patients” (Singh & Ajinkya, 2012:399). Singh and Ajinkya (2012:400) agree that religion is integral in coping with the stress of illness.

### **2.12.2 Spirituality and coping with illness**

Spirituality is a resource when it comes to coping with life threatening illnesses (Kay & Raghavan, 2002:233). This implies therefore the need to seriously explore issues of spirituality when managing HIV and TB co-infected patients. For instance, spirituality was found to be linked with decreased fear of death, decreased discomfort, decreased loneliness, increased emotional adjustment and positive death perspective (Daaleman & Dobbs, 2010:232). People who are close to death have been reported to have a greater number of spiritual experiences (Greyson, 2006:393).

### **2.12.3 Implications for health care**

Based on the above literature findings, Kay and Raghavan (2002:238) recommend that health care providers should encourage and facilitate spiritual relationships. This can be accomplished by way of encouraging faith community members to phone and visit patients diagnosed with HIV and TB co-infection on a regular basis so as to provide social and spiritual support. In addition, faith community members can assist by preparing and bringing meals to the ill person’s home. Furthermore, eating together with the sick patient and his/her family is another way in which the faith congregation can help decrease loneliness and increase the social support rendered to the patient (Kay & Raghavan, 2002:238). Spiritual faith should therefore be mainstreamed in patient care resulting in more satisfying outcomes (Kay & Raghavan, 2002:238). However, this is only possible in health care systems hinged upon the multi-disciplinary framework (see sub-section 2.13.1.1), where chaplains and the clergy are utilised to help the patient find purpose and meaning, irrespective of their prognosis (Kay & Raghavan, 2002:238).

As religious items and rituals that are symbolic and important to one's individual faith often provide comfort to the patient, religious practices such as reading favourite spiritually related materials should be encouraged. Furthermore, faith symbols important to the patient's faith should be availed to them even in the intensive care unit (ICU) or in ordinary wards (Kay & Raghavan, 2002:238). Evidence (Kay & Raghavan, 2002:239) shows that placing important personal faith items like a cross, a rosary or any other symbolic spiritual item in a semi-conscious terminally ill patient's hand may contribute to a sense of calmness.

Feldstein, Grudzen, Johnson and LeBaron (2008:78) also add an interesting dimension whereby the concept of medical culture versus patient culture and spiritual values are explored. Feldstein et al. (2008:78) note that medical culture can lead to many misunderstandings when pitted against patient culture, because of its predominantly Western roots. This is because the language of medical culture is largely descriptive and factual as opposed to the language of cultural meaning or spirituality and religion which are often metaphorical and poetic (Feldstein et al., 2008:78). Hence the implication of this scenario for health care practice is the need to compromise on medical culture by way of taking off the lenses of a medical perspective and putting on the lenses of patient culture and begin to be willing to listen more to patient perspectives about their medical conditions (Feldstein et al., 2008:78). Being aware of the patient's cultural and spiritual contexts, will help health care workers to respond effectively to barriers in communication with patients (Feldstein et al., 2008:78). The next section examines home based care as a strategy for managing co-infected patients. Under this section, the continuum of care and the multi-disciplinary team concepts are discussed.

### **2.13 Home based care as a strategy for managing co-infected patients**

HBC is defined as "a form of community care whose benefits are to promote the development of domiciliary, day care and respite services to enable people to live in their own homes wherever possible" (Jacques & Stegling, 2004:177). HBC in the era of HIV/AIDS was meant to reduce pressure on hospitals and other health care systems (Makoae & Jubber, 2008:37). Jacques and Stegling (2004:178) acknowledge that in countries like Botswana, HIV and TB exerted immense pressure on the health system and dictated the need to relocate HIV and TB patients back into the community. The

advantage of uniting aspects of care with prevention also made HBC more appealing. Furthermore, including the family members and the community members in general in the management of patients makes it possible to discuss prevention of both HIV and TB within the community (Jacques & Stegling, 2004:178). However, in spite of the noble objectives of HBC, the practice has been riddled with so many shortcomings, especially in the advent of HIV and TB (Makoae & Jubber, 2008:43).

Studies by Thabethe (2011:789); Jacques and Stegling (2004:179) reveal some of these shortcomings. An example is the fact that HBC tends to place a greater burden of care for sick patients on women and the elderly. As such it is very important to consider the socio-economic context, when structuring HBC models. Jacques and Stegling (2004:179) also allude to the negative influences of culture. In their study, women and caregivers were reluctant to wear protective clothing, such as gloves, in the belief that such protective items created a barrier between them and their sick family members. In the process, culture tended to place caregivers, the majority of whom are women, at risk of contracting TB and other infectious illnesses.

### **2.13.1 The continuum of care**

Jacques and Stegling (2004:179) also argue that HBC should be understood as part of the continuum of care for terminally ill patients. Care of HIV and TB co-infected patients starts at the point of diagnosis with either HIV, TB or both and when the diagnosed patient receives counselling, nutritional advice and emotional support, to assist him/her to cope with the illness up until when the patient falls ill. Furthermore, care for the co-infected patient should continue until the patient recovers or dies (Jacques & Stegling, 2004:180). Additionally, uninhibited communication between the various actors involved in the provision of care should be maintained throughout (Makoae & Jubber, 2008:43). This includes involving family members in the diagnosis, prognosis and treatment of patients (Makoae & Jubber, 2008:43).

#### **2.13.1.1 The multi-disciplinary team (MDT)**

Enmeshed in the continuum of care concept is the multi-disciplinary team (MDT). MDT is defined as “a number of individuals from various disciplines who are involved in a project but work independently” (Shofield & Amodeo, 1999:217). Members of these teams should have clearly defined roles and should have appropriate education

(Kemp, Harris & Comino, 2005 in Cioffi, Wilkes, Cummings, Warne & Harrison, 2010:62). This team could include doctors, nurses, pharmacists, patient educators, social workers, occupational therapists and physiotherapists among other professionals (Osborn, 2009:154; Levin & Herbert, 2001:90).

However, in the context of HBC, scholars (Levin & Herbert, 2001:90) note that there is need for a particular educational preparation for certain members of the MDT to equip them to function better in community work. Levin and Herbert (2001) provides some insight into how to improve the curriculum to suit the skills needed by professionals operating as members of the MDT in communities. Among the skills deficits identified for MDT members working in HBC teams were; time management skills, community development skills, and skills related to working with diverse cultural groups (Levin & Herbert, 2001:93). According to Levin and Herbert (2001:94-95) members of the MDT were generally found wanting in the following areas:

- Dealing with difficult clients
- Lack of knowledge of communities
- Inadequate knowledge of community resources
- Inadequate counselling skills
- Lack of advocacy skills
- Lack of group facilitation skills.

The skills deficit highlighted above, clearly point to the need for a paradigm shift in structuring the curriculums of social workers, physiotherapists, occupational therapists, nurses and respiratory therapists as members of the MDT, in order to equip them to function better in communities in the context of HBC. Fifty three out of fifty four nurses interviewed (Levin & Herbert, 2001:95) reported a big difference between institution and community based practice. It was noted that in community based practice, the patient had greater control. The social workers in this study noted that in community based practice, there was a high likelihood for client self-determination. Moreover, social workers appreciated the greater possibility for professionals to apply a person in environment perspective (Levin & Herbert, 2001:95).

### **2.13.1.2 Tension in multi-disciplinary teams (MDTs)**

Causes of tension in MDTs are associated with roles and relationships, interim care, cohesion, referrals and client care issues (Cioffi et al., 2010:67). Where teams tend to emerge haphazardly without proper planning based on the need to react to the needs of chronically ill patients, the question of leadership is ignored (Cioffi et al., 2010:67). However, in efficient MDTs, the question of leadership needs to be adequately addressed if team growth is to be sustained. If there is a clear leader in the team, tension is likely to be greatly reduced. There is also need to rotate leadership positions in MDTs in order to enhance member integration (Cioffi et al., 2010:67).

### **2.13.1.3 Improving multi-disciplinary teams (MDTs)**

Cioffi et al. (2010: 67) recommend the following in order to improve MDTs in the context of HBC:

- Role clarity for team members
- Monitoring of team performance regularly
- Adoption of an accessible, common and centralised patient information system
- Team members need to stay in the same building if possible
- Regular MDT meetings.

A well-functioning MDT, operating in the context of HBC could contribute to positive treatment experiences by co-infected patients.

### **2.13.2 Creating an effective home based care model**

HBC is a very complex concept which has been defined differently by different people to suit their own needs. The quotation below sums this view:

To the politician community care is a useful piece of rhetoric; To the sociologist it is a stick (with which) to beat institutional care...; to the civil servant it is a cheap alternative to institutional care which can be passed to the local authorities for action or inaction; to the visionary it is a dream of a new society in which people really do care; to social service departments, it is a nightmare of heightened public expectations and inadequate resources to meet them (Jones, Brown & Bradshaw, 1978:114).

The above observation, though made way back in 1978, appears to have relevance in HBC as it is practised today. Even though care is multi-faceted in nature, the needs of caregivers have tended to be ignored completely at the expense of the patient's needs (Thabethe, 2011:790). Ignoring these needs has led to shifting the burden of care entirely on communities, with the false assumption that communities can cope. Hence any model of HBC should take note of the needs of the caregivers as well by considering the following elements (Thabethe, 2011:790):

- **Care work as a job:** Voluntary work is not practical under the conditions of poverty and where women and the elderly, who are already vulnerable themselves, usually form the bulk of the caregivers (see also Jacques & Stegling, 2004:179).
- **Integration:** It is important to integrate the social and economic objectives of any HBC programme.
- **Fluidity and streamlining:** HBC duties should be clearly defined as measures to provide temporary relief.
- **Consciousness:** Policy makers and development planners should adopt models that are sensitive to the political, social and economic context. This means using models that uphold the standard of women.
- **Interdependence:** The challenges faced by caregivers in managing HIV patients and the associated opportunistic infections like TB, call for a multi-pronged approach to address broader socio-economic conditions. All stakeholders including government, non-governmental organisations (NGOs), communities and other relevant stakeholders should participate. The tendency to leave NGOs to bear the bulk of the HBC tasks is likely to offer limited solutions.

In addition, the following adherence programmes suggested by Andrews, Sarita Shah, Gandhi, Moll, Friedland and Tugela Ferry Care and Research Collaboration (TF CARES) (2007:487) could also be implemented to strengthen HBC models:

- Treatment literacy training
- Community based therapy
- Use of community health workers or treatment supporters for observing therapy
- Community monitors for illnesses and drug toxicities
- Nutritional support with food parcels and micro-nutrient supplements
- Clinic transportation support or stipends.

An HBC model which takes into consideration the factors above could be effective in meeting the needs of both the patient and the caregiver and in the process, is likely to be owned by the community.

## **2.14 The ecological context of the patient and family from a biopsychosocial perspective**

According to Nash et al. (2005:45) the ecological systems framework is a perspective that can be used by practitioners and clients to analyse and understand the complex network of relationships and systems that influence the client's world. One of its major strengths is that it incorporates an analysis of both formal and informal networks around the client, including relationships with individuals, groups, family, community and the environment as a whole (see theoretical framework in section 2.2). This enables the social worker to gain an appreciation of the multiple factors that contribute to, or inhibit client well-being (Nash et al., 2005:44). This framework therefore affords the health care workers the chance to explore the major sources of patient tension and support. In relation to HIV and TB co-infected patients who were the unit of analysis in this research, the ecological systems theory helps to isolate the ecological levels directly affecting patients, and analyses the dynamics of interaction between the patients and systems at each level. Marshall (2004:165) identifies these systems as the micro-system, the meso-system, the exo-system and the macro-system.

In the same way that the ecological systems theory places child development in an ecological perspective in which an individual's experience is nested within interconnected systems (Bronfenbrenner, 1989 cited in Marshall, 2004:165), patient experiences also take place at various ecological levels. These levels include the family, the health care facility, the community at large, the religious setting as well as the larger political systems in which policies are made.

### **2.14.1 The family**

Marshall (2004:165) reports that in Bronfenbrenner's (1989) model, the family is identified as the micro-system. The family has a large influence when it comes to the management and treatment of HIV and TB co-infected patients. In literature it has been detailed how the family set-up was shaken by the prospect of having a family member afflicted with HIV and TB co-infection. For instance, Chileshe and Bond

(2010:53) in their study of co-infected patients in Zambia found out that marriages had collapsed in all but one of the seven households they targeted. This study identified the family system as the first level at which stigma was experienced by the HIV and TB co-infected patients. Chileshe and Bond (2010:53) note that all the co-infected patients were isolated and were made to eat and sleep separately and at times were not being bathed. Such findings show that in the context of HIV and TB co-infection, the family system, contrary to its traditional function of providing love and care to family members, tend to be found wanting and becomes the first level at which stigma and discrimination is experienced.

#### **2.14.2 The health care facility**

According to Marshall (2004:165) the mesosystem consists of two or more micro-systems and the linkages or processes that combine or connect them. In this case the family and health facility systems' interaction with one another was seen in literature to be integral to the management of HIV and TB co-infected patients. Daftary and Padayatch (2012:1485) also note that health facilities have become symbols of HIV stigma and co-infected patients do not feel comfortable being seen at ART clinics. In the context of HIV and TB co-infection, stigma for the patient constitutes stigma for the family members as well (Chileshe & Bond 2010) and therefore the health facility as a social system has implications for the whole family system and not only the patient whenever it is not functioning as expected.

#### **2.14.3 The community**

The exo-system consists of formalised institutions such as the workplace, one's community and the local government (Marshall, 2004:165). In relation to co-infected patients, literature has shown that community TB/HIV stigma (Chileshe & Bond, 2010:57) made it harder and sometimes impossible to access ART for the co-infected patients. TB and HIV stigma enhanced denial of HIV and fear of HIV testing (Chileshe & Bond, 2010:57). HBC was shown to be a very effective model of managing co-infected patients, especially in the context where community structures are fully operational (Jacques & Stegling, 2004:177). Moreover, for MDTs to work effectively, the need to shift from a medical to a biopsychosocial perspective in the training of MDT members was stressed (Levin & Herbert, 2001:90). Patients who received care

within the community setting tended to have greater control of their treatment process and enjoyed a higher level of client self-determination (Levin & Herbert, 2001:95).

#### **2.14.4 The religious setting**

The need to encourage spiritual relationships and experiences was highlighted in the literature (Kay & Raghavan, 2002:238). It was noted that spiritual faith could be mainstreamed in patient care and support with more satisfying outcomes (Kay & Raghavan, 2002:238). Such findings prove the need for a multi-disciplinary approach to managing HIV and TB co-infected patients (Shofield & Amodeo, 1999:217; Osborn, 2009:154) (MDTs have been discussed in detail earlier in subsection 2.13.1.1). The findings also vindicate the importance of employing a biopsychosocial perspective in modern day health care as opposed to a purely medical perspective (Gehlert & Browne, 2012:20).

