

Psychosocial care of people living with HIV: The case of Tzaneen, South Africa

by

STEVEN CHARLES MASHELE

Submitted in partial fulfilment for the degree

Master in Curationis

at

Stellenbosch University



Faculty of Health Sciences

Division of Nursing

Supervisor: Dr Kate Joyner

Co-supervisor: Dr Naeema Abrahaams

Date: March 2012

Declaration

By submitting this thesis electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the copyright owner thereof (unless to the extent explicitly otherwise stated) and that I have not previously in its entirety in or part submitted in for obtaining any qualification.

March 2012

Acknowledgements

My sincere thanks are first due to my fiancée Eunice Modiba for having encouraged me to take up the challenge of continuous learning. Without your encouragement my profession could have stalled.

I would like to extend my genuine gratitude to my supervisor Dr. K Joyner and co-supervisor Dr Naeema Abrahaams for having helped me to see the “bigger picture”. In recognising the potential that lay in the initial conceptualisation of the focus of study, you expanded its reach. For sacrificing time for your families and friends, and even your own work, I cannot thank you enough.

My unqualified thanks are also extended to HIV positive clients, lay counsellors, and managers of the facilities where this study was conducted. Even during industrial action you still participated in my study. You provided me with a space to work in and participated whole heartedly.

I thank my previous manager, Ms T.B. Nyathi, for having given me time to study. Despite your zeal to ensure that I focused on the work I was employed to do for you, you had a soft spot for my academic work. You chose to see it come to fruition.

To all others who assisted in making this project a success, I thank you all.

Abstract

The overall objective of this study was to ascertain whether lay counsellors offer psychosocial counselling to clients at antiretroviral therapy clinics. The study was conducted at two clinics in the Greater Tzaneen municipality, Limpopo province, South Africa. The sample of 14 consisted of seven female lay counsellors and seven HIV positive clients, three females and four males, at Xihlovo and Nyeleti antiretroviral clinics. They were interviewed using 11-item and 12-item interview guides, respectively. Interviews were conducted in the local languages. Qualitative data were collected for the study. The data were audiotaped, translated, transcribed and then categorised into a thematic framework. HIV positive participants were found to be suffering from psychosocial consequences of living with HIV, such as shock, denial, anger and blame, fear of death, fear of disclosure, and intimate-partner violence. However, lay counsellors did not offer effective counselling that could relieve the psychosocial consequences. They instead used religion to console clients, discouraged clients from expressing their feelings, and minimised their clients' concerns. It is recommended that lay counsellors be taught basic counselling theories as part of their training so that they are better able to screen their clients for psychosocial problems and provide basic counselling.

Opsomming

Die algehele doelwit van dié studie is om te bepaal of leke-beraders psigo-sosiale berading aan kliënte by die anti-retrovale terapie klinieke bied. Kwalitatiewe data is vir dié studie versamel. Die studie is by twee klinieke in die groter Tzaneen-munisipaliteit in Limpopo provinsie in Suid-Afrika gedoen. Die eksperimentele groep van 14 het bestaan uit sewe vroulike leke-beraders en sewe MIV-positiewe kliënte: drie vrouens en vier mans, by Xihlovo en Nyeleti anti-retrovale klinieke. Daar was onderskeidelike onderhoude met hulle gevoer en die 11-item en 12-item onderhoud-riglyne is toegepas. Onderhoude is in inheemse tale gevoer. Die data was opgeneem, vertaal, getranskribeer en in 'n tematiese raamwerk vasgevang. Daar is gevind dat die MIV-positiewe persone negatiewe psigo-sosiale gevolge ervaar: skok, ontkenning, woede, blaam, vrees vir die dood, vrees dat hul status openbaar sal word, asook geweld binne hul verhoudings. Leke-beraders het egter nie doeltreffende berading gegee om bogenoemde psigo-sosiale gevolge te verlig nie. Hulle het eerder godsdiens gebruik in 'n poging om hul kliënte te vertroos, nie die kliënte aangemoedig om hul gevoelens uit te druk nie en hul gevoelens en kommer afgemaak. Daar word aanbeveel dat leke-beraders basiese beradingsteorie as deel van hul opleiding ontvang sodat hulle psigo-sosiale probleme in hul kliente kan uitken en beter basiese berading kan verskaf.

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List of abbreviations

AIDS	Acquired immunodeficiency syndrome
ART	Antiretroviral therapy
HIV	Human immuno virus
NGO's	non governmental organizations
PLWHA	People living with HIV/AIDS
TB	Tuberculosis
VCT	voluntary counseling and testing
WHO	World Health Organization

CHAPTER ONE

INTRODUCTION

1.1 Introduction

This chapter briefly describes the study. It includes the reasons and motivation for conducting the study, the process followed in conducting the study, the objectives, ethical considerations, and limitations of the study.

1.2 Rationale

In the Mopani District municipality, within which the Tzaneen local municipality is situated, there is a 23.8% prevalence of HIV (Limpopo sero-prevalence survey report, 2007). The HIV prevalence in Tzaneen, a local municipality with a population of 330 000, in the province of Limpopo, is double that of South Africa (22% compared to 11.9%), while the provincial prevalence is slightly lower than the national estimate (8.8%) (Shisana et al., 2008: 32). HIV is thus a major health concern in this district.

Previous studies have identified a variety of psychosocial problems as a consequence of HIV positive diagnosis. They include, but are not limited to, trauma, depression and intimate partner violence (Dematteo et al., 2002; Berg et al., 2007; Brou et al., 2007). Socially, people living with HIV/AIDS (PLWHA) are faced with challenges, such as stigma, and negative consequences of disclosure such as blame and loss of jobs and relationships (Sikkema et al., 2000; Kmita et al., 2002; Mawar et al., 2007). HIV positive diagnosis therefore has a profound psychological impact on the PLWHA, and providing services to alleviate such adverse psychosocial effects, i.e. psychosocial counselling, is critical for effective treatment and care (Sikkema et al., 2000: 613).

Counselling in the HIV/AIDS context is a task that has been generally been shifted to lay counsellors (HIV & AIDS and STI National strategic plan for South Africa 2007-2011, 2006). The lay counsellor programme was introduced in response to programmes such

as voluntary counselling and testing, prevention of mother-to-child transmission, and adherence to antiretroviral therapy (ART) (Schneider et al., 2008). Psychosocial care has been added by default because it is a critical aspect of all the other HIV counselling activities. They are essentially community health workers who have 'received' several brief courses to enable them to carry out HIV counselling.

Given the evidence that PLWHA suffer from a range of psychosocial consequences, it is imperative to establish whether they receive any psychosocial counselling. It is of interest to know whether lay counsellors provide psychosocial counselling as well as what the nature of this counselling is, given the biomedical training focus in HIV counselling.

1.3 Research problem

Psychosocial counselling is a critical aspect of care, as noted in the HIV & AIDS and STI national strategic plan for South Africa 2007-2011 (2006). However, it is not known whether clients at the ART clinics receive Psychosocial counselling or not, or – if provided– of what nature is it? This research study was carried out to determine whether lay counsellors offer psychosocial counselling to HIV positive clients, and also what the psychological needs of clients on ART are.

1.4 Research aim

Living with HIV is associated with a range of psychosocial problems. The aim of this study was to explore what psychosocial care is provided to clients attending ART clinics by lay counsellors, in order to describe how psychosocial needs are met.

1.5 Research objectives

- To explore HIV positive clients' perceived psychosocial needs and support required
- To explore how these clients cope with receiving an HIV positive diagnosis

- To explore the role that lay counsellors currently play in the provision of psychosocial care
- To explore how clients cope with ART initiation in relation to their support system
- To delineate how lay counsellors could better conduct their role as a psychosocial counsellor.

1.6 Research methodology

1.6.1 Research design

A qualitative approach was used to conduct the study because it allowed the researcher to meet the objectives of the study and answer the research question. It enabled the researcher to describe the services provided by lay counsellors to clients attending ART clinics in the Tzaneen municipality. Both lay counsellors and their clients were interviewed to ascertain what transpired during the counselling sessions.

1.6.2 Population and sampling

The study was conducted at Xihlovo and Nyeleti ART clinics. As of October 2011, the clinics had 1371 and 3872 HIV positive clients on their registers, respectively. The study participants were female and male HIV positive patients aged 18 years and older. The second group comprised lay counsellors working at these two ART clinics.

1.6.2.1 Inclusion criteria

The participants interviewed were HIV positive, aged 18 years and older, who were attending one of the ART clinics in Tzaneen. They had to be physically and mentally fit to endure the duration of the interview. The HIV positive participants also had to be mentally sound enough to make an informed consent.

1.6.2.2 Exclusion criteria

Clients who were not fit enough to endure the interview, not mentally competent to make an informed decision, and those below the age of 18 were excluded from the study

1.6.3 Instrumentation

Two interview guides were developed by the researcher in collaboration with the study supervisor and co-supervisor. However, clients were encouraged to discuss matters beyond the stated questions in the guide.

1.6.4 Reliability and validity

Triangulation between the data from previous studies, the literature reviewed and data obtained was assessed for convergence and divergence in order to ensure validity.

1.6.5 Data collection

Semi-structured, in-depth interviews were conducted with both lay counsellors and their clients by the researcher. The interviews were recorded on a tape recorder. A tool was developed to assist during the interview to enable the researcher to cover areas that were probed (see Appendixes E and H). The interview guides were translated into the local languages Tsonga and Sotho to enhance communication between the researcher and participants. The interviews were transcribed and translated into English for preparation to be analysed.

1.6.6 Data analysis

The data were read several times for familiarisation. A thematic framework was developed in order to index the data. Charts were then developed in order to bring together all the points made under one theme. Charts were used to interpret the data and derive meaning, which was then reflected upon.

1.6.7 Ethical considerations

The study was conducted according to the International Declaration of Helsinki, SA-GCP and ICH-GCP. The researcher obtained written informed consent from clients after explaining the research process to them in their native language. The participants or legal representative (in the cases of those clients who are not able to read) were given sufficient time to inquire about the study and decide whether they were prepared to participate in the study. Participation in the study was voluntary and participants could withdraw from the study without penalties. The clients were not unduly coerced or influenced to participate in the study. The researcher was cognisant that, should the interview prove to be emotionally evocative and distressing, the researcher would refer the participant to a mental health service. Furthermore, participants were provided with a telephone number that they could use to contact the researcher should they have any questions regarding the study or require any help. Privacy and confidentiality were maintained at all times, and all records were kept in a locked cupboard. Furthermore, information to be shared with other stakeholders would not reveal the identity of the participants.

1.6.8 Limitations

One of the limitations of this study is that there was no mental health assessment tool used to identify specific diagnoses. This limited the ability to identify what was the prevalence of specific conditions among the participants. The second limitation is that both patients and lay counsellors found it difficult to describe mental health concepts. However, the latter was counteracted by the fact that the researcher spoke the local language and was able to encourage the participants to describe their feelings

1.7 Conceptual frameworks

The researcher/author worked as a mental health nurse, which included his providing debriefing sessions to lay counsellors and attending to patients referred for counselling at ART clinics. He has observed that, as a consequence of HIV positive results, clients

suffer extensive psychosocial difficulties. Lay counsellors admit that they often see that clients are not “all right”, despite them verbalising the opposite. This sparked an interest in wishing to establish whether the counselling offered by lay counsellors covers the clients’ psychological and social consequences of living with HIV.

1.8 Duration of the study

The study was conducted over a period of two years, from 2010 to 2011.

1.9 Lay out of document

Chapter 2 presents a literature review of AIDS and related mental health, to provide understanding about common mental health conditions, prevalence, impact on the family, mental health complications for vulnerable groups (i.e. women and children), and service delivery aspects of mental health care for PLWHA.

Chapter 3 details the methodological aspects applicable to this thesis.

Chapter 4 presents the study findings (results) after examining the experiences of seven lay counsellors and seven HIV positive clients.

Chapter 5 discusses the findings in relation to the literature, and explores the points of divergence and convergence.

Chapter 6 addresses limitations of the study, and provides conclusions to the work. Recommendations on processes and skills that could better position lay counsellors to offer psychosocial counselling to PLWHA are made.

1.10 Conclusion

This chapter has briefly summarises the contents of the current study. It further briefly outlines the contents of each of the six chapter of the thesis.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

HIV/AIDS is the largest contributor to the health burden in the country: South Africa has an estimated 5.4 million PLWHA (Kapp, 2008: 1207). HIV/AIDS impacts the mental health of infected and affected people. A Cape Town study (sample 269) carried out among HIV positive participants reported an average mental health prevalence of 43% (depression 19%, adjustment disorder 19%, anxiety disorder 17%, mania 3%) (Breuer et al., 2007). Another South African study, carried out among a larger sample of 900 participants, found a similar prevalence at 43.7%. The study further showed how mental health disorders increase with the severity of HIV/AIDS staging according to the World Health Organization (WHO). Those at stage 3 had a prevalence of 49.7% and those at stage 4 had a prevalence of 68% (Freeman et al., 2007: 1205). Similar diagnoses have been reported worldwide, such as positive symptoms of somatisation, obsessive-compulsive disorder, depression, anxiety, and paranoid ideation (Sun et al., 2007: 136).

Mental health complications are not confined to personal and family spheres. This impact also has major social and economic consequences (Freeman et al., 2005: 1). Today, the introduction of ART has changed HIV from a fatal disease to a chronic one. This has necessitated improved understanding of psychosocial factors to improve HIV-related health care (Uphold et al., 2005: 356). As a special population, PLWHA endure the difficulties of the disease, social discrimination, and inadequate health resources to care for their illness. Vulnerable groups such as women and children are particularly at risk.

This chapter describes the problem of mental health among PLWHA and the challenge of addressing this in the public health care sector.

2.2 Mental health complications for individuals infected with HIV

HIV/AIDS is a devastating disease that inflicts physical injury and mental anguish. It is therefore expected that PLWHA will suffer significant psychosocial consequences that tend to be chronic. Great contributors to the psychosocial challenges that PLWHA face is its association with fatality, its unpredictable progress toward terminal illness, and the lack of a cure (Woodring, 2005). PLWHA face a unique set of existential and deeply emotional problems as they are faced with issues of hope, death, grief, purpose, stigma, discrimination and loss (Cotton et al., 2006: 5). HIV care that neglects mental health issues risks eliciting co-morbid psychosocial conditions such as suicide and premature death. These result largely from poor social support (Zanjani et al., 2007: 347). The following paragraphs address emotional reactions to HIV and social consequences of living with HIV.

2.2.1 Time of diagnosis

The period immediately following an HIV positive diagnosis is characterised by a range of personal challenges. A Canadian study (sample size 110) of recently diagnosed individuals found trauma, turmoil, despair, confusion, sadness, uncertainty, outrage, loss, and anger towards the individuals thought to have infected the individual (Dematteo et al., 2002: 264). Such responses have a profound impact on how a recently diagnosed person responds to treatment and care, and recognising and alleviating these psychosocial issues is clearly an important part of initial care (Sikkema et al., 2000: 613). Psychosocial issues affecting PLWHA include self-blame, discrimination, denial, fear of disclosure, stigma, low self-esteem, isolation, anxiety, depression, and suicidal ideation (Green and Smith, 2004: 20). Some clients deal with the shock of HIV positive results by denial, which is a form of cognitive escape. This denial is related to an avoidance and acceptance-resignation coping strategy, as they do not want to think about the illness and feel like giving in to the illness, which is considered to be maladaptive (Sun et al., 2007: 133). Such denial is evident in the study carried out by Berg et al. (2007: 187): 81% of men refused to wear condoms, while 33% of infected individuals continued to engage in high-risk behaviours. This is thought to

result from a decreased perception of risk and a tendency to deal with problems through avoidance.

