

**PRE- AND POST- HIV DIAGNOSIS HELP-SEEKING BEHAVIOUR BY PATIENTS
RECEIVING ANTIRETROVIRAL TREATMENT AT WITBANK HOSPITAL IN
MPUMALANGA PROVINCE**

MASTER OF ARTS

In

CLINICAL PSYCHOLOGY

M.P MOHALENI

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**PRE- AND POST- HIV DIAGNOSIS HELP-SEEKING BEHAVIOUR BY PATIENTS
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MPUMALANGA PROVINCE**

by

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MINI-DISSERTATION

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SUPERVISOR: Prof. Tholene Sodi

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DEDICATION

I dedicate this work to my late grandmother Martha Tlamaka Mtsweni Mashabela for her words of encouragement and for believing in me. Her kindness, love, care, and support will always be remembered. May her soul Rest in Peace.

DECLARATION

I declare that the, **PRE- AND POST- HIV DIAGNOSIS HELP-SEEKING BEHAVIOUR BY PATIENTS RECEIVING ANTIRETROVIRAL TREATMENT AT WITBANK HOSPITAL IN MPUMALANGA PROVINCE** hereby submitted to the University of Limpopo, for the degree of master of arts in clinical psychology has not previously been submitted by me for a degree at this or any other university; that it is my work in design and in execution, and that all material contained herein has been duly acknowledged.

Mohaleni M. P

Date

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ABSTRACT

Studies have indicated that help-seeking behaviour of people living with HIV is not predictable and linear and may entail the utilization of western medicine, traditional medicine and/or complementary medicine. The aim of this study was to explore pre- and post- HIV diagnosis help-seeking behaviour by patients receiving antiretroviral treatment at Witbank Hospital in Mpumalanga Province (South Africa). A qualitative, descriptive phenomenological approach was utilized in the study. Ten participants (male = 5; female = 5, and aged between 30 and 50 years) diagnosed with HIV and who came to the hospital to collect their treatment and for medical review were interviewed using semi-structured interviews. Interpretive analysis method was used to analyse the data. The results suggest the preference for western medicine pre- and post-HIV diagnosis. The results further suggest that help-seeking behaviour is a dynamic process embedded mainly in the conceptualization of the health problem, perception of its severity, the treatment given, and social support experienced.

LIST OF ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
ARV	Antiretroviral
HIV	Human Immunodeficiency Virus
TB	Tuberculosis
UNAIDS	Joint United Nations Programme on HIV/AIDS
VCT	Voluntary Counselling and Testing
WHO	World Health Organization

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CHAPTER 1

INTRODUCTION

1.1. Introduction

According to the Joint United Nations Programme on HIV/AIDS (UNAIDS) (2008), there are an estimated 33 million people living with HIV globally, with over 5700 persons dying from AIDS every day. The estimated number of deaths due to AIDS in 2007 was 2.0 million annually worldwide, of which 75% occurred in Sub-Saharan Africa (UNAIDS, 2008). South Africa is one of the countries in the world with a very large number of people suffering from HIV and AIDS. About 11.4% of the population in South Africa is estimated to be infected with HIV. HIV infections are mainly detected in antenatal clinics, where about 29% of pregnant women attending these public health clinics are found to be infected (National Department of Health South Africa, 2008). Different provinces in South Africa, however, experience different levels of HIV infection. The provinces that have been rated as having the highest HIV prevalence are KwaZulu-Natal, Gauteng and Mpumalanga (National Department of Health South Africa, 2008). According to MacIntyre and Holzemer (1997), Bormann, Uphold and Maynard (2009) and Bodeker, Carter, Burford and Dvorak-Little (2006), whilst many people suffering from HIV utilize western health-care systems, there is evidence to suggest that a considerable number of people utilize non-Western methods for the treatment of HIV.

Babb, Pemba, Seatlanyane, Charalambous, Churchyard and Grant (2007) conducted a survey among individuals with HIV disease attending a workplace clinic providing antiretroviral therapy, and 84% of the individuals reported the use of traditional medicine. Peltzer, Preez, Ramlagan and Fomundam (2008) further emphasised that the use of traditional medicine is common among individuals with moderate and advanced HIV disease. However, according to UNAIDS (2006), since the beginning of the AIDS epidemic patients have consulted both biomedical doctors and traditional healers.

O'Mahony and Hegarty (cited in O'Mahony, Hegarty & McCarthy, 2010) have suggested that the response to health or help-seeking behaviour is influenced by

many factors. Most people experience health symptoms all the time, but interpretation and actions vary (Cardol, Groenewegen, Spreeuwenberg, Van Dijk, Van Den Bosch & De Bakker, 2006). Cultural factors, past experiences, and family background affect beliefs about the seriousness of health complaints and the subsequent help-seeking behaviour that will follow (Kirscht, cited in Cardol *et al.*, 2006).

1.2. Statement of the problem

The help-seeking behaviour of people living with HIV includes visits to traditional healers, health facilities such as hospitals (Plummer, Mshana, Wamoyi, Shigongo, Hayes, Ross & Wight, 2006), and the usage of other complementary alternative health-care services such as spiritual therapies, herbal medication, self-treatment or home remedies (Bormann *et al.*, 2009). Studies have indicated that people living with HIV use complementary and alternative medicine to improve their general health, prevent opportunistic infections, treat symptoms, reduce side effects from biomedical treatment, and to relieve pain and stress (MacIntyre & Holzemer 1997; Peltzer *et al.*, 2008). However, according to Abelheim (2011), a positive experience contributes to an individual's motivation to keep visiting her or his health care centre and to use the treatment modalities supplied by that centre.

The use of different health care centres and different treatment modalities by individuals living with HIV as well as their motivation to use those treatment modalities as reflected above is what has motivated the researcher to embark on the current study. This study investigates the pre- and post- HIV diagnosis help-seeking behaviour among individuals with HIV in Mpumalanga Province.

1.3. Aim of the study

The aim of this study was to explore pre- and post- HIV diagnosis help-seeking behaviour by patients receiving antiretroviral treatment at Witbank Hospital in Mpumalanga Province.

1.4. Objectives of the study

The objectives of the study were:

- To investigate the help-seeking pathways followed by patients before and after an HIV diagnosis;
- To investigate the treatment modalities utilized by these patients in the management of their HIV condition before and after an HIV diagnosis.

1.5. Research questions

The research questions that this study sought to answer were the following:

- What help-seeking pathways were followed by these patients before they were diagnosed with HIV?
- What help-seeking pathways were followed by these patients after they were diagnosed with HIV?
- What treatment modalities were utilized by these patients before they were diagnosed with HIV?
- What treatment modalities were utilized by these patients after they were diagnosed with HIV?

1.6. Operational definitions

1.6.1 Help-seeking behaviour: In this study, help-seeking behaviour is operationally defined as the actions undertaken by individuals in seeking treatment to maintain their health.

1.6.2 Help-seeking pathways: This refers to the sequence of contacts made with individuals and organizations by the distressed person and the effort of his or her significant others in seeking help, as well as the help that is supplied in response to those efforts (Tseng, 2001).

1.6.3 HIV (Human Immunodeficiency Virus): It is a virus that causes AIDS (Van Dyk, 2005).

- 1.6.4 Antiretroviral therapy (ART):** This refers to the drugs currently used for the treatment of HIV and AIDS. These drugs suppress or prevent the replication of HIV in cells (Van Dyk, 2005)
- 1.6.5 CD4 cells:** These are type T cells, which are particularly responsive to viral activity in the immune system. HIV infection damages CD4 cells, which ultimately reduce the ability of the immune system to fight both viruses and bacteria (Paul, Cohen & Stern, 2002).
- 1.6.6 CD4 count:** This is the number of CD4 cells in a sample of blood. A CD4 count measures how well the immune system is working (United States Department of Health and Human Services, 2011)
- 1.6.7 Traditional method of treatment:** This is operationally defined as practices in the treatment of illnesses which are based on indigenous beliefs and experiences.
- 1.6.8 Western health-care systems:** This refers to medical health-care systems such as hospitals, clinics, and private medical practitioners.
- 1.6.9 Hospital treatment:** This term is used to refer to the antiretroviral therapy that patients obtain at the hospital.

CHAPTER 2

LITERATURE REVIEW

2.1. Introduction

In this chapter I will start by presenting the literature on help-seeking behaviour, the pathways available to care for various health problems, including HIV, and the factors affecting help-seeking. This will be followed by a review of South African studies that have focused on help-seeking behaviour by people with a wide range of illnesses, including HIV. In the third section I will present popular theories on help-seeking, including HIV help-seeking strategies and behaviour. The last part of this section will be a presentation of the theoretical framework that informed this study.

2.2. Illness help-seeking behaviour

There is a substantial body of literature that explores help-seeking behaviour for various health problems worldwide. Help-seeking behaviour in the context of health studies involves what people do and where people go (i.e. the help-seeking pathways) when they suspect they have an illness, or when they encounter a symptom of a certain illness, or when they are diagnosed with a certain disease (Grundy & Annear, 2010). The starting point for most help-seeking behaviour is a recognition of various symptoms, depending on the nature and the stage of infection (WHO, 1995). This recognition is followed by actions (i.e. what people do) that are intended to bring relief to the illness. Where the people go when they have the illness then becomes the process of seeking help, which includes the routes (the help-seeking pathways) that are followed (Grundy & Annear, 2010). Such pathways to help-seeking include identifying symptoms and the condition, seeking information and advice, and seeking and accessing treatment (Pearson & Makadzange, 2008). In other words, following the symptoms identification a strategy for treatment action is devised.

However, Alberts, Sanderman and Van den Heuvel (1998) argue that symptoms identification and illness behaviour have large individual differences. A given symptom may be differentially perceived, evaluated and acted upon by different kinds of people (Mechanic & Volkart, 1960). Corner, Hopkinson and Roffe (2006) conducted a study among individuals diagnosed with early and late stage lung cancer. They found that regardless of their disease stage or their social background,

individuals failed to recognise the symptoms that they experienced over many months prior to their diagnosis as serious and warranting medical attention. Symptoms that were found to be severe were often attributed to everyday causes and were not interpreted as indicative of ill-health. In accordance with the above study Rahman, Islam, Islam, Sadhya and Latif (2011) explain that the type of symptom experienced for the illness and the number of days of illness are the major determinants of help-seeking behaviour and the choice of a care provider. However, other studies have indicated that sometimes the problem lies in acknowledging and accepting the ill-health, which results in individuals interpreting the symptoms of ill health as not being serious. On the topic of symptom identification Kraemer (2000) indicates that as compared to women, men are slower to notice signs of illness. HIV symptoms may not be identified at the onset of the disease but commonly manifest themselves in people in advanced stages of the illness (Golooba-Mutebi & Tollman, 2007).

Studies have indicated that there are two main types of health-care seeking behaviours. The first focuses on the barriers to care that lie between the patients and the services (Grundy & Annear, 2010). These barriers may include several factors, some of which are discussed below. The second type investigates the process of health-care seeking (Mackian, 2003). According to Grundy and Annear (2010), the process of health-care seeking involves the identification of pathways to the formal health-care system, often commencing with home care and traditional healers and extending to the formal systems, the pathways differing according to the presenting condition. This current study reviewed literature on both types of health-care seeking behaviours, with special reference to the process of health-care seeking behaviour of people diagnosed with HIV.