#### **2.14.5 The political system**

The macro-system includes a variety of influences such as laws, resources and cultural values as per Bronfenbrenner's (1989) model. Literature has shown that HIV and TB are diseases caused by poverty (Suri, Gan & Carpenter, 2007:509). Koenig (2008:894) concurs that MDR-TB cases tend to be concentrated in regions of inadequate health care services. It can therefore be inferred from literature that analysing the macro system is crucial to addressing the needs of patients with HIV and TB co-infection. Boggio et al. (2008:122) also explored the moral and legal debates behind quarantining HIV and TB co-infected patients and involuntarily diagnosing and treating them under the pretext that it is in public health interests.

Whatever the trajectory that this debate takes, it is important to note that if HIV and TB co-infected patients' rights are to be respected, the legal framework has to be modelled in their best interests. The ecological systems framework therefore enables a holistic assessment of the situation of HIV and TB co-infected patients and in that sense is a fitting and appropriate framework for this research.

### **2.15 Summary**

The chapter explored the ecological systems and the BPS perspectives which are the theoretical frameworks underpinning this study. Thereafter, a review of literature

related to the debate on the involuntary treatment of co-infected patients, as well as the human rights issues attached to that debate was provided. The need to employ a preventative human rights-based approach when it comes to HIV and TB, in order to empower communities to take ownership of their health was recommended. The chapter also discussed stigma as a concept, and how co-infected patients experienced it. Issues of spirituality and religion were then discussed and explored. Spirituality can be seen as a coping resource when it comes to the management of patients with chronic and life threatening conditions. Thereafter, HBC was presented as a strategy to manage co-infected patients. In the context of HBC, the importance of utilising a MDT approach is also discussed. The chapter ends by discussing the ecological context of the patient and family from a biopsychosocial perspective.

The next chapter, (chapter three) presents the research design and methodology in detail as well as the empirical findings.

## **CHAPTER THREE**

### **RESEARCH METHODOLOGY AND EMPIRICAL FINDINGS**

#### **3.1 Introduction**

Much progress has been made in developed nations like the United States of America (USA) in combating mortality rates among HIV and TB co-infected patients (Centre for Disease Control & Prevention, 2010:1512). However, the situation in Africa is different (Koenig, 2008:894). In Namibia, which was the setting for this study, treatment outcomes for HIV positive TB patients were said to be poor (MoHSS, 2012:17). As already mentioned in chapter one, the most productive age group of the Namibian population is affected by HIV and TB co-infection with serious implications for the development of the country (MoHSS, 2012:14). This study sought to understand the experiences of HIV and TB co-infected patients from the perspective of co-infected patients in Rundu, Namibia. It is envisaged that this study will contribute to the body of knowledge on HIV and TB co-infection in Namibia.

In this chapter, an in-depth discussion of the research methodology that was used in this research will be provided. The research approach, research type and the research design used will also be elaborated on in greater detail. The ethical considerations observed by the researcher in conducting the study will also be explored, as well as how the trustworthiness of the research was ensured. Lastly, the empirical findings are then presented.

##### **3.1.1 Goal and objectives**

The following were the goal and objectives of the study:

###### **3.1.1.1 Goal**

The goal of the study was to explore and describe the experiences of patients with HIV and TB co-infection in Rundu, Namibia.

###### **3.1.1.2 Objectives**

The objectives through which this goal was realised were as follows:

- To describe the phenomenon of HIV and TB co-infection.

- To explore the impact of HIV and TB on the daily functioning of persons who are co-infected.
- To determine the biopsychosocial challenges of patients affected by HIV and TB co-infection and treatment.
- To devise strategies for social work intervention with HIV and TB co-infected persons.

### **3.2 Research approach**

This was a qualitative study and no variable was controlled. The study was open-ended and it envisaged to lead the researcher into discovering the life world of HIV and TB co-infected patients from the stand point of their personal experiences (Rubin & Babbie, 2011:437). The researcher managed to explore the personal experiences of being co-infected with HIV and TB through interviewing participants co-infected with HIV and TB. This study took a descriptive and an exploratory thrust because there was a dearth of knowledge in HIV and TB co-infection in Namibia (Seeling et al., 2014:269). As far as the Namibian context was concerned, the study was the first of its kind. The use of exploratory-descriptive research therefore enabled the researcher to gain insight into the phenomenon of HIV and TB co-infection (Blaike, 2000 cited in Fouché and De Vos, 2011:95).

### **3.3 Research type**

This was an applied study as it was practice and policy oriented (Fouché & De Vos, 2011:80). The study sought to provide recommendations in relation to management of patients with HIV and TB co-infection as well as to devise strategies for social work intervention with HIV and TB co-infected patients. For social workers, the ultimate goal of applied studies is to improve human conditions (Babbie, 2007:74). The study was therefore descriptive and exploratory in nature in order to provide social workers with in-depth information on the phenomenon of HIV and TB co-infection and how the affected patients experience it. The researcher adopted the belief that the human conditions of patients with HIV and TB co-infection cannot be adequately addressed without a thorough understanding of their challenges from their own personal experiences.

### **3.4 Research design**

The research utilised a phenomenological research design. Human experiences were examined through the descriptions that were provided by HIV and TB co-infected patients in Rundu, Namibia (Fouché & Schurink, 2011:316; Brink, 2006:113). A phenomenological research design was most appropriate in this research in that it allowed the research participants to explore their own lived experiences in detail. The use of a phenomenological design also accorded research participants the atmosphere to describe the hidden emotions associated with HIV and TB co-infection (Brink, 2006:113). Although the goal of the research was not to heal the patients emotionally, participants expressed gratitude to the researcher for the chance to talk about their problems and challenges openly and with guarantees of confidentiality (see subsection 3.7.2). It could therefore be argued that participating in this research had a therapeutic effect on the participants. Participants who were overwhelmed with emotions during interviews were referred for counselling to the Ministry of Health and Social Services social workers at the Rundu district offices.

The researcher hopes that the rich descriptions of the experiences of participants as detailed in this study, will lead to informed interventions by Namibian policy makers and planners as well as social workers in responding to the needs of HIV and TB co-infected patients.

### **3.5 Research methodology**

This section discusses the study population and sampling techniques that were used in this research. In addition, methods of data collection and analysis will also be explored.

#### **3.5.1 Study population and sampling**

The population for this study consisted of all TB and HIV co-infected patients at the TB Ward in the Rundu Intermediate Referral Hospital. All the hospitals and clinics in the Okavango region refer their TB cases for further treatment and management to the Rundu Intermediate Referral Hospital. The researcher therefore chose this study population because it was composed of patients from all over the region and therefore addresses the question of representativeness. As this was a qualitative phenomenological study, the sample size was ten (10) patients with HIV and TB co-

infection. This sample was identified using the systematic sampling technique, a form of probability sampling. Probability sampling is one in which every member of the population has an equal chance of being selected (Grinnell & Unrau, 2008:143 in Strydom, 2011b:228). Systematic sampling is a kind of probability sampling whereby the first case is selected randomly and the subsequent cases are selected according to a particular interval (Strydom, 2011b:228). This sampling technique was convenient for this study as the researcher had a compiled list of all HIV and TB co-infected patients from the hospital admissions.

Participants selected for the study, had to meet the following sampling criteria:

- Being either a man or woman aged 18 years and above.
- Being a Namibian citizen or having been a legal resident of Namibia for the last 6 months (calculated from the day of the interviews).
- Being HIV and TB co-infected and admitted in the Rundu Intermediate Referral Hospital TB ward or MDR-TB ward.
- Having been diagnosed with HIV and TB con-infection for at least three months and being on treatment for both HIV and TB.
- Being willing to participate in the study.

From the list the researcher selected the first participant randomly. The sampling interval was then calculated by dividing the total population (total number of HIV and TB co-infected patients on the list) by the sample size which in this case was 10 participants (Kumar, 2012:209). Since there were 30 patients on the list, the sampling interval was **30 (number of co-infected patients on the list)/10 (sample size) = 3 (sampling interval)**.

This entailed that from the first randomly selected participant, the researcher then selected every third patient as per the calculated sampling interval until the required number of 10 participants was reached. Data saturation was reached after 10 participants, so selection of additional participants was not possible. The advantage of this sampling method was that every patient on the list had an equal chance of being selected, thereby minimising researcher bias (Rubin & Babbie, 2011:369).

### 3.5.2 Data collection

Unstructured one-on-one interviews were the primary means used to collect data from participants (see appendix 3). The unstructured nature of the interviews was more suitable for this study as the purpose of this research was not to obtain answers to questions, nor to test hypothesis and evaluate, but to understand the experiences of patients co-infected with HIV and TB and the meaning they made of that experience (Greeff, 2011:348). Since the phenomenon of being co-infected with HIV and TB is emotionally and psychologically draining to patients, unstructured interviews enabled patients to describe their most intimate experiences. The advantage of using unstructured interviews is that they are more free-flowing and their structure is limited only by the focus of the research and they are conducted more like a normal conversation, but with a purpose (Brink, 2006:152). The researcher assumed the role of a facilitator, using the technique of probing to focus the interviews (Brink, 2006:152). The researcher made use of a translator who sat in in the interviews to translate where participants did not understand certain English concepts. The translator signed a confidentiality agreement beforehand.

The participants were taken through the informed consent forms individually (see appendix 4), until they understood the provisions of the consent forms. Thereafter, consent forms were signed. Once the participants had signed the consent forms, the interviews commenced. A digital voice recorder was used to record the interviews, with the permission of the participants. Interviews were conducted in a private room at the TB ward of the Rundu Intermediate Referral Hospital. The researcher started the interviews by way of asking the primary research question. This question was asked as follows: Would you like to share with me your experiences since you were diagnosed with HIV and TB? You are free to include experiences in every area of your life be it at home, in your marriage if you are married or your relationship in general, in your family, your community, your health care facility or experiences at any other level in your life which may deem necessary to share with me.

Probe follow ups were used to encourage participants to elaborate, for example, tell me more about, what do you mean by? (Brink, 2006:152). This technique provided the balance necessary for maintaining enough flexibility for participants and at the same

time gathering information with enough consistency to allow for comparison among subjects (Greeff, 2011:349).

As HIV and TB co-infection is cloaked in stigma (SAFAIDS, 2008:3), accordingly, the researcher was careful to establish an atmosphere of trust between himself and the participants by showing a non-judgmental attitude and acceptance of participants as people with inherent worth and dignity. Kumar (2012:160) states that unstructured interviews will enable repeated face-to-face interaction. The researcher therefore utilised this extended face-to-face interaction to elicit trust from participants, which was instrumental in determining the quality of data that was collected.

### **3.5.3 Data analysis**

The researcher used the five steps of data analysis as put forward by Creswell (2009:126-129). However, the five steps only served to provide a theoretical guide to the data analysis process. The reality was that the data analysis process was not necessarily linear since the researcher started with data analysis during the data collection phase where data patterns were noticed, and possible themes were identified (Schurink, Fouché, & De Vos, 2011:405).

- ***Planning***

The researcher prepared for data analysis by putting together the resources that he needed for the process. These included the colouring pens for coding purposes, headphones, the recording device and the computer for storing the data collected.

- ***Managing data***

Data collected was saved on the computer and back-ups were created by saving the data on a hard drive and memory stick. Data saved on the hard drive and the memory stick constituted the back-up data. The researcher went on to listen carefully to the audio recordings whilst they played. Typed transcripts were formulated from the audio recordings before they were saved onto the computer. As with the audio recordings, back-ups were created by saving the typed transcripts on an external hard drive and on a memory stick. Where participants used their Rukwangali vernacular language during the interview, the researcher used the translator to translate those parts in the transcripts.

- ***Reading and writing memos***

The researcher studied the transcripts thoroughly in order to reflect on possible meanings and relationships of the data (Brink, 2006:184). During the reflection process, the researcher drafted some notes on the margins of the transcripts. Comments from field notes were also added.

- ***Describing, drawing patterns, themes and coding***

The researcher identified the main themes reflected in the descriptions of experiences of participants while studying the transcripts and reflecting on meanings and relationships of the data (Kumar, 2012:278). Different colour codes were assigned to different themes. These codes were the basis upon which the researcher determined the frequency of the various themes from participants' descriptions of their experiences.

- ***Visualising, representing and displaying data***

Later in this chapter, the researcher will present the data in a table format as well as by means of graphical representations which depict the generated themes. The themes will be substantiated by verbatim quotations of participants' experiences, thus enabling readers to give their own interpretation of the data and to draw their own conclusions.

### **3.5.4 Trustworthiness of data**

The researcher employed the constructs of **credibility** and **dependability** (Schurink, Fouché & De Vos, 2011:419) in order to ensure the trustworthiness of collected data. "Trustworthiness is established when findings as closely as possible reflect the meanings as described by the participants" (Lincoln & Guba, 1985 in Lietz, Langer & Furman, 2006:443).

#### **3.5.4.1 Credibility**

The aim of credibility is to guarantee accuracy in the manner in which the subject was identified and described (Schurink et al., 2011:419). **Peer debriefing** and **member checking** are the strategies that the researcher used (Lietz et al., 2010:451, 453) to increase the credibility of the research.

#### **3.5.4.1.1 Peer debriefing**

The researcher used the peer debriefing technique by involving a social work colleague in the Ministry of Health and Social Services throughout the study and shared experiences and interpretations with the researcher. Hence this social work colleague served as a bouncing board to ensure credibility. Since this colleague was already in the health field his experience and knowledge also increased the credibility of this research. Lietz et al. (2010:451) note that peer debriefing reflects efforts to increase trustworthiness of the research and reduces bias.

#### **3.5.4.1.2 Member checking**

Participants to the study were given the opportunity to review the findings of the study before the final research report was produced. The researcher checked the contents of the interviews with participants individually when they came to Rundu Intermediate Referral Hospital for medical follow up, after the interviews had been transcribed and themes generated. This was meant to determine whether the interpretations were a reflection of the data as elicited from the participants (Leedy & Ormrod, 2010:101). Given that the participants had the chance to discuss the findings, credibility was enhanced. Member checking therefore was a form of data verification.

#### **3.5.4.2 Dependability**

This refers to whether the research process is logical, well documented and susceptible to audit trailing (Schurink et al., 2011:420). Though there were no significant deviations from the research proposal when the study was conducted, the researcher documented as far as possible all the changes in decisions in accordance with the practical realities of the research setting (Schurink et al., 2011:420). The fact that the study was conducted according to the research proposal makes it susceptible to audit trailing.