2.2.2 Moral aspects

In the early days HIV/AIDS was associated with promiscuity and infidelity, and this negative projection can exacerbate HIV positive clients' tendency towards self-blame. The societal belief that HIV positive clients have behaved immorally seems reinforced by the fact that their disease is incurable and is easy to transmit (Li et al., 2008). It is also compounded by associated cultural stereotypes and taboos about sex and drug use (Woodring, 2005). Some clients internalise this blame and demonstrate self-blame through regrets and the belief that in acquiring HIV they have transgressed societal, moral and behavioural codes (Zou et al., 2009). Such moral perceptions of the HIV pandemic contribute to the HIV/AIDS stigma worldwide. The HIV/AIDS stigma has been identified as one of the biggest obstacles to the effective management of HIV patients.

In an international study conducted in five countries (655 participants), it was found that South African participants did not want to go to ART clinics or social grants points because they feared people will know that they are HIV positive and stigmatise them (Maman et al., 2009: 2275).

Moreover, women, far more than men, are blamed for HIV infection because they are thought to be promiscuous. A South African study of 304 HIV positive females found that 92% screened positive for six items on a seven-item scale that measured external stigma, i.e., stigma experiences (van Rensburg, 2007: 701).

2.2.3 Stigma

Stigma occurs when a person is devalued because of a trait such as race, gender or illness (Skinner and Mfecane, 2004: 159). For HIV positive people, it is their HIV status that makes them different, and which could also lead to them being discriminated against. Such stigma has been positively linked to many mental health problems, including depression, anxiety and hopelessness (Lee et al., 2002: 315). Furthermore, some PLWHA protect themselves from stigma by isolating themselves, however, this

results in negative psychosocial consequences such as loneliness and despair (Maman et al., 2009: 2276). Often clients do not disclose their status for fear of rejection, wanting to preserve their privacy, and protecting themselves and others (Berg et al., 2007: 188). For example, parents tend to withhold information about their HIV positive status from their children in an effort to protect them from being discriminated against by the community, including while they are at school (Dematteo et al., 2002: 269). PLWHA also fear bringing shame, harm and stigma to the family, which becomes psychologically burdensome. Stigma is a particular barrier to prevention and care. It prevents PLWHA from getting care in various ways, such as refuting risk, refusing testing, delaying treatment, non-disclosure of their HIV status, or not seeking social support, all of which lead to a poor quality of life (Li et al., 2008). Stigma is also responsible for a longer delay in disclosure of HIV infection (Thorne et al., 2000: 36). Non-disclosure has been found to be detrimental as disclosure is positively linked to increased social support and self-competence, and decreased high-risk behaviour (Battles and Wiener, 2002: 161). A rural Chinese study carried out among PLWHA (sample size 200) found that social support decreased mood disturbance, reduced levels of depression, and contributed to positive psychological wellbeing (Sun et al., 2007: 133).

Disclosure has however been found to affect women differently, with disclosure leading to conflict with their partners; the partner thinks she has infected him (Murray et al., 2006). This association between disclosure and intimate partner violence has been reported in studies that explored the association between HIV and intimate partner violence; hence non-disclosure is not surprising, given women's subordinate position in many African societies. Women in violent relationships may be reluctant to adopt protective measures for themselves and their partners, such as negotiating safe sex and formula feeding because of fear that this would expose their HIV positive status to their partners (Maman et al., 2002: 1336).

Of concern is the fact that stigma is also linked to professionals and institutions that provide services to PLWHA (hospitals and social agencies). Clients continue to encounter experiences that are demeaning and hurtful when coming into contact with

health services (Dematteo et al., 2002: 271). In a study conducted in Bangladesh (sample size of 522 participants: doctors, nurses, medical technicians and support staff), 40-70% had stigmatising attitudes on 7-15 items on the scale used. Of significance was that stigmatising attitudes were, on average, significantly higher among support staff (56%) than among health professionals (Hossain et al., 2009: 173).

A recent Chilean study carried out using focus group discussions with 84 health workers reported continued stigmatising attitudes (Cianelli et al., 2011: 5). PLWHA that do not get the required support live 'on the edge' and in the midst of a range of losses, including relationships, employment, lifestyle, sense of control, intellectual and behavioural functioning and, ultimately, their own lives. Observing others with AIDS evokes fear of what will happen to them as their disease progresses (Sikkema et al., 2000: 622).

HIV-related loss and bereavement is complicated by social stigma because family and friends often feel mute about acknowledging the cause of death. This exacerbates the bereavement process by intensifying emotional reactions (Battles and Wiener, 2002: 162). Unresolved bereavement is problematic in the context of PLWHA as bereavement is lead to loss of CD4 cells and a decline of the immune system (Leserman et al., 2005: 500).

2.2.4 Issues related to being on ART

PLWHA on ART experience health-related stressors because they feel that health is dependent on chance. This is due to uncertainty regarding how long they will continue to benefit from the treatment, their need to maintain high levels of adherence, and trying to manage the side effects of highly active antiretrovirals (HAART) (Siegel et al., 2005: 225). In addition, routine tests to monitor health (CD4 counts) done at clinics can lead to psychosocial problems. For example, when blood test results show no benefits from the medication, anxiety levels may increase (Dematteo et al., 2002: 266).

Despite the hope that the continuous improvement of drugs will lead to decreased negative side-effects, some mental health conditions can be exacerbated by the side-effects of some HIV treatments, for example depression, nervousness, euphoria,

hallucination, and psychosis (Prince et al., 2007: 865). A Swiss study (sample size 130) found that 10% of patients on efavirenz experienced side-effects such as feeling drunk, out of control, nightmares, loss of concentration, and restlessness (Marzolini et al., 2001: 74). A study conducted in Botswana demonstrated that ART can lower cognitive functions, including verbal learning, memory, and executive functions such as decision making (Lewer et al., 2011: 6). Moreover, viral infection of the brain causes cognitive impairment and dementia (Freeman et al., 2005: 1).

2.3 Mental health experiences

PLWHA are also in constant state of anxiety about their health and the well-being of their families. Their constant contact with the health system mirrors the disease to them (Dematteo et al., 2002: 262). The possibility of loss of work and accompanying financial strain can intensify their anxiety (Sun et al., 2007: 139). On the work front, the HIV positive client is faced with limited ability to perform his/her work; this is coupled with economic and occupational insecurity as a result of HIV-related symptoms, such as periodic illness and fatigue. Physical and cognitive limitations can result in the client having to stop work, which causes depression, anxiety, social isolation, low self-esteem, suicidal ideation, and decreased quality of life (Blaalock et al., 2002: 400).

Uncertainty of income is particularly high in South Africa, where social support in the form of disability grants is linked to the level of illness and disability, rather than assisting the family. When the CD4 count of PLWHA drops to less than 200, PLWHA receive grants. However, as they take treatment and their CD4 count increases, the grant is withdrawn, despite the fact that the infected person is not working. A Canadian study found that when social assistance is taken away, PLWHA often lose hope (Dematteo 2002: 272).

Social, psychological and biological factors have been found to result in depression among PLWHA (Judd et al., 2005: 826). HIV is associated with direct injury to subcortical areas of the brain (this is particularly evident in the months before the development of full-blown AIDS). HIV is also linked with chronic stress, increasing social

isolation, occupational disability, body image changes, poor self-care, and worsening health prognosis, which may lead to depression (Berg et al., 2007: 186). Depression may also stem from the impact of HIV infection on the person's lifestyle, such as alcohol and drug use, side-effects of some medication (e.g. efavirenz) and discrimination (Freeman et al., 2005: 1). Depressive illness is linked with cognitive deficits, psychomotor slowing and executive dysfunction. PLWHA are particularly vulnerable to becoming functionally disabled in their social roles, physical abilities, general health and overall well-being (Judd et al., 2005: 830). Moreover, depression has been shown to accelerate HIV disease progression by reducing killer lymphocyte cells and changing serotonin and norephedrine functions, which results in neuroendocrine impairment and depression-related behavior, such as non-adherence to medication and reduced food intake, causing wasting (Antelman et al., 2007: 470). Significantly, depressed PLWHA are twice more likely to die within five to nine years of diagnosis than those who never had depression (Leserman et al., 2005: 500). This finding is supported by other reports of the risk of depressed PLWHAs progressing to stage 4 of the disease (terminal stage), with a 60% greater chance and a twofold increased risk of death (Antelman et al., 2007: 473). Although depression is one of the most prevalent mental health disorders among PLWHA (Zanjani et al., 2007: 348), it is under-diagnosed in the context of HIV treatment (Berg et al., 2007: 186). People who suffer from it are less likely to receive treatment compared to those with less prevalent conditions such as psychosis and mania (Zanjani et al., 2007: 353).

Mental health disorders are a major impediment to adherence to ART (Freeman et al., 2005: 1) and other social factors further complicate the ability of PLWHA to cope with the disease. Social factors such as poverty, unemployment, and poor levels of education are more common in a province such as Limpopo, and women in particular are affected. These factors impact on the ability of PLWHA to acquire adequate income, stable accommodation, and nutritious food. They are then less able to adhere to, and benefit from, ART (Newman et al., 2007: 14). Other psychosocial factors influencing why PLWHA do not adhere to treatment are cited as follows: it reminds them of their status, when they are in social situations they cannot expose themselves by having such medication on them; if they are emotionally upset about something they have not

got the energy or focus to take their treatment, or if they are too drunk to remember (Walsh et al., 2001: 712).

2.4 Prevalence

An American study among PLWHA (sample size 2864) used a short version of the Composite International Diagnostic interview to measure the prevalence of mental health problems. It reported depression at 36%, dysthymia at 26%, generalised anxiety disorder at 16%, panic disorder at 11%, and drug dependence at 12% (Sherbourne et al., 2000: 250). Another US study reported 20-37% of PLWHA meeting the criteria for depression (Berg et al., 2007: 185). Higher prevalences of depression were reported in Africa: a Tanzanian study reported 43% 12 months after initial diagnosis, while a Ugandan study reported a higher prevalence of 47% (Antelman et al., 2007: 470). Such mental health problems could be major contributors to non-adherence to treatment, and presents personal and public health risks (Remien et al., 2007: 671).

A recent American study (sample size 2819) found that 2.2% of patients were lost to follow-up at decentralised clinics compared with 19.3% at centralised clinics located in hospitals and decentralised ART clinics (Callaghan et al., 2010: 8). A similar pattern between centralised and non-centralised services, but with much higher levels, has been reported in Tzaneen. Using the 2010 data from the district information system, a rate of 15% was reported at Xihlovo (a decentralised clinic) while 26% was reported at Nyeleti (a centralised clinic).

2.5 The effect of mental health complications on the family

HIV infection should be viewed within the family context (Kmita et al., 2002: 280), since HIV diagnosis of a family member dramatically affects the family's psychosocial needs. The family live with uncertainty for years, while health care services neglect psychosocial issues of non-infected family members (Dematteo et al., 2002: 261). Family members are very often discriminated against and stigmatised because the

behaviour and lifestyle of the infected individual is thought to be a family trait, and they are blamed for failure to correct the behaviour that led to infection (Li et al., 2008). Family bonds transform in response to HIV positive diagnosis or disclosure due to the following adjustment problems: negative feelings about self, uncertainty about the true feelings of the partner, loss of satisfaction, communication problems, guilt feelings, distrust, fear of infecting the partner or of re-infection, lack of intimacy, impotence, blaming partner for infection, fear, rejection, and dealing with partners who refuse to use condoms (Dematteo et al., 2002: 267). The family roles also change as parents become ill and children are forced prematurely into care giving roles (Woodring, 2005). Parents are also haunted by the challenge of having to plan for who will take care of the children in case they die. Arrangements for future custody can cause legal complications, and delays in finding an alternative home have adverse psychological effects on female parents (Thorne et al., 2000: 31).

2.6 Mental health complications among vulnerable groups

Women's position in society creates stress in itself. Their care giving role and other experiences, such as gender-based violence, can render women more vulnerable to mental ill-health. Within male-dominated society, women tend to deny their own feelings and needs in favour of those of their children and partners. Consequently, mothers very often do not disclose their HIV positive status for fear of upsetting their children and to avoid them being stigmatised for having a mother who is HIV positive. This silencing of one's feelings and needs is done to preserve self-esteem and relationships (Demarco, et al., 2002: 90). Often they face double jeopardy when it comes to HIV disclosure to their partners, as those who test HIV negative are blamed for not discussing it with their partner prior to the test, while on the other hand those who test positive often experience negative reactions such as violence, separation and desertion. A study carried out in Abidjan among HIV positive women (n = 546) and HIV negative women (n = 393) found that 53.8% of women who test HIV positive do not disclose their status (compared to 3.3% negative women) for fear of these negative reactions from their intimate partners (Brou et al., 2007: 1915). These negative reactions include ongoing

emotional abuse. This abuse is more prevalent at the time of disclosure and negotiating for the use of condoms (Dematteo et al., 2002: 273).

Prevalent cultural norms define a woman's success by her ability to have and keep a man, while, simultaneously, successful manhood is predicated upon him having multiple partners. Moreover, the economic dependence of women on men limits their ability to insist/negotiate that male partners use condoms (Jewkes et al., 2003: 126). Furthermore, some men do not believe their partner's positive test (Brou et al., 2007: 1915). Male reluctance to use condoms, even when they know the HIV positive status of their partner, causes tension, frustration, fear and anger for women (Demmateo et al., 2002: 268). The opposition to condom use is also due to their contraceptive value, as women are to bear children and grow the family (MacPhail and Campbell, 2001: 1616), and the belief that condoms use is not necessary in a steady relationship (MacPhail et al., 2001: 1620). Women's request for condom use is often misinterpreted by men to be an admission of infidelity because condoms are associated with promiscuity and they challenge men's right to multiple partners (Jewkes et al., 2003: 126).

Despite their high partner turnover, only 14.6% of men who have HIV positive partners test for HIV, due to their fear of discovering their HIV positive status and a belief that couples cannot be sero-discordant (Brou et al., 2007: 1918). Often these women are blamed for infecting their husbands, when, in fact, it is usually the other way around (Shisana et al., 2009: 32).

HIV prevalence among women is higher than among men (Shisana et al., 2008: 30). Women represent 59% of PLWHA in Southern Africa (Antelman et al., 2007: 470) and a similar proportion of the adult women population living with HIV (59%) have been infected by their stable sexual partners because they were thought to be risk-free (Brou et al., 2007: 1916).

Furthermore, in an American study (sample 100), 52% of women infected with HIV reported traumatic life experiences such as sexual, physical and cultural abuse, which predisposes the development of other mental illnesses such as anxiety, post-traumatic stress disorder and substance abuse (Brandy et al., 2002: 122). Previous trauma in

PLWHA is associated with poor physical functioning (e.g., walking and lifting), decreased occupational ability, elevated pain, impaired cognitive functioning leading to poor quality of life, and a decrease in CD4 cells (Leserman et al., 2005: 505).