2.3. Pathways to health care

When in need of health care, people may seek help from a wide range of available service providers (WHO, 1995). This may involve people shopping around for care. Howell, Smith and Roman (2008) indicate that help seeking is the first step on the pathway to diagnosis and should occur promptly.

A wide range of therapeutic choices are available, ranging from information seeking and self care to folk and western medicine. Pearson and Makadzange (2008) note that seeking information is a useful strategy to help determine appropriate help seeking. They further indicate that most of the discussion of the issue is centred on human sources rather than on the use of media such as books, magazines and websites. Barnett and Whiteside (cited in Golooba-Mutebi & Tollman, 2007) note that members of social and kin networks, acting as therapy referees are important sources of advice on the causes of illness and on suitable treatment. Golooba-Mutebi and Tollman (2007) indicate that self- medication is usually the first line of defence, and it may entail the use of traditional and allopathic medicine separately or in combination. This occurs when the perception is that the illness is minor, easily treatable, and does not require special attention. According to Golooba-Mutebi and Tollman (2007), when an illness fails to respond to self-medication, herbalists are the second line of defence, while diviners and healers are the third line of defence consulted about serious and life-threatening illness. Treatment from hospitals or clinics is sought only as a last resort. According to Rahman et al. (2011), traditional beliefs tend to be interwoven with the peculiarities of the illness itself and a variety of circumstantial and social factors. Rahman et al. (2011) also indicates that in the case of a mild, single symptom such as fever, home remedies or folk prescriptions are used, whereas with multiple symptoms and longer period of illness, a biomedical health provider is more likely to be consulted.

A study conducted by Nonye and Oseloka (2009) in Nigeria indicates that the treatment options first employed by 34.5% of the respondents were prayer houses, followed by 32% of the respondents going to psychiatric hospitals for the management of mental illness. Gochman (cited in Pillay, 1996) indicates that patients, after evaluating their symptoms, treat themselves, seek help from medical professionals or consult folk/traditional healers. Jegede (2002) finds that the pathways to prevention and care in Nigeria usually favour the patronage of the traditional healing process. Steen and Mazonde (cited in Mackian, 2003) finds that 95% of the patients in Botswana visit a modern health facility as a first step in seeking help with regard to tuberculosis (TB). However, after initiating modern treatment, 47% then go on to visit a traditional or faith healer. According to Steen and Mazonde (cited in Mackian, 2003), modern or western medicine is used as a

quick-fix solution, while traditional medicine is used for providing answers that may be asked about the meaning of the misfortune, and to deal with the real causes of the illness. According to Chomat, Wilson, Wanke, Selvakumar, John and Isaac (2009), while most people in India use the allopathic medical system as their primary source of health care, 60% to 85% of primary care provision occurs in the largely unregulated private sectors, and an estimated 70% to 80% of the population uses non-allopathic medicine from one of the various Indian systems of medicine.

People living with HIV also seek help from a wide range of service providers in dealing with their HIV condition. Hatchett, Kaponda, Chihana, Chilemba, Nyando, Simwaka and Levy (2004) conducted a study in Malawi examining the health-seeking practices of families affected by AIDS. According to their findings, traditional care and treatment by family members is sought first, followed by remedies from traditional healers. Modern treatment from hospitals or clinics was sought as a last alternative. On the other hand Case, Menendez and Ardington, (2005) indicate the simultaneous use of both western and traditional medicine among people living with HIV.

2.4. Factors affecting help seeking

There are various factors that may affect help-seeking behaviour. Mackian (2003) indicates that help-seeking behaviour is more dynamic, collective and interactive. The choice of treatment involves a myriad of factors related to the type of illness, its severity, pre-existing lay beliefs about the causes of illness, the range and accessibility of therapeutic options available, and their perceived efficacy, convenience, opportunity cost, the quality of the service offered, the attitude of the medical staff, as well as the age, gender and social circumstances of the sick individual (Rahman et al., 2011). On the other hand Burman (1996) puts emphasis on factors such as health knowledge, cultural background and socio-demographic characteristics while Pearson and Makadzange (2008) focus on the complex and dynamic socio-cultural context of help-seeking behaviour and the pathways followed.

2.4.1. The conceptualization of the aetiology of health problems and help seeking

Jain, Nandan and Misra (2006) indicate that how people conceptualize the aetiology of health problems and how symptoms are perceived are important factors in deciding the first step of treatment seeking. Steen and Mazonde (cited in Mackian, 2003) also emphasise the importance of an individual's beliefs and interpretation of diseases in contributing to the outcome of TB control.

According to Jones (cited in Kgwatalala, 2003), the belief of illness causation according to the biomedical explanatory will lead to help-seeking behaviour from health-care professionals and scientifically developed diagnosis and treatment options. But, cultural factors may also relate to beliefs about disease causation and to the potential efficacy of different forms of care, and have been said to affect the tolerance or intolerance of different symptoms (WHO, 1995). The belief of illness causation in terms of cultural or religious explanations will lead to consultations with traditional health-care providers such as a faith healer or a traditional healer. In this instance help is sought through prayer, or by appeasing the ancestors (Kgwatalala, 2003). A dynamic explanation of the nature of an illness also exists. In this case the illness is determined by the symptoms it presents and the progression of the disease. An individual may administer self-treatment before consulting a traditional healer or a medical practitioner (Kgwatalala, 2003).

In their study Pearson and Makadzange (2008) find that health is grounded in cultural, spiritual and religious contexts. They conducted a study among adult men in Zimbabwe, exploring the decision-making process associated with help-seeking behaviour for concerns of sexual health. They found that men interpret sexual-health concerns as due to either natural or supernatural causes and these interpretations influence their choice of treatment and health-service provider - either medical or traditional.

Golooba-Mutebi and Tollman (2007) indicate that illness such as strokes and poisoning attributed to human agency are treated only by traditional therapy, some illnesses such as TB and HIV/AIDS are considered treatable by both traditional and allopathic therapy, and others such as diabetes and high blood pressure are treated

only by biomedicine and do not respond to traditional therapy. Steen and Mazonde (cited in Mackian, 2003) say that TB is seen as a European disease that will respond to western medicine. A traditional healer is also consulted, but only to explain the meaning of the disease. This may be an indication that several distinct therapeutic systems exist in a single cultural setting. This was found by Rahman et al. (2011) to be an important feature of the health-care system.

According to Mbonu, Van den Borne and De Vries (2009) a cultural construction of HIV/AIDS based on beliefs about contamination, sexuality and religion plays a crucial role and contributes to the strength of distancing reactions and discrimination in society. The study of Pearson and Makadzange (2008) also indicates that according to their respondents the appearance of HIV/AIDS means that the previously useful knowledge and advice of elders may be redundant. According to Plummer et al. (2006), HIV/AIDS is also attributed to witchcraft.

Some studies indicate that HIV is seen as a death sentence. Studies such as those of Mohammadpour, Yekta, Nasrabadi and Mohraz (2009) find that most participants in their study perceive a diagnosis of HIV infection as fatal; the knowledge that they are infected causes them to be preoccupied with death. Such perception can also impact on the help seeking of an infected individual, who may either not seek help at all and wait for death, or have multiple encounters with health-care providers to prevent death.

2.4.2. Health knowledge and help seeking

The individual's ability to understand and act on health information by itself contributes to health knowledge. Health knowledge is one of the significant factors determining the help-seeking pathways taken. Focusing on the influence of health knowledge, Howell et al. (2008) conducted a study among patients diagnosed with lymphoma in West Yorkshire, examining their beliefs and actions about help seeking. They found that a lack of knowledge and the interpretation of symptoms as not being serious led to delays in help-seeking.

According to Mbonu et al. (2009), knowledge about HIV, which includes knowledge about one's HIV status, modes of HIV transmission and effective treatment, is

important for people living with HIV if they are to obtain adequate care. Morrison, Banushi, Sarnquist, Gashi, Osterberg, Maldonado and Harxhi (2011) conducted a study in Albania assessing the barriers to the care of HIV-positive patients. They found that a lack of knowledge of HIV medical care is associated with the existence of barriers to care. Patients do not know where they can find medical help for HIV/AIDS. A study by Chomat et al. (2009) finds that patients generally have little knowledge of the available treatments for HIV, despite their good knowledge of HIV transmission and prevention, and that Indian women tend to be less knowledgeable about HIV and its treatment than men. Djokic, Englund, Daum, Martin, Dozier, Potts, Verber and Marcinak (2009) in their study found that most of their respondents were knowledgeable about HIV transmission risk factors, but misinformation about treatment existed.

Studies have indicated that a lack of knowledge is a barrier to care not only for patients. Morrison et al. (2011) finds that medical providers' lack of knowledge is also associated with barriers to care. According to Chomat et al. (2009), who conducted their study in India, most Indian medicine providers reported dangerous misconceptions about HIV transmission, diagnosis and treatment. Van Schalkwyk, Maree and Wright (2008) in their study among women with advanced cervical cancer also find that a lack of knowledge and awareness among health-care professionals results in a low suspicion of cancer and misdiagnosis.

2.4.3. Socioeconomic status

Ahmed (2005) indicates that socioeconomic status emerges as the most common significant determinant of seeking any healthcare, especially seeking allopathic care. Hausmann-Muela, Ribera and Nyamongo (2003) state that direct and indirect costs are among the most commonly mentioned obstacles to adequate help-seeking behaviour of the poor in their attempt to obtain prompt and adequate treatment. In their study in China exploring the perception of tuberculosis (TB) and help-seeking pathways, Zhang, Liu, Bromley and Tang (2007) find that both financial and structural barriers stop individuals from seeking health care. People were found to seek health care only after they failed to treat themselves. Less educated people, low-income groups and old people are identified as less likely to seek care or are most likely to seek help in the village, where it is cheaper (Zhang et al., 2007).

According to Spark-du Preez, Griffiths and Cameron (2005), socioeconomic status determines whether help is sought in the private or public sector. Mahendra, Panda, Bajaj, George, Gilborn and Bharat (2002) also indicate that socio-economic factors contribute to the help-seeking behaviour of people living with HIV. They indicate that those who can afford to visit private health care providers do so to avoid long queues in government hospitals and to receive timely care. As the cost for on-going care accumulates, they eventually turn to the public sector for free or subsidized services.

2.4.4. Gender and age

Ahmed (2005) indicates that age and gender are found to be determinants of treatment choice. Studies have indicated that there are differences in gendered patterns of help-seeking. According to Kraemer (2000), men are slower to notice signs of illness and when they do they are less likely to consult their doctors. This implies that men have limited contacts with physicians and health-care services (Kraemer 2000). According to Pearson and Makadzange (2008), dominant gender norms of resilience and self-reliance, shyness and embarrassment delay men's treatment seeking. Pearson and Makadzange (2008) found that once the symptoms of illness have been recognised, some men will proceed directly to accessing treatment, particularly if they have previous experience of similar symptoms. On the other hand, other men in the same situation may spend time seeking information and advice, but not progress further if the symptoms diminish. However, on contradiction to the findings of these studies, Ahmed (2005) finds that the likelihood of men accessing any type of health care or qualified allopathic care is greater than of women doing the same. In supporting Ahmed's statement Hausmann-Muela et al. (2003) indicate that inequality in access is associated with the finding that women have to overcome more obstacles than men to reach treatment.