#### **3.6 Pilot study**

The researcher conducted a pilot study to examine the suitability of the research design and the general feasibility of the study. The pilot study offered the researcher the opportunity to test the voice recorder as well as to determine the time to be accorded to the interview sessions. The researcher identified two participants for the

pilot study from the same research population (see sub-section 3.5.1). These two participants were not included in the main enquiry (Rubin & Babbie, 2011:219; Strydom, 2011a:237). The main question was asked to the participants of the pilot study (see 3.5.2 above) and the researcher was careful to observe possible emotional discomfort in the manner that the participants narrated their experiences. Based on the pilot study, the researcher was convinced that a social worker had to be on standby to attend to participants who will show unresolved emotions and feelings. In general, the pilot study enabled the researcher to determine the feasibility of the study in terms of testing its practical aspects.

### **3.7 Ethical considerations**

In this study, the researcher paid attention to the need to respect ethical principles relating both to the subjects' protection as well as pertaining to the responsibilities of the researcher (Brink, 2006:31). Approval to conduct the research was obtained from the Research Panel of the Department of Social Work and Criminology and the Research Ethics Committee of the Faculty of Humanities at the University of Pretoria (see appendix 5). Within Namibia, authorisation to conduct the study was granted by MoHSS (see appendix 2). The following ethical considerations informed this research:

#### **3.7.1 Right to protection from discomfort and harm**

Patients co-infected with HIV and TB are generally subjected to stigma (Chileshe & Bond, 2010:56) and therefore it was possible that their participation in the study could expose them to emotional harm (Leedy & Ormrod, 2010:101). Brink (2006:31) points out that qualitative researchers enter the participants' lives and there is a risk of exploring yet unresolved issues, which can upset participants. Therefore, the researcher was particularly alert about participants who showed emotional harm during the interviews. Consequently, all the follow up questions were structured in a manner that was sensitive to potential participants' distress. The researcher also used the debriefing technique whereby participants had the opportunity to ask questions or voice complaints in the middle of the interview sessions. Moreover, a social worker was on standby to intervene with participants exhibiting emotional distress (Poli, Berk & Hungler, 2001 in Brink, 2006:33).

### **3.7.2 Privacy, anonymity and confidentiality**

The researcher was careful to respect the privacy of participants and no information about participants was shared without their consent. Voice recording of interviews was done with the consent of participants. Above all, the research subjects' identities remained a secret throughout the research process as well as in the writing of this report. Furthermore, participants' responses remained anonymous as participants assumed false names that ranged from January to October, during the interviews as a measure to ensure that data was not to be linked back to the participants (Strydom, 2011a:120).

### **3.7.3 Informed consent**

The researcher provided participants with comprehensive and clear information pertaining to their participation in the study (Strydom, 2011a:117). Written consent forms were used and after participants were furnished with information regarding their participation in the study, and its nature and scope, they appended their signatures on the consent forms as a show of informed consent (see appendix 4). It was clearly stated in the informed consent forms that participants were free to opt out of the research at any given time without any negative consequences.

The participants were also made aware of the sensitive nature of the study and the potential to invoke sad memories related to their experiences as HIV and TB co-infected individuals. The researcher, however, spelt out to the participants the perceived benefits of the study and indicated to them that no monetary compensation or incentives would be offered for their participation in the study. This served as a measure to ensure that participants' involvement in the study was absolutely voluntary (see 3.7.4 below).

### **3.7.4 Voluntary participation**

No one was coerced or unduly influenced to participate in this study (Brink, 2006:37). The researcher explained fully the rationale behind the study and its significance in relation to people with HIV and TB co-infection. Participants were also made aware that there was no monetary compensation or incentives for participating. They were also informed that they were free to opt out of the research at any time if they will feel uncomfortable to continue.

### **3.7.5 Deception of participants**

The researcher made sure that participants were well-informed throughout the research process by not misrepresenting facts and not withholding important information from participants (Struwig & Stead, 2001:69 in Strydom, 2011a:118). Debriefing interview sessions were conducted after every interview session to ensure that participants fully understood the research procedures and also the importance of each activity or session in relation to the overall research objectives.

### **3.7.6 Publication of findings**

Kumar (2012:246) states that deliberately attempting to hide what the researcher has found in the study or reporting on the false existence of issues to serve the researcher's interests is unethical and should therefore be avoided. The researcher therefore was careful to present the study findings as accurately as possible and to make sure that the themes drawn from the transcripts reflected the responses as elicited from participants. Furthermore, this study avoided presenting biased findings (Creswell, 2009:67).

### **3.8 Empirical findings**

This section starts by presenting participants' biographical information. Thereafter, the dominant themes and sub-themes that were generated from the data are presented. The researcher will complement the themes with direct quotations from the research participants and substantiate these findings with literature.

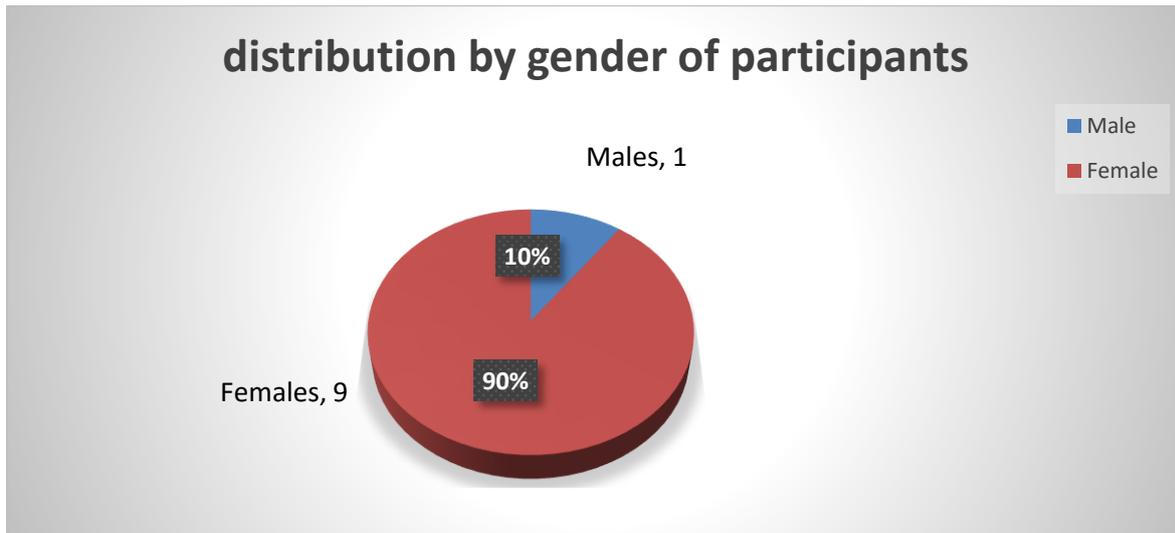
### 3.8.1 Socio-demographic details of participants

**Table 3.1: Socio-demographic details of participants**

Participant (Pseudonym)	Gender	Age	Number Of children	Marital status	Education level	Church	Employment status
January	Male	21	1	Separated	Grade 5	Catholic	Farm worker
February	Female	43	1	Married	Grade 8	Catholic	Unemployed
March	Female	21	0	Single	Grade 0	Catholic	Unemployed
April	Female	60	4	Divorced	Grade 0	Catholic	Unemployed
May	Female	38	2	Married	Grade 1	Lutheran	Farm worker
June	Female	34	6	Married	Grade 12	Catholic	Unemployed
July	Female	32	2	Separated	Grade 0	Catholic	Vendor
August	Female	62	4	Married	Grade 9	New Apostolic	Unemployed
September	Female	24	2	Cohabiting	Grade 9	Catholic	Hair-dresser
October	Female	23	1	Single		Full Gospel	Unemployed

Table 3.1 above shows the socio-demographic details of the participants in this study. The demographic variables depicted in the table are gender, age, number of children, marital status, education level, church and employment status of participants. The majority of participants (nine out of ten) were female. The youngest participant was twenty-one years old (21) and the oldest was sixty (60) years. The participant with the largest number of children had six (6) children whereas the participant with the least number of children had no child at all. Only four out of the ten participants were married. The most educated participant had gone to school as far as grade 12, whilst three of the participants did not even make it to grade one. All participants were Christians and the majority of the participants (six out of ten) were unemployed. Each variable will be discussed in detail in the sub-sections below.

### 3.8.1.1 Distribution of participants by gender

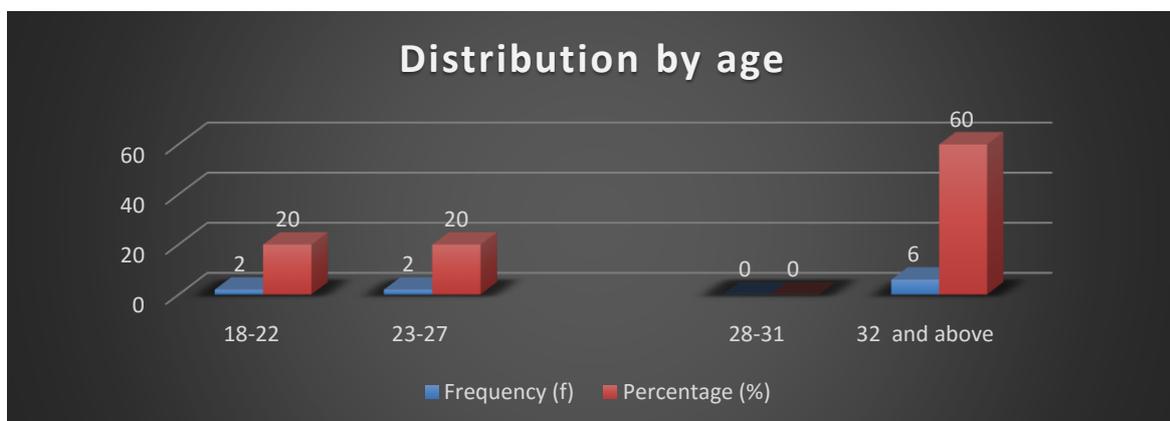


n=10

**Figure 3.1 Distribution by gender of participants**

The pie chart above shows that of the ten (10) participants who took part in the study, only one (1) [10 %] was male, the remaining nine (9) [90%] were female. This small percentage in male representation may be due to the fact that men usually do not want to go for testing and usually prefer to send their wives alone for testing if they are married.

### 3.8.1.2 Distribution by age of participants

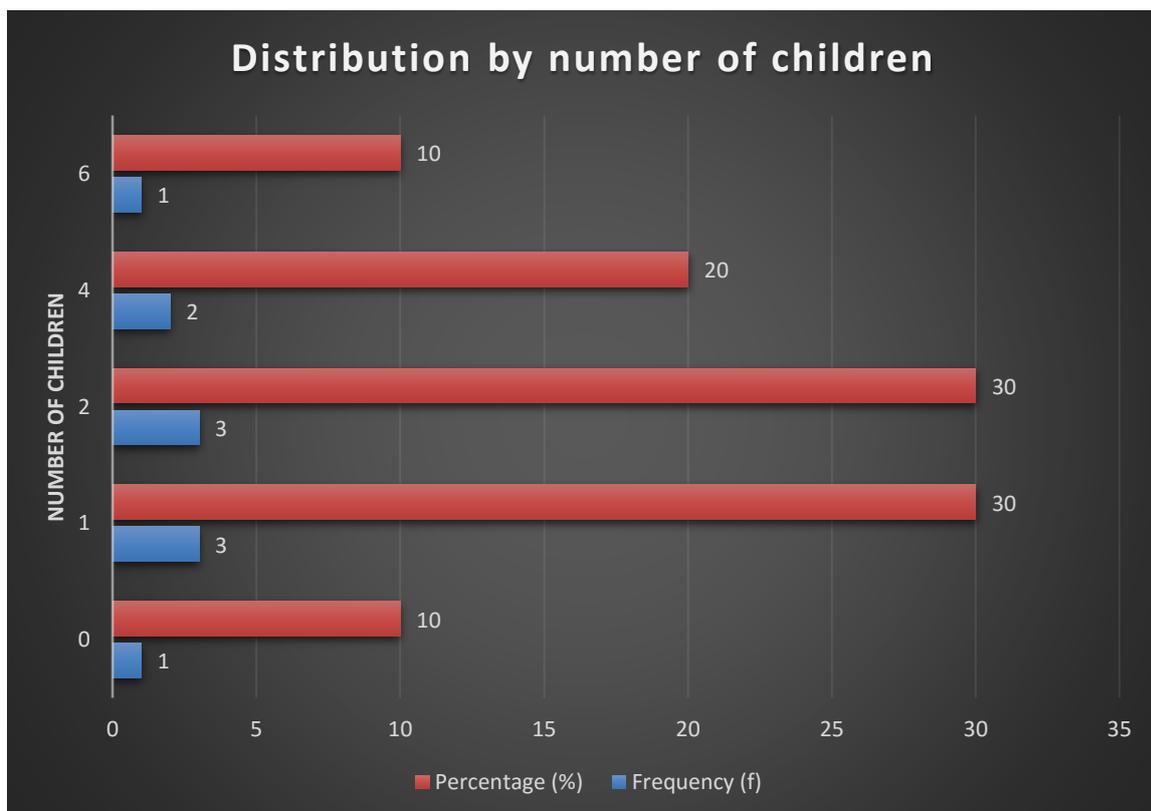


n=10

**Figure 3.2 Distribution of participants by age**

In this study, it was mandatory for participants to be 18 years and above. The bar chart above shows that all the participants were 18 years and above and hence satisfied the age criteria of the study. Two participants were between the ages 18-22 and this constituted 20% of the total participants of the study. A further two participants were aged between the ages of 23-27 years, constituting an additional 20% of the total participants. The majority of the participants six (60%) fell into the 32 and above category. Of the 4 688 patients who were co-infected with HIV and TB in Namibia in 2012, 1 135 were aged between 25 and 44, meaning that the most productive age group is primarily affected by HIV and TB co-infection with significant implications for the development of the country (MoHSS, 2012:14). In this study eight out of the ten participants were forty-four (44) years and below meaning that, to a certain extent, the study vindicates the Ministry of Health and Social Services in Namibia’s findings.