In South Africa, the economic, social and cultural realities expose women to sexual abuse, violence and rape (HIV & AIDS and STI strategic plan for South Africa 2007-2011, 2006: 33). Young women are also vulnerable, and often experience their first sexual encounter through coercion and force (MacPhail et al., 2001: 1615). Furthermore, feminine socialisation, societal and institutional expectations, and cultural pressures, discourage women's self-expression and direct communication. Thus women endure abuse and tend to stay in abusive relationships. This has a negative impact on women's value systems and their mental health (Demarco et al., 2002: 90). Breastfeeding also create vulnerability for some women. HIV positive mothers sometimes feel forced to choose breastfeeding to prevent their status being disclosed. Alternative feeding methods arouse suspicion because it is not 'normal' practice – especially in Africa (Mawar et al., 2007: 204).

Another vulnerable group is children and adolescents, and mental health concerns among them are different to the adult population. In South Africa, a significant number of children are born to HIV positive mothers (estimated 35 000, in 2005) (Chigwedere et al., 2008: 410). During the pre-ART phase, these children were not expected to live beyond ten years. Thus they were unprepared for adolescence and independent living. Now there are an increasing number of vertically infected (HIV transmitted from mother) children surviving into adolescence and young adulthood because of improved medical management of paediatric HIV (Thorne et al., 2000: 29). Adolescence is a period of experimentation (e.g., with sex, drugs and alcohol), risk taking, and assertion of one's independence. For the HIV positive adolescent this is complicated by living with a life-threatening disease, issues of disclosure, and stigma, which may lead to psychological distress (Battles and Wiener, 2002: 162). Sexual activity is of particular concern for HIV positive adolescents. In South Africa, 8.5% of adolescents have their sexual debut before the age of fifteen years (Shisana et al., 2009: 39). A longitudinal study (conducted over 3 years) among the general population in KwaZulu-Natal (sample size

4 029 males and 4 724 females) revealed the average sexual debut at 19 years and 18 years among males and females, respectively (McGrath et al., 2009: 52). At this stage, they are not yet emotionally and cognitively ready for responsible sexual decision making, and engage in sex impulsively. This can place them at increased risk, with possible high partner turnover and unprotected sexual contacts (Bachanas et. al., 2002: 374). Furthermore, condom use among the youth is particularly challenging, and is often hindered by a lack of perceived risk, peer norms, gendered power relations, attitudes to condoms and sex, and the economic context of adolescent sexuality (MacPhail et al., 2001: 1613). This exposes the HIV positive client to reinfection.

Adolescents often grow up without knowing their HIV status. A study by Cluver et al. (2007: 756) showed that a large proportion of parents die without having disclosed their status to their children. Often they do not know when and how to tell them, and fear that the child would tell others. Furthermore, parents are torn between the obligation to inform teachers and health care providers, and the resulting fear of stigmatisation and rejection towards the children. The WHO recommends that adolescents be informed by the age of ten years, and participate in their treatment programme (Thorne et al., 2000: 29). However, disclosure may be impeded by reluctance to disclose multiple 'secrets', which include disclosing past drug abuse, sexual history and how the parent contracted HIV, and the need to protect the children from the news of the diagnosis (Woodring, 2005). The reluctance of parents to disclose their status is also because they fear the child would not be able to handle it emotionally, and they may not want to discuss how they acquired it with the child (Thorne et al., 2000: 36). However, this is more likely to be the fear of their own inability to stay real emotionally for the children in the face of such a painful and anxiety-provoking subject. Furthermore, HIV positive children are not sent to school due to risk of disclosure and expected rejection (Kmita et al., 2002: 282). The primary concern for children living with HIV positive parents is the fear of losing their parent(s), which is related to the fear of being left alone (Woodring, 2005).

Children who are born to HIV positive parents experience a range of psychosocial problems. Although 90% will not be infected themselves, they are nevertheless affected by the HIV infection in their family and tend to lose one or both parents before or during

adolescence (Thorne et al., 2000: 29). Furthermore, living with an HIV positive parent demands personal and emotional adjustments that can slow the child's cognitive development, making the child vulnerable to disorganised attachment in relationships (Rotheram-Borus et al., 2006: 2). It predisposes children to behavioural disorders, separation problems, somatic disorders, elevated anxiety, low self-esteem, and feelings of rejection, neglect and isolation. This results in negative feelings about school, truancy, and ultimately poor school performance (Woodring, 2005).

There is also an increase in the number of older adults who are living with HIV/AIDS (Uphold et al., 2005: 356). In South Africa, the figures for HIV prevalence among females are the following: 14.1% among those aged 45-49 years, 10.2% among those aged 50-54 years, 7.7% among those aged 55-59, while figures for males of the same age group figures are 8.4%, 10.4% and 6.2%, respectively (Shisana et al., 2009: 31). HIV infection adds to a range of psychosocial issues that the older adult has to deal with, such as decreasing physical health and sexual status, changes in occupational status (reduced income), limited social support due to death of spouse, cognitive decline, and growing up in a conservative era in which behaviours associated with HIV were highly stigmatised (Uphold et al., 2005: 357). Ageing PLWHA have a twofold risk for dementia (Becker et al., 2004: 18) because of the effect of the normal ageing process and the effects that HIV has on the brain (Stoff et al., 2004: 2). They are also less educated and tend to have a diminished quality of life (Leserman et al., 2005: 506). This can limit the ability to understand the pathology of HIV and the complex treatment regimens.

2.7 Health service aspects of mental health care of HIV

Mental health issues are fused with the reality of living with HIV/AIDS, and dealing with prognosis, management and outcome of the disease. Despite high levels of mental health disorders, PLWHA do not receive appropriate mental health treatment. HIV treatment focuses largely on fluctuation of CD4 cells and viral load (Leserman et al., 2005: 506). On a personal level, the client tries to cope with HIV unsupported, which

often results in the adoption of negative coping mechanisms. Such negative coping mechanisms include avoidance, denial, sublimation, and displacement of anger. Positive coping mechanisms include positive self-talk, discussing the situation with trustworthy friends or family members, and actively seeking support (Woodring, 2005: 13). PLWHA who are fatally ill use confrontational coping strategies, which are associated with better mental health, while those who feel their life is not threatened tend to adopt avoidance and acceptance-resignation strategies (Sun et al., 2007: 133). This can partly explain why most patients present at the health facilities in the late stages of HIV. Some PLWHA use spirituality to cope with HIV – referred to as positive religious coping. This helps them to reframe their lives and derive meaning and purpose in life from their spiritual beliefs. However, negative religious coping has been associated with pessimism due to feeling that one's illness is a punishment from God (Cotton et al., 2006: 6).

The HIV & AIDS and STI National strategic plan for South Africa 2007-2011 (2006: 78) makes provision for clients living with HIV to be provided with psychological support as well as counselling for bereavement, disclosure of HIV status, and adherence to ART. Policy dictates that ongoing psychosocial counselling must be provided to help clients deal with the outcome of a positive HIV test in order to accept the positive status and to adjust to living positively with HIV/AIDS (The national policy on voluntary counselling and testing for HIV/AIDS in South Africa, 2004: 21). However, anecdotal evidence suggests that in the context of HIV treatment only a small number of programmes in the developed countries provide mental health services; it is not known how PLWHA in the developing countries seek or receive mental health care (Freeman et al., 2005: 1).

Different approaches are used in HIV counselling world-wide, they include client-centered techniques, cognitive behavioural therapy, psychoanalysis, and health education. In South Africa, the counselling techniques range from client-centred to more directive health-advice and information giving (Rohlender et al., 2005: 398). A range of therapeutic techniques has shown to be effective in addressing high risk behaviour, reduction of psychological distress, and promotion of adherence to medication. These include cognitive behavioural psychotherapy, structured psycho-education,

psychotherapy, supportive therapy, psychosocial intervention/counselling, and group therapy. A meta-analytic review of 19 US based randomised controlled trials showed that clients that were offered psychosocial counselling had a 95% better health outcome than those who did not receive such intervention (Berg et al., 2007: 184). Furthermore, psychosocial counselling has been found to be effective in treating depression (Berg et al., 2007: 186). Cognitive behavioural therapy helps clients manage stress, cope with HIV, form and sustain supportive relationships, openly express feelings about living with HIV, and assert their needs when using health services (Molassiotis et al., 2002: 88).

ART clinics are the primary facilities for HIV treatment and are therefore ideally placed to screen PLWHA for mental health problems and provide care in this regard (Zanjani et al., 2007: 353).

2.8 Lay counsellors

Currently, in Limpopo province, counselling at the ART sites is provided mainly by lay counsellors. The lay counsellor programme has been introduced in response to the burden of HIV on the health system in South Africa (Schneider et al., 2008: 180). The task of counselling has been shifted to lay counsellor so that nurses can focus on the medical aspects of HIV. The length of training for lay counsellors is brief (generally only a few days). Training offered to lay counselors is restricted to the following options: ten-day voluntary counselling and testing, five-day TB, five-day adherence, and five-day prevention of mother-to-child transmission.

Their role is commonly associated with specific behaviour (e.g., encouraging clients to test and enhancing antiretroviral adherence) rather than relieving affective distress) (Evangeli et al., 2009: 190). Counselling offered by lay counsellors is goal-orientated rather than client-oriented. Lay counsellors were introduced to increase the uptake of the HIV/AIDS programme and therefore there is an obsession with the number of clients the lay counsellors have counselled rather than the quality of counselling they offer (Rholeder and Swartz, 2005: 401).

Lay counsellors, if provided with basic training on the management of psychosocial disorders, seem well-placed to provide front-line mental health care. This is particularly important as it is they who observe, on a daily basis, the acute distress of clients responding to an HIV positive result. (Freeman et al., 2005: 2). However, it is of concern that in South Africa the technique currently used in HIV counselling is a directive, health-advising approach (Rholeder and Swartz, 2005: 398). Often this technique fails to meet the clients' emotional needs, or impact on their behaviour (Rholeder and Swartz, 2005: 399).

The intensity of a client's emotions in response to the distressing aspects of HIV/AIDS may cause anxiety for the lay counsellors (Rholeder and Swartz, 2005: 403). Furthermore, lay counsellors are inadequately supported, and are at risk of emotional distress, relationship difficulties, somatic disorders, intrusive experiences, and grief (Pakenham et al., 2002: 732). Thus they are unable to offer effective services to their clients.

The training of lay counsellors in psychosocial management of mental health disorders in the context of HIV care would promote integrated primary health care supplemented by the establishment of relationships with professional mental health care providers, to offer better supervision and support (Freeman et al., 2005: 2).

2.9 Conclusion

This chapter summarises some of the findings of previous studies with regards to psychosocial reactions of PLWHA. The reactions range from the time of diagnosis and explore the effects on the family and other vulnerable groups. It is clear that PLWHA suffer a range of psychosocial problem due to their HIV positive status. Literature was further reviewed for good practice of how to deal with HIV.

CHAPTER THREE

RESEARCH METHODOLOGY

3.1 Introduction

Psychological care should be a fundamental dimension of care as noted in the HIV & AIDS and STI national strategic plan for South Africa 2007-2011 (2006: 78). However, in South Africa, little attention has been given to the nature thereof or whether clients even receive it. The researcher works as a mental health clinical specialist and is aware of the psychological turmoil experienced by HIV positive clients. This research study explored both the psychological needs of clients on ART and whether HIV lay counsellors offer psychosocial counselling.

3.2 Research design

A qualitative approach was used to conduct the study. A descriptive phenomenological approach was applied in this project. The subjects were studied in their natural environment/setting. This was done to describe the experiences of people as they are lived, i.e. to record the lived experience. The descriptive aspect of the approach provided a picture of what happens in the counseling sessions and identified problems with the current practice. The researcher became a colleague of the subjects being studied by putting themselves in the participant's shoes because behavior cannot be understood without the understanding of the context in which it takes place (Walsh, 2001:9). This is advantageous as the researcher will gain the trust of the participants.

3.2.1 Overall aim of the study

The overall aim of this study was to describe the services provided by lay counsellors to clients attending ART clinics in the Greater Tzaneen area.

3.2.2 Research question

Previous studies have identified a range of psychosocial consequences as a result of living being diagnosed and living with HIV. Psychosocial reactions such as denial, anger and fear lead to clients not adhering to medication and non-disclosure. It is therefore essential to offer psychosocial counselling to PLWHA. The question that the research sought to answer is whether lay counsellors do offer psychosocial counselling to the clients at the antiretroviral clinics.

3.2.3 Study setting

The study was conducted at two ART clinics situated in the Greater Tzaneen municipality of Limpopo province. Tzaneen is situated about 120 kilometers from Polokwane, the capital city of the province. The Greater Tzaneen area is predominantly rural; it comprises two of the town's three townships and 63 villages. Xihlovo clinic was opened in 2006 and Nyeleti clinic was opened in 2004. As of October 2011, they have 1371 and 3872 HIV positive clients in their registers, respectively. They serve mainly the three townships and villages. They are both stand-alone clinics, offering services to clients who have been referred because of their low CD4 count. Nyeleti clinic is located within a regional hospital yard and Xihlovo is in the yard of a health center. These two clinics are nurse-driven, with the doctors coming in after all the preparatory work has been done, to write prescriptions and review treatment.

The citizens in this area are mainly Sotho and Tsonga speaking. The sources of employment are mainly the retail, agricultural and hospitality industries; a small but significant number work in the public sector. However, most of the males are migrant labourers in

Johannesburg, leaving the females and grandparents to fend for their families with meager resources. The inhabitants have, in the past, been moved from their ancestral area to make way for the creation of farms.

3.3 Population and sampling

The study comprised two groups of participants. The first group comprised four male and three female HIV positive clients aged 18 years and older who attend the two ART clinics. The second group comprised seven female lay counsellors working at the two ART clinics. All lay counsellors in the two clinics were females. The researcher used purposive sampling to select seven HIV positive clients. This was done to include participants of different ages, gender and stages of HIV infection. Five were chosen from amongst those on ART and two were chosen from those who are not yet on ART but attending a wellness clinic and adherence counselling. Clients were selected from stage one (asymptomatic) to stage four (have AIDS-defining symptoms) of HIV/AIDS. Their ages ranged from late twenties to early fifties. The researcher thought that challenges experienced by these clients would not be the same thus enriching the study.

The same approach was used to select seven lay counselors however their criteria was the number of years they have been practicing as lay counselors. This was done to establish whether the counseling skills of counselors improves or deteriorates over time. The research was explained to them and they were approached individually to participate.

3.3.1 Inclusion criteria

Clients at the ART clinics had to meet the following criteria in order to participate in the study:

- they had to be HIV positive

- their age had to be eighteen years and above
- they had to be a client in one of the two clinics where the study was conducted
- they had to be mentally competent to give consent on their own.

3.3.2 Exclusion criteria

Clients who had one of the following characteristics were excluded from the study:

- those who were so ill that they could not cope with the duration of the interview (45–60 minutes)
- those who were mentally incompetent to give consent i.e. those who are under the age of eighteen or suffering from mental illness
- those who at one point had been referred to the researcher for mental health services
- those under the age of eighteen years.