In the context of age differences in help-seeking behaviour Ahmed (2005) finds no difference in help-seeking between the elderly and younger adults. He finds self-treatment to be the most common choice of treatment for most illnesses irrespective of age group (Ahmed, 2005). However, Case et al. (2005) conducted a study examining the choices made concerning public and private medicine, western and traditional medicine, and non-prescribed self-medication. Their study finds that most adults who are ill seek treatment from western medical providers, visiting either a

public clinic or a private doctor. Jain et al. (2006), find that most adolescents and young, unmarried females first discuss their health problem with their mothers or elder sisters.

2.4.5. Stigma and help seeking

People's attitudes towards illnesses have become a barrier to treatment. Studies on mental health indicate that mental health services are underutilized due to stigma. This implies that many people who could benefit from mental health services do not seek help for their problems (Zartaloudi & Madianos, 2010). People living with HIV are also faced with the related stigma of living with the disease. Such a stigma may hinder the treatment and care of people living with HIV. However, a study by Gosling (cited in Mbonu et al., 2009) indicates that a person who is able to overcome stigma and shame is consequently able to seek appropriate treatment by publicly stating his or her HIV-positive status, whereas, according to the study of Morrison et al. (2011) the majority of patients indicate that a major barrier they faced in seeking care is that they do not want others to know that they are HIV-positive.

Pearson and Makadzange (2008) also emphasise that HIV-related stigma can hinder men's help-seeking for sexual health concerns - particularly for sexually-transmitted infections. Mbonu et al. (2009) indicate that people living with HIV make different healthcare-seeking choices as a result of the stigma, which may lead to non-utilization of healthcare institutions. Mahendra et al. (2002) indicate that people living with HIV utilize a number of strategies for accessing care without incurring negative repercussions, and this includes concealing their HIV status as long as possible, and seeking care outside their own community to protect their anonymity. Mohammadpour et al. (2009) find that participants fear disclosing their statuses to others because of fear of rejection, fear of being blamed, misjudged and labelled, and that their participants did not believe that their statuses would be kept confidential.

Enwereji and Enwereji (2010) find low patronage for hospital services. In their study assessing the factors that affect the childbirth choices of people living with HIV/AIDS, 82% of people living with HIV/AIDS did not use hospital services due to their fear of a lack of confidentiality and 64% had their childbirth with traditional birth attendants

at home. Embarrassment, rejection, non-confidentiality, cultural stigma and discrimination are among the factors that encouraged childbirth choices. Enwereji and Enwereji (2010) further indicated that 85% of them discontinued anti-natal-care because of the fear of stigmatization.

Traditional healers and private doctors were liked for their perceived confidentiality and their ability to minimize embarrassment (Pearson & Makadzange, 2008). Living with HIV and the stigma attached not only poses challenges to the infected persons, but prevents the delivery of effective social and medical care and enhances the number of HIV infections (Mbonu et al., 2009). According to Mbonu et al. (2009), people hide behind witchcraft by claiming that they are bewitched since this is more culturally acceptable and it avoids personal shame. Many stop taking antiretroviral medication when the symptoms are gone and resort to traditional medication.

In conclusion, among all the factors identified, as noted by Rebhan (2010), it is difficult to identify which determinants are most influential in help-seeking and the utilization of a particular kind of health care; culture, economics, perceptions, belief in efficacy, age, gender, and social roles are all items on the extensive list of factors influencing both the choice to seek health care and the assessment of which health care system to choose for the treatment of an illness. The literature also indicates that the process of health-care seeking is not direct. It depends on individualistic and contextual manner of evaluating symptoms.

2.5. Illness help-seeking behaviour for various illnesses including HIV: South African studies

Several studies suggest that, in South Africa as in many other parts of the world, help-seeking behaviour is not predictable and linear. It may include backward and forward movement between western and traditional health care systems. Studies in South Africa also indicate that African people will simultaneously access the services of western and traditional healers for the same symptoms, based on the cultural conception that illness is both physical and spiritual (Berg; Swartz, cited in Zondo, 2008).

In many African studies, including those situated in South Africa, illness is also conceptualised as caused by disharmony or conflict in the social relationship between humans or conflict in the spiritual relationships between humans and religious or ancestral spirits. If an important ancestral spirit has been displeased or angered, the spirit causes illness in a family member, using supernatural forces to do so. Alternatively, the spiritual cause of illness may be interpreted in a Christian tradition, with the inflicted person believed to be possessed by demons. Illnesses resulting from supernatural causes may be interpreted as a punishment for man's immoral, social or sexual behaviours (Pearson & Makadzange, 2008). Pearson and Makadzange (2008) further indicate that illness is also believed to be supernatural but human induced. Enemies may enlist a witch to place a spell or curse on a person. In the context of such conceptions of the causes of illness, help may be sought from traditional healers for divination, treatment and reconciliation with the wronged person or ancestor. Alternatively, multiple health services may be used serially or concurrently. Golooba-Mutebi and Tollman (2007) indicate that, as in the case of other illnesses, afflictions related to HIV are interpreted within a prevailing framework of folk beliefs regarding illness and its causes, and responses are confined to what is locally believed to be appropriate therapy. According to Van Dyk (cited in Van Dyk, 2012), there is no indication in the literature that traditional Africans attribute AIDS to the anger of the ancestor, but the influence of Christianity can be seen in the belief of some African Christians that AIDS is God's punishment for immorality and sins. Van Dyk (2012) further states that witchcraft is believed by some people to be the causal agent in HIV transmission. Ashforth (cited in Van Dyk, 2012) found that residents of Soweto often interpret the symptoms of HIV as a type of poisoning caused by witches.

Cultural influences affect not only perspectives on health, illness and disease but also a variety of health-related behaviours, such as the beliefs that underlie the utilization of service, response to pain, response to symptoms, the sick role and the use of traditional healers (Berkanovic & Reeder, 1974; Berkanovic & Telesky, 1985; Gutmucher & Elinson, 1971; Kleinman & Sung, 1979; Davis 1984; Freeman & Motsei, 1992). A study by Golooba-Mutebi and Tollman (2007) finds that folk beliefs are important in decision making concerning the choice of treatment modality. Broadly, reactions to illness consist of self-treatment and engagement in allopathic

and/or traditional practitioners. Spark-du Preez et al. (2005) indicate that home remedies, over-the-counter medicine, traditional medicine and church medicine have an important role in the management of illness in South Africa.

It is not only folk beliefs that influence the usage of non-western treatment in South Africa. There are other factors which contribute to the help-seeking of western treatment being compromised. For example, Matebesi, Meulemans and Timmerman's (2005) study of health care-seeking behaviour among tuberculosis patients indicates that patients seek help mainly from primary healthcare clinics and private doctors. However, lack of awareness of tuberculosis and the use of home remedies were significantly associated with a delay in help seeking. O'Mahony et al. (2010) suggest that denials, fear, social factors, lack of knowledge and beliefs systems are linked with delay in help-seeking. In investigating attitudes towards and knowledge of mental illness in South Africa, Hugo, Boshoff, Traunt, Zungu-Dirwayi and Stein (2003) find that most cases of mental illness are conceptualized as stress-related or the outcome of a lack of willpower rather than as medical disorders. They further indicate that the treatment advocated is more often to talk the problem over than to consult professional help. Rudell, Bhui and Priebe (2008) investigated alternative help-seeking strategies for mental distress in a multi-ethnic community in East London and examined the patients' relationship with primary care. They found that alternative health-care seeking such as talking to a family member; utilizing traditional healers and the severity of distress were positively associated with the use of primary care services for people with common mental disorders. However, according to Woodward, Chatter, Taylor, Neighbors and Jackson (2010), help-seeking in response to stressful personal problems is probably different from help-seeking for medical issues.

For many African people in South Africa, the western medical system of health care exists alongside the traditional system (Pillay, 1996). The study by Pronyk et al. (cited in Mackian, 2003) finds that TB patients in South Africa attended government facilities more readily than patients suffering from some other conditions; 72% presented initially to a hospital or clinic, with only 15% presenting to a spiritual or traditional healer, and 13% to a private doctor. Kruger, Greeff, Watson and Fourie (2009) conducted a study exploring healthcare-seeking behaviour of the newly

diagnosed HIV patients after having been referred to health-care facilities and after receiving pre- and post-test counselling in the North West Province of South Africa. Their study indicates that only 27.7% of these participants had sought medical care after post-test counselling. This is an indication that not all patients diagnosed with HIV sought western treatment after they had been diagnosed.

Swanson, Keithley, Zeller and Cronin-Stubbs (2000) reported a substantial use of complementary and alternative medical therapies among persons diagnosed with HIV. Marie Modeste and Majeke (2010) conducted a study in Kwazulu-Natal exploring the self-care symptom management strategies used by women living with HIV and AIDS. Their study indicates that a number of different methods of self-care symptom management were reported by the participants. These include medication either prescribed by health care providers after consultation, purchased from a pharmacy, or home remedy. Other symptom management strategies include seeking complementary treatment such as taking traditional medication and spiritual care. According to Sukati, Mndebele, Makoa, Ramukumba, Makoe, Seboni, Human and Holzemer (2005), a myriad of symptoms that may be due to opportunistic infections experienced by infected persons, might contribute to the person seeking other treatment strategies. Peltzer (2009) emphasises that the use of traditional practitioners is also important in health-care delivery in South Africa as these providers of alternative health care deal with a wide range of conditions like HIV and other sexually transmitted infections.

However, the use of western treatment modalities (especially the utilization of antiretroviral medication) is also common among people living with HIV in South Africa. Gilbert and Walker's (2009) study in Johannesburg reveals that the western treatment for HIV (ARVs) is being perceived as lifesaving, and patients have expressed their long-term commitment to adhering to the treatment, as well as their trust in health professionals. Emphasizing the use of the western health-care facilities among people living with HIV, Abelheim (2011) finds that positive experiences such as support from health-care workers and practitioners as well as the services the patients receive in their health-care settings serve as a motivating factor for these patients to keep visiting these health-care facilities.

2.6. Theoretical perspectives

There are several models which address help-seeking behaviour. The present study focuses on only some of the models, including the theory of planned behaviour, the health-utilization model, the pathway model, and the model that guided the present study, which is the health-belief model.

2.6.1. The Theory of Planned Behaviour

According to the Theory of Planned Behaviour, help-seeking behaviour is a planned action that is dependent on the individual's evaluation of performing a particular behaviour, the individual's perception of social pressure to perform the behaviour, and a sense of self-efficacy or that the person is able to perform the behaviour (Ajzen, 2005). Omer and Haidar (2010) emphasise that this model aids in understanding and predicting social behaviour in terms of specifying the relationship between potentially modifiable behaviours or determinants. According to Ajzen (cited in Vissmana, Hergenratherb, Rojasc, Langdonc, Wilkind & Rhodesa, 2011), the Theory of Planned Behaviour suggests that a person's behaviour is best predicted by his or her intentions to perform a particular action, and intention is predicted by following three cognitive determinants as explained by Fishbein; Fishbein; Bandura (cited in Vissmana et al., 2011):

2.6.1.1. Attitude: the individual's overall grasp of the consequences or outcomes of performing a specific behaviour

2.6.1.2. Subjective norms: the social pressure an individual feels to perform or not perform the behaviour

2.6.1.3. Perceived behavioural control: the individual's perception of the extent to which the behaviour is easy or difficult to perform. This determinant especially can directly influence behaviour.