### 3.8.1.3 Distribution of participants by number of children

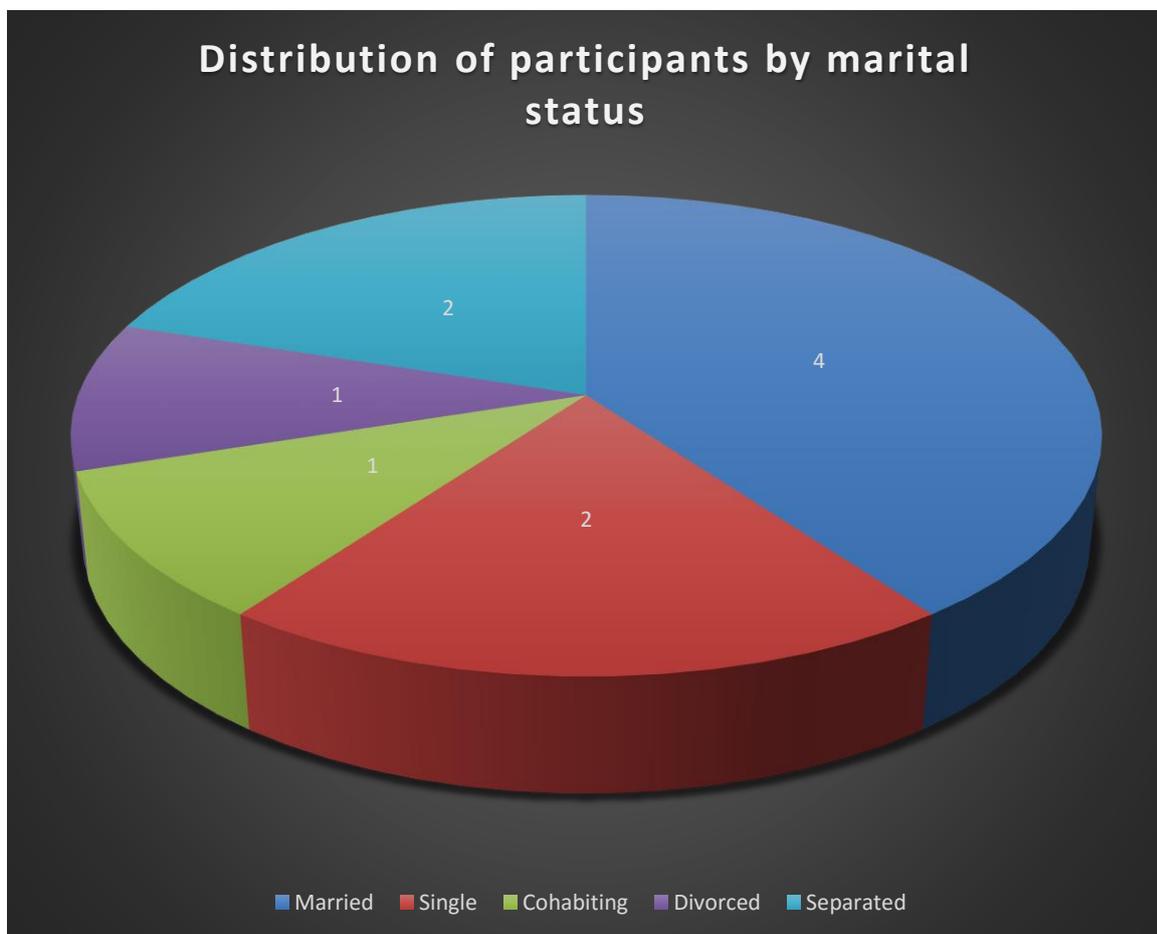


n=10

**Figure 3.3 Distribution of participants by number of children**

Figure 3.3 shows that only one participant [10%] had no child. Three participants [30%] had one child each whereas three [30%] of the participants had two children each. A further two participants [20%] had four children each and the last participant [10%] had six children. Apart from the extra burden of bringing up their children, HIV and TB co-infection therefore places victims in an economically precarious situation due to the added need to meet nutritional demands and other health care costs.

### 3.8.1.4 Distribution of participants by marital status



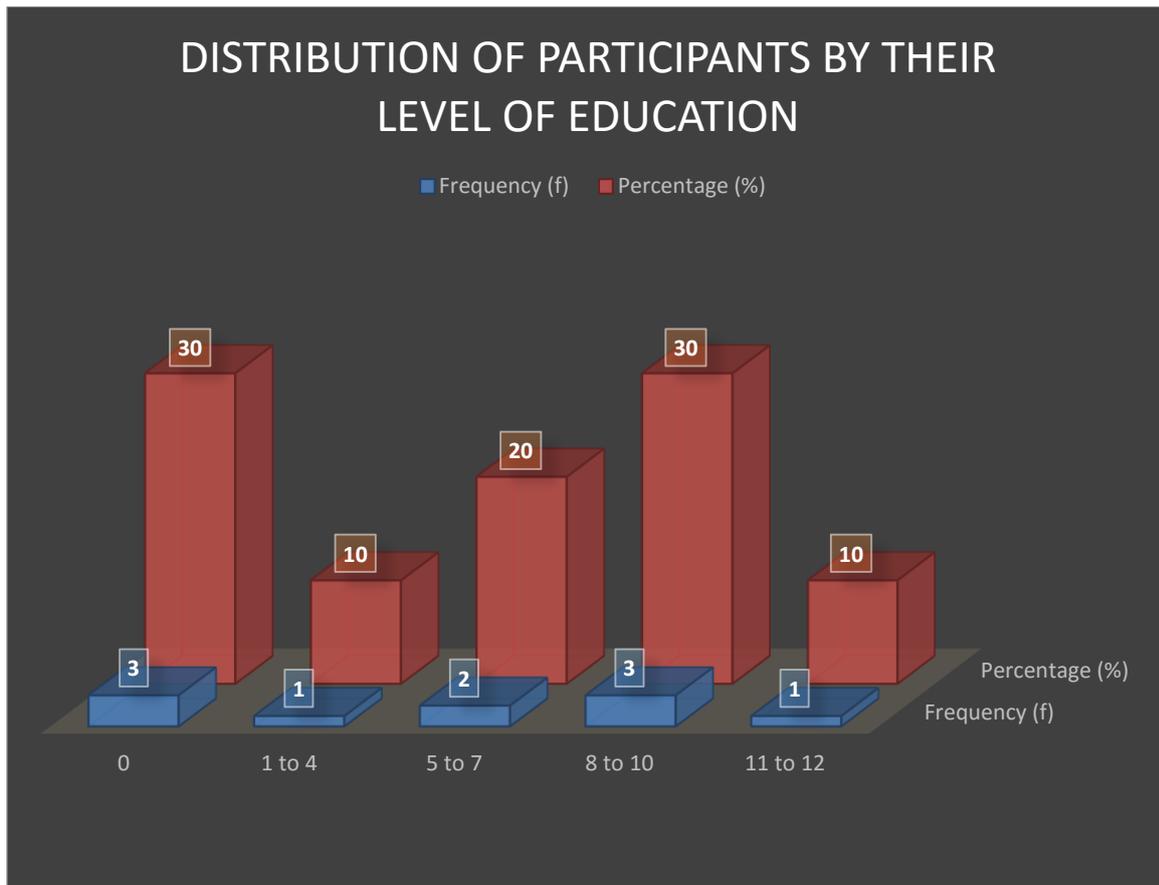
n=10

**Figure: 3.4 Distribution of participants by marital status**

Figure 3.4 above shows that four [40%] of participants were married, two [20%] were single, one participant [10%] was cohabiting, one [10%] was divorced and the remaining two participants [20%] were separated from their spouses. These statistics

are supporting a Zambian study with HIV and TB co-infected patients by Chileshe and Bond (2010:53) whereby only one out of the seven participants in their study remained married after their diagnosis. The rest ended up being divorced as a result of HIV and TB co-infection and the associated stigma.

### 3.8.1.5 Distribution of participants by their level of education



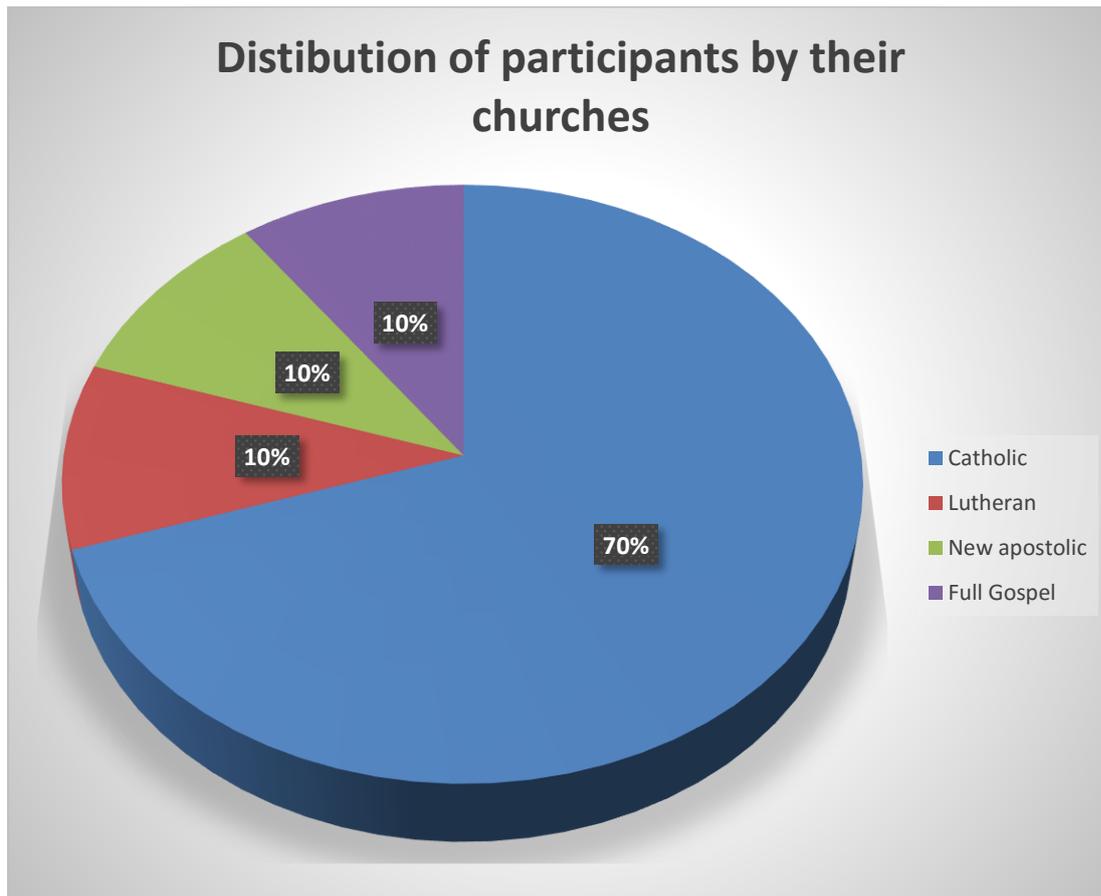
n=10

**Figure 3.5 Distribution by participants' level of education**

Figure 3.5 shows that three participants [30%] went as far as grade 0, while 1 participant [10%] fell in the grade 1 to grade 4 category. Two participants [20%] were in the grade five to grade seven category. In the grade eight to grade 10 category were three participants [30%], while only one participant [10%] fell in the grade 11 to grade 12 category. What can be inferred from the above table is that the average participant in this research was poorly educated and lacked tertiary level qualifications. This

scenario seems to confirm the assertion that HIV and TB are diseases related to poverty and that they are intricately linked to malnutrition and unemployment amongst other things (SAFAIDS, 2008:3). Bartlett (2007:S124) also supports the notion that HIV and TB are normally concentrated in areas of poverty.

### 3.8.1.6 Distribution of participants by the church that they belong to



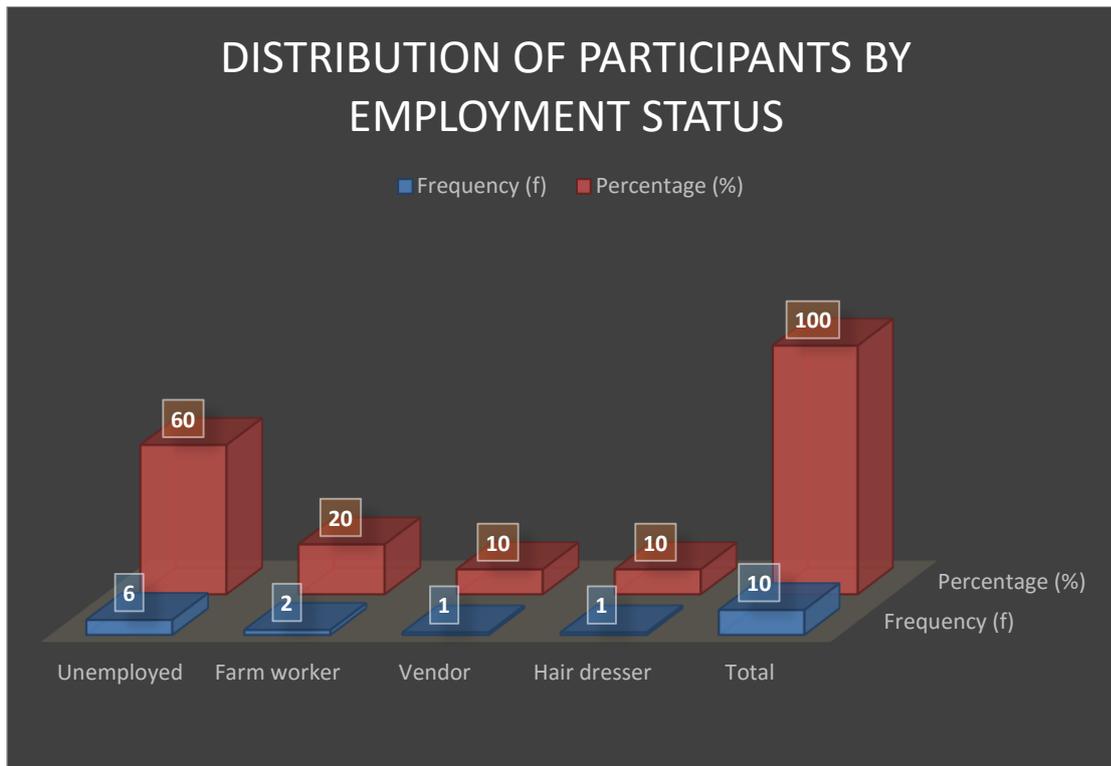
n= 10

**Figure 3.6 Distribution of participants by their churches**

The chart above shows that all participants were Christians. The majority of participants seven [70%] in this study were Catholics. The remaining three [30%] was shared equally amongst new Apostolic, Full Gospel and Lutheran congregants. These findings seem to suggest that perhaps, Catholics do not put bottle necks on their members not to go for medical check-up and for testing. Apart from Lutheran, the new Apostolicism, Full Gospel church believers represented in this study are the so called

born again Christians. These two denominations' belief system is grounded in faith healing. Seeling et al. (2014:272) in their Windhoek study report that some patients defaulted treatment following orders from their pastors who promised them faith healing.

### 3.8.1.7 Distribution of participants by employment status



**n=10**

**Figure 3.7 Distribution of participants by their employment status**

The chart above shows that six out of ten [60%] participants were unemployed. Two of the participants [20%] were farm workers, one [10%] was a vendor and the remaining one participant [10%] was a hairdresser. As farm life is often characterised by over crowdedness and the spread of TB tends to thrive in such conditions.