3.4 Instrumentation

The researcher, with the assistance of the supervisor and co-supervisor, developed two tools that were used in the study – one for each of the two groups (lay counsellors, and HIV positive men and women). The interview guide for the lay counsellors was an 11-item open-ended questions interview guide. This was used to ensure that all participants are asked the same questions, but also to allow for flexibility. The researcher could ask follow up question or request the participants to clarify what they had said. Participants were encouraged to give information beyond the set questions. Further, the researcher used probing to obtain the individual perspective of the interviewee. The interview guide for HIV positive participants was a 12-item interview guide. This interview guide was used in a similar fashion to the one for lay counsellors.

3.5 Reliability and validity

Triangulation was used to ensure validity. In this study the researcher used triangulation as a validity procedure and searched for convergence amongst the different sets of data (Golafshani, 2003: 604), namely, from the interviews with counsellors and clients and literature. Data from the literature and interviews conducted were examined for convergence; if data from these sources showed a high relationship it illustrated convergent validity (Welma et al., 2007: 143). The information produced by the study demonstrated significant commonalities with previous study. In order to strengthen reliability, an accurate account of data collated during the data collection process was ensured (Fox et al., 2007: 107). The researcher is the first language speaker of Tsonga the language used to conduct interviews. This allowed for recognizing figurative meaning and clarity was sought to ascertain the exact meaning.

Participants were not asked to confirm the accuracy of the study however other methods were used to achieve credibility and trustworthiness. The taped interviews assisted the researcher to transcribe accurately. The skill of the researcher also assisted to corroborate the interpretation of data during the interviews. The researcher validated and verified interpretations done to ensure that the facts were not misconstrued (Brink et al., 2006: 118). As the researcher was not a first language English speaker help was sought from the supervisors help translate the transcripts. The use of multiple methods, i.e., interviews and interview transcription, led to a more valid, reliable and diverse construction of reality (Golafshani, 2003: 604). In the process of formulating the research question, the researcher was helped by the research supervisors to ensure that the research method was appropriate to answer the research questions. Furthermore, a guide was developed to guide the interviews towards achieving the objectives of the study and ensuring validity.

The HIV positive clients in this study were largely from a rural area and their education level were up to a level of grade 12. They were a combination of both unemployed and others employed in semi-skilled jobs in farms and factories. The results from this perspective can be transferred to other similar environment in terms of demographics.

The lay counselors resemble the cadre of lay counselors in South Africa and the results from their perspective could be transferred to other environments.

3.6 Data collection

Semi-structured, in-depth interviews were conducted with all participants by the researcher personally. Semi-structured interviews were more appropriate as it allowed for follow up questions and participants to volunteer information. The interview questions were open-ended (see Appendixes E and H) and allowed the researcher to ask all participants the same questions during the interviews, though the participants were encouraged to raise issues not addressed by the researcher (Burns and Groove, 2006: 78). This is a strength for this qualitative study as it seeks to obtain as much data as possible from the participants. The data from the participants provided the researcher with details on how the participants experience their world and how they make sense of their world. This allowed the researcher to apply a scientific approach to analyse their perceptions and experiences (de Vos et al., 2008: 293). The researcher got to learn about the participants' thoughts and feelings by encouraging them to describe their worlds in their own terms (Fox and Bayat, 2007: 73)

A consent procedure was followed before data collection commenced – see 3.9.1 below. The interviews were recorded on a tape recorder. The interview questions were translated into the local languages, namely, Tsonga and Sotho, to enhance communication between the researcher and participants. Participants were interviewed in the language they are most comfortable in.

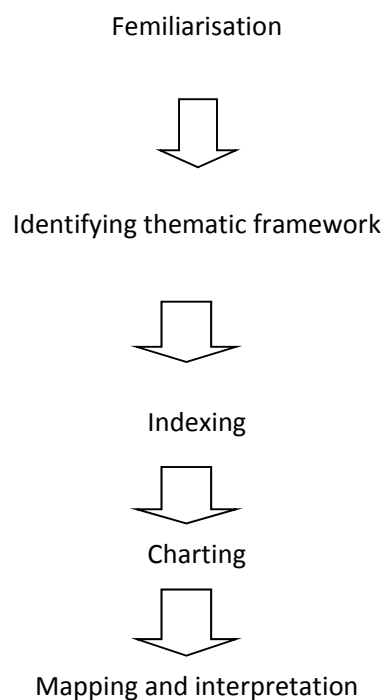
The researcher's sensitivity to and familiarity with the participants' cultural and ethnographic background enabled the researcher to understand the participants' frame of reference and further enhanced communication (de Vos et al., 2008: 297). The interviews took place in a private counselling room at the clinics.

The environment in these rooms was quiet, where no interruptions could take place. The setting provided for privacy and comfort, in a non-threatening environment; it was

easily accessible and offered a seating arrangement that encouraged interaction (de Vos et al., 2008: 294). A tape recorder was used to capture the interview and this was transcribed verbatim in preparation for analysis.

3.7 Data analyses

The transcripts were translated into English in preparation for analysis. A series of steps was employed in the coding process and themes were analysed using the thematic framework method (Ritchie and Spencer, 1993) described below. Triangulation of the data was also done to create an in-depth picture of the situation. The stages are illustrated and explained below:



Familiarisation. The researcher immersed himself in the raw data while transcribing the data and thereafter studied each transcript several times in order to list key and recurrent themes. His focus was on being aware of his reactions, prior assumptions and prejudices that may bias his perspective. He interrogated these issues with Dr Joyner in

supervision. He endeavored to remain open, neutral and curious in the reading of the data.

Identifying a thematic framework. The researcher identified all the key themes and specific issues under each theme, according to which the data was examined and referenced. Direct quotes from the transcripts were grouped under a specific theme. The quotes under each theme were discussed with the supervisor in order to eliminate bias. The end product of this stage was detailed indexes of the themes and sub-issues specific to each research objective.

Indexing. The thematic framework was applied by systematically indexing all the data by annotating all transcripts in the margins.

Charting. A chart for each theme with columns for the different aspects of the theme was created. The data were rearranged by cutting, and pasting the actual text onto the chart. The data was referenced using the patient number (interview transcripts arranged according to chronology of the interviews) followed by page and line numbers: this created charts that brought all the viewpoints made on a specific issue under a specific theme. The charting process involved a considerable amount of abstraction and synthesis.

Mapping and interpretation. The charts were used to make sense of and interpret the data to extrapolate meaning at deep, essential levels. A range of opinions and diverse topics, and multiple connections between different issues and themes and how they might influence each other, was observed and reflected upon. Contradictory information provided further pause for deeper insight and understanding. Further interviews were not conducted to obtain better understanding however dependability was used as quality criteria. During this stage the triangulation was applied. Data from transcripts of lay counselors and clients was assessed for common themes. The findings of data analysis process was compared to previous studies for similarities.

3.8 Ethical considerations

The study was conducted according to the International Declaration of Helsinki, SA-GCP and ICH-GCP, and received approval from the Ethics Committee of Stellenbosch University (see Appendix A). In executing the study, the laws and regulations of South Africa were adhered to, including the Health Care Act 61 of 2003. During the study no changes were made to the protocol.

3.8.1 Consent procedure

The researcher obtained written informed consent (see Appendixes C and D) from clients and lay counsellors after he explained the research process in a language that was easy to understand. The content of the consent included the aims, methods, anticipated benefits and potential risks of the study and the discomfort it may entail to the effect that study participants had a right to refuse to participate further in the study at any time without retaliation (Declaration of Helsinki, 2008:3). The participants were given enough time to inquire about the study and decide whether they wanted to participate in the study. The participants personally signed and dated the consent form. The clients were also asked to give consent for the interviews to be recorded.

3.8.2 Voluntary participation

Participation in the study was voluntary and participants could withdraw from the study at any time without negative consequences. Non-participation did not adversely affect treatment that is due to the client. No clients were coerced to participate in the study. The researcher did not approach any client that has already been referred to him to avoid coercion. The clients were interviewed on the same day that they were recruited.

3.8.3 Risk to participants

Should the interview prove to be evocative and distressing, the researcher was ready to provide crisis intervention and then refer the participant to a mental health clinical

specialist at the Xihlovo ART clinic and/or a psychologist at Letaba Hospital where, the Nyeleti ART clinic is located. Furthermore, the participants were provided with a telephone number to use to contact the researcher in case of questions regarding the study, or if they needed help. The study participants were not compensated and they did not incur any financial loss in taking part in the study.

Since lay counselors refer clients to the researcher who is a mental health specialist. To prevent clients from feeling obliged to participate the researcher will only ask patient who have not been referred to him for mental health service. The researcher negotiated with the staff at the ART clinics for clients who lost their position in the queue to be the prioritised so that they do not have to re-enter the back of the queue. Further the lay counselors were assured that information obtained from will not be used negatively against them but would be used to recommend improvements to their training program.

3.8.4 Confidentiality

Privacy and confidentiality were maintained at all times. No names were recorded on the data transcripts and synonyms were used to maintain anonymity. All research records were kept in a locked cupboard to which only the researcher has access. The data on the computer were also not shared with others except with supervisors. The data was password protected. It was also ensured that information shared with other stake holders would not reveal the identity of the participants. The participants were allocated numbers which were used to identify each individual in the communication between the researcher and supervisors instead of their real names.

3.10 Conclusion

This chapter describes how the study was conducted. It details the research design, including the study setting, population and sampling. Further the factors taken into when choosing eligible participants for the study were discussed. In order for the study to comply with research best practice, the ethical considerations that were taken into

account when conducting the study are explained, and the reasons for them. The following chapter will report the findings of this study.

CHAPTER FOUR

FINDINGS

4.1 Introduction

The findings, with focus on the emotional and social consequences of living with HIV, are presented in this chapter. The direct experiences and perceptions of seven participants as well as the experiences of seven lay counsellors are presented. This provides an interesting mix of data. The study findings include participants' reactions from immediately after testing positive to their experiences as they progress through treatment, showing the mental health impact and their adjustments as they try to cope with their new identities. The contribution of the social context to their mental health is also presented. Furthermore, the self-identified needs of both PLWHA and lay counsellors within this counselling context are described.

4.2 Demographic data of the participants

The participants interviewed for this study were seven PLWHA, and seven lay counsellors providing services at the ART clinics. The PLWHA comprised three females and four males. One female had never married while the other two were divorced. On interview, the two divorced women reported being involved in intimate relationships while the single female participant was not. One of the divorced women was married more than once and her first husband had died of AIDS. Two of the female participants were not yet on ART while the third has been on ART for 23 months.

Among the four male participants, two were married, one widowed and one never married at the time of the interviews. Among the two unmarried participants, one said he occasionally has sex with women while the widowed participant reported not being involved in an intimate relationship since his wife passed away. All the male participants were on ART, and the period ranged from three years to seven years. The two married

men had their wives as their treatment supporters while the other two said they were supported by their sisters.

The seven lay counsellors interviewed for this study were all females. They were 33-44 years of age. The majority had high-school qualifications, ranging from Grade 11 to having completed three-year diplomas. There was no consistency in the short courses they had done to enable them to carry out HIV counselling and testing. Although all had been trained in voluntary counselling and testing, five had training in the prevention of mother-to-child-transmission and three had attended an adherence counselling course. The other short courses included: TB, couple counselling, TB/HIV collaboration, and 'pricking' (the taking of blood for HIV testing). Two lay counsellors were trained in trauma counselling, which they said was available when they started at the non-government organisation that they are working for.

4.3 Emotional responses to a HIV positive result

4.3.1 Shock

Just over half of the participants (4/7) expressed the experience of emotional difficulties in reaction to their HIV positive result. The reactions were different immediately after receiving the positive result from those they experienced later as they live with the disease. The emotions at the time of diagnosis were predominantly shock, anger and denial. Later, while living with HIV, their emotional problems were rooted in anxiety related to the uncertainty relating to living with HIV in relation to death, disclosure and employment. Just under half (3/7) of the participants expressed not "*having a problem*" with having an HIV positive diagnosis. The two women attributed this to the fact that they had expected the positive results because they knew how they were infected and who infected them. One woman also had HIV positive family members, which assisted her in accepting the HIV positive diagnosis, "*I did not have a problem, I accepted it. I went to the clinic, for me I accepted, at home we had my sister (who was HIV positive)*" PT4:1; 26-28 (i.e. patient transcript number 4: page 1; line numbers 26-28). A man who expressed not having a problem found his solace in the fact that it happens to anyone.

Five of the patients were introduced to HIV counselling and testing when they attended the health services for other health care needs such as antenatal care, with one saying: *"I was going to the clinic to be weighed (ANC visit) and they told me that ... (I am positive)"* PT3:1; 20-22.

Insufficient information provided during counseling did not enable clients to anticipate denial as an emotional reaction to HIV positive results. Although the clients were counselled before testing, it appeared that they had limited opportunity to fully understand the emotional implications of a HIV test, particularly a positive test. From the interviews with the lay counsellors, it was clear that the pre-test counselling sessions are usually brief and mainly focused on the biomedical aspects of HIV. Three lay counsellors reported that their focus is on *"HIV"* (referring to the biomedical aspect). They regarded dealing with psychosocial aspects as irrelevant to their main duty. They do not seem to have the necessary skills to deal with broader issues that are still pertinent to HIV. One lay counsellor reported: *"Most of the time we talk to them about HIV. We try not to veer off the topic because if we do that sometimes we find ourselves in a situation where we are not able to give them answers that they want"* LC6: 5; 261-263 (i.e. lay counselor transcription 6: page 5; line numbers 261-263). Meanwhile, they also reported that their workload is huge and that seeing many clients resulted in them not being able to focus on the psychosocial aspect of HIV. When asked what prevents lay counsellors from helping clients with psychosocial problems a lay counsellor recounted: *"You see if you can talk to more than ten patients per day, things start not to go right"*. Here she refers to a subtext of vicarious trauma, which leaves her incapacitated to deliver effective counselling after seeing many clients LC4:8; 350.

Furthermore, clients revealed that they consented to the test but hoped that they are not HIV positive. One client stated: *"I did not know. I thought I won't have it"* PT3:6; 250-251. It is then a shock when they discover that they are indeed HIV positive. After the initial experience of shock, the client tries to find an explanation as to who infected them with HIV. Those with known infected partners accept their status, while those who thought they could not be infected also expressed denial.

4.3.2 Denial

Denial was a common defense displayed by patients in response to an HIV positive test. This was evident in the way participants construe HIV illness, perceptions of their own vulnerability to HIV infection, their understanding of discordant results, and their use of witchcraft as an explanation.

Participants' understanding of HIV is largely informed by the belief that HIV is a debilitating and fatal disease and therefore a person who is HIV positive has to exhibit signs of impending death. They did not expect a person who is physically healthy to have a positive HIV test. They therefore denied their positive status while they were *'physically healthy'*. To support their perceptions of HIV as a debilitating illness, some males and females, upon HIV positive diagnosis, thought that their positive result was due to *'faulty'* test kits:

"I did not take it as a problem because I did not feel pain anywhere. I was living the same way I used to live in the past. There was no change in my body or that sometimes I was lying down because my body is painful. I took it that it is possible that they might have checked and said it is there (HIV+) while it is incorrect" PT2:2; 61-64. Here the patient refers to a false positive. At the time of the interview this female participant, who was coming to the ART clinic for the first time, explained how she came to accept her positive status saying: *"once they send me to the hospital it means it's true because people whom they send here are sick, they do not just send people to hospital"* PT2:2: 77-78.