Based on this model, people would be strongly motivated to use a particular treatment approach if they believe that particular approach will help manage their HIV condition or improve their health, or when important people in their lives approve

the use of such an approach, or when they believe that the approach was efficacious in managing their health in the past.

In examining the applicability of the Theory of Planned Behaviour to predicting the intended use of Voluntary HIV Counselling and Testing (VCT), Omer and Haidar (2010) highlight some of the factors associated with the utilization of VCT, which include perceived susceptibility to HIV infection, partner involvement in counselling and testing, the providers confidential handling of the HIV test results, the perception of the subject's health status and a range of socio-demographic characters of clients. Their findings also indicate that the perceived severity of the illness, normative beliefs, and having a high level of self-control are the major predictors of the intention to use VCT.

Whilst this theory commendably looks at an individual's intention to perform a behaviour, self-efficacy and how social pressure influences help-seeking behaviour, it does unfortunately not consider how the nature of illness, its severity, and the availability of effective treatment could impact on help-seeking behaviour.

2.6.2. The Health-Care Utilization Model

The Health-Care Utilization Model or the socio-behavioural model look into three categories of factors which can influence health behaviour: predisposing factors, enabling factors, and need factors. Predisposing factors include age, gender, religion, formal education, the general attitude towards health services, knowledge about the illness etc. Enabling factors include the availability of services, financial resources, social networks etc. And lastly need factors include the perception of severity. Such factors will influence treatment actions or the choice of a particular health-care resource, whether it is a traditional healer, a modern healer, self-treatment, or no treatment at all (Hausmann-Muela et al., 2003).

According to Kunches, Reinhalter, Musolino and Hirschhorn (2005), HIV/AIDS treatment has been one of the areas in which inequalities in care and outcomes have been identified for racial/ethnic minorities and women. There have also been concerns that other disadvantaged groups of people living with HIV might be receiving suboptimal treatment or not benefiting equally from medical care with

respect to disease stabilization. Kunches et al. (2005) conducted a study using the Healthcare Utilization Model and Multi-level Logistic Regression Models. They identified the predisposing, enabling and need factors that predicted five selected process and outcome measures. The predisposing factors were evaluated as patient characteristics of gender, race, country of birth, age, substance use, and mental health diagnosis. They also found that 18% of the patients experienced prolonged gaps between medical care visits at the sites.

Hutchinson and Mahlalela's (2006) study of the utilization of voluntary counselling services in Eastern Cape find that the overall use of VCT is low, and that the utilization of VCT services is positively associated with age, education, socio-economic status, proximity to clinics, the availability of rapid testing and outreach services, and lower levels of HIV/AIDS stigma. Danso-Appiah, Stolk, Bosompem, Otchere, Looman, Habbema and de Vlas (2010) also find age, socio-economic status and time for hospital visit as having a significant impact on help-seeking.

This theory looks at very important variables in terms of help seeking behaviour. Literature also indicates that some of these factors do act as barriers to help-seeking. However, the main criticism against this theory is that it does not consider the process of help-seeking behaviour in terms of how individuals identify the pathways to health-care systems.

2.6.3. Pathway Model

The Pathway Model assumes that a path that people follow in the treatment of an illness or disease may be influenced by several factors. These factors include the perception of the illness and the opinion of significant others. The path taken from the first contact is investigated using the Pathway Model. Those using this model will investigate the path taken from the recognition of the symptoms to the use of different health services, and the role of the extended groups of relatives and friends in the illness negotiation and management is given importance (Ahmed, 2005). According to Ahmed (2005), the strength of the Pathway Model is that it depicts help-seeking as a dynamic process.

This model identify pathways to health care systems, and the role of significant others in decision making. However, it does not outline factors that influence the use of different health services and/or the movement from one health care system to another.

2.6.4. The theoretical framework for the present study: the Health Belief Model

The present study was guided by the Health Belief Model. This model provides insight as to why people make certain help-seeking decisions. According to this model, help-seeking behaviour is influenced by the following factors:

2.6.4.1 Perceived severity: the belief about the seriousness of a health problem.

Spark-du Preez et al. (2005) find this factor to be a strong determinant of whether no treatment, home treatment or professional help is sought. When an illness is in its early stages, the sufferer seeks to establish how serious it might be (Golooba-Mutebi & Tollman, 2007). In their study Danso-Appiah et al. (2010) find that perceived severity is the main and most important predictor or determinant of whether the subject will seek care or visit a health facility. Howell et al. (2008) find that many patients seek help if their symptoms become progressively worse.

2.6.4.2 Perceived threat: the belief that one is susceptible to a problem. The perception of a personal health threat is itself influenced by at least three factors: general health values, which include interest and concern about health; specific beliefs about vulnerability to a particular disorder or disease; and beliefs about the consequences of the disease or disorder. When an illness causes anxiety about its cause and progression, therapy is sought (Golooba-Mutebi & Tollman, 2007).

2.6.4.3 Perceived benefit: the belief that a particular health practice will be effective in reducing the threat. Whether or not the perception of a threat leads to changed health behaviour also depends on whether a person believes a health measure will reduce the threat. This factor also breaks down into two subcomponents: whether or not the individual thinks a particular health practice will be effective against the disorder in question,

and whether or not the cost of the measure undertaken exceeds the benefits of the measure (Taylor, 1995). The perceived benefit factor emphasises that patient's satisfaction with treatment plays an important role in help seeking (Rahman et.al, 2011). Corno (2011) finds that previous health outcomes play a crucial role in shifting individual preferences to a particular type of care. She indicates that patients who were healed by a particular healthcare system, either formal or informal, are likely to seek care from that particular system in the future and those who remained sick are likely to switch to an alternative system (Corno, 2011). If treatment is assessed as ineffective, help-seeking may become cyclical, and further information and advice or further treatment may be sought and accessed (Pearson & Makadzange, 2008).

2.6.4.4 Perceived barriers: a perception of the obstacles to help seeking. There are factors that exist as barriers to help seeking. Golooba-Mutebi and Tollman (2007) indicated that these are distance, confidentiality, a shortage of medicine especially for chronic illnesses, and poverty.

In this model people's help-seeking behaviour is preceded by a decision-making process that is governed by the individual's perceptions of the nature of the illness, followed by perceptions of the effectiveness of a treatment modality. People are assumed to rationally weigh their options and take action once they have adequate information and perceive that change will benefit them (Adedimeji, 2005). The perceived nature of an illness may necessitate their seeking care from various health providers. However, when treatment fails there may be a return to the health provider or an alternative care provider might be sought.

According to this model, help-seeking behaviour is based on the cognitive perception of the person who seeks help. People's health beliefs strongly influence their health and illness behaviour. Such beliefs influence whether people treat themselves or consult with health-care providers. In their study conducted in South Africa among children's caregivers, Spark-du Preez et al. (2005) indicate that beliefs as determined by religion, background and the influence of an older relative are important for deciding whether or not a child is given traditional medicine.

Plummer et al. (2006) conducted a study examining general illness, sexually transmitted infection and HIV/AIDS treatment-seeking behaviour in Tanzania. They found that treatments were pluralistic and opportunistic, usually beginning with home remedies, followed by visits to traditional healers and/or health facilities. However, traditional healers were preferred to health facilities because of the subjects' perceptions of the cause, nature and severity of the illness, as well as the perceived benefits of accessibility, trust, familiarity, and payment plans. In addition, traditional healers were believed to be able to successfully treat bewitchment (perceived effectiveness), which was important as the illnesses were perceived to be the result of bewitchment. Plummer et al. (2006) further indicate that most of the individuals stopped attending health facilities because they came to believe that they could not treat witchcraft-induced illnesses (a perceived barrier).

CHAPTER 3

RESEARCH METHODOLOGY

3.1. Introduction

This chapter focuses on the methodological framework used in the study. The chapter will start by focussing on the research design, which highlights the approach of the study, followed by a description of the sampling, which outlines how the population of the study was selected. This chapter will also discuss the method used in collecting and analysing data, and how the researcher ensured the reliability, validity, and objectivity of the study. Lastly, the ethical issues that were considered in this study will be discussed.

3.2. Research design

This was a qualitative study which was conducted using a descriptive phenomenological approach with the aim of exploring pre- and post-HIV diagnosis help-seeking behaviour by patients receiving antiretroviral treatment. Qualitative studies describe and interpret people's feelings and experiences in human terms rather than through quantification and measurement (Terre Blanche, Durrheim & Painter, 2008). Phenomenological research is concerned with exploring the lived experiences of people. Its aim is to understand the phenomena from the perspective of the participant (Marks, Murray, Evans, Willig, Woodall & Sykes, 2005).

3.3. Sampling

The population for this study was defined as patients diagnosed with HIV and receiving antiretroviral medication from the Witbank Hospital of Mpumalanga Province (South Africa) during the sampling time period. A purposive sample of ten (10) HIV-infected patients was interviewed. The small number of participants was chosen. According to Ritchie and Lewis (2003), qualitative samples are usually small because qualitative investigation aims for depth as well as breadth of the phenomenon. The analysis of large numbers of in-depth interviews would be unmanageable. The researcher continued to interview each of the patients so identified until a saturation point was reached. Saturation was achieved after 10 interviews with 10 participants. Saturation is the point at which the researcher no

longer encounters new information or continually encounters the same information (Pitney & Parker, 2009).

Purposive sampling, which was the sampling method used in the study, is a nonprobability method of sampling that is based on selecting individuals according to the purpose of the researcher. Individuals are selected because of their possession of some characteristic (Paler-Calmorin & Calmorin, 2007). In this study the selection criteria included the following:

- 3.3.1.** Patients diagnosed with HIV according to clinical evidence. Knowledge of a person's HIV status can be obtained only by seeing the results of a person's HIV test. In this study patients were selected from the HIV clinic within the hospital and information was also obtained from the participants' hospital files.
- 3.3.2.** Patients from the age of 25 years and above.
- 3.3.3.** Those who are willing to participate in the study. The criterion of willingness to participate was a very important criterion in the study. According to Orb, Eisenhauer and Wynaden (2000), the desire to participate in a research study depends upon a participant's willingness to share his or her experience. In other words, participants are autonomous people who will share information willingly.
- 3.3.4.** Participants who are able to communicate verbally, because the research was based mainly on dialogue with the participants.
- 3.3.5.** Participants with a CD4 count that ranged from 200 and above. This criterion was as a result of selecting participants who would be able to understand what the interviews were about and participants who would be able to give accurate information without any form of mental disturbance or limitation. As described by Paul et al. (2002), there is strong evidence that cognitive impairment is more common in patients with a very impaired immune function - usually with a CD4 count of less than 200 cells.
- 3.3.6.** Participants who had already started on the antiretroviral medication.