Having discussed the profile of participants to this study, a thematic analysis of the themes and sub-themes generated from the study will be provided.

### 3.8.2 Themes and sub-themes

This section will present the thematic analysis of the themes and sub-themes that emerged from the interviews. Direct quotations as elicited from the participants will be used to illustrate both the themes and sub-themes. In addition, literature will be used to substantiate what came out from the interviews.

**Table 3.2: Themes and sub-themes**

Theme	Sub-theme
1. Problems of institutionalisation and quarantine	1.1 Loss of freedom 1.2 Alienation from family
2. Psychological and emotional experiences	2.1 Suicidal ideation 2.2 Stress
3. Stigma	3.1 Internal stigma 3.2 External stigma
4. Socio and cultural implications of HIV and TB co-infection	4.1 Breakdown of marriages/relationships 4.2 Misconceptions and myths regarding HIV and TB 4.3 Loss of ability to perform social roles/daily functioning 4.4 Poverty
5. Medical and health care-related problems	5.1 Treatment side effects 5.2 Tablets overload and tablets strength 5.3 Attitude of health professionals 5.4 Non-integration of HIV and TB services
6. Spirituality	6.1 Strengthening of beliefs in God

#### 3.8.2.1 Theme 1: Problems of institutionalisation and quarantining

This theme was expressed by the majority of the participants. Participants noted that being isolated in a TB treatment institution, away from their families and other patients made them feel as though they were in a prison. The following are some of the participants' views:

*“Life in the hospital...it’s not fine...because you look like people in the jail. Me I am not happy with this...because I know I have TB that is spread by other people...I accept it but the condition now...”*

*“Aah, being in the hospital...it’s not good but, at all times, I always remind myself that I have come here to be treated. So I have to accept and stay in the hospital for just staying...it’s not a good place to stay in because we are just in closed doors.”*

Boggio et al. (2008:122) agree that compulsory isolation or detention of HIV and TB co-infected patients is a sensitive issue. This research showed that the majority of participants preferred taking their medication from home as depicted in the following quotations:

*“Me I will [prefer to] go to drink my tablets at Nkarapamwe clinic at home.”*

*“I would rather take my medicine from home as well because it’s better that way as I will take care of other responsibilities at home especially the kids that I have left at home.”*

Jacques and Stegling (2004:178) support the idea that apart from releasing pressure on the health care system, HBC offers family members and community members with the chance to participate in patient care. The participation of families and communities will ultimately empower the communities and such participation and engagement by communities is indispensable if programmes focused on HIV and TB are to succeed (Chopra & Ford, 2005:384).

Institutionalising co-infected patients also tends to take away their freedom, as well as to alienate them from their family members. Loss of freedom and alienation will therefore be discussed as the next sub-themes.

- **Sub-theme 1.1: Loss of freedom**

Most participants noted that being institutionalised took away their freedom, particularly with regard to movement and choice of food. The following quotes reflect this view:

*“The nurses treat us like we are in jail because back then when we came...sometimes we will go outside the TB ward and just stay there for some fresh air. But now they tell us not to go outside...that we have to stay in most of the time. So that makes me feel like I shouldn’t be here...I should go home. Even if we just have to go outside the entrance and seat, they will tell you to come inside but there is nothing to do inside unless you just have to sleep or you just have to be in that thinking mode, depression...yaa.”*

*“When I am at home I will eat this and I will be full. Here you just wait [until] when the food is coming. Maybe the food is coming [but] I am not eating rice, they will [still] bring rice [and] I will just sleep like that [without eating].”*

The above views are in line with the notion that involuntary confinement of patients represents an infringement on an individual’s freedom of movement and could also result in the violation of other civil liberties like privacy and freedom from arbitrary detention (Boggio et al., 2008:123). The Siracusa principles (Boggio et al., 2008:122) give the criteria that should be met for a restriction of human rights to be considered legitimate. One of the criteria statements state the need to explore all the other less restrictive options before settling on institutionalisation. In the context of quarantining HIV and TB co-infected patients, therefore, it means that all other options of managing them should be explored before institutionalising them and risking violating their rights is considered. In essence, institutionalising co-infected patients should be the last option if one has to go by the criteria set up by the Siracusa principles.

- **Sub-theme 1.2: Alienation from family members**

The long-term placement of co-infected patients had the effect of alienating the participants from their family members and beloved ones. The following quotes highlight this assertion:

*“...but if I take my treatment at home, my kids are around...I feel happy because I am seeing them.”*

*“...so that way our family members are now... are not coming often...they are kind of letting us go. They are not even supporting us...they are not bringing food because they are afraid of what the nurses have told them that they are going to get TB if they come more often.”*

*“...I don’t have issues about staying in the hospital. But at times I feel like I am in prison. Sometimes I feel inhuman because I am not around the people that I love the most. I am not seeing my father...I am not seeing the people that I know...so it’s difficult.”*

The family involvement is an important dynamic of this research given that the biopsychosocial perspective is one of the two theoretical frameworks which informed this study. Consequently, the involvement of family members in the treatment and recovery of HIV and TB co-infected patients cannot be overemphasised. It is believed that a strong commitment at micro-level by the family members as treatment supporters and caregivers is paramount to treatment and recovery, as well as the psycho-social well-being of the patient (Dinitto & McNeece, 1997:58). In fact, scholars

(Makoae & Jubber, 2008:43) have stressed the need to involve family members in the diagnosis, prognosis and treatment of patients. Alienating HIV and TB co-infected patients from their family members should therefore be avoided if the findings from both literature and the views of the participants who took part in this research are considered.

### **Key findings of theme 1**

It can therefore be inferred from the above discussions that the majority of participants were against the idea of being managed in an institutional environment, far removed from their social contexts. They preferred being managed at home with the full participation of their family members. This finding is in sync with the ecological systems perspective which holds the view that the patient always has to be an active participant who changes, restructures and finds mutual accommodation with their environment (Nash, Robyn & O'Donogue, 2005:37). The fact that the majority of participants in this study considered themselves as inseparable elements of their families and communities is an illustration of just how much powerful and strong are the forces of the person in environment concept (Levin & Herbert, 2001:95). This is an indication that the macro dimension should always be factored in when managing co-infected patients.

#### **3.8.2.2 Theme 2: Psychological and emotional experiences**

Participants also expressed how they felt both emotionally and psychologically once they learnt that they were co-infected with HIV and TB. It seemed as if the imagined fears of being co-infected with two of the most feared diseases triggered a psycho-emotional reaction in the majority of participants as captured in these quotes:

*"I felt very bad...I accepted that...I must just drink my tablets...And I was getting a lot of people who counselled me...gave me advice [saying] just live...drink your tablets...whatever...whatever."*

*"Ok since I was infected with HIV and TB...aah...when I heard that I was positive I was shivering and thinking a lot of things...thinking aah, maybe I cannot be a human being again..."*

A study carried out by Peltzer et al. (2013:394) supports the fact that HIV and TB co-infected patients tend to experience psychological and emotional trauma related to their diagnosis. About 294 participants in the study of Peltzer et al. (2013:394) considered an HIV and TB diagnosis to be worse and more traumatic than witnessing

killing, shooting or assault of a family member. The other specific associated sub-themes which emerged were that participants professed to have suicidal ideations and stress. These are discussed below.

- **Sub-theme 2.1: Suicidal ideations**

Participants made references to their suicidal thoughts once they became aware of their diagnosis. However, it appeared that participants tended to accept their fate once they realised that there were other patients in the same predicament as them. In general, suicidal thoughts dominated the patients' minds during the first days of receiving their diagnosis. Some of the participants' responses were as follows:

*“At first I felt like committing suicide myself...because I was thinking that maybe I am now not free in the community...but when I came to the follow-up, I found a lot of people in the line. The queue was very long. Now I realised, no, it's not me alone. There are a lot of people [with HIV and TB]. So [I thought] why should I kill myself. I should just be free.*

*“I am not feeling well. I am not feeling well. Even one day...I wanted to commit suicide...Yes, I lose my temper and then that man saw me. I wanted to drink all my tablets for HIV...my ARVs.”*

*“So I will take different things...substances to want to commit suicide but when I would always want to commit suicide, I will still think about my children...like if I commit suicide who am I going to leave these children with.”*

The researcher surprisingly did not come across literature that refers to suicidal ideation in HIV and TB co-infected patients. This is in spite of the fact that, the majority of participants in this study experienced some suicidal thoughts at some point after being diagnosed with HIV and TB.

- **Sub-theme 2.2: Stress**

According to Roger et al. (2013:302), an HIV diagnosis often leads to a number of health and bio-chemical stressors including fatigue, increased substance use and sleep disturbances. Outright depression has been reported in some HIV and TB co-infected patients, particularly elderly patients (Rodger et al., 2013:302). Most of the participants in this study also mentioned that they experienced some stress at some point after their co-infection diagnosis. The following quotes capture this scenario:

*“When I was diagnosed with HIV it's when I had the problem that I was thinking a lot and I was stressed but now since I took the medication for three months and [so on], I have just become free to everyone [who] is coming to me...[I have decided that I] will [be] friendly again.”*

*“...when I take my medicine...It can lead me to be stressed up...”*

*“...so it’s always trouble...stress too much...and if the Lord can just make me well. While I am taking my treatment, [I wish] I can recover [and] go home and drink my treatment [medication].”*

The prevalence of stress in HIV and TB co-infected patients is confirmed by a study by Peltzer et al. (2013:391). In this study, 29.6% of participants screened positive for post-traumatic stress disorder. Co-infected patients identified co-infection as one of the most commonly prevalent traumatic event in their life. The next theme to be discussed is stigma as it affected participants in this study.

### **Key findings of theme 2**

The majority of participants in this study tended to experience psychological maladaptation during the early stages of being diagnosed with HIV and TB. This maladaptation resulted in them having suicidal ideations and, consequently, developing stress. However, participants admitted that they accepted the reality of their diagnosis once they realised that other community members were also in the same predicament. Once they were able to relate to the situations of other community members, participants began to cope better with their diagnosis. This is an illustration of the influence of the person in environment concept of the ecological systems perspective. The interrelatedness of the bio, psycho and social components of the biopsychosocial approach, when trying to cope with the stress through suicidal ideations (psycho), of living with both of these illnesses (bio) which affects their behaviour (social), is also evident (Gehlert & Browne, 2012:20).

### **3.8.2.3 Theme 3: Stigma**

Almost all the participants in this study mentioned stigma and how it affected them in their day to day lives. Stigma is an “attribute that is deeply discrediting” (Goffman, 1963:3) and the perception of the society determines the extent to which it is a stigmatised attribute. Participants were aware of the fact that the society did not have respect for confirmed HIV and TB co-infected patients. This resulted in the patients, in most cases, choosing to hide their health status from their family members and from the society at large. Under the stigma theme, there were basically two sub-themes, namely; internal stigma and external stigma which participants’ narratives tended to point to. These sub-themes will be discussed next.

- **Sub theme 3.1: internal stigma**

Uebel et al. (2007:S500) note that internal stigma is a scenario whereby co-infected patients experience feelings of self-hatred, shame and self-blame due to being exposed to judgement by others. The following participants' quotes illustrate this self-hatred, shame and self-blame by participants:

*"...my sister talked to me [and] I said aah, me I am HIV positive. [She will ask me]...how are you feeling [and I will say], I am not feeling well because I am dead already..."*

*"...I don't want everybody to know that I am HIV [positive]...some people don't keep quiet...they share everything they see."*

*"...I visited one of my cousins but she would tell me not to come into the house...so it made me feel scared to visit people from that time on. So going through that, it made me feel bad I lost control of my life."*

A study by Gebrekristos et al. (2009:3) supports the existence of internal stigma in co-infected patients. In their study, patients would lie to their partners that both the HIV and TB medications they were taking were TB medications only. Moreover, although participants in the study by Gebrekristos et al. (2009:3) understood the importance of disclosing their actual status to their partners, they did not do so due to fear of being rejected. In a separate study by Chileshe and Bond (2010:57) participants experienced perpetual denial of their HIV status and were living in fear and in one particular case, the participant preferred witchcraft and spiritual healing as opposed to mainstream medicine. The stigma experienced by these participants was termed TB/HIV stigma (Chileshe & Bond, 2010:57).

- **Sub-theme 3.2: External stigma**

External stigma refers to perceptions, feelings or actions towards the co-infected patients from community members (Uebel et al., 2007:S500). Participants in this study gave some narratives which attest to this type of stigma. The following are some of the narratives pointing to external stigma:

*"At times when I am in the community, you get into an issue with somebody...when we are arguing...the person will tell me to move from that place because I am HIV positive but most of the times I just let it be..."*

*"Then I was here with my cousin. She said aah, you are sick with TB? Aah, me I cannot eat with someone who is sick [with] TB."*

*"Because like the moment I see that maybe I am thinking too much...then [I will say] let me go to be with my friends...when they saw me [the other HIV and TB co-infected patients], then they run [away from me] again [and] they go outside."*

The three narratives above all point to external stigma as defined by Uebel et al. (2007:S500). However, the last response is interesting because it is stigma directed at a fellow co-infected patient. The paradox of HIV and AIDS co-infected patients stigmatising other co-infected patients is explained by the quote below:

*“... [The reason] why you used to see that these people they are not even closer to you... [it’s] just because your sputum result...it’s not yet clean [it’s still positive]...”*

The above narrative is from a fellow co-infected patient who was explaining why a newly admitted patient would be shunned by other co-infected patients. Therefore, what happens in the ward is that senior patients [in terms of duration of stay in the ward] who would have received a negative TB culture result, would run away from newly admitted patients in order to avoid re-infection. Whatever the reasons behind it, external stigma is documented in literature (Chileshe & Bond, 2010:56), as a negative force which affects the psychological and emotional well-being of patients on the receiving end of the stigma. In the study by Chileshe and Bond (2010:56), co-infected patients were isolated, and were made to eat and sleep separately, and at times not being bathed. This confirms the findings in this study that HIV and TB co-infected patients are victims of external stigma.

### **Key findings of theme 3**

The pertinent issue which stood out under theme three was the existence of stigma directed at the co-infected patients. The majority of participants noted that they were labelled on the basis of their HIV and TB status. In most cases the stigma amounted to discrimination and exclusion from social participation, just because participants had HIV and TB. It appeared that external stigma directed at patients culminated in them losing a sense of their self-worthiness and dignity, a scenario referred to as internal stigma (Uebel et al. (2007:S500). It is therefore evident that the social context within which social relations take place, heavily influences the behavioural trajectory of the people who reside in the particular social environment. Understanding this important aspect may help in understanding the reasons why HIV and TB co-infected patients, for instance, do not adhere to treatment and do not disclose their status. It is therefore important, as revealed in theme three, to look holistically at the patient from a biopsychosocial perspective, in order to manage these patients effectively. It is clear

that the bio, the psycho and the social aspects are interrelated, as emerged in this theme of stigmatisation.