Denial was also perpetuated by the fact that they perceived that HIV is for *'other people'* such as sex workers or promiscuous people. A lay counsellor commented about how clients reacted to HIV diagnosis: *"it's because, as people, we tell ourselves that HIV is for 'those ones', not me. There are those people who believe HIV is for others"* LC4:5; 188-189.

Furthermore, discordant results among couples also influenced denial. A male client used proxy diagnosis to determine his HIV status. They thought that if their partner tested positive then they were also positive, and vice versa. When his HIV test turned out positive he initially did not believe the outcome. He thought that if his partner is

negative he should also be negative. He explained: *“because the woman (my wife) was found to be not positive and I was positive. So I said why is it that the woman is not positive and I am positive? So, eish, I found that I did not believe”* PT1:2; 62-64.

Some clients denied their HIV positive status attributing it to witchcraft. Lay counsellors reported that some clients think that, contrary to what the test says, they have been bewitched. Foreigners and refugees such as Mozambicans were the groups most often blamed for the witchcraft. One counsellor commented on how a client reacted to a positive test: *“A person stay for long time without knowing their status and when they start to have signs they start to think that they have been bewitched saying, ‘it’s the Mozambicans why I have these things”* LC7:6; 351-353.

In some cases clients refuted their HIV positive, instead using their cultural beliefs to explain their illnesses. Lay counsellors spoke of how clients believed that the ailment was a sign of a calling from the ancestors. Some clients believe that if they heed a call to become a sangoma they will be cured of HIV/AIDS. They believe this, despite having seen their positive results. A lay counsellor related what a client did after discovering she was HIV positive: *“I remember she ended up going to bush (Bushbuck Ridge) to be initiated as a sangoma”* LC3:153-154. It is a common-held belief among Africans that illness may be sign of a calling to become a traditional African healer.

As a consequence of denial, clients often do not return to the clinic for HIV management. One lay counsellor explained: *“This one of denial is difficult because you will see it by a person not coming back that they have denial, even if they come back they ignore you”* LC4:6; 240-241.

In the primary health care clinics, clients often do not return for routine assessments. They choose instead to take traditional remedies or going to faith and/or traditional healers.

4.3.3 Anger and blame

Anger was commonly reported by the HIV positive clients. A counsellor explained: *“From her reaction I could see that if the man was here she could have torn him apart*

with her hands; she was angry, very angry" LC4:4; 170-172. One woman interviewed did not direct anger towards the partner whom she assumed had infected her. Although the other two did not mention their HIV positive diagnosis as a reason for divorce, they believed that their ex-partners had infected them. Furthermore, they got divorced after they discovered they were HIV positive. They also reported contemplating to leave their current fiancées for their refusal to use condoms. However, lay counsellors related cases where female patients had divorced their partners because of their conclusion that their husbands had infected them. One counsellor said: *"Yes, some do get angry, to the extent that they divorce if they are married"* LC6:3; 129-130. Furthermore, they reported angry responses from women who said they had remained faithful in the relationship while their partners' infidelity had resulted in their HIV infection. One lay counsellor said: *"Things that make their heart sore when they come here is that you find that the person say they were settled, not 'fooling around'"* LC5:2; 87-89.

Men's infidelity and consequent risk of infection to their partners was a common theme. Lay counsellors spoke about how male partners' multiple relationships left women feeling bitter and abused. Lay counsellors indicated that male partners' dishonest response, and their rejection of accusations of infidelity, added insult to injury. Patients' anger was also fuelled by the males' refusal to use condoms, thereby endangering their partners' lives and posing a threat to parenting their children to adulthood.

Some female participants believed their partner had deliberately infected them, which compounded their anger. They think that even though they are faithful, their partners do not use condoms with their girlfriends outside marriage. Furthermore, even when the men knew their status they often did not disclose it to their partners, despite having sex with them. A lay counsellor explained what her client had told her when she was suspicious of the antiretroviral tablets her husband was taking: *"He used to hide and drink them secretly"* LC3:4; 146. Men were also very hurtful when women confronted them about knowledge of their status. A lay counsellor related how a man chased his wife away from their home when she confronted him about his status. The husband said *"Go well because I have given you the disease to take with"* LC6:4; 175. It was clear that some women felt strongly enough about this to terminate their relationships.

Counsellors reported that men also blame their partners for their HIV infection. This was described as follows by a lay counsellor: *“The husband can become defensive and say ‘I am not positive – it means you came with the disease from wherever’”* LC5:2; 74-75. Furthermore, these women had to bear the wrath of their partners when they asked them to come with them for couple counselling. Such an invitation was interpreted by men to suggest that the women accused them of being HIV positive and, justifiably, of manslaughter, since they are guilty of having infected them (the women) with a deadly disease in the name of love. This led to women being assaulted and even killed. A counsellor reported what happened to her client: *“She was killed (by the husband); he killed her with a knife”* LC3:7; 253.

Some men displayed vengeance; they sought to infect people of the opposite sex – not necessarily the person who infected them. Two men described how, at the beginning of knowing their status, they *“fooled around”*. One explained: *“Isn’t it if a person is a person who feel bad about themselves they want to go to many places (have multiple partners)”* PT1:3; 110-111. They sought sexual relationships with women while having unprotected sex with their wives even though they knew that they were HIV positive. These men would then tell their partners that they are HIV positive when they terminate the relationship. It was felt that they used this to deliberately hurt their wife’s feelings. A lay counsellor reported on what occurred to a female client when she confronted her husband about the ARV’s he was taking, *“He said that they (ARVs) were for TB. There was a quarrel between them, and then the man assaulted her and chased her away from home”* LC6:4; 173-175.

4.3.4 Fear of death

A lay counsellor said: *“When they are told that they are HIV positive they feel that they won’t survive for a week. They think that they will have died by then”* LC2:3; 96-98. Fear of death is due to misconceptions about HIV. In the ART clinics they observe clients who mostly enter the health system in advanced stages of AIDS. They may also have observed others dying of HIV and fear for themselves. It is worth noting that even though post-test HIV counselling is predominantly biomedical, with emphasis on the life-prolonging value of ARVs, most clients’ fear of death was a dominant concern. One

client said: *"I thought now that I am HIV positive it means I am going to die"* PT5:1; 13-14. Another said: *"Isn't it they say once you infected by this disease you are going to die"* PT6:1; 19. They thought that they would die quickly; some even accepted it as their *'time to die'*. A client described it as follows: *"I just accepted it, I said if my death has arrived ..."* (did not finish the sentence) PT5:1; 37.

Messages from health providers also contributed to the fear of death, with a pregnant woman being admonished by a lay counsellor during counselling that it is inadvisable to fall pregnant while one is HIV positive, especially when the CD4 count is low. A client related her experience at the clinic: *"I had a problem when they withdrew blood (tested me) because they say it's not good for one to have a child, it might put you in danger"*. Her fear of death was still palpable during the interview and she was tearful when she talking about her fear of death during the interview.

Denial and fear of death seemed ongoing and remained part of clients' emotional response despite the fact that they had been on treatment for a while. Lay counsellors even reported that there are still clients who said that despite taking medication they do not believe that they are HIV positive. Fear of death was due to uncertainty about the continuous benefit from medications and messages from lay counsellors. Clients reported that they were no longer experiencing anger and blame. It is however not known if the expression of acceptance could have been influenced by lay counsellor's messages to suppress this feeling.

4.4 Social problems

4.4.1 Stigma

"They say it to hurt you" PT6:2; 34-35. Participants in this study experienced both anticipatory and actual stigma, and this was supported by lay counsellors. Participants expected to be stigmatised, and reported real stigma experience. These experiences occurred at home, school and the workplace. Being stigmatised at home was the most painful for the clients because the family was expected to provide refuge from the stigma experienced outside the family. A lay counsellor accounted how a client felt about being stigmatised by the family: *"If they do not treat me well, what about people from outside?"* LC 2:2; 67-68.

People living with HIV/AIDS reported that stigma hurt them emotionally more than the fact that they are HIV positive. When asked how it felt being stigmatized, one participant said *"It hurt you when they tell you about it, not that you feel hurt because you are sick. They say it to hurt you"* LC6:2; 34-35. Furthermore, they (both men and women) are thought to be sexually promiscuous or sex workers. A lay counsellor narrated how people living with HIV are judged by the community: *"They (community) think that the person got HIV because she/he was not stable (had lots of sexual partners)"* LC1:3; 104-105. Patients reported how community members despised them and regarded them as inferior or worthless for having become infected. A lay counsellor stated how children are treated in the community: *"When the child gets something wrong they would say 'look at this one who is so and so! (HIV positive)'. At school, when the child plays, the others would say 'look at this one who is so and so!'"* LC6:3; 99-101.

Furthermore, the community stigmatised the client for fear of contagion. They thought they could be infected with HIV by sitting on the same chair, sharing utensils, or even sharing the same air when breathing. This is exacerbated by the fact that the community is also aware that PLWHA have a greater incidence of TB infection. Stigma from community was explained by a male participant who said: *"Some, when you are HIV positive, they despise you, when you cough they say 'this one will infect us with his TB'. When you have HIV they say 'let's sit far from him, he is going to infect us, we must not breath the same air with him'"* PT5:5; 198-201.

Anticipated stigma was related to how the client thought people would react to them if their status was known. Clients thought the community would think of them as having

been reckless to have been infected with HIV and feared that they would fall victim to gossip in the community. A lay counsellor explained a client's reason for defaulting: *"I was ashamed to come because I did not know how people were going to react to it (coming to the clinic)"* LC1:3; 96-98. They further thought that their family members would be ashamed of them and would not love them anymore, and would reject them, leaving them completely unsupported. One client anticipated: *"They will take my blood (withdraw and test) and tell me that I am HIV positive, as if that will take away something from me, or people will not love me any longer"* PT4:4; 178-180.

Lay counsellors explained how married females chose not to disclose their positive status to their partners because of anticipated blame. A female lay counsellor reported how men reacted to disclosure: *"When you as a woman tell them you are HIV positive they say: you are the one who brought it, where did you get it?"* LC:4:3; 128-129. The gendered nature of stigma is revealed by the fact that women are thought to be the ones who brought HIV/AIDS to the family. As mentioned previously, this caused women to fear reprisal if found to be positive. It further led to poor adherence to medications and limited the ability to negotiate safe sex due to fear of stigma after disclosure.

Stigma also led to selective disclosure to people whom they thought would be supportive, with some preferring to disclose outside the immediate family: *"I won't tell my husband that I am positive ... when he asks what the milk (for formula feeding) is meant for I will tell him that they say that I have a problem with my breast"* LC5:2; 56-59.

As result of stigma, some exhibit despair. They became hopeless, since they cannot reverse it. In addition to this, there is nothing they can say to those who have infected them. This was observed among clients who had been infected by people who had already passed away. They also felt hopeless and outraged about the cruelty that was meted to them by the community. This resulted in a situation where they resign themselves to the disease and the negative reaction of the community. One client explained how it felt: *"What will I do if it's like that, there is nothing I can do"* PT3; 126-127.

Disclosure by association was also related to unwillingness to visit to the clinic. Clients feared the stigma they may experience as a result of being seen at the ART clinic, causing treatment defaulting. A lay counsellor reported how clients find themselves in difficult situations if they had not yet disclosed their positive status to their partner and had to go to the ART clinic: *“If the husband stays at home the whole week it means he won’t be able to come to the hospital because if she leaves home the husband would ask where she is going”* LC5:2; 66-68.

4.4.2 Needs identified by patients.

Clients were most worried about how they were going to disclose their HIV status. This was closely related to anxiety of how people were going to react. They anticipated a negative reaction. They wanted to be helped on how to disclose without the associated negative consequences. In the context where there is a lot of denial by partners, the clients were also concerned about what they should do to ensure adherence to positive living. This included how to negotiate for condoms. They further worried about the prospect of losing their intimate relationships. They wanted to know how to ensure that that their relationships could continue, despite them being positive.

4.4.2.1 Dealing with disclosure

Participants indicated that they did not disclose soon after the test to their partners, employers and children for a variety of reasons. Four of them delayed for days. PLWHA in this study who disclosed soon after the test had usually been very sick and were accompanied by someone supportive when they tested. For females, non-disclosure was related to fear of anticipated or actual abuse by their partners. One lay counsellor reported what a female client said about her non-disclosure: *“I was not able to disclose because the man I am staying with abuses me”* LC3:6; 237. Two of the three women who participated in this study were living in abusive relationships. They expressed having being divorced in their previous marriages and currently lived in fear of being abandoned by the present partner, including being left for another woman (mistress).

This happens in the cultural context of the Limpopo province, which promotes male engagement in multiple relationships and where women’s economic dependency on

men frequently traps them in abusive relationships. Only one of the three women participants was in employment compared to three of the four males. Significantly, the financially independent woman was the single woman who had never been married. The women feared that if they were to disclose, their partners would leave them destitute. Non-disclosure may therefore be a protective strategy for women in abusive relationships.

The plausibility of the women's fears was confirmed by the men, who attributed this non-disclosure to fear of abandonment. A male participant said: *"Especially if when you visit you give her money to help at home she won't tell you (that she is HIV positive), because you won't give her anymore. You will say 'this one has a disease'"* PT5:6; 250-252. Lay counsellors described how, many times, when clients disclose, divorce and being banished from the former common home follow. One female client explained her choice not to disclose to her husband thus: *"I am afraid that he will make me go home"* LC6:4; 158. In one case a woman got killed by her partner. A lay counsellor commented on how she had lost one of her clients: *"There came a time that there was an unfortunate incident ... he killed her with a knife"* LC:7; 253-254. Furthermore, clients reported to lay counsellors that their partners had intimated that if the woman were found to be HIV positive they would have to leave the house, for example: *"If you go for testing and find that you are positive you must pack your things and go"* LC6:4; 154-156. This frequently led to females concealing their results.

In this context, where males have multiple partners, women feared that men would leave them for the 'other woman' if they were to disclose. This was compounded by fact that these women knew their men were involved in adultery. Moreover, women did not think men deserved to know their status if they were not primary partners. A client explained why she had not disclosed to her partner: *"I have not yet told him. He has his own wife"* PT3:4; 178-179.

Lay counsellors also spoke about how disclosure after the birth of a baby could influence relationships. Furthermore, women often found it difficult to follow instructions of exclusive bottle feeding and often did not succeed in exclusive formula feeding. Non-disclosure often meant women had to lie about using formula feeding. A counsellor

reported on how powerless women are and how they are not able to disclose and protect their children: *"(her partner) started to scold her, asking her 'why do you want to bottle-feed my child?'. So she became afraid to bottle-feed and decided to breastfeed the child"* LC7:5; 208-215.

Non-disclosure meant that they often continued to engage in unsafe sex. They feared that if they were to ask their partner to use condoms they would have to disclose their status first. A client recounted her predicament to a counsellor: *"I can't tell him that now we are going to use a condom because I got this information. The first thing he would then want to know is why we should be using a condom, because all along we were not using a condom, so why now?"* LC4:2; 86-88.