Participants were recruited from among the out-patients at the hospital's HIV clinic (the Wellness Clinic within the Witbank Hospital). Patients who came to collect treatment and those who came for medical review were approached and asked to participate in the study. The participants consisted of five males and five females between 30 and 50 years of age. Their CD4 count ranged from 234 to 510 cells/mm³. The participants had all been on the antiretroviral treatment, since their diagnosed between 2004 and 2011, and all of them had started taking the treatment in the year of diagnosis.

3.4. Data collection

The researcher used in-depth semi structured one-to-one interviews during the performance of the study. According to Marks et al. (2005), semi-structured interviews are designed to explore the participant's views of things with the minimal amount of interference from the interviewer. The respondents are able to express their opinions, thoughts and feelings freely using their own words in ways that are less constrained by the particular wording of the questions. A pre-drafted interview schedule was used to ensure that the core research questions were answered. A pre-drafted interview schedule or guide is a list of questions or general topics that the interviewer wants to explore during each interview, which helps to keep the interactions focused and helps to make sure that the core research questions are answered. Although this list is prepared to ensure that basically the same area of information is covered with each participant, there are no predetermined responses (Hoepfl, 1997). The interviews were recorded, professionally transcribed and other information, such as age, gender, level of education, and CD4 count, was recorded through taking written notes.

The interviews were conducted in the participants' home languages, which were mainly Sotho and Zulu and were recorded on audiotapes. Before the recording took place the researcher explained the aims and objectives of the study to the participants. When a participant agreed, a consent form was signed and then the researcher would record the subject's demographic information through taking written notes. For the purpose of confidentiality, the researcher avoided referring to participants by name during the interviews, to avoid recording the names on the tapes. During the data collection period questions were added and/or revised

according to emerging information during the review of the recorded interviews. Interviews were repeated until no new themes emerged. As described above, saturation was achieved after 10 interviews with 10 participants. The interviews that had been recorded were then sent to a professional to be transcribed and translated from the participants' language of origin into English.

3.5. Data analysis

Interpretative phenomenological analysis was used to analyse the data. This method of analysis focuses on the cognitive processing of the participants. It is concerned with exploring meaning-making rather than information processing. The aim of interpretative phenomenological analysis is to explore in detail how participants are making sense of their personal and social world. It attempts to explore personal experience and is concerned with an individual's personal perception or account of an object or event (Smith & Osborn, 2003). According to Marks et al. (2005), interpretative phenomenological analysis involves taking the following steps, which were followed in analysing data in this study.

3.5.1. Familiarisation and immersion

The researcher began by listening to the tape recordings repeatedly, to extract the true meaning of the data obtained. All of the transcripts were read repeatedly and compared with the recordings. The researcher then read through all of the interview transcripts, obtained an overall understanding of the data, made notes on the transcriptions and identified features of interest in the text. Each transcribed interview was read over several times to understand the contents.

3.5.2. Inducing themes

The researcher then re-read the text and developed a higher-order thematic analysis by deducing general rules or classes from specific instances. Having identified the key themes or categories in the transcripts, the researcher then proceeded to look for connections between them by identifying clusters. Similar ideas were identified and grouped to form themes. Thereafter the themes were again identified from each interview by word, and a list of the main themes was made.

3.5.3. Coding

Coding involves reducing the data in an analytically relevant way. This entails marking different sections of the data as being instances of or relevant to one or more of the themes. A combined list of themes from all ten interviews was drawn up and the integration of the themes in the combined list was performed so as to establish similarities and differences.

3.5.4. Elaboration, interpretation and checking

In this step the researcher kept on coding, elaborating and coding until no further significant new insight appear to emerge.

3.5.5. Presentation of results

This step includes writing an account of the phenomenon studied. The data was then presented in text form, outlining the meanings inherent in the participants' experience. This part of the work is covered in detail in Chapter 4 of this paper.

3.6. Reliability, validity and objectivity

In this study reliability, validity and objectivity were ensured by undertaking the following:

The researcher ensured that the participants were given an opportunity to refuse to participate in the study so as to ensure those who participated in the study were only those who were genuinely willing to take part, and to offer information freely and honestly. The researcher utilized a previously drafted interview schedule to ensure that the participants were asked the same questions. Adequate time was spent on the core research questions in each interview, with the interviewer allowing the topic to be exhausted, which was when no new information was emerging. At the end of each interview the researcher would highlight the salient points she had gathered from the participant, to confirm that this was what the participant meant to say. All of the transcripts were read repeatedly and compared with the recordings to confirm the accuracy of the data. Rational analysis followed, where the researcher continued to look at the data to see if the patterns fitted together logically, and if the same elements could be arranged to constitute an entirely different pattern. The reliability

and validity of the study were further ensured by submitting the analysed data for confirmation to a different researcher to look for identical patterns and to an external reader who could recognize the logic of the experience and how it related to his or her own experience.

3.7. Ethical considerations

Consent to conduct this study was obtained from the Research and Ethics Committee of the University of Limpopo and the Mpumalanga Provincial Department of Health. Permission to gain access in the hospital was obtained from the office of the Chief Executive Officer (CEO) at Witbank hospital. Since the study would deal with sensitive and very confidential issues, the researcher ensured that the physical location where the interviews took place provided for the privacy of the participants. Permission was given by the hospital to use the hospital's consultation room. Therefore, individual interviews with the participants took place in the consulting rooms at the HIV clinic (the Wellness Clinic) within the hospital. Furthermore, care was taken to ensure that the participants understand what was involved when they were recruited for the study, and how they were being recruited. Along with this, the principles of the voluntariness of their participation and their freedom to decline or withdraw during the study were emphasised and explained thoroughly to the participants. Permission in the form of written informed consent was obtained from each participant after they had been thoroughly and truthfully informed about the purpose of the interview and the investigation before engaging in the interview with the researcher.

The participants were made aware that the study might be perceived as dealing with private, painful and perhaps embarrassing issues; therefore confidentiality, autonomy and privacy was assured and emphasised. The participants were also assured that they would be protected against any harm, be it physical or emotional. At some point during the interview process there were some participants who were affected emotionally. In such cases, the researcher had to stop the interview and refer such participants to the hospital psychology professionals. Participants who had additional medical complaints were also referred for medical attention.

CHAPTER 4 RESULTS

4.1. Introduction

In this chapter, the researcher will first present the demographic profile of the participants. This will be followed by a presentation of the themes that emerged from the phenomenological explication of the data. In this regard, the following themes were identified: (a) The perception of HIV and its causes; (b) The experience of the hospital treatment; (c) Presentation to the hospital; (d) Pre-and post-HIV treatment methods; (e) The perception of other treatment methods and; (f) Help-seeking determinants. The chapter is concluded by giving a summary of the findings.

4.2. The socio-demographic characteristics of the participants

As reflected in Table 1 below, there were 10 participants (male = 5; female = 5), aged between 30 and 50 years, who were recruited to participate in the study. The participants' CD4 count ranged from 234 to 510 cells/mm³. All of the participants had started on the antiretroviral treatment and had been on treatment since they were diagnosed between the years 2004 and 2011. In terms of language diversity, half of the participants spoke isiZulu whilst the other half were Sotho speaking.

Table 1: Socio-demographic characteristics

Participant's Identification	Age	Home Language	Level of Education	CD4 count Cells/mm ³
1	35	Sotho	Completed sec school	264
2	45	Zulu	Did not complete sec school	365
3	37	Sotho	Did not complete sec school	238
4	32	Zulu	Did not complete sec school	478
5	43	Zulu	Did not complete sec school	347
6	30	Sotho	Completed sec school	510
7	41	Zulu	Completed sec school	251
8	32	Zulu	Completed sec school	234

9	50	Sotho	Did not complete sec school	268
10	46	Sotho	Completed sec school	251

4.3. The themes that emerged

4.3.1. The perception of HIV and its causes

From the accounts given by the participants, it appears that most of them have some knowledge of HIV and how it is transmitted. The participants were of the view that the HIV condition is mainly transmitted from one person to another, mainly through sexual intercourse and contact with contaminated blood. Furthermore, the participants tended to accept their status and to understand that HIV, like any other illness, could infect or affect anyone. The participants further emphasised the importance of treatment adherence in order to effectively manage the condition. The following extracts illustrate the above points:

“HIV may be transferred through sexual intercourse. If one engages in unprotected sex one may be infected with HIV.” (Participant 10)

“HIV is caused by sexual intercourse. Sometimes you get it when you help someone at an accident scene when one gets the blood of someone into his bloodstream through contact.” (Participant 1)

“I leaned it is transmitted by sexual intercourse and when one gets into contact with someone’s blood into maybe an open wound... Cuts and accidents, but from infancy I only knew that it’s caused by sexual intercourse.” (Participant 5)

“When one lives carelessly with regard to sexual practices one can get HIV, but if one is honest to their partners they may not get it. One can also be at risk if they go sleep around with more than one partner.” (Participant 2)

“In my understanding HIV is a virus that enters the body through sexual intercourse. When one has HIV one doesn’t feel any pain in their body.” (Participant 6)

“It is caused by sexual intercourse....I think is sexual intercourse only.” (Participant 3)

“Sometimes HIV comes through sexually transmitted infections. From there you can get it through blood contact, when cutting your hair with a razor or machine.” (Participant 9)

“In my understanding it’s a disease that anyone can get. Because there is no small death but there is death, but at least now God has provided us with some treatment for this disease...” (Participant 5)

“I can say that if one accepts that they have HIV, and take their treatment regularly they may live longer.” (Participant 2)

“HIV is like any other disease, as long as you take your treatment accordingly.” (Participant 1)

“They say if you have this disease you need to take your medication accordingly and on time and that when having sex with a partner one needs to use a condom.” (Participant 3)

“What I can explain is what I found out after I went to a doctor that HIV is caused by sexual intercourse. After you have been diagnosed HIV positive you need to visit a doctor so that he can identify what tablets are right for you; as it happened to me when I started taking these ARVs.” (Participant 7)

“I do understand this disease but not that much. I compare this disease to TB; you need not worry about it or stress yourself about what other people will say, because everyone is living their own life.” (Participant 9)

4.3.2. The experience of the hospital treatment

The findings of the study suggest that most participants benefited from the hospital treatment. They experienced the treatment and their relationship with hospital staff

and the health practitioners as satisfactory. The following extracts reflect this level of satisfaction by the participants:

“Since 2007 I never took any other medication because this one is treating me well.”
(Participant 2)

“It treats me well because when I take it, I feel healthy, I don’t feel any pain. I am also diabetic and my feet sometimes feel so stiff. But even my diabetic problem was attended by the same doctors who told me how to take care of it, how to wash my feet to prevent ulcers.” **(Participant 2)**

“These tablets help me a lot.” **(Participant 1)**

“Since last year taking this treatment and I feel this medication is helping me, I am now able to eat and I feel healthy and my body is not weak in any way.” **(Participant 7)**

“I am satisfied here in hospital, the treatment is fine and the nurses are also patient with us...” **(Participant 5)**

“It [the hospital treatment] treats me well because I manage to eat food and it doesn’t cause me to vomit or become dizzy, because the saying goes that if something makes you vomit it’s not treating you well.” **(Participant 5)**

“My health is improving a lot but I am now concerned with my viral load, it is too high, but otherwise my health is improving.” **(Participant 5)**

Whilst the treatment was experienced by the participants as satisfactory, most of them were also concerned about the unpleasant side effects of the medication, as reflected in the extracts below:

“My only problem now is my ears and eyes I think these are side effects of the medication.” **(Participant 5)**

"It treats me well but there were some tablets that were creating a headache for me, but they were changed and now I am fine." **(Participant 4)**

"It is fine, it works well on me. I started it in 2010. During 2010 it was not treating me well... I had side effects then they changed me to another medication, now I am fine..." **(Participant 1)**

"Currently I am not experiencing any problems, but a few months ago I had sore legs but I have explained that to the doctors, I do feel pains sometimes but it does not bother me that much." **(Participant 7)**

"For me I never had site effects, but in the beginning when I started taking the tablets my body was itchy and it was disturbing me at night. I could not sleep well." **(Participant 8)**

"I continued with it and I got used to it... It didn't last long, until today I don't have problems, I do not want to lie." **(Participant 8)**

"I used the treatment for a month and I started feeling dizzy and not having energy until I got used to them. After I got used to the treatment I started to have more energy. My feet were able to function since they didn't when I started the treatment, at the moment I am able to walk for a long distance, I can walk to Klipfontein and Tasbet Park but in the beginning I couldn't even reach the police station which is nearer than Klipfontein and Tasbet Park." **(Participant 9)**

Looking at the above extracts, it is noteworthy that the participants who experienced the side effects did not opt to default from their treatment. Instead the participants opted to either continue with their medication until their bodies adjusted, or in some cases they went back to their medical practitioners to have the medication reviewed.