Some studies (Daftary et al. 2014:1107) refer to preferential adherence whereby some participants adhered to HIV treatment at the expense of TB treatment. It appeared that such behaviour was influenced by the perceived relatively greater stigma placed on HIV than TB. It also emerged under theme three of this study that participants were aware of the greater stigma of HIV than TB and in some instances, disclosed the TB diagnosis and kept quiet about their HIV diagnosis.

The next theme focuses on the socio-cultural implications of HIV and TB co-infection.

#### **3.8.2.4 Theme 4: Social and cultural implications of HIV and TB co-infection**

With regards to the social and cultural implications of HIV and TB co-infection, the associated sub-themes that prominently came out from the participants' narratives include: breakdown of marriages/relationships, perpetuation of misconceptions and myths, loss of social roles, as well as inadequate knowledge about HIV and TB.

Most of the participants' detailed how they were affected within the context of the social and cultural realm that they found themselves in. This is because HIV and TB co-infection as a phenomenon was interpreted in the context of the communities within which participants belonged to. The ecological systems perspective, one of the theoretical underpinnings of this study, calls for the need to understand the complex network of relationships and systems that influence the client's world view (Nash et al., 2005:45). This implies for instance that how HIV and TB co-infection was perceived as a phenomenon in the communities to which participants belonged, had a direct impact on the nature and scope of participants' experiences. For instance this quote reflected on the general level of knowledge in a community about HIV and TB co-infection:

*"...It's only a few people that know within the community where I am coming from...a few of them know about HIV and TB."*

The abovementioned sub-themes will be discussed in the next paragraphs.

- **Sub-theme 4.1: Break down of marriages/relationships**

Most of the participants expressed how their relationships or marriages ended as soon as their partners got to know of their co-infection status. The following quotes capture this view:

*“...but when I went home [and] I told my husband...my partner that my result was positive...then the problem was started. He don’t want to share the same bed with me. He don’t want to use the same plate with me [and] me ...I must sleep on the floor...he must sleep on the bed...then he told me that he don’t want to stay with me because he is negative...me I am positive...while me I didn’t see his result up to now...then it caused a problem until we divorced.”*

*“... [In] 2008 is when I was getting HIV. From that day I told him [about my HIV status], we don’t used to talk to each other...just quarrelling [and] talking [bad things to each other]... [in] 2009 then me I go back to my parents.”*

*“From that moment she just only took the kid...she gave it to my mum, then she said that from now...everything is over.”*

A study by Chileshe and Bond (2010:53) confirms the break-down of marriages as a result of HIV and TB co-infection. Of the seven HIV and TB co-infected patients who participated in their study, only one managed to stay married and lived in the same household with the partner (Chileshe & Bond, 2010:53). This trend probably explains why co-infected patients in other studies (Daftary et al., 2012:1485), tended to embark on selective disclosures motivated by the need to access resources earmarked for people living with HIV. In addition, some co-infected patients disclosed TB over HIV because of the perceived relatively greater stigma of HIV (Chileshe & Bond, 2010:53).

- **Sub-theme 4.2: Misconceptions and myths regarding HIV and TB**

The following quotes also show that participants in this study were exposed to myths and misconceptions regarding HIV and TB:

*“...he refused. He said that this is not TB. It’s just something like for our tradition...in our tradition they used to say that... maybe if a woman is on a period then [if] she cook[s] for you food...then you [will] start coughing.”*

*“...and the other went to Angola...Oshikango...whatever business [she was doing] I don’t know. When she came back she says...the family is bewitching her...she said the family is bewitching her and I said...there is no [be]witching story...lets go to the hospital [and get tested]...but now she is fine.”*

*“They just phone but they don’t used to come...because there are some people who spoil them... [saying that] this MDR-TB...they tell the people that once you come here, you will just [get] affect[ed]...you will get the TB disease...if you phone they tell that...now me I am afraid because we hear the story that ...that TB is very strong...even bringing food no-one is bringing...”*

The effect of the myths and misconception as presented in the above quotes is to misinform people into making wrong decisions regarding HIV and TB health seeking behaviours. For example in the first two narratives participants were placed in a position where they delayed to seek medical attention for their MDR-TB due to the myths and misconceptions that they held about TB. In the last narrative, family members were misinformed into refusing to visit their loved ones in the MDR-TB ward with the erroneous belief that once they come to the ward, they will be infected with TB.

Seeling et al. (2014:272) unearthed the existence of misconceptions and myths, especially regarding HIV infection. For example in their study one nurse was quoted saying: "...some races feel like this is not a disease for them; it's a disease for other people. And even if they are sick, dying sick, they won't be tested."

Such a misconception is likely to mislead people into high risk sexual behaviour thereby contributing to either new infections with HIV or to re-infection if they were already infected.

- **Sub-theme 4.3: Loss of capacity to perform social roles/activities of daily living (ADLs)**

The majority of participants also reported an inability to perform their expected social roles in the family. In other words, HIV and TB co-infection placed participants in a position of physiological incapacitation to perform activities of daily living. The following were the participants' own words:

*"I can no longer carry a bucket of water on my head and I cannot be able to carry firewood...like more of them. Every time I feel sick if I do hard work..."*

*"...Yes. I was going to Oshikango...buying clothes and come to sell. And I used to take that liquor...maybe you don't know the liquor...we call it in English...a beer but its traditional...I used to make it and take to Grootfontein to go and sell to the farms...yes, I was doing that...but now I cant."*

*"At times when I want to work...I feel dizzy and that would make me not do anything more because as I try to do a little work...as soon as I stand up I already feel dizzy. So that does not allow me to do a lot of work...so I just sit."*

The confirmation that HIV and TB patients tend to experience incapacitation to perform their routine social roles and functions is provided by the study of Akintola (2006:240). In this study caregivers had to deal with the oral hygiene of co-infected patients and

had to care for their sores and wounds. In other cases some patients had to put on nappies like new-born babies due to diarrhoea associated with HIV and TB co-infection. These roles show that HIV and TB is a lethal combination that incapacitates patients and renders them unable to perform activities of daily living.

HIV and TB co-infection also expose the infected patients to gastrointestinal disturbances and drug-induced hepatotoxicity which renders them to be unable to perform their social roles (Sharma et al., 2005:559).

- **Sub theme 4.4: Poverty**

Poverty featured prominently in quite a significant number of participants' responses. This is not surprising considering the profile of the participants (see socio-demographic details of participants in section 3.8.1 earlier in this chapter). As alluded to in section 3.8.1, all ten participants had no tertiary level qualifications and therefore were not gainfully employed. The fact that participants struggled to make ends meet is shown in the quotes below:

*"...then he said that how...are you going now to stay here in the hospital or how? Then I told him that, no, I cannot afford, unless if they will accept [they] have to take me to Nyangana."*

*"...the only challenges that I have was of poverty...there was not enough food to eat...and I was constantly getting sick from time to time. Otherwise there are no other challenges."*

*"Poverty has made it difficult for me because if I don't get to do agricultural work like ploughing, then I don't get anything to eat. At times we get to get food but not enough to sustain or be there until...or to stay there for a long time..."*

*"I can give an example of myself...I am not living an easy life. I have children who are going to school but they don't have clothes. Their lives are not really up to standard and life has been difficult. So those are the types of basic needs like food and clothes...that they will need to be provided [with]."*

*"...and to the government [side] they must help us because it's difficult for us. [Some of us] we don't have jobs. [We just only sit] waiting to drink our tablets...we don't have food. Some [patients] can even stop [taking medication] because they don't have something to eat...Then it's not good. [patients can die fast] because they don't have power [energy] [if they don't have food to eat while on HIV and TB treatment]."*

These quotes provide a relevant demonstration of the importance of the BPS approach in managing HIV and TB co-infected (Gehlert & Browne, 2012:20). The last narrative for instance hints that if patients don't have food on the table, it may be an exercise in futility to continue prescribing medicine to them (bio), since they will just stop taking it (social). It is in this sense therefore that the social context of the patient being treated

becomes cardinal to the success of treatment. In fact, Gehlert and Browne (2012:21) have noted that a patient who, for instance, does not have health insurance or transport money to visit the health facility and to buy nutritional supplements and special dietary requirements, may fail to adhere to treatment. Considering the above narratives from participants, Gehlert and Browne's above assertion holds weight in light of participants' accounts.

In a study on HIV and TB co-infected patients in Zambia, carried out by Chileshe and Bond (2010:53), food insecurity actually worsened in the households of six of their seven participants. Moreover, participants in another study by Grant and Parpart (2010:511) lost their livelihoods, assets and income and sank into debt due to the cost of transport and requirements for special food. It is clear therefore, in the light of these findings, that HIV and TB are not only diseases affecting poor people (Bartlett, 2007:124), but they also make poor people poorer.

#### **Key findings for theme 4**

Theme four was about the social and cultural implications of an HIV and TB co-infection diagnosis. The majority of participants in this study stressed that they experience breakdown of their marriages and also that they have to endure the confusing realities of myths and misconceptions regarding HIV and TB. Moreover, apart from HIV and TB being diseases of poverty, a key finding in this study was that co-infection tended to perpetuate poverty as well. These implications are all social and, for instance, imply that if marriages break down because of the diagnosis, patients may lose their support systems, particularly if the spouse was a breadwinner. This will also result in the patient sinking into more poverty and may render the patient unable to buy the nutritional supplements demanded for their treatment regimens. These issues emphasise the importance of applying the biopsychosocial approach, with the poverty (social context) influencing how patients experience their co-infection diagnosis (psychological). Giving them medication for example (bio), without giving them food to eat (social) may only result in patients defaulting treatment, as has been found out under theme four (see sub-theme 4.4 above).

### 3.8.2.5 Theme 5: Medical and health care related factors

Participants also cited a range of factors that were related to their medical conditions, as well as to their interaction with the health facility. Chileshe and Bond (2010:56) note that how the health facility is structured and how it renders its services to its clients could either promote adherence to treatment or could constitute a barrier to treatment. The researcher managed to identify a range of sub-themes that were associated with the medical and the health care dimension of patient care. These were; treatment side effects, tablet overload, attitude of health professionals, non-integration of HIV and TB services, as well the physical changes experienced by patients during the course of disease and sickness. These will be discussed one by one in the sub-themes below:

- **Sub-theme 5.1: Treatment side effects**

A significant number of participants bemoaned the wide range of treatment side effects that they experienced while on treatment. These side-effects include; headaches, dizziness, bodily weakness and body aches. The quotes below give a reflection of participants' experiences with side effects:

*"That's about it. It's just the headache and the dizziness...when I am experiencing these things, I feel powerless or I feel like I don't have energy with me in the body."*

*"I used to feel weak, weak [and] weak. When I finish drinking the tablets I will just sleep. When I just wake up to go to the toilet I [would] want to fall down...like someone who is...maybe to want to feel...because of the tablet[s]...I don't know why."*

*"...so when I started my medicine it gave me side-effects...and body ache and they suggested that I should be send to Rundu for further assessment and to get a little education on HIV and AIDS...so when in in the process I even got sicker...so they just said they will refer and transfer me to Rundu."*

According to Sharma et al. (2005:559), skin rash, gastrointestinal disturbances and drug-induced hepatotoxicity were among the most reported side effects in their study. Although the nature of the side effects reported in the study of Sharma et al. (2005:559) differ from those reported in this study, it is clear that a range of side effects are experienced by co-infected patients taking treatment. In a study by Munroe et al. (2007:1236), treatment adverse events are mentioned as a reason for non-adherence to treatment by co-infected patients. In some studies (Isaakidis et al., 2013:5), patients described the side effects of taking HIV and TB treatment as being worse than the diseases themselves. It is therefore imperative for the multi-disciplinary team to

increasingly track and manage drug side effects when managing HIV and TB co-infected patients.

Participants only cited doctors, nurses and social workers as the professionals who came to review them. Although the Rundu Intermediate Referral Hospital employs diverse medical professionals such as physiotherapists, occupational therapists and audiologists, participants made no mention of being attended to by these multi-disciplinary team members. This means that, for instance HIV and TB co-infected patients who developed hearing problems were detected rather belatedly, due to the absence of routine monitoring for treatment side effects. One of the participants had this to say when asked whether other professionals were coming to review them:

*“...maybe they come to check for those that don't hear but as for me, they don't [come to assess me]...I cannot pronounce the names [of professionals]...[but I only know those that]...come to give us support on how to be as a person [ meaning social workers]...support on how to drink our medicine...”*

The above quotation shows that patients did not get the opportunity to be reviewed by all members of the multi-disciplinary team at the hospital where the study was conducted. This shows that more could be done to improve surveillance of treatment side effects by team members in co-infected.

- **Sub theme 5.2: Tablets overload and strength.**

The quantity of tablets as well as their strength was also cited by most participants as a concern. The following are participants' own words:

*“The medicine that we take...it's too strong. So if you don't have enough food or you haven't eaten enough food it will make you [to] feel] nausea [and] sometimes you will vomit everything that you had or sometimes if you drink medicine you will also vomit it out at the end of the day...”*

*“...but the medicine is too much...like they are too many. Twenty-one or twenty-seven is too many for one person to take...”*

*“...the only problem is that the medication we are taking is very ...very strong. So I cannot take it if I am not eating...if I don't have food at home...so sometimes I don't even think of taking it because it will just affect me that much...”*

*“I am taking twenty-one tablets...the tablets are a lot...because sometimes I feel nausea...I feel sick...but all that I know is they go hand-in hand with my sickness...”*

Tablet overload has been reported to be the cause of preferential adherence in other studies (Daftary et al., 2014:1107). In the mentioned study, participants expressed

preference for HIV medicines over TB medicines because of greater pill tolerability and lower pill burden. One participant in the study said the following:

*“If I can dodge, I can dodge TB. I can take for HIV; even if I can take them my whole life I don’t have a problem. But for TB, no, I can dodge them if I can be given a chance...there are many injections, lots of tablets, they are bitter, they are sour. It’s all mixed here; it’s something you don’t know. But HIV, you just get three, maybe once daily.”*

It is evident therefore that the number of tablets is quite a huge concern for HIV and TB co-infected patients. This also reflects the high possibility of not adhering, specifically with the TB medicine’s high pill overload.