Clients also did not disclose to their employers primarily for fear of losing their jobs. They feared that their employer would not *'understand'*, because of ignorance, and therefore discharge them from work. A lay counsellor related: *"They are afraid they will be fired"* LC7:2; 89-91. The perception of employers' ignorance reflects that of the surrounding community in general.

Clients also defaulted on clinic appointments for fear of losing a day's wages. If they were to go to the clinic they would have to explain to their employer why they went to the clinic. This posed a predicament for them if their employers are not sympathetic to their plight. Yet their letter from the clinic did not indicate what they were suffering from. Clients seemed happy that the letter did not disclose their status. This enabled clients to attend an ART clinic without repercussions and disclosure. A male client described what happened at work before and after he comes back from the ART clinic: *"I tell them I am going for check-up and they would say 'it's ok, you must come back with a letter'. Then I take a letter from the doctor and give them and that's all"* PT1:3; 100-102. Both men and women in the study shared the concern that if they were to lose their jobs due to HIV/AIDS they would no longer be able to provide for their children or their households.

Vulnerability to infection is a major repercussion of non-disclosure to people who care for sick people. Family members who tend not to take universal precautions are primarily at risk. A counsellor related a story of client who believed she had been

infected by caring for a client who did not disclose: “..... *I did (care for a HIV positive person) but was not told anything (that they were positive). ‘I am surprised now that I came for the test and found to be positive’* LC6:2; 63-66.

Patients who were parents seemed to deeply fear disclosing their status to their children. They were particularly afraid the children would disclose their status to their in-laws. Female clients referred to strained relationships with in-laws due to divorce or death of a spouse. Disclosure was undesirable for them as they thought the in-laws would use this negatively against them. A female client who was divorced from her husband said: “*Me and those people don’t see eye to eye, you understand*” PT3:2; 72-73.

Lay counsellors reported that unmarried women were concerned about securing intimate relationships and marriage to a partner. Their main concern was how to disclose and explain the infection. A lay counsellor said: “*The young ones ask that ‘as I am HIV positive, how am I going to get a husband, in my whole life, because I am still young, am I going to have a child?’ Is there a man who is going to marry me being positive?’* LC5:3; 107-109.

4.4.2.2 Concerns about children

All three women and one of the four males in this study expressed concern for their children after being infected by HIV. One was worried that she could not be a positive role model for her children since HIV infection is still associated with sexual promiscuity and people infected by it are judged to have been careless at best and sinful at worst.

These women felt extremely anxious about leaving their children motherless should they die. They anticipated that their partners would become involved with other women and would neglect their offspring. A male patient whose partner had died admitted that his children were now living with his in-laws. This is a common practice: if a mother dies the in-laws raise her offspring until they are old enough to cook and wash for themselves. This is when they could go back and live with their father if they want to. Some fathers neglect their children by not helping financially and by not being emotionally available for their children. A counsellor explained: “*Mostly when they come*

here they say 'now I am sick, I might die, when I die my husband might go outside and look for other women and he will neglect the children and they will become orphans because I will have died'" LC5:3; 94-96. A client also explained: *"He does not want to support his child"* PT2:4; 169-170. This feeds the fear that women have that their children would in essence be orphaned by their passing.

Both male and female participants said they wanted to protect their children from emotional upheaval by not disclosing because of their young age. One male participant indicated why he did not disclose to his children, saying: *"My children are still young, they are still too young"* PT7:3; 66.

Non-disclosure to children may explain a cultural context of participants which provides no context or support for emotional experiences and therefore people remain unskilled and inept when facing situations that require emotional courage.

4.5 Counselling

4.5.1 What happens during counselling sessions?

Most of the lay counsellors who participated in the study regarded their roles as being that of 'teacher'. When asked how they help the clients, they said their work involved teaching clients about the prevention of HIV, prevention of mother-to-child infection, positive living and the importance of adhering to treatment. They referred to the counselling session as a 'class'. The information imparted during this session is of a biomedical nature, with emphasis on how does one get infected with HIV, what one can do to protect themselves from being infected, signs and symptoms of HIV infection, and opportunistic infections. These sessions were directive, because the client is seen as needing information with counsellors as the providers of that information. A counsellor explained: *"Support them by giving them the correct information regarding the HIV/AIDS disease and encourage them to follow what is needed for one to live well"* LC4:1; 25-26. Clients also saw the role of a counsellor as a teacher; a client said: *"They must still teach us about how we must drink the pills"* PT1:1; 23-25.

Moreover, the sessions were not patient-centered. The clients' psychological and social concerns were overlooked. When clients presented with psychosocial problems, the counsellors thought that they could be dealt with through information giving. A lay counsellor explained how she helped a client who had a fear of death: *"He said 'this means that I am dead'. I told him that that was not correct; he was still going to live. The most important thing is to drink the pills"* LC2:4; 158-160. This indicates lay counsellors' limitations when it comes to dealing with psychosocial problems.

4.5.2 Vulnerability of lay counsellors within the clinical environment

Lay counsellors work in an environment where they feel unappreciated and unrecognised by both co-workers and government. The co-workers also felt that the government did not recognise them because they are not on the government payroll and the government does nothing to ensure that NGOs pay them on time. The staff (particularly nursing staff) continuously emotionally abuse them by talking down to them about their job status. They are told they are not educated and are referred to as "lay doms" (lay stupid). The professional nurses brag about their epaulettes, inferring that their education makes them superior. They also brag about how much they are being paid, knowing that the lay counsellors only get a stipend, and often late. This is used to silence them when they raise their concerns about work-related issues. A lay counsellor described how they are treated by the professional nurses: *"When we have meetings and you want to say how you feel they tell you that you don't talk back to a sister. You get told that 'epaulettes are not for sale; you must go and learn to have them'"* LC5:8; 324-327. She explained further: *"They call you names. Some call you 'lay dom'"* LC5:8; 307-308.

Since lay counsellors were trained to 'prick' (take blood for HIV testing by piercing clients' fingers to withdraw blood), they have been victimised by the nursing staff. This is because it was thought that the government had overlooked the educated people (i.e., enrolled nursing assistants and enrolled nurses, who are at present not allowed to prick) when they took on lay counsellors for the course. A lay counsellor explained: *"Like now*

that we have started pricking they asked, 'why they (government) took the 'lay doms' for pricking (course) when did they go to school?' LC5; 8; 311-315. This makes lay counsellors feel emotionally violated and useless. They feel vulnerable and exploited because they do not belong to a professional body or a union that would protect them in case of failure in the line of duty. They felt that if their scope of practice was not well-defined and that if they were to be charged for any act or omission, there would be no one to represent them. One lay counsellor said: *"We also want to be registered with the nursing council. So that we may know at what level we belong as lay counsellors (in the hierarchy of professions). So that we can be protected, because now we are pricking. We handle needles and withdraw blood with the sachets in order to test the patient, but the nursing council does not know us"* LC2:6; 261-265.

Lay counsellors work with traumatised clients, which is evocative work, with the potential to arouse a sense of vulnerability to HIV and its consequences. This leads to fear for their lives and even the well-being of their own families. A counsellor described how she felt about working with HIV positive clients: *"That bothers me because, let's say the patient talk about the fact that they will die, then I start to remember that I am also a parent, and what if I die? The way she was telling me it touches me, the fact that when I die my children will suffer..."* LC5:5; 191-193. This is a source of vicarious trauma for the lay counsellors.

Dealing with emotional issues was overwhelming for lay counsellors. They felt unable to deal with the emotional aspect of HIV. They felt unskilled to provide answers to their clients' psychosocial problems. When asked how she helps clients with emotional and social problems, one counsellor responded as follows: *"Most of the time we talk to them about HIV. We try not to veer off the topic because if we do that sometimes we find ourselves in a situation where we are not able to give them answers that they want"* LC6:5; 225-227. Another said: *"So it's better if we talk about HIV where I know I will answer all their questions"* LC6:6; 233-234.

The lay counsellors explained about the high caseloads that they have to attend to: 10-30 per day. Such an intensive workload was found to be emotionally draining as they have to deal with an array of clients' negative emotional reactions. They described

feeling tired after seeing ten patients, and thereafter felt that they were no longer doing justice to the client. Further, time management then becomes a priority. The sessions become shorter, thus shifting the focus from the client's needs. *"You see, if you can talk to more than ten patients per day, things start not to go right. You get tired in the head; you are tired, honestly"* LC4:8; 350-353.

Anxiety about the client's well-being was common among lay counsellors. Their sense of inadequacy left them anxious after sessions and concerned about how clients will cope. As explained by one counsellor: *"When they leave then I start to worry in my heart because I don't know where they are going or how they are going to manage. I don't know whether, when they arrive at home because they have these problems, they are going to be able to take their pills or are they going to lose hope and say 'if I am going to lose my life then let it be'"* LC5:5; 200-204.

Lack of continuity of care further compounded the anxiety of lay counsellors. Because of the arrangements in these services, lay counsellors were unable to develop a therapeutic relationship with the clients. Counsellors were not able to see the same client and this meant they were unable to follow clients through their treatment. They described becoming anxious if they received no feedback about their clients.

4.6 Shortcomings during counselling

4.6.1 Religiosity

Two lay counsellors referred to the use of religion when they explained how they assisted patients to come to terms with their HIV diagnosis. Further They also used religion to assist patients when they had difficulties in disclosing their HIV status. It was clear that in the absence of a psychosocial framework, lay counsellors used what was available to them (e.g., religion) to assist patients. A female lay counsellor explained: *"Ok, according to me religion plays a very big role because if we find a person who is HIV positive, we also counsel them according to the Word of God. When we read from Proverbs, it says 'the heart (spirit) that is happy heals the body'. This means the heart*

that is sad makes the body sad. This means a person must heal spiritually before we come to the body of a person" LC3:5; 177-181. Religion and medical treatment were thus viewed as complimentary to each other, with the lay counsellor further explaining: *"Like now that we give pills that help the word of God to help people going forward"* LC3:5; 189.

They refer to emotions as 'spirit', implying that this has to be dealt with spiritually in the context of religion. When confronted by the emotional reactions of the client they rely on the Bible to quote verses that they think would comfort the client. This could be because of possible lack of mental health literacy among lay counsellors. They therefore do not have the language to describe mental health. This is an indication for a need for mental health training, which will be discussed further in Chapter 5.

The danger that lay counsellors impose strong religious beliefs on clients is noteworthy. As one lay counsellor stated: *"The Holy Spirit is the one that comforts a person until they get power ... We just make them believe so that their spirit can be settled but the body will be cured"*. Furthermore, this could alienate those believing in faiths other than Christianity. One lay counsellor identified this shortcoming: *"Some accept that prayer helps but some even if they do not tell you, you are able to see if a person is receptive to the Word of God. Isn't it some do not believe in the word of God?"* LC6:1; 37-39.

Clients also found religion to be a useful tool to deal with their illness and the consequences of HIV, such as looking up to God to save them from death. They looked at treatment as a phase that they must go through as they await God to enable government (science) to find treatment for HIV. Adherence to treatment was viewed as a bargaining tool to exchange with God for a 'good health' and cure for HIV. Their belief in God was also a source of hope. One counsellor talked about what clients say to each other during support groups. They say: *"Let's persevere and drink the pills, sometimes God can bless us, and our government can get treatment to cure this disease"* PT1:5; 224-225.

Participants also used religion to fend off painful, difficult emotions. One client explained: *"When you are infected and give yourself a problem (worry yourself) that*

what will make you to die before time while God still wants us to live". When asked how religion helped her she stated: *"I take it like everyone who is not sick. I take like I am also not sick"* P4:2; 55. They did not only use religion to find comfort but they also found zeal to live because of their belief that God wants them to live. Some clients also resigned themselves to God as the one who has the power ... *"everything is known by God. He is the one who knows what will happen to me. I must not give myself up to death"* PT4:3; 200-201. When such clients recover they attribute their recovery to God.

4.6.2 Counsellor-centred rather than client-centred approach

Clients' concerns were often overlooked, as the counsellors focused on imparting information. The counsellor decided what is important to talk about during counselling sessions, while often ignoring the clients' concerns. The clients' emotional and social concerns were dealt with through false reassurance and minimisation. A client recounted on one of her visits to the clinic when she had side-effects, saying: *"Some, when they take it, they have hallucinations in the night. When you explain to them they take you for counselling. They tell you it's not a problem!"* PT1:7; 277-278.

When client expressed their fears about being HIV positive the counsellors 'comforted' them by telling them that they were not going to die, that they are not supposed to be angry toward the people who infected them, or they must not be frightened of the fact that they are HIV positive. One counsellor explained how she helped a client deal with a psychosocial problem: *"If they are found to be positive we try to comfort them so that they know that the situation they are in does not mean that it is the end of life, their death or a death sentence. It is just a situation that has taken place"* LC6:1; 13-16. Another counsellor further explained: *"We tell them 'you know what, it won't help you to be angry toward the person you are staying (having a relationship) with, telling yourself that he is the one who infected you with HIV'"* LC7:4; 152-154.

This false reassurance and minimisation spilled over to support groups managed by the counsellors. When clients raise their concerns in a support group the other clients would comfort them by telling them: *"They are not the only ones who have a problem, or that*

what they are raising is not a problem, that in these times everyone is sick, it does not matter”.

Worryingly, this also occurs during the pre-test counselling, where clients are told that if they become HIV positive they must not worry because treatment is available. This could also explain why some clients (3/7), after the positive result, indicated that they are ok with being HIV positive, because they had been discouraged from experiencing, let alone expressing, their feelings: *“So they told me even if you are found to be positive you must not have a problem. A person who has this disease they are still a person. They then tested me and told me what the situation was. I started to get worried”* PT3:6; 251-254.

4.7 Lay counsellors’ needs

The lay counsellors identified their needs, mainly as related to their wishes to have improved job status and income. They therefore identified training that could lead to them being employed by government instead of by non-governmental organisations (NGO’s) and have access to benefits that are enjoyed by nurses, such as a uniform allowance. After interviewing seven lay counsellors regarding what training they thought they needed, the following responses were obtained: only one said she would like to be trained in professional counselling, two said they would like to train as nurses, the other four wanted updates for the short courses they had attended. One counsellor offered suggestions on what she thinks government should do for lay counsellors to enable them to feel recognised. She said: *“This people, it is long that they have been here. Their earnings are not enough to support their families. Like now that they are taking orphans for nursing training. They should also come to the hospital and look for orphans among lay counsellors and take them for training”* LC5:11; 443-447. Another commented: *“Yes, we want to be updated because changes occur, especially on TB”* LC2:6; 242.

4.8 Conclusion

Intra-personal reactions to a HIV positive result included denial, shock, anger, sadness, blame, and fear of death. Despite the biomedical focus of counsellors with emphasis on the benefits of ART, fear of death remained a primary reaction to a HIV positive result. Participants tended to blame their partners for having infected them, even if they had a history of multiple partners. This resulted in anger towards their sexual partners.

Socially, HIV infection resulted in a variety of difficulties, such as stigma, finding it hard to disclose, and concern for the children. Concern for the children was related to association of HIV infection with immediate death. Female parents feared that the father would abandon their children after they die. Stigma and abuse often prevented participants from disclosing their HIV status. This gave rise to the participants need to know how can they disclose without risk of abuse and stigma

Counselling was observed to be ineffective in meeting the psychosocial needs of PLWHA. Lay counsellors conceded that they are not trained for the task at hand. They expressed working in an environment that is fraught with bullying from professional nurses, work overload and uncertainty about security of their jobs and income.