4.3.3. Presentation to the hospital

It does appear from the accounts obtained that most of the participants were not aware that they were HIV positive when they first came to the hospital. They initially presented with other ailments that they did not seem to associate with HIV. It was

only when they were given the diagnosis that they started to take note that the initial ailments that brought them to the hospital were symptomatic of the HIV condition. In some cases, some of the participants were brought to the hospital when they were critically ill. The following extracts illustrate these points:

“Before I came here I used to have tonsils, and when I arrived here they requested me to test for HIV. When testing me, they found that I am HIV positive. Then I accepted it and disclosed to my family.” (Participant 2)

“I started having sores in my face then I came to the hospital. This other doctor requested me to take a blood test to find out what kind of disease I was suffering from. After two or three weeks the results came back and I was HIV positive and my CD4 count was then 163. Then I started with a treatment but it failed because my viral load was too high and my CD4 count was very low.” (Participant 10)

“I was raped. Then the doctor did a blood test and found out that I have a problem, that I was already infected.” (Participant 3)

“I was already sick, therefore I went to the clinic where I was diagnosed and they said my CD4 count was low and referred me here.” (Participant 4)

“With me, as I was sitting at home one day I started feeling sick, my partner disclosed to his friend that he is HIV positive and the friend asked him if he told me and he said no. I was wondering why he was no longer intimate with me and I heard after he died that he was HIV positive and by then I was critical. I found out here in hospital that I was HIV positive.” (Participant 5)

While various illnesses other than HIV were the reason most of the participants came to consult in the hospital, there were two participants who presented to the health-care systems with concerns of HIV, although there were some causal factors. The following are their explanations:

“I started (treatment) in 2004. What happened was that I started sweating at night, then I went to the clinic and I heard them talking about HIV, how the disease

progress and I wanted to find out more, then I was referred to the hospital, that is where the doctor tested me and found out that I am HIV positive.” (Participant 9)

“My parents and my sisters at home encouraged me. What happened was that my girlfriend died of HIV, so at home they encouraged me to come here, to get counselling so that they can explain to me in detail about this disease and to be cured.” (Participant 8)

4.3.4. Pre- and post- HIV treatment methods

The results of the study suggest that most of the participants had been using Western medicine for their ailments even before they were diagnosed to be HIV positive. They would consult private medical practitioners and would go to clinics and hospitals when they had some health problems. Only a small number of the participants (two out of ten) indicated that they had sought treatment from traditional or spiritual healers for their conditions. The following extracts reflect these views by the participants:

“I used to go to clinics.” (Participant 1, 4, 5, 9, & 10)

“I used to go to hospitals.” (Participant 6)

“...right from the start when I started feeling ill, I visited the hospital.” (Participant 3)

“I used to go to a clinic here in town. When they found out that I am too sick they referred me to the hospital. They have referred me here for several times.” (Participant 10)

“I had never used traditional medicine, or traditional doctors. I was always going to clinics and hospitals.” (Participant 2)

“I used to go to doctors at the surgery at Nkomazi where I used to stay. ... Mostly it was Western doctors. That’s where I used to consult and get my medication.” (Participant 7)

“At that time we were using traditional herbs.” (Participant 8)

“...I never went elsewhere to seek help after I started with the hospital treatment. However, before the doctor explained to me I used to visit churches wanting to know what troubled me.” (Participant 9)

The results further indicate that after the diagnosis of HIV almost all of the participants (100%) are using the hospital treatment; but only one participant is using a traditional method of treatment involving the use of herbs, throwing up etc. concurrently with the western treatment.

“I just requested for a blood test at the hospital, after that I started to take the treatment.” (Participant 3)

“I did not seek help anywhere else (after the diagnosis) because I do not believe in getting help anywhere else.....my faith is that here in hospital they will be able to help me.” (Participant 6)

“I don’t want to lie... I did not go anywhere else. I chose to stick to the treatment the doctor prescribed for me.” (Participant 7)

“As soon as I found out that I am sick, I started to take this treatment, I never used other treatments. I am using the hospital tablets only.” (Participant 8)

Interestingly, it emerged that even after the HIV diagnosis most of the participants opted to adhere to hospital treatment. Even for the one participant who had used hospital treatment and traditional medicine concurrently, there was recognition that this combined treatment is not the best arrangement, as reflected in the extract below:

“There is nothing preventing me from using other treatments, in fact if there is something prescribed for me elsewhere I do use it. However, that depends on

whether it works well with the hospital treatment, because sometimes I do use them at the same time, but if it does not work well with the hospital treatment I stop the other treatment. ...I can feel it in my body (if it does not work). Sometimes it causes swellings or it can cause a running stomach and I will know it's the other treatment because I am used to the hospital treatment which does not cause any complications for me anymore. But if it does that I can either stop the other treatment completely or I will look for another one.” (Participant 9)

Based on the above accounts, it does appear that the participants in the study appreciated the importance of antiretroviral treatment for their conditions. They did not seem to have any desire to try other forms of treatment for their HIV conditions.

4.3.5. The perception of other treatment methods

From the interviews it is apparent that most participants did not perceive other treatment methods as being useful in the management of their HIV condition. Instead, they tended to perceive traditional forms of treatment, like herbs, as less helpful in managing their conditions. The following extracts illustrate the participants' views about other treatment methods:

“...other help would be herbs while herbs are not accepted here in hospital” (Participant 3)

“Going somewhere else, I know they will try to help but they are going to give me some herbs that might cause me to vomit or cause me a running stomach, while the hospital treatment is trying to build my immune system...I got this from the hospital; we got some counselling when we started with the treatment.” (Participant 3)

“During counselling they told us that if you are taking the hospital treatments you are not supposed to use traditional herbs that will cause a running stomach or make you throw up, you must use the tablets only. Because you don't know if using these herbs will make you weak and the herbs will also take out the tablets in your body when you throw up or when having a running stomach.” (Participant 8)

“...when we get here at the hospital we get counselling and they told us that when we are taking this treatment we are not supposed to take other medicines like using laxative, or going to other health practitioners and besides that when I am here I am fine.” (Participant 10)

“I heard that if you use the hospital treatment with other treatments such as traditional medicine, the treatments would not work properly, so I believed what I heard and I had to choose one treatment and I chose to continue with the Western treatment.” (Participant 7)

“...if I decide to go to Ermelo (to a traditional doctor) for help and if things are not going well there I will be forced to come back here, therefore I will stay here as long as I will manage to go to work.” (Participant 5)

4.3.6. Help-seeking determinants

The findings of the study indicate that the participants were influenced by several factors in seeking treatment for their HIV conditions. Support from significant others (like family members and friends) and a sense of belonging appeared to be the main determinants that motivated the participants to seek help and to adhere to the treatment regimen. The following are some of the views expressed by the participants:

“...at home they encouraged me to come here [to the hospital] to get counselling so that they can explain to me in detail about this disease and to be cured.” (Participant 8)

“They [people who are close] don't have a problem as they encourage me to take my treatment.” (Participant 6)

“At home they understand that HIV is a common disease. So they don't have a problem with this treatment.” (Participant 10)

“...they [family members] are supporting it [the hospital treatment] a lot.” (Participant 5)

“Talking to other people about your problem and most of them they encourage you to go to the hospital and to take your treatment...” (Participant 1)

“...they [people who are close] are fully supporting me sometimes they accompany me to collect treatment here at the hospital.” (Participant 9)

“It didn’t affect them [family members] that much, since we had family members who were HIV positive, and have already passed away. My wife accepted it also, and she also started with treatment.” (Participant 2)

On the other hand 20% did not disclose to significant others because of their fear of HIV as a fatal disease and their fear of being stigmatized. The following quotations elucidate this:

“I feel sorry for my children in case I die. Even now I am afraid to disclose to them, they don’t even know why I am taking this medication.” (Participant 4)

“I didn’t want to talk to people about my status because people have a tendency of stigmatizing and gossiping about you... I have not disclosed to her (his partner) yet and she doesn’t know I am taking this treatment... I did not even disclose to my family.” (Participant 7)

Having a sense of belonging and having live role models also appeared to be influential factors in treatment seeking and adherence. The participants seemed to be verbally encouraged by people who suffered from the same condition to take their treatment, and they could also see the health improving of the people who were taking the treatment. The following quotations are illustrative:

“...besides getting positive advices from people who are also infected with this disease, they used to tell me that I have a serious disease, so when a doctor prescribe a treatment for me I need to stick to it, so I did not go anywhere else but chose to stick to the treatment the doctor prescribed for me.” (Participant 7)

“I was in a support group, the support group arranged a trip to Limpopo, we were showed people with HIV and were healthy and beautiful. I could not believe they had HIV, and I wanted to be like them, I do not know about others but I just knew I wanted to be healthy like them, and by then I was critical, my CD count was 47.”

(Participant 5)

*“...seeing other people getting helped, many of them who have TB, who have HIV and who take this treatment, their health improves.”***(Participant 6)**

4.4. Summary of findings

Ten participants between the ages of 30 and 50 years participated in the study. The participants had all started on the antiretroviral treatment and had been on treatment since they were diagnosed. In terms of language diversity, half of the participants spoke isiZulu whilst the other half were Sotho speaking. This study revealed that the participants had not been aware of their HIV status when they first presented to the hospital. The ailments that they initially presented with were not associated with HIV and were the compelling reasons for the participants to get tested. The results also indicated that the participants delayed seeking help.

The results of the study also revealed that the participants know of HIV and how it is transmitted. Furthermore, they tend to perceive HIV as similar to any other chronic condition that can be effectively managed. The findings further revealed that the participants benefit from the antiretroviral (ARV) therapy and from other services they receive at the hospital, such as HIV counselling and treatment from the hospital staff. The results also indicated that most of the participants had been utilizing western medicine even before they were diagnosed. Even post the HIV diagnosis they opted to adhere to hospital treatment and had no desire to try other forms of treatment. The participants were of the opinion that other forms of treatment could have a detrimental interaction with the hospital treatment. The results further indicated that help seeking and adherence to treatment is determined by factors such as receiving support from significant others, a sense of belonging, and a sense of sharing similar sentiments with others.