- **Sub-theme 5.3: Attitude of health professionals**

Research has shown that nurses and health professionals prefer not to work in TB wards because of fear of contracting the disease (Seeling et al., 2014:271). This unwillingness to work in these high risk areas, probably explains the negative attitude of some health professionals as captured in the narratives below:

*“...they don’t care if you have to fall...or if you woke up with less energy...or you are feeling nausea...they wouldn’t care. They just seat on their desk there...unlike other nurses...unlike other nurses that are in other wards where they take care...good care of their patients if they know that ...that patient is really sick...then they will do something...or they will do things for their patient...but here it’s different.”*

*“[The nurses will say]...me I am tired...just seating and waiting [for our attention]...we are also human beings...we must eat and...who told you to get HIV.”*

*“At times the only challenge that I go through is that of transport that I have to travel from village to town and when I reach town sometimes the doctors are not [yet] there and I have to wait for long hours and then I will leave town late.”*

Chileshe and Bond (2010:56) noted in their study that co-infected patients tended to be frustrated by the bureaucratic procedures that the health professionals adhered to. It is probable that what participants in this study interpreted as a negative attitude by health professionals could in actual fact have been the professional health care workers’ routine ways of doing things.

- **Sub theme 5.4: Non- integration of HIV and TB services.**

Hausner et al. (2007:149) described an interesting model of integration of HIV and TB services in Uzbekistan, Tajikistan and Kyrgystan (see chapter 2: Section 2.6.1). In that model all ART patients were managed in TB hospitals for in patients, in ambulatory TB facilities during the continuation phase of TB treatment and this was done

depending on what was convenient for the patient. ART professionals were housed in the same building as patients. In short, this model was designed to provide the best possible experience for HIV and TB co-infected patients in terms of accessing health care. Although the MoHSS (2006:94) advocates for the implementation of an integrated model for managing HIV and TB patients, this study's findings show that in reality HIV and TB in co-infected patients in Rundu, Namibia, are managed separately. The following narratives testify to the non-integrated nature of HIV and TB services in Namibia:

*"During our follow-ups, its nurses that go there [to the ART clinic] and bring our medicine this side."*

*"...and when it comes to HIV, the nurses take our [health] passports to the Centre for Disease Control [also ART clinic] to collect our medicine...So that's how it usually is."*

*"...they will not monitor you to drink it [HIV tablets]. They will just bring it and then it's your own responsibility to make sure that you drink it or not...unless if you really sick that you are energy-free, then they will try to monitor that you have to drink them."*

*"...now they will go and bring my tablets. They call me and check my weight...everything. Even if those people [at ART clinic] go and tell them that they must take my blood, they will take [my blood from] me."*

Heunis et al. (2012:344) note that "independent and disconnected TB and HIV services" do not take into account the best interests of the co-infected patient. WHO (2013:68) also recommends the implementation of TB/HIV collaborative activities. Collaboration of HIV and TB services should ultimately see co-infected patients receiving treatment and care under one roof (SAFAIDS, 2008:3). In spite of resource constraints therefore, Namibia has to push towards full collaboration of HIV and TB services if HIV and TB co-infected patients are to fully benefit.

### **Key findings for theme 5**

This theme clearly showed the medical and health-related effects of side effects on co-infected patients. This was evidenced by the fact that the majority of participants in this study, alluded to the wide-range of side effects that they had to endure whilst on treatment. Some patients were also concerned about the negative attitude they received from health professionals, particularly the nurses whom they allege to be half-heartedly taking care of them. It was also clear that patients' interests were not best served in this situation where they had to access HIV and TB services separately. The

biopsychosocial approach emerges clearly with regard to this theme, namely, the side effects of the medication on the patients and the pill burden, the physical (bio), the attitude of health professionals towards patients and non-integration of services affecting them psychologically (psycho), and the attitude of the health professionals towards them affecting their relationship (social).

### 3.8.2.6 Theme 6: Spirituality

Spirituality has been shown in literature as a coping mechanism for patients, especially those afflicted by chronic and life threatening illnesses (Greyson, 2006:393). Participants in this particular study also made suggestions to the effect that they rely on God for strength and power in the face of HIV and TB co-infection. Participants' own words with regards to issues of spirituality are presented under sub-theme 6.1, namely; strengthening of beliefs in God.

- **Sub-theme 6.1: Strengthening of beliefs in God**

Participants noted that they increasingly relied on God to see them return to normal functioning. It is important to note that participants' beliefs in God did not promote non-adherence to treatment as was found in the study by Seeling et al. (2014:272), whereby patients defaulted treatment following the instruction from their Pentecostal pastors, who promised them spiritual healing. The following are the participants' own words:

*“On the side of TB, it's all just the same. So I accept[ed] all of them...that it has come to me and I only put my trust in God who has allowed this to come to me.”*

*“Just through my Christian experience, I have just allowed God to do his will. If this sickness is going to kill me and the Lord is fine with it, it will just go like that. If this sickness is in me but I will remain alive and it's God's will, then it's fine.”*

*“My belief in God helps me to be strong...that I should pray for mercy and strength and forgiveness from my God and it keeps me going that every time I will always have to pray to him for my problems or anything concerning my life.”*

*“My benefit from the church [is that they used to] give me power [and] strength.”*

*“Yes...even though I get stress or whatever, but when I reach the church, I just forget everything. I just...used to be fine.”*

Another participant even believed that it was God's will that she was co-infected by HIV and TB. These were her own words:

*“The only thing that I can say is that it’s the will of God that things are happening the way they are happening...and that I have the disease...there is nothing that I can do about it...it’s just the will of God that I am having a disease.”*

It is evident from participants’ narratives that spirituality enabled them to cope better with their sicknesses. In the context of the multi-disciplinary team (Levin & Herbert, 2001:94-95), faith community members for patients should therefore be allowed to phone and visit them on a regular basis to provide social and spiritual support (Kay & Raghavan, 2002:238). Moreover, Kay and Raghavan (2002:238) note that spiritual faith should be mainstreamed in patient care in order for satisfying outcomes to be realised. Knowledge of the patient’s cultural and spiritual contexts will help health professionals to respond effectively to barriers in communication with patients (Feldstein et al., 2008:78).

### **Key findings for theme 6**

The theme of spirituality was referred to by almost all the participants, as all ten participants were Christians. Participants were in agreement that their Christian beliefs were paramount in how they coped with their diagnosis. However, the advantages that spirituality provides were not fully harnessed by the health system due to the absence of a defined multi-disciplinary team framework in the management of patients. Patients did not even know some of the professionals that attended to them during their stay in the ward due to the sporadic nature of the interventions by the multi-disciplinary team members. It is therefore imperative that such structural issues be addressed as a matter of urgency to allow these fundamental moral dimensions to be incorporated in the management of HIV and TB co-infected patients. Literature supports this view by pointing out that faith symbols important to the person’s faith should be availed to patients even if it is in the ICU or in ordinary wards (Kay & Raghavan, 2002:238). Placing important personal faith items like a cross, a rosary or any other symbolic spiritual item in a semi-conscious terminally ill patient’s hand may contribute to a sense of calmness (Kay & Raghavan, 2002:239). The ecological system perspective is illustrated here, emphasising how important it is to take all the ecological systems into consideration, including the spiritual and religious aspects of a patient’s life.

### **3.9 Summary**

This chapter started by giving an overview of the research methodology that was utilised in the study. Ethical principles governing the research were then discussed. A discussion of the empirical findings then ensued, with a presentation of the biographical information of participants preceding the presentation of the themes and sub-themes generated from the participants' interview quotes about their experiences. Evidence from literature was used to support participants' personal accounts. Key findings were then discussed for each theme.

The next chapter (chapter four) presents the study's key findings as well as conclusions and recommendations.

## **CHAPTER FOUR**

### **KEY FINDINGS, CONCLUSIONS AND RECOMMENDATIONS**

#### **4.1 Introduction**

In this chapter, a summary of the extent to which the goal and the objectives of the study were met is discussed. The focus of this chapter is on providing the key findings, drawing conclusions and making recommendations based on the findings.

#### **4.2 Summary**

The goal and objectives of the study were, to a large extent, realised as will be revealed in the next sub-sections.

##### **4.2.1 Goal and objectives**

The goal and objectives of this study were as follows:

###### **4.2.1.1 Goal**

The goal of the study was to explore and describe the experiences of patients with HIV and TB co-infection in Rundu, Namibia.

###### **4.2.1.2 Objectives**

The objectives through which this goal was realised were as follows:

- To describe the phenomenon of HIV and TB co-infection.
- To explore the impact of HIV and TB on the daily functioning of persons who are co-infected.
- To determine the biopsychosocial challenges of patients affected by HIV and TB co-infection and treatment.
- To devise strategies for social work intervention with HIV and TB co-infected persons.

These objectives are discussed one-by-one in the consecutive paragraphs in relation to how they were met.

###### **Objective 1**

- To describe the phenomenon of HIV and TB co-infection.

This objective was realised right from chapter one (sub-section 1.1) whereby the researcher pointed out that HIV and TB co-infection refers to a scenario where a patient is simultaneously infected with HIV and TB. To buttress this definition, chapter 2 (sub-section 2.3.3) discusses HIV and TB common characteristics, including the fact that each disease accelerates the other and that they are both concentrated in areas of poverty where there are minimal resources for diagnosing, treatment and infection control (Bartlett, 2007:S124). The phenomenon of HIV and TB co-infection is further explored in chapter two where the daily functioning of co-infected patients is described. It is noted that co-infected patients have a tendency of being critically sick at some point until both HIV and TB treatment are initiated (Andersen, 2012:206). An HIV diagnosis for instance is reported to lead to a number of health and biochemical stressors which include, but are not limited to fatigue and sleep disturbances (Roger et al., 2013:302). The manner in which co-infection compromises the daily functioning of patients, with their roles being taken over by the caregivers is well-documented (Akintola, 2006:240) (see chapter 2, sub-section 2.11).

## **Objective 2**

- To explore the impact of HIV and TB on the daily functioning of persons who are co-infected.

The daily functioning of HIV and TB co-infected patients is discussed in chapter two (sub-section 2.11). The devastating effect of the synergy of HIV and TB on the patients is revealed in this section, as well as the impact on their daily functioning. Co-infected patients tend to develop sores and wounds and at times will experience diarrhoea as well as become weak (Akintola, 2006:240). All these problems make patients weak and therefore render them unable to perform activities of daily living. Impairment of cognitive functioning was also reported in some patients (Vance, 2010 cited in Andersen, 2012:302). In chapter three (sub-theme 4.3) participants described the various activities that they can no longer perform as a result of co-infection.

In chapter 3 (sub-theme 5.1) participants also bemoaned the wide range of treatment side effects that they endured whilst on treatment. These side effects also point to impairment of capacity to perform activities of daily living. Moreover, co-infection was noted to be exposing patients to gastrointestinal disturbances and drug-induced

hepatotoxicity which also rendered them unable to perform their social roles (Sharma, et al., 2005:559).

In the same chapter (sub-theme 2.1 and sub-theme 2.2), participants revealed that they had experienced suicidal thoughts as well as stress due to their co-infection diagnosis. These findings corroborate with earlier findings by Peltzer et al. (2013:394) that co-infected patients experience psychological and emotional trauma related to their diagnosis. These experiences tended to impair patients' capacity to perform activities of daily living.

In chapter three (sub-theme 3.2), participants gave some narratives relating to their experiences of external stigma from community members. For instance, one participant noted that she was once told to move away from where she was seated just because she had HIV and TB. Another participant noted that she was told by her cousin to eat alone because of her co-infection diagnosis. These findings are in line with the findings of Chileshe and Bond (2010:56) in which co-infected patients had their own separate eating and sleeping arrangements due to their co-infection diagnosis. External stigma tended to push co-infected patients to the periphery in as far as participation in family and community programmes was concerned and in that sense, affected their daily functioning. Uebel (2007:S500) noted that external stigma could lead to the development of feelings of self-hatred, shame and self-blame in the targeted individuals. These negative feelings are referred to as internal stigma (Uebel, 2007:S500). In chapter three (sub-theme 3.1) participants described how they lost confidence in themselves due to their diagnosis, as well as the external stigma directed at them by family and community members. This had a direct impact on how these individuals carried out activities of daily living.

### **Objective 3**

- To determine the bio-psychosocial challenges of patients affected by HIV and TB co-infection and treatment.

In chapter two sub-sections 2.10.1, 2.10.2 and 2.10.3 the researcher discussed the various barriers that co-infected patients face during the course of treatment. These include health system barriers whereby patients grappled with staff-shortages related problems whenever they visited health facilities. It was also reported that nurses

working with TB patients, lacked training in HIV aspects and this had a negative bearing on their communication skills with co-infected patients. Hence, the professional relationship between these nurses and patients was ultimately compromised (Seeling et al., 2014:271). Fear of stigma and discrimination was also noted amongst the challenges experienced by patients (Seeling et al., 2014:271). In chapter 3, sub-themes 1.1: loss of freedom, 1.2: alienation from family members, 4.1: break down of marriages/relationships, 4.2: misconceptions and myths regarding HIV and TB, 4.3: loss of capacity to perform social roles/activities of daily living, 4.4: poverty, 5.1: treatment side effects, 5.2: tablet overload and strength, 5.3: attitude of health professionals and 5.4: non-integration of HIV and TB services, cover the biopsychosocial challenges related to HIV and TB co-infection from the perspective of the participants in this study. As suggested by the sub-themes listed above, loss of freedom, alienation from family members, breakdown of marriages and relationships, misconceptions and myths regarding HIV and TB, loss of capacity to perform social roles/activities of daily living, poverty, treatment side effects, tablet overload and strength, attitude of health professionals as well as the non-integration of HIV and TB services, are some of the challenges experienced by the participants.

#### **Objective 4**

- To devise strategies for social work intervention with HIV and TB co-infected persons.

This objective was realised in chapter two and three as well as in the recommendations section of this chapter. In chapter two, sub-section 2.12 discussed the role of spirituality in the management of HIV and TB co-infected patients. Scholars agree that spirituality is a potential health resource that allows for coping in illness and distress (Greyson, 2006:393; Kay & Raghavan, 2002:233). Spirituality was found to be linked with decreased discomfort, decreased loneliness, increased emotional adjustment and positive death perspective (Daaleman & Dobbs, 2010:232). Based on these findings, health care providers were encouraged to facilitate these spiritual relationships (Kay & Raghavan, 2002:238). It was noted that faith community members could be encouraged to phone and visit co-infected patients on a regular basis to the advantage of the patients. Kay and Raghavan (2002:238) recommended mainstreaming of spiritual faith in patient care so as to achieve satisfying outcomes.

In chapter three (theme 6- spirituality and sub-theme 6.1- strengthening of beliefs in God), participants made suggestions to the effect that they relied on God for strength and power in the face of HIV and TB co-infection.