CHAPTER FIVE

DISCUSSION

5.1 Introduction

The findings of this qualitative study indicate the range and depth of psychosocial experiences and needs amongst HIV positive patients in Limpopo, and how they are largely neglected by existing health services. It also highlights the health service challenges that a rural province such as Limpopo has to deal with, given the increasing number of clients entering ART services, with the associated increase for adequate mental health care. It was clear that mental health care for PLWHA has been largely left for lay counsellors to manage, but their limited training and skill, and service level constraints, prevents them from providing even the most basics mental health support care.

5.2 Emotional responses

Most participants in this study reported being emotionally disturbed, and anticipated social difficulties related to them being HIV positive. This emerges from a number of social situation experiences that are fairly common to many South Africans, namely, poverty, unemployment, inadequate child care, and intimate partner violence. These findings are similar to those recorded in previous studies, by others (Uphold et al., 2005; Sun et al., 2007)

Clients in this study were anxious about impending death after a HIV positive result. This was evident in that clients reported that they were 'thinking' a lot about their status. An HIV positive result was perceived to be so life threatening that some patients thought their time to die has come. A South African study by Olley et al. (2005: 551) has found a 45% prevalence of post-traumatic disorder among patients recently diagnosed of HIV, confirming HIV diagnosis as a traumatic event. Post-traumatic stress disorder occurs

when an individual has confronted with a life threatening event, they experience symptoms such as intrusive thoughts, avoidance of stimuli related to the trauma, and hyper arousal (Uys and Middleton, 2004: 287). They avoid people, activities and places that serve as reminders of the illness (Olley et al., 2005: 551). Similar to clients with denial, clients who experience trauma avoid appointments for ongoing assessments. Furthermore, clients in this study reported that they were preoccupied with the disease (thinking about the infection). This affected their relationships with their families.

Shock was a common emotional reaction to receiving a positive result after testing – this is in keeping with reaction to traumatic news (Uys and Middleton, 2004: 682). This shock response was not surprising, since HIV testing was often not the main purpose for clients coming to the health facility and they have not had time to think about the outcome. Although the pre-test counselling is supposed to deal with people's potential responses (to a positive HIV test), it seems this is not really being given attention. It was most often these psychosocial reactions that made lay counsellors feel inadequate due to their poor skill base to draw from. They recognised their limited ability to assist clients, and this created anxieties for them as well, as they remained concerned about the well-being of their patients.

Lay counsellors also reported that some clients did not openly discuss their feelings. They responded by saying they were 'ok' or keeping quiet when asked how they felt after a positive test. However, despite their verbal reassurance of coping, clients often cried, which is an indication that they had definite emotional reactions to a positive test. It is very likely that clients were already prompted in the pre-test counselling that they should not be concerned or worried about a positive test because HIV is a common occurrence and they are not the only ones infected, and that HIV is a condition that is medically manageable.

There were many ways in which clients in this study demonstrated denial. Avoidance is a common response when dealing with problems (Berg et al., 2007: 187). The ways in which denial manifested were through participants' 'explanations', which were often their way of making sense of their situation, such as attributing their positive result to faulty test kits. These coping strategies are referred to as cognitive escape (Sun et al.,

2007: 1330). Some women participants thought that by being faithful to their partners they would not be positive. Another form of denial was when women struggled to comprehend their positive status in the light of having ensured that they practice safe sex. They therefore denied being HIV positive because it was contrary to their self-concept. Such responses often help to reduce the client's consciousness of the threats associated with being HIV positive. A further form of denial shown was when clients sought different medical opinions for official refutation of their status. This behaviour is also described in literature (Vlok, 1998: 243). Clients in this study sought second opinions from different HIV counsellors, medical institution or traditional healers.

Other ways in which initial denial was evident was when participants took a while to go back to health facilities for ongoing management. Such avoidance may be due to clients needing more time to deal with the diagnosis. Avoiding the counsellor with whom they had initial contact could also be a form of denial, but it is unlikely, because participants had returned to the health service. It is more likely that such avoidance is related to other factors, such as interpersonal relations with the counsellor, the experience during that first interview, shame and stigma.

Furthermore, denial in this study was related to a belief that HIV is caused by witchcraft. A similar finding was reported in a Cape Town survey, where 11% of 487 black participants (male and females) attributed AIDS to spirits/supernatural forces (Kalichman and Simbayi, 2004: 572). The reference to foreigners as those that bewitched them was new in this study – it has not been reported before. South Africa has recently, over the past two years, experienced huge homophobic reactions against foreigners from neighbouring African states. Violent reactions to the foreigners were spurred by the belief that they are responsible for local South Africans' inability to find jobs and houses, and lack of success in small businesses. This (foreigners being the cause of bewitchment) may be an extension of this belief, although this was not explored in any depth in the present study. Another explanation, based on anecdotal evidence, is that foreigners have the most potent 'muti' (an African 'concoction' thought to bring bad luck).

Denial of a HIV diagnosis by clients' intimate partners (predominately male partners) was shown through their continuation of risky sexual practices. Women reported to lay counsellors that their partners refused to use condoms despite knowing their HIV status. This mirrors the findings of a study carried out by Berg et al. (2007); they found that people who deal with HIV infection through denial continued to engage in risky behaviour. Such denial is not surprising, because loss to follow-up rate at two clinics were reported to be 15-26% in Tzaneen. Denial is therefore an undesirable reaction to a HIV positive result. Clients in denial are non-adherent to treatment and PLWHA can develop a resistant virus and transmit it to uninfected partners (Rieman et al., 2007: 671). The partners then further re-infect each thereby, reducing their life expectancy. Denial cause problems with regard to access to care and support as these clients refuse to acknowledge infection and therefore they do not actively help.

Anger was an emotion described by both the counsellors and the patients as a reaction after hearing their status. It is a normal healthy emotion that alerts an individual to impending threat or trauma (Townsend, 2009: 255). It has been shown that anger could be directed either outwards towards family, friends and caregivers, or inwards towards self (Dexter and Wash, 1997: 190), and is associated with blame of others for what has happened to them (Uys and Middleton, 2004: 682). Female participants blamed their partners for having infected them. They became frustrated with the fact that they had been faithful but yet they contracted HIV. Moreover, they were angry that their partners did not use condoms when they had sex outside the relationship. Similarly, lay counsellors were accused of being incompetent and liars when the HIV test result turned out to be positive – a perception that arose from their trying to cope with a positive status.

Anger becomes increasingly destructive when an individual is not able to vent it or when it is expressed aggressively. Given previous findings of the high prevalence of women abuse in general (Brandy et al., 2002; Brou et al., 2007), it was not surprising that two of the three female participants were already involved in relationships where they were abused emotionally, physically and financially. Anger at discovering an HIV positive status seemed to have given women the impetus to terminate their intimate

relationships. Leaving an intimate relationship is not easy, and making such a decision after a HIV diagnosis is an indication of the women's strength in the light of the huge difficulties they will have to face.

It is most important that HIV services recognise that gender-based violence is a reality in many HIV positive women's lives and support should be an important aspect of HIV comprehensive care. This is especially important, given the fact the violence against women increases at the time of disclosure and when they try to negotiate safe sex (Dematteo et al., 2002).

Severe emotional responses were evident in two participants (male and female), who expressed a wish to kill themselves at various stages (of being HIV infected). A male participant reported his suicidal thoughts, which was to kill himself by throwing himself in front of a moving lorry, in reaction to his discovery of his HIV positive result. A female participant expressed suicidal thoughts, which was to set both herself and her husband alight, to a lay counsellor. Her thoughts were caused by her blaming the male partner for infecting her. This suicidal ideation has been reported by others (Green and Smith, 2004), and could be due inability to express emotions (Dexter et al., 2001). The suicidal tendency was also due to the shame associated with being HIV positive. The male participant reported that he was no longer helpful because he would not be able to work anymore; he thought he was not able to live up to his masculine role of being a provider. Furthermore, men perceive themselves as being weak if they are sick.

Lay counsellors dealt with anger by discouraging the clients from getting angry. This is a concern, because they often, instead, encouraged clients to concentrate on positive living and looking after the well-being of their children. Such an approach is most unhelpful and unhealthy, as internalised anger causes depression, which can further result in suicide (Dexter and Wash, 2001: 190). Lay counsellors recognised that their help was insufficient, and reported feeling anxious after their clients left in a states of anger, or when suicidal thoughts were expressed. They were worried that clients would not be able to cope and could commit suicide and that they have not being able to help. Of major concern is that, in this case, the lay counsellor did not refer the client to other members of the team.

HIV is traditionally associated with death, and although ART has changed the mortality risk this was not something that the participants understood well, hence fear of dying remained a huge concern. Mostly clients visit the health facilities when they were in an advanced stage of HIV. For them, a HIV positive result is confirmation of impending death. This fear also emanated from them having seen other clients dying of HIV. In a study carried out by Sikkema et al. (2000), it was established that observing others die of HIV/AIDS evokes fear in clients. This was compounded by information they got from lay counsellors about the danger associated with pregnancy while being HIV positive. Furthermore, clients were aware that ARVs do not cure HIV, and hence they feel ambivalent about their benefits. This echoes the findings of a previous study, namely that when clients are told that their blood results show no benefit from medication their anxiety levels increase (Dematteo et al., 2002: 262). Fear of death was further related to concern for the well-being of children. Women participants feared that when they die their children will have no one to look after them.

5.3 Social reaction to living with HIV

Women in this study delayed disclosure to their partners in particular because they anticipated abuse, abandonment and divorce if they were to disclose. The anxieties arose from many different social problems women encounter in their daily living such as abuse and a need to protect them from it, need to protect their children and lack of employment opportunities. In a previous study generalised anxiety was found to affect 16% of PLWHA (Zanjani et al., 2007). Lay counsellors reported how female clients were abused as a consequence of disclosure. Fear and experiences of violence have been reported in many other HIV studies the intimate partner violence reported in this study resonates with the high levels of violence reported in South Africa. Some live in abusive relationships and feared that it could worsen after disclosure. In a study in Abidjan, it emerged that due to intimate partner violence 53% of women do not disclose their HIV positive status (Brou et al., 2007: 1915). Lay counsellors related how their economical dependency on men made them fear the prospect of being divorced by their partner. Abandonment was also a concern for females who were not primary partners; they

thought the men would find it easy to abandon them. For these women non-disclosure is a protective measure against an array of abuse. Non-disclosure prevented women from practicing many protective behaviors such as negotiating safe sex and attending the clinic regularly. Further in case of pregnancy, inability to disclose meant that they could protect their children through exclusive breast/bottle feeding. Bottle feeding often can lead to unintentional disclosure as it is common knowledge that HIV positive mothers are encourage to breastfeed exclusively (Mawar et al., 2007).

For the unmarried woman, her concern about disclosure was related to fear that she would neither secure an intimate relationship nor marriage.

Non-disclosure to employers was related to fear of losing employment. Participants anticipated that their employer would not 'understand' their status. They thought that the employers are not well informed about HIV and that this could lead to them being fired. Fear of losing one's job has been shown to intensify anxiety among PLWHA in a study by Sun et al. (2002). This led to depression, low self-esteem and suicidal ideation (Blaalock et al., 2002: 400). This also led to participants defaulting on clinic appointments. The result is that they do not disclose to employers at all. In cases where they did honor appointments, they found that they letter to employer from the clinic was discreet thereby protecting them from being victimised.

Participants who were parents also delayed disclosure to their children. They feared that the children would disclose their status to people they do not want to tell about their status. They further thought that the children were too young to handle the emotional upheaval. Other study demonstrated that the need to protect the child from the news, unwillingness to discuss how HIV was acquired were some the reasons why parents did not disclose their children (Thorne et al., 1999; Woodring et al., 2005). Yet past studies have shown that children can successfully handle it at age of 10 years onwards (Thorne et al., 1999).

Last but not least, participants did not want to visit the ART clinic for fear of disclosure by association. They regarded visiting the antiretroviral clinic as confirmation that they are HIV positive which was undesirable.

Stigma at the time of diagnosis was largely anticipatory, i.e., clients perceived that they will be blamed, shamed and discriminated against. Anticipatory stigma is associated with clients' beliefs that by being HIV positive they have transgressed societal moral code (Zou et al., 2009: 3) due to societal beliefs that they have behaved immorally (Li et al., 2008: 4). It had a direct bearing on psychosocial issues such as fear of disclosure, suicidal ideation and intimate partner violence. The communities perceive a person diagnosed with HIV as dying and infectious. The HIV positive clients feared bringing shame to their family. The extension of stigma is due to the belief that the immoral behavior is a family trait (Li et al., 2008). Prior to HIV testing, most clients had already experienced stigma from the community. When they lose weight, the community starts talking behind their back, saying they are positive. They therefore anticipate stigma to worsen now that they are positive. This fuels their need to keep their status secret. Participants also anticipated that their family would stigmatise them. Lay counsellors reported that being stigmatised at home was the most painful for the patient. This is regrettable as social support especially from the family has proven to have positive impact on clients' prognosis (Battles and Weiner, 2002). This was because the family was seen as the core of social support. Stigma of HIV people was still a common response from communities and families. This is consistent with a previous study that found PLWHA has to contend with rejection from the community (Berg et al., 2007). Some clients however opposed stigma by responding to people stigmatising them, telling that they were better off because they knew their status.

Stigma led to selective disclosure or complete non-disclosure. Stigma has been linked to non-disclosure which leads to inability to take preventive measures in a previous study (Woodring et al., 2005). This is of concern because in some instances participants chose to keep their diagnosis to people close to them. They would disclose to people who they thought would be sympathetic to them, while not disclosing to partners and children. Further stigma led to despair and hopelessness. When asked what they do in instances where they experienced stigma? Most participants replied "*there is nothing I can do*", thereby resigning themselves to the abuse meted to them by the community.

5.4 Clients perceived psychosocial needs and support.

The clients in the study wanted the lay counsellors to help them regarding how to disclose. This was prompted by the predicament of disclosing and risking abandonment. However clients knew that by not disclosing they run the risk of re-infection because they could not negotiate for safe sex. They also knew that re-infection lead to quicker progression to AIDS and ultimately death. They anticipated that their partners and the broader family would not support them. They wanted the counsellor to help them disclose in a way that they would not be treated badly at home. Lack of psychosocial support lead clients to forsake the issue of disclosure: this indication of how services are unable meeting their needs. However, lay counsellor did not see this as their core competency.

5.5 The role that lay counsellors currently play in the provision of psychosocial care

Lay counsellors are not well equipped with essential counselling skills despite the explicit need to provide mental health services to PLWHA (Uphold et al., 2005). The model used for HIV counselling is a directive health education approach (Rhondler and Swartz, 2005), which does not address affective distress (Evangeli et al., 2009: 190). Further training for lay counsellors does not include psychosocial counselling. The short courses they attend include voluntary counselling and testing, a TB course, adherence counselling and prevention of mother-to-child transmission. This could explain why they see psychosocial counselling as not being their work, and feel ill equipped to execute it.