CHAPTER 5 DISCUSSION

5.1. Introduction

In this chapter the findings will be discussed in the context of the existing literature. These findings will also be discussed according to the emerged themes presented in Chapter 4. This will be followed by the discussion of the results in accordance with the theoretical framework that informed the present study, and a setting out of the implications of the theory.

5.2. Emerged themes

5.2.1. The perception of HIV and its causes

In this study, the participants were found to have knowledge about HIV and how it is transmitted. The participants were of the view that HIV is transmitted mainly from one person to another, mainly through sexual intercourse and contact with contaminated blood. This supports the findings of Odu and Akanle (2008) and Djokic et al. (2009); they also reported to have found high basic knowledge on HIV and knowledge about transmission risk factors among participants in their studies. This study also supports the views of Mishra, Agrawal, Alva, Gu and Wang (2009), that in most sub-Saharan countries comprehensive knowledge about HIV has increased. However, Chomat et al. (2009), Odu and Akanle (2008) and Djokic et al. (2009) found that despite the basic knowledge their participants tended to engage in high-risk sexual activity, and that some of them tended to be misinformed that treatment and prevention exist.

The participants in this study tended to accept their status and they were of the opinion that HIV, like any other illness, could infect and affect anyone and could be effectively managed through adherence to treatment. Luseno, Wechsberg, Kline and Ellerson (2010) indicate that denial of one's HIV status may be the barrier to care, leading participants to avoid utilizing health service specific to their disease. According to the literature cited in Gilbert and Walker (2009) and Campbell, Scott, Madanhire, Nyamukapa and Gregson (2011), with the availability of ARV medical treatment HIV is now transformed from an acute life-threatening condition to a chronic disease which can be effectively managed through on-going hospital visits and a carefully managed drug regime.

Jain et al. (2006) state that the conceptualisation of the aetiology of health problems and the perception of an illness are important factors in deciding the first step in treatment seeking. In this study, HIV was found to be attributed to biomedical causation. As this was the case with the conceptualisation of the condition in this study, the decision on how and where participants sought help is explored and discussed later in the chapter.

5.2.2. The experience of the hospital treatment

The hospital treatment was found to be of greatest benefit to the participants in this study. The antiretroviral therapy itself, the experience of the hospital staff and the relationship of the participants and their health-care providers was found satisfactory by the participants. This study tends to lend support to studies conducted by Gilbert and Walker (2009) and Mhlongo (2010) which revealed that ARVs are transforming the experience of living with HIV/AIDS. Patients share positive outcomes and experiences. They see the ARVs as life-saving and have expressed their long-term commitment to adhere to the drug regimen, as well as their trust in the health professionals. According to Mhlongo (2010), the positive outcomes and experiences among others included an improvement in physical, social and emotional wellbeing as well as a greater sense of optimism about the present and the future.

This study also gives support to the findings of Mhlongo (2010) and Abelheim (2011), that positive experience such as support from health care providers and positive relationship serve as motivators for patients to continue care. In line with the above mentioned studies, Campbell et al. (2011) also emphasise the importance of the health-care providers' (the nurses') kindness, understanding, confidentiality and acceptance (i.e., treating patients like normal people) to inducing the patients to adhere to the regimen of medication.

Whilst the treatment itself was thought by the participants to be satisfactory, most of them were concerned about the unpleasant side effects of the medication. This finding tends to lend support to the views of Sidat et al.; Vervoort et al. and Golin et al. (cited in Mhlongo, 2010), that although people living with HIV/AIDS perceive HIV medication as life-saving there are concerns about the effects and the demands of the medication. However, it is noteworthy that the participants who experienced the

side effects did not opt to default from their treatment. Instead the participants opted either to continue with their medication until their bodies adjusted or, in some cases, to go back to their medical practitioners to have the medication reviewed. These findings support those of Gilbert and Walker (2009), who also find that despite the difficulties attached to taking ARVs, respondents signalled their willingness to adhere to the medication.

5.2.3. Presentation to the hospital

This study found that most of the participants were not aware of their HIV-positive status when they first came to the hospital, and that they did not seem to associate their initial ailments with HIV. It was only after the HIV diagnosis that their initial ailments were understood as symptomatic of the HIV condition. These findings give support to the findings of Mhlongo (2010) that most participants highlighted that before knowing their HIV-positive status they were suffering from multiple illnesses.

Studies indicate that many challenges face people who need to determine their HIV status including fear of HIV as a fatal disease, fear of being blamed, rejected and stigmatized, lack of knowledge and insight about HIV, false beliefs and denial (Mohammadpour et al., 2009; O'Mahony et al., 2010; Semakula, 2010). Discovering that one has any serious illness can be a traumatic experience, and these psychological challenges can affect when and how people decide to be tested (Mohammadpour et al., 2009). According to Lorenzo and Zhou (cited in Mohammadpour et al., 2009) whatever the outcome, HIV test results can change the entire context of an individual's life. However, Mohammadpour et al. (2009) indicate that knowledge of one's status could lead to a healthier lifestyle, counselling, medical treatment and a delay in the progression of HIV to AIDS. Mohammadpour et al. (2009) further indicate that treatment and prevention implemented as early as possible also help to prevent HIV transmission to others.

Some of the participants in this study were brought to the hospital when they were already critically ill. These findings give support to the study of Mohammadpour et al. (2009), who also found that people often showed up at the clinic after a long delay and some of them found out they had HIV only after having advanced symptoms of the disease. The findings of Semakula (2010) suggest that among other things,

ignorance and the lack of a perceived risk of infection with HIV were the reasons for delaying to take the test, and the reasons for the late presentation to the medical facilities.

5.2.4. Pre-and post- HIV treatment methods

According to the findings of the study, the participants had been using Western medicine for their ailments even before they were diagnosed to be HIV positive. They would consult private medical practitioners and would go to clinics and hospitals when they had health problems. Only a small number of the participants (two out of ten) indicated that they had sought treatment from traditional or spiritual healers for their conditions. This study supports the views of Steen and Mazonde (cited in Mackian, 2003) that 95% of patients visited a modern health facility as a first step in seeking help.

Interestingly, it emerged that even after the HIV diagnosis, most of the participants opted to adhere to hospital treatment. This suggests that the participants in the study appreciated the importance of antiretroviral treatment for their conditions. They did not seem to have any desire to try other forms of treatment for their HIV conditions. According to Mbonu et al. (2009), knowledge about HIV, which includes knowledge about one's HIV status, modes of HIV transmission and effective treatment, is important for people living with HIV if they are to obtain adequate care. In this study it was very clear that the attribution of HIV to biomedical causation led to help-seeking from scientifically developed health-care institutions (i.e., western medicine). The participants' knowledge about HIV and its medical causes found in the study also contributed to participants utilizing these medical services. This supports the views of Morrison et al. (2011) that a lack of knowledge of the medical cause of HIV is associated with barriers to care.

5.2.5. The perception of other treatment methods

It was found in the study that the participants did not perceive other treatment methods as useful in the management of their HIV condition. Instead, they tended to perceive traditional forms of treatment, such as herbs, as less helpful in managing their conditions. These findings support those of Gilbert and Walker (2009), who found that patients perceive ARVs as the means by which they survive. The ARVs

represent the possibilities of health and future, for without them the illness will prevail. Gilbert and Walker (2009) find that patients tend to perceive ARVs as being more useful in the management of their HIV condition than any other forms of treatment (i.e. traditional forms of treatment). In other words, the participants tend to believe that HIV can be treated only by biomedicine and does not respond to traditional therapy, as was the case with diabetes and high blood pressure in the study of Golooba-Mutebi and Tollman (2007).

It was also apparent in this study that besides the perception of the traditional forms of treatment as being less helpful, participants were also concerned about the interaction of traditional forms of treatment with the ARVs. They thought that herbs would have a detrimental interaction with the ARVs. According to Homsy (cited in Langlois-Klassen, Kipp & Rubaale, 2008), many of the therapeutic effects and pharmacological actions of herbal medicine remain unknown due to the relatively scarcity of rigorous scientific testing. Langlois-Klassen et al. (2008) further state that this knowledge deficit is particularly apparent given the lack of pharmacokinetic and pharmacodynamics studies examining interactions between herbal medicines and the ARVs. In this study one participant who was found to be concurrently utilizing ARVs and herbs reported that the concurrent use of these medicines at times had negative effects.

5.2.6. Help-seeking determinants

The findings of the study indicated that the participants were influenced by several factors in seeking treatment for their HIV condition. Support from significant others appeared to be one of the significant factors. This study also lends support to Gilbert and Walker (2009), Mhlongo (2010), Mohammadpour et al. (2009) and many other studies that have also found that support from significant others (children, employers, partners and families) plays an important role in help-seeking and in treatment adherence; and conversely, lack of support from significant others has been identified as a barrier. Barnett and Whiteside (cited in Golooba-Mutebi & Tollman, 2007) note that members of social and kin networks acting as therapy referees are important sources of advice on the causes of illness and on suitable treatment.

A sense of belonging and a sense of sharing similar sentiments as well as having live role models also appeared to be significant factors in help seeking and adherence to treatment in this study. The participants seemed to be verbally encouraged to take their treatment by people who suffer from the same condition and also by seeing the improvement in the health of other people who are taking the treatment. In this regard the participants felt they are not alone, that they are waging the same struggle as others, and that the ARVs improve the lives of others. These findings give support to the views of Mohammadpour et al. (2009) that support groups are essential to overcome the emotional upheavals after diagnosis with HIV and for treatment seeking and adherence.

5.3. The implications for theory

5.3.1. The Health Belief Model

As previously indicated in Chapter 2, this study was guided by the Health Belief Model. According to this model, help-seeking behaviour is influenced by the following factors: a). Perceived severity; b). Perceived threat; c). Perceived benefit; and, d). Perceived barriers. Generally, the findings of this study seemed to concur with this theoretical model. A belief in the seriousness of a health problem appeared to be the main motivating factor to the participants' presentation to hospitals. It appeared that the participants sought help in the latter stage of their ailments and initially these ailments were not perceived as being as serious as HIV-related conditions. This may also imply that the participants did not believe that they were susceptible to HIV. The study further concurs with the model in that the perceived benefit is an important factor in help-seeking and in the utilization of health-care systems. Participants expressed their satisfaction with the western health-care facilities. Western medicine was perceived to be effective in the management of the participants' HIV condition, and they did not wish to seek help anywhere else. In this study the perceived barrier against using other treatment methods was found to be the perceived possible negative effect that might result from the interaction of other treatment methods with the ARVs.

CHAPTER 6

SUMMARY AND CONCLUSION

6.1. Introduction

This chapter provides a summary of the research findings discussed in Chapter 5. This will be followed by describing the limitations of the study. Concluding comments and recommendations for future research are also presented.