Home-based care is also discussed in chapter two (sub-section 2.13) as a strategy for managing co-infected patients. It is noted that HBC enables family and community members to participate in patient care (Jacques & Stegling, 2004:178). In chapter three (sub-theme 1.2- alienation from family members), participants describe how institutional care alienates them from their family members and are clear about their preference to be managed in their home environments.

In sub-section 4.4, the researcher recommends the strengthening of HBC as a strategy for managing co-infected patients. The researcher also recommends that the Ministry of Health and Social Services in Namibia allows patients to practice their belief systems and associated rituals even in hospital wards.

### **4.3 Key findings, conclusions and recommendations**

The study's key findings, conclusions and recommendations regarding the appropriateness and value of the research methodology, the literature review, as well as the empirical study are presented in the next sub-headings.

#### **4.3.1 Key findings and conclusions regarding the appropriateness of the research methodology**

This research was a qualitative, phenomenological study. The open-endedness of the unstructured interview utilised in this study, enabled participants to describe their experiences in detail. A key finding in this regard was that the participants were able to dictate the direction of the interviews and to explore their experiences openly. It can be concluded, based on the experience from this study that qualitative studies allow researchers to gain insight into a phenomenon by allowing the participants to freely explore their experiences (Blaike, 2000 cited in Fouché & De Vos, 2011:95).

The phenomenological design was appropriate as it enabled an examination of the lived experiences of HIV and TB co-infected patients through their own descriptions (Fouché and Schurink, 2011:316). The key finding in this regard was that the phenomenological design enabled participants to explore their experiences regarding

HIV and TB co-infection freely, with guarantees of confidentiality from the researcher. It can be concluded that a phenomenological design is efficient in studies dealing with sensitive issues such as HIV and TB.

The population for this study consisted of all TB and HIV co-infected patients admitted at the TB ward in the Rundu Intermediate Referral Hospital, in Rundu, Namibia. The ten participants who participated in this study were identified using the systematic sampling technique, a form of probability sampling. However, even though a probability sampling technique was meant to guard against researcher bias in the selection of subjects (Strydom, 2011:228), nine out of ten participants selected ended up being females. A key finding in this domain was that in sensitive phenomenological studies, it should not be taken for granted that a probability sampling technique will produce the desired outcome in terms of the representativeness of the sample. It can be concluded that the systematic sampling technique utilised in this research produced a gender biased sample as nine out of ten participants turned out to be female. It is probable that the use of another sampling technique, such as non-probability purposive sampling, could have evaded this weakness. It is recommended that the more sensitive a study topic is, the more the sampling technique should be carefully thought out. It is likely that in this study the population was biased in favour of females, because males usually do not freely go for HIV or TB testing as much as women do. Hence the list that was used to do the sampling was already dominated by women leading to a sample dominated by females.

#### **4.3.2 Key findings and conclusions regarding literature review**

The key literature review findings did not differ much from the actual study findings. For instance, literature showed that co-infected patients experience stigma related to their diagnosis (Chileshe & Bond, 2010:57). The same study also showed that marriages are affected by HIV and TB co-infection to the extent that partners tend to divorce (Chileshe & Bond, 2010:53). Other key literature review findings include the presence of post-traumatic stress symptoms in co-infected patients (Peltzer et al., 2013:391), the impairment of co-infected patients' capacity to perform activities of daily living (Akintola, 2006:240), as well as the importance of spirituality as a coping mechanism for co-infected patients (Kay & Raghavan, 2002:233).

Literature also showed that the biopsychosocial approach enables the problems of patients to be addressed holistically. This is because the approach enables the expansion of focus to social networks and cultural contexts of patients. For instance, adherence to treatment (bio) is dependent upon the patient's ability to access health insurance, transport money to the hospital as well as money to buy nutritional supplements and special dietary requirements (social) (Gehlert & Browne, 2012:20). It can be concluded that HIV and TB patients who fail to adhere to treatment, may do so partly because their psychological and social contexts are not adequately taken into consideration in the treatment process.

### **4.3.3 Key findings regarding the empirical study**

These will be discussed according to the themes which were generated from the data as already highlighted in chapter three. After a discussion of the key findings, conclusions and recommendations will be given according to each theme.

#### **4.3.3.1 Theme 1: Problems of institutionalisation and quarantine**

This theme pertained to participants' experiences regarding being quarantined in TB hospital wards.

##### **4.3.3.1.1 Key findings**

The findings show that participants prefer to be treated in the context of their home environment by means of home based care as opposed to confinement in a TB hospital ward. Participants equated staying in hospital wards to being in prison. The majority of participants were against the prospect of not being allowed to go outside the TB ward for fresh air. Participants also did not like the idea of eating the same food every day. They complained that the food was of insufficient quantities and that the quality of the food was a bit poor compared to what is prepared by their families back home.

Participants were also against the idea of being alienated from their family members. They even believed that institutionalising and quarantining them had the effect of scaring away their family members. Most of the participants even concluded that their family members were no longer visiting them due to fear of being infected with TB.

#### **4.3.3.1.2 Conclusions**

It can be concluded that quarantining and institutionalising patients does not serve the best interests of HIV and TB co-infected patients in their quest to recover. Moreover, it can also be concluded that institutionalising co-infected patients negate the need to consider the patient in his or her social environment. It can be concluded that the “person in environment” concept is important when managing co-infected patients (Levin & Herbert, 2001:95), hence supporting the ecological systems theoretical framework that guided this study.

#### **4.3.3.1.3 Recommendations**

- The researcher recommends the strengthening of HBC as a strategy of managing co-infected patients.
- The researcher holds the view that family members of HIV and TB co-infected patients should actively participate in rendering health care support to these patients throughout the treatment cycle.

#### **4.3.3.2 Theme 2: Psychological and emotional experiences**

This theme concentrated on the psychological and emotional dimensions of participants’ experiences of co-infection.

##### **4.3.3.2.1 Key findings**

The majority of participants tended to experience psychological maladaptation during the early stages of their co-infection diagnosis. Suicidal ideations and stress were noted to be directly connected to the psychological maladaptation. Participants noted that it was difficult to come to terms with their co-infection diagnosis, particularly during the first days of receiving news of the diagnosis. Once the participants realised that there were other people with HIV and TB in their community, they were able to accept and cope with their diagnosis.

##### **4.3.3.2.2 Conclusions**

It can be concluded that co-infected patients experience suicidal ideations and stress due to the failure to cope with their co-infection diagnosis, particularly at the early stages of the diagnosis. It can further be concluded that the combination of HIV and

TB is considered deadly by most co-infected patients. This shows that the phenomenon of HIV and TB co-infection affects patients psychologically depending on the perceptions that they hold about these two diseases. These perceptions according to Williams (2014:149) are socially constructed. In this way, the bio, the psycho and the social are shown to be connected, showing the relevance of the BPS approach as an additional theoretical framework for this study.

#### **4.3.3.2.3 Recommendations**

- It is recommended the Ministry of Health and Social Services in Namibia, employ more social workers and clinical psychologists to work with co-infected patients from the point of their diagnosis, through treatment and until they recover and live positively adhering to treatment or until their death.
- It is also recommended that social workers should facilitate support groups for HIV and TB co-infected patients in order to strengthen these patients' resolve to deal with the challenges related to their dual diagnosis.
- The interdependence of the biopsychosocial approach should always be taken into consideration/be point of departure in the treatment of HIV and TB co-infected patients in Namibia's health care facilities.

#### **4.3.3.3 Theme 3: Stigma**

This theme was about participants' experiences regarding HIV and TB stigma both in the community and at the health care facility.

##### **4.3.3.3.1 Key findings**

Participants narrated that they experienced stigma both in their families and communities, as well as at the health care level. One participant pointed out that she was once told by a community member to move away from her chair because she was diagnosed with HIV and TB. Another participant noted that she was told by a family member that they could not eat together because the participant had TB.

In the hospital wards, participants noted that newly admitted patients were shunned by the old patients until their sputum results became TB negative. Internal stigma also emerged as one of the issues affecting participants. Participants pointed out that they

lost confidence in themselves and at times would prefer to stay indoors to avoid stigma-related humiliation by other community members.

#### **4.3.3.3.2 Conclusions**

It can be concluded that communities do not have enough information about HIV and TB co-infection. Moreover, it can be concluded that the lack of adequate information regarding HIV and TB contribute to external stigma which in turn triggers internal stigma in co-infected patients. Communities could be equipped with important information regarding HIV and TB more easily when a biopsychosocial approach is adopted in the management of co-infected patients. In this way, the BPS approach was a fitting framework for this study.

#### **4.3.3.3.3 Recommendations**

- There is need to conduct community awareness campaigns in Namibia to address the problem of HIV and TB related stigma.
- It is recommended that the Ministry of Health and Social Services in Namibia fund these initiatives and give them priority.

#### **4.3.3.4 Theme 4: Social and cultural implications of HIV and TB co-infection**

This theme pertained to the social and cultural implications of an HIV and TB co-infection diagnosis for the participants.

##### **4.3.3.4.1 Key findings**

Participants experienced break-down of their marriages and relationships as a result of their HIV and TB co-infection diagnosis. Some participants pointed out that once their spouses were aware of their diagnosis, they refused to share a bed with them and ultimately most marriages ended in divorce. This study unearthed the existence of myths and misconceptions in communities regarding HIV and TB. Participants tended to delay seeking treatment for both HIV and TB, believing that they were being bewitched by family members. In addition, most participants recounted how they incurred hospital bills and expended significant financial amounts in buying nutritional supplements that boost their immune systems.

#### **4.3.3.4.2 Conclusions**

It can be concluded that co-infected patients lose their social safety nets as a result of HIV and TB. Participants who relied on their husbands for income, lost their source of income when their marriages collapsed. It can also be concluded that marriages collapse due to stigma. Moreover, it can be concluded that co-infected patients fail to get tested or to adhere to treatment due to misconceptions and myths regarding HIV and TB in their communities (psycho). It can also be concluded that apart from HIV and TB (bio) being diseases affecting the poor (social), they also make poor people poorer. This may be due to the need to adhere to strict dietary requirements to complement treatment. It is therefore clear that the bio, the psycho, and the social are interlinked, hence why the biopsychosocial approach was an appropriate theoretical framework for this study.

#### **4.3.3.4.3 Recommendations**

- Social workers should always address all the eco-systems surrounding the patient when it comes to managing co-infected patients.
- There is need to engage communities at all levels and to educate them about HIV and TB so as to clear any misconceptions and myths surrounding HIV and TB.
- It is recommended that all co-infected patients in Namibia be registered for temporary social grants at least until they are TB-free and able to function independently.

#### **4.3.3.5 Theme 5: Medical and health care related factors**

This theme concentrated mainly on medical and health care related challenges that affected participants.

##### **4.3.3.5.1 Key findings**

Participants experienced a wide range of treatment side effects once they started treatment. Headaches and feelings of dizziness were the most commonly reported side effects. In addition, some of the health care professionals did not respect participants. Participants complained about having to wait for long hours before being attended to by doctors. Nurses were also accused of having developed an impersonal

attitude, whereby they did not have a sense of urgency regarding attending to very sick patients. Lack of integration of HIV and TB services in Namibia was also a concern for participants. Participants noted that nurses had to go to the ART clinic on their behalf on follow-up days. Nurses were also said to be more concerned about monitoring TB medications than HIV medications.

#### **4.3.3.5.2 Conclusions**

It can be concluded that treatment side effects contribute to non-adherence to treatment by co-infected patients. It can also be concluded that caring for HIV and TB patients is a tiresome experience which contributes to the development of an impersonal attitude and apathy by health professionals. In addition, it can be concluded that non-integration of HIV and TB services is contributing to the negative experiences by co-infected patients receiving treatment at the health care facility level. The fact that patients alluded to non-medical aspects in the descriptions of their experiences is a reflection of the interconnectedness of the biological, the psychological and the social in patient dynamics.

#### **4.3.3.5.3 Recommendations**

- There is need to increasingly put in place side-effects surveillance mechanisms once patients initiate treatment for HIV and TB.
- Health professionals taking care of co-infected patients should receive refresher training courses periodically.
- Incentives can also be considered to combat large scale resignations by these professionals.
- The Ministry of Health and Social Services in Namibia should expedite the integration of HIV and TB services, particularly in relation to patients getting services under one roof.
- A care policy for HIV and TB co-infected patients should be drafted as soon as possible if the needs of these patients are to be adequately addressed.

#### **4.3.3.6 Theme 6: Spirituality**

This theme deals with the spiritual dimensions of coping with HIV and TB by participants.

#### **4.3.3.6.1 Key findings**

The findings show that participants resorted to their spiritual beliefs to cope with their co-infection diagnosis. Participants noted that they drew strength and power from their beliefs in God and hinted that the church provided a comfort zone in their battle with HIV and TB.

#### **4.3.3.6.2 Conclusions**

It can be concluded that spirituality is an important coping mechanism for patients with life threatening chronic conditions. It can also be concluded that spirituality can be mainstreamed in the management of co-infected patients with satisfying outcomes. If addressing the spiritual side of patients could improve adherence outcomes for co-infected patients, then the psychological and the spiritual aspects of patients are relevant in addressing the needs of patients. This shows that the biopsychosocial perspective provided a fitting theoretical framework for this study.

#### **4.3.3.6.3 Recommendations**

- The Ministry of Health and Social Services in Namibia should allow patients to practice their belief systems even in hospital wards. This can be done in the context of the multi-disciplinary team approach and may include allowing pastors and traditional healers (sangomas) to visit their patients.

#### **4.4 Recommendations for further research**

- As highlighted in chapter one (sub-section 1.5), one of the limitations of this study is that MDR-TB patients, drug susceptible TB patients and XDR-TB patients were not separated. The researcher is aware of the fact that treatment regimens given to these three categories of patients are different and that they therefore may be affected by their treatment regimens differently. Future research could therefore focus on co-infection which involves HIV and either drug susceptible TB, MDR-TB or XDR-TB patients.
- One of the key findings of this study was that participants registered their preference to be managed in the context of their home environments. Future research could therefore also focus on the feasibility of implementing a full scale

home-based care strategy in Namibia, in the context of HIV and TB co-infected patients.

- Moreover, even though spirituality was noted in this study to be an important dimension in coping with co-infection, it is still a grey area in Namibia. Not a single study was found by the researcher regarding spirituality in HIV and TB patients in the Namibian context. Further research could therefore focus on spirituality as a coping mechanism for HIV and TB co-infected patients.
- Future studies could also include larger populations and represent more geographical regions in Namibia.
- Comparative studies can be done in South Africa to draw lessons and best practices in the management of HIV and TB patients.

#### **4.5 Conclusion**

The study managed to explore the lived experiences of co-infected patients in Rundu, Namibia and to give recommendations in accordance with the key findings. The goal and objectives of the study were achieved. The researcher also gave recommendations for further study with a view to complementing the findings of this study as well as to cater for its limitations.

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