6.2. Summary

This study investigated pre- and post-HIV diagnosis help-seeking behaviour by patients receiving antiretroviral treatment at Witbank Hospital. Ten patients who came to the Wellness Clinic (the HIV clinic) at Witbank Hospital to collect their medication and to be reviewed medically participated in the study. The findings suggest the existence of a lack of voluntariness in HIV testing and a delay in help-seeking. The study also suggest that knowledge about HIV and its modes of transmission, the conceptualisation of illness, the support of significant others and the presence of live role models, the development of positive relationship with health-care providers and the perceived effectiveness of treatment play an important role in treatment seeking and adherence. This study further illustrates the preference for western medicine pre- and post-HIV diagnosis over other treatment modalities.

This study should be of use especially to the health-care providers of patients suffering from HIV. The findings provide them with an understanding of the dynamics of the help-seeking behaviour of people suffering from HIV and can assist them to deliver beneficial services to patients as well as help patients to adhere to treatment. This knowledge could also be extended to policy planners to assist them in the development and implementation of HIV intervention programmes. In conclusion, the researcher affirms that the findings of the study support other research findings and theoretical frameworks on HIV help- seeking behaviour.

6.3. Limitations of the study

This study has some methodological limitations, as is the case in many qualitative studies. The study was performed with a limited number of participants. The sample size and the nature of the study limit the possibility of the generalization of the results

to a larger population of patients diagnosed with HIV. Another methodological limitation was the translation of data from the participants' languages of origin to English, which might have led to a failure to reproduce the true meaning of the original data.

The researcher had a limited time with the participants, as the participants were recruited while they were present to collect their medication or for medical review. They had been there from an early hour to get into the queue, and were therefore already in a hurry to be seen by the medical practitioner and queue for medication collection. For this reason the researcher had to rush the interviews so that the participants could be seen by their medical practitioners. This prevented the researcher from going into depth with some issues. However, the time was adequate for the researcher to cover the core research questions and to exhaust them.

Most participants had sought help from only one health-care system i.e. the western health-care system, which entailed visits to hospitals, clinics, or private doctors. This meant that information regarding their help-seeking pathways could not be obtained. Another limitation is that the participants were recruited from the hospital and this might have predisposed the participants to supply one set of answers which might have influenced the results resulting in the data being biased.

6.4. Contributions and recommendations

The current study shows that help-seeking behaviour is a dynamic process which is embedded mainly in the individual's perception with regard to the severity and the conceptualization of the health problem, the effectiveness of the treatment given, and social support experienced. The study has provided qualitative information to the existing literature on help-seeking behaviour related to HIV, and its contribution and recommendations may be summarized as follows:

- Further research with bigger samples needs to be conducted to make it possible to generalize the findings to the population of people living with HIV.

- Though the study was conducted with a small sample size, the researcher was faced with the question of whether help-seeking for medical conditions differs with the nature of the condition for which help is sought. For instance, do patients with mental illness seek help in the same way as those who are HIV positive? It could be interesting to conduct comparative research in this regard.
- The researcher further asserts that the study highlights the shift from a belief in the efficacy of traditional medicine to more scientifically-oriented treatment. Further research needs to explore this area, especially in South Africa.
- The study notes the underutilization of voluntary counselling and testing services. Patients do not voluntarily approach health facilities to seek HIV testing. This suggests that HIV infection is likely to continue and even become unmanageable.
- As suggested by the literature, HIV has long been regarded as fatal, difficult to accept, to live with and to deal with. The stigma that has been attached to it has also hindered the treatment and care of people living with HIV. Those living with HIV have made different health-care-seeking choices, which include the non-utilization of health-care institutions and the health services specific to their disease. However, this study shows that ARVs, the positive relationship of patients with health-care providers, and the availability of social support have transformed the experience and the help-seeking behaviour of people suffering from HIV.

The following recommendations are therefore made:

- On-going educational programmes should continue and be extended to communities at large about voluntary counselling and testing, for the early detection of HIV. This could lead to the provision of effective care, amelioration of the condition, prevention of HIV transmission to others and promotion of a healthy lifestyle among the population at large.

- The rendering of comprehensive and supportive services to people suffering from the disease should be continued in terms of support groups with the utilization of live role models, to encourage treatment-seeking and adherence to the regimen of medication. This support should extend to the significant others of the patients. It is further recommended that health-care providers maintain an empathic understanding and unconditional positive attitude towards service delivery to this special population.

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APPENDICES

Appendix 1(a): Participant consent letter and form

Department of Psychology
University of Limpopo (Turfloop Campus)
Private Bag X1106
Sovenga
0727
Date _____

Dear Participant

Thank you for showing interest in this study that focuses on pre- and- post HIV diagnosis help-seeking behaviour by patients receiving antiretroviral treatment at Witbank Hospital.

Your responses to this interview will remain strictly confidential. The researcher will attempt not to identify you with the responses you give during the interview or disclose your name as a participant in the study. Please note that your participation in this study is voluntary and that you have the right to terminate your participation at any time.

Please answer all the questions as honest as possible. Your participation in this research is very important. Thank you for your time and cooperation.

Yours Truly

Mohaleni M.P
Masters Student

Date

Prof T. Sodi
Supervisor

Date

Appendix 1(b): Participant consent letter and form in Zulu
Incwadi yemvume ne fomu lo mhlanganyeli

Umnyango weWezocwangisizo lwemiqondo nezompatho (Psychology)
We Nyuvesi yase Limpopo (Turfloop Campus)
Private Bag X1106
Sovenga
0727
Idethi_____

Mhlanganyeli othandiwe

Siyabonga kulabo abagqugquzela nakulabo abaseka loluphenyo olubhekene nesimo asiphambi kokuzithola nezimpawu zesandulala ngculali (HIV) kanye nesimo esingemva kokuzithola nesandulela ngculazi (HIV), kanye nokuziphatha kwe ziguli ezilashwa ngamaphilisi okulwa negciwane (ARV) esibhedlela sase Witbank.

Impendulo yomhlanganyeli kuloluphenyo izizogcinwa njengemfihlo. Umcwangisi akavunyelwe ukugcwangisisa izimpendulo zomhlanganyeli ezinikezwe kuloluphenyo, kanye nokuvezwa kwegama lomhlanganyeli. Umhlanganyeli iyexwayiswa ngokuseka loluphenyo uma engahambisani nezimpawu zophenyo unelungelo lokumisa uphenyo noma inini.

Uyanxuswa ukuthi uphendule ngokweqiniso. Ukuseka kwakho nokunakekela kubalulekile kakhulu kuloluphenyo. Siyabonga isikhashana osibonisile kuloluphenyo.

Obhalile

Mohaleni M.P

Umfundi weMasters

Prof T. Sodi

Umphathi

Idethi

Idethi

Appendix2 (a): Consent form to be signed by the participant

Consent Form

I _____ hereby agree to participate in a Masters Research Project that focuses on pre- and post- HIV diagnosis help-seeking behaviour by patients receiving antiretroviral treatment at Witbank hospital.

The purpose of this study has been fully explained to me. I further understand that I am participating freely and without being forced in any way to do so. I also understand that I can terminate my participation in this study at any point should I not want to continue and that decision will not affect me negatively in any way.

I understand that this is a research project, whose purpose is not necessarily to benefit me personally. I understand that my details as they appear in this form will not be linked to the interview scheduled and that my answers will remain confidential.

Signature _____

Date _____

Appendix 2(b): Consent form to be signed by the participant in Zulu

Ifomu lemvumo

Mina u _____ngiyavumelana nokuseka loluphenyo lwe phrojkethi yeMasters ebhekene nesimo asiphambi kokuzithola nezimpawu zesandulala ngculali (HIV) kanye nesimo esingemva kokuzithola nesandulela ngculazi (HIV) nokuziphatha kwe ziguli ezilashwa ngamaphilisi okulwa negciwane (ARV) esibhedlela sase Witbank.

Inhloso nencazelo yaluphenyo ngchazelwe. Ngiyazi angigqugquzelwanga ngokungehloso kuloluphenyo. Nginemvume yokumisa loluphenyo uma nginga hambisani nalo noma inini, ngiyazi ukuthi lesinqumo angeke size singithinte kabi.

Nginolwazi lokuthi loluphenyo lephrojekthi aluqondile ukungisiza ngasese. Nginolwazi futhi lokuthi imininingwanwe yami egcwaliswe efomini angeke isetshenziswe ngokuhlanganyela nocwaningo, kanye nezimpendulo zami zizophathwa njengemfihlo.

Signature _____

Idethi _____

Appendix 3: Permission to conduct research

Department of Psychology
University of Limpopo (Turfloop Campus)
Private Bag X1106
Sovenga
0727
Date _____

The Chief Executive Officer
Department of Health and Social Development
Witbank Hospital
Private Bag X7206
Witbank
1035

Re: Permission to Conduct Research within Witbank Hospital and to Use the Hospital Psychologists' Consulting Rooms

I am a registered student in the above-mentioned institution. As part of the requirement for the Masters degree in Clinical Psychology, I am doing a research project. The title of the research project is: **Pre- and post- HIV diagnosis help-seeking behaviour by patients receiving antiretroviral treatment at Witbank Hospital in Mpumalanga Province.** The purpose of this study is to understand help-seeking behaviour of patients in managing their HIV conditions.

I hereby apply to be granted permission to conduct this research within the Witbank hospital. It is important to point out that the researcher undertakes to maintain confidentiality regarding the identity of the participants in this research project. The participants will be assured about the voluntary nature of this study and further that they are free to withdraw from the study at any time should they wish to do so.

Given the sensitivity of the study, the participants will need to be interviewed in a very private environment within the hospital premises. In this regard, I do hereby

request the permission to be allowed to use the consulting rooms of the psychologists in your hospital for this purpose.

Yours Truly

Mohaleni M.P
Masters Student

Date

Prof T. Sodi
Supervisor

Date

Appendix 4(a): Interview guide

1. Share with me your understanding of HIV
2. Before you were diagnosed with HIV where did you seek help with regard to your health?
3. After you fell ill, what treatment methods were you using before you started going to the hospital?
4. Kindly share with me your experiences of the treatment that you were using before you came to the hospital.
5. What motivated you to seek help in the hospital?
6. Kindly share with me your experiences of the treatment that you have been receiving from the hospital.
7. What other treatments methods are you currently using?

Appendix 4(b): Interview guide in Zulu

1. Ngitsele mayelana ngolwazi lwakho ngesifo se sandulela ngculazi
2. Ngaphambi koku zithola uthelwe ngesifo sesandulela ngculazi uke wazama ukuzihlola mayelana nempilo yakho?
3. Ngemva kokuqala ukugula uluphi usizo olumayelana nokwelashwa kwakho oke walizama ngaphambi kokuthi uze lapha esibhedlela?
4. Ngicela ungichazisele kabanzi mayelana no sizo lokwelashwa kwakho oke walizama ngaphambi kokuthi uphumelele ukuza lapha esibhedlela
5. Ngabe kukhona into eyakuqguqguzela noma leyo eyakwenza ukuthi uzame ukuthola usizo lapha esibhedlela?
6. Ngicela ungichazele kabanzi ngemizwa yakho mayelana no sizo lokwelashwa kwakho osuke walithola lapha esibhedlela
7. Ngabe kunenye indlela yosizo lokwelashwa kwakho oyisebenzisayo njengamanje?