However, they do feel obliged to assist people, and then use their own resources (including their own religious beliefs) to try to assist. Although this has been found to provide meaning and purpose to life, it could also be problematic to those who believe that the illness is punishment from God (Cotton et al., 2006). Lay counsellors also use information about the availability and effectiveness of ART to reassure clients that they will not die. However, it was encouraging to note that counsellors are aware of their deficiencies, although, simultaneously, they were unable to identify how to resolve their

lack of skills – other than requesting for more training. However, the training requested was not for more mental health skills, but to train as a nurse, which was motivated by the attraction of being employed within the government health system. This provides a clear indication of how lay counsellors do not value providing mental health care to HIV patients.

Lay counsellors seemed uncomfortable with clients expressing their feelings. They discouraged expression of feelings by telling clients that they are not the only ones who are infected. Instead of helping the clients understand their feelings, lay counsellors told clients to neither get angry nor to fear death. Evidence of them trying to extricate themselves from responsibility of assisting their clients with social problems is evident from the statement: *“everyone knows their husband; they will know how to talk to disclose to them”*.

This study showed how the counsellors viewed themselves as possessing knowledge that they have to impart to the clients, describing themselves as teachers. Not surprisingly, lay counsellors and patients also described the post-test counselling session as a ‘class’. Thus the sessions become counsellor-centered. The lay counsellor decided what the issues to be discussed were. The expression of emotions such as fear, denial and anger was seen as a sign that the clients had not understood the bioscience of HIV.

Referral to the social workers, physicians and professional nurses was one way in which they dealt with clients. However, the social workers in these clinic facilities were only available once a week. Although professional nurses are available daily, due to their task shifting, they refer clients with psychosocial problems to the lay counsellors.

Lack of continuity of care also lay at the center of the inability to offer adequate psychosocial care. Clients came to the ART clinic they see any counsellor available. There is therefore no follow-up on the issues discussed in previous visits. However, lay counsellors recognised this anomaly. Some reported that if they saw a client they had counselled in previous sessions they would call them and find out how they were doing.

5.6 Conclusion

Clients at ART clinics are confronted by emotional and social problems as result of living with HIV. Emotions such as shock, denial, anxiety related to perception of impending death, and anger were particularly noticeable in the study participants. In their social interactions, PLWHA are faced with challenges such as disclosure versus abuse associated with such disclosure. Health systems challenges such as lack of clear policy with regard to the role of lay counsellors in assisting clients with mental health issues, lack of training makes it difficult for lay counsellors to provide psychosocial counseling and work overload. These health systems challenges are further expanded on in the next chapter.

CHAPTER 6

CONCLUSIONS AND RECOMMENDATIONS

6.1 Introduction

This study addressed the psychosocial care of people living with HIV in a rural area of South Africa. This chapter summarises the interpretations of the findings of this study. This is done in line with the objectives of the study described in Chapter 1. It will demonstrate how the objectives of the study have been met. The chapter also outlines the limitations of the study and offers recommendations for how lay counsellors can better fulfil their role as psychosocial counsellors.

6.2 Conclusions

This study's overall aim was to explore whether lay counsellors offer psychosocial counselling at the ART sites. Clearly, despite psychosocial support being a key component care for PLWHA, as stipulated by the HIV & AIDS and STI national strategic plan for South Africa 2007-2011, it is not provided by lay counsellors here. While extensive literature reveals that attention to mental health services can be of great benefit to supporting PLWHA, despite this the biomedical paradigm still dominates the services offered at the ART sites.

There are several issues that result in counsellors being unable to offer psychosocial counselling: lack of training on mental health issues, poor emotional support, a hostile working environment, poor pay (and often not on time), and a high work load. Their inability to conceptualise mental health concepts among their clients further compounds the problem.

Participants in this study found it hard to describe how it felt when they received a HIV positive result. Lay counsellors encouraged their clients to suppress their feelings, this was amplified by a lack of continuity of care, which makes it impossible for lay

counsellors to have follow-up sessions with clients. Thus no therapeutic relationship could be formed where a the client could trust the counselors enough to share their emotions. Participants described seeing a new counsellor each time they visited the ART clinics.

It was nonetheless encouraging to find that clients were able to identify relevant mental health issues, such as denial of their HIV status and intimate partner violence. They also indicated awareness that should be dealt with which left them feeling anxious and insecure about their standard of work. The hostile environment in which lay counsellors work with some nurses constantly belittling them further undermines their confidence and work satisfaction.

Clients' self-identified needs were focused on the social aspect of HIV. They wished that the lay counsellors could help them with approach they could use to disclose without having to bear the negative consequences of such disclosure. This was a consequence of widespread intimate partner violence, mainly against women. They worried about being abandoned if they were to disclose. Although participants did not identify disclosure to children as an aspect where they need help it was clear that they found it difficult to disclose to their children. They further wanted to be helped with negotiating for condom use as they feared this could result in their partner terminating their relationship.

At the time of diagnosis, clients reacted in a variety of ways, including shock, denial, fear of death, anger and blame. At the time of the interview the participants were no longer in denial. They did however report that when they were still in denial they described not going to the clinics for ongoing care because they did not believe they were ill. The fact that a HIV positive result was associated with being bewitched by foreigners was noteworthy, and of great concern. This could result in xenophobic attacks. Anger was mainly directed at the individuals whom the participant thought had infected them. Anger elicited negative consequences, such as divorce and suicidal ideation. Clients felt that these intense negative emotions would dissipate with time.

Having a treatment supporter is one of prerequisite before clients are started on ART in the clinics. Two male participants brought their sisters who were not staying with them as treatment supporters. The supporters described buying the participants food and going to the clinic to collect their treatment as how they supported them. The other two males were married, and supported by their spouses, who reminded them of times to take treatment, gave them food before taking treatment and supported them emotionally. It was a noteworthy that one of the female participants was supported by her child who was still at school. This child made sure that he prepared soft porridge and bathing water for his mother before he went to school.

6.3 Recommendations

The titles of the following sub-sections describe approaches that have been implemented in other poor mental health resource (i.e. lack psychologists, psychiatrists, mental health nurses etc.) settings like South Africa where community health workers are used to render mental health services. The community health workers were briefly trained to screen for and deal with psychosocial problems such post-traumatic stress disorder and intimate partner violence. The approaches however, require further research for suitability and adaptation to the HIV counselling context in South Africa.

6.3.1 Case management approach

It should be said from the outset that clients will not benefit from the following proposal if the status quo remains, namely that clients are seen by different counsellors each time they visit the ART site. It is recommended that, in future, each lay counsellor be allocated a caseload. This will both ensure both continuity of care and contribute to making the environment more conducive to a therapeutic relationship.

6.3.2 Screening for common mental health disorders

Both the literature review and data analysis in this study reveal that psychosocial issues play a role in the prognosis of PLWHA. Yet the tests that are conducted during clients' visits only address issues related to the effectiveness of ARTs. It has however been shown that by not giving attention to mental health issues the health system may perpetuate them. Mental illness health that is not treated also affects issues such as adherence to ART's, and poor attendance of follow-up visits. Lay counselors, with the aid of a screening tool can routinely screen patients for common mental health disorders such as depression and post-traumatic response/disorder. A Bob tool for common mental health, which has been 'South Africanised' for the WHO is recommended.

6.3.3 Psycho-educational counselling

This type of counselling focuses on providing basic information about recognising the onset symptoms mental health problems, their causes, and coping strategies (Lazarus et al., 2009: 16). This is could help lay counsellors to alleviate clients' symptoms such as denial, shock and anger, which have been found to be prevalent in this study. The theories taught should include Maslow's hierarchy of needs and Kubler Ross stages of grieving. This will enable lay counsellors to better understand what clients are going through and thus, through appropriate mentoring, would be better able to help clients to deal with their anxiety, and normalise the situation.

6.3.4 Cognitive behavioural therapy

A study carried out in rural Pakistan has shown that cognitive behavioural therapy can be offered by lay counsellors after three days of training and monthly supervision. It was further shown to be sustainable over a one year period (Patel and Kirkwood, 2008: 868). Cognitive behavioural therapy establishes the relationship between thoughts, emotions and behaviour. This will help lay counsellors to better understand negative behaviours such as resistance to return to the clinic, unwillingness to disclose HIV status, and, with an emphasis on positive thinking, they will help clients to endeavour to live more positively with HIV.

6.3.5 Cognitive processing and post-traumatic growth

Clients in this study revealed experiencing symptoms consistent with post-traumatic stress disorder, such as recurrent intrusive thoughts and avoiding people or places that reminded them of their HIV positive diagnosis. Furthermore, a South African retrospective data analysis study found the prevalence of post-traumatic stress disorder due to HIV positive diagnosis to be 30-64% (Olley et al., 2005: 556). The study further recommended that all HIV positive clients should be screened for post-traumatic stress disorder, particularly women who have been subjected to sexual violation and intimate partner violence. It is therefore important for lay counsellors not only to encourage positive living but also to support clients to find their own meaning, and increase their appreciation of life, meaningful interpersonal relationships, personal strength, changed priorities and a richer spiritual life (Lazarus and Freeman, 2009: 45).

6.3.6 Interpersonal psychotherapy

Intimate partner violence and issues relating to non-disclosure were dominant findings of the study. For example, clients who were parents found it difficult to disclose their status to their children. This makes it impossible for them to benefit from the support of significant people in their lives. They rather sought support from friends outside the family. Another South African study has however demonstrated that family support compared to support from friends is highly associated with lower levels of depression, anxiety and loneliness (Freeman et al., 2007: 1202). Lay counsellors must therefore help clients to deal with disturbing life events, build social skills, and reorganise their lives. Specific skills can include self-reliance and assertiveness (Lazarus et al., 2009: 17).

6.4 Limitations of the study

One of the limitations of this study is that there was no mental health assessment tool used to identify specific diagnoses. This limited the ability to identify what the specific mental conditions are that are prevalent in the study area. The second limitation is that

both patients and lay counsellors found it difficult to describe mental health concepts. However, the later was counteracted by the fact that the researcher spoke the local language and was able to direct the participants to describe their feelings.

6.5 Conclusion

It is very clear that lay counsellors are neither trained to offer psychosocial counselling nor are they providing it. However, it is encouraging they are able to recognise when their clients are not emotional well. Studies quoted in this thesis indicate that, with some basic training, lay counsellors would be able to offer basic psychosocial counselling. Hence, policymakers should make provision for the training of lay counsellors to provide this much needed service. It is also desirable to professionalise this category of workers in order to uplift their social standing and for them to be remunerated accordingly.

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APPENDIX A: Stellenbosch University ethics clearance



UNIVERSITEIT • STELLENBOSCH • UNIVERSITY
jou kennisvenoot • your knowledge partner

26 April 2010 **MAILED**

Mr S Mashele
Department of Nursing
2nd Floor, Teaching building
Stellenbosch University
Tygerberg campus
7505

Dear Mr Mashele

"Psychosocial care of people living with HIV: The case of Tzaneen, South Africa."

ETHICS REFERENCE NO: N10/02/035

RE : APPROVED

It is a pleasure to inform you that a review panel of the Health Research Ethics Committee has approved the above-mentioned project on 26 April 2010, including the ethical aspects involved, for a period of one year from this date.

This project is therefore now registered and you can proceed with the work. Please quote the above-mentioned project number in ALL future correspondence. You may start with the project. Notwithstanding this approval, the Committee can request that work on this project be halted temporarily in anticipation of more information that they might deem necessary.

Please note a template of the progress report is obtainable on www.sun.ac.za/rds and should be submitted to the Committee before the year has expired. The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly and subjected to an external audit.


Translations of the consent document in the languages applicable to the study participants should be submitted.


Federal Wide Assurance Number: 00001372
Institutional Review Board (IRB) Number: IRB0005239

The Health Research Ethics Committee complies with the SA National Health Act No.61 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

Please note that for research at primary or secondary healthcare facility permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Contact persons are Ms Claudette Abrahams at Western Cape Department of Health (healthres@pgwc.gov.za Tel: +27 21 483 9907) and Dr Hélène Visser at City Health (Helene.Visser@capetown.gov.za Tel: +27 21 400 3981). Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

26 April 2010 14:49 Page 1 of 2



Fakulteit Gesondheidswetenskappe - Faculty of Health Sciences 

Verbind tot Optimale Gesondheid - Committed to Optimal Health
Afdeling Navorsingsontwikkeling en -steun - Division of Research Development and Support
Posbus/PO Box 19063 - Tygerberg 7505 - Suid-Afrika/South Africa
Tel.: +27 21 938 9075 - Faks/Fax: +27 21 931 3352

APPENDIX B: Limpopo Department of Health, permission



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH AND SOCIAL DEVELOPMENT

Enquiries: Ramalivhana NJ/Malomane EL

Ref: 4/2/2

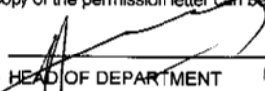
25 May, 2010
Mr S Mashele
Department of Nursing
2nd Floor
Teaching bulding
Stellenbcsch
Tygerberg campus
7505

Dear Mr S Mashele

"Psychosocial care of people living with HIV: the case of Tzaneen, South Africa".

Permission is hereby granted to Mr S Mashele to conduct a study as mentioned above in Limpopo Province, South Africa

- The Department of Health and Social Development will expect a copy of the completed research for its own resource centre after completion of the study.
- The researcher is expected to avoid disrupting services in the course of his study
- The research results must be used only for the purpose of the study
- The Researcher/s should be prepared to assist in interpretation and implementation of the recommendations where possible
- The Institution management where the study is being conducted should be made aware of this,
- A copy of the permission letter can be forwarded to Management of the Institutions concerned



HEAD OF DEPARTMENT
HEALTH AND SOCIAL DEVELOPMENT
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APPENDIX C: Informed consent for lay counsellors

**PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM
FOR LAY COUNSELLORS.**

TITLE OF THE RESEARCH PROJECT: PSYCHOSOCIAL CARE OF PEOPLE LIVING WITH HIV: THE CASE OF TZANEEN, SOUTH AFRICA.

REFERENCE NUMBER:

PRINCIPAL INVESTIGATOR: Mr. S.C. Mashele

ADDRESS: P.O. Box 463, Shiluvane, 0873.

CONTACT NUMBER: 0827761712

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

This study has been approved by the **Health Research Ethics Committee (HREC) at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

- The purpose of this study is to understand how we can better help people who are attending ARV clinics to cope with their HIV positive status. We are especially interested in how to assist with their mental health.

Why have you been invited to participate?

- *You have been invited because as a lay counsellor you can shed light on mental and social health issues as aspects of care offered by lay counsellors and also you can shed light on the needs of HIV positive clients*

What will your responsibilities be?

- *Your responsibility in this study will be to take part in an approximately one hour uninterrupted interview.*

Will you benefit from taking part in this research?

- *The study recommendations could help improve the service you provide.*

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

- *No. The information you share in this interview will be kept completely confidential.*

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

In the event that you experience any psychological trauma you will be referred to a mental health care specialist for assistance.

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

No. There will be no costs involved for you, if you do take part.

Is there anything else that you should know or do?

- You can contact Mr. S.C. Mashele at 0827761712 if you have any further queries or encounter any problems.
- You can contact the **Health Research Ethics Committee** at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by your study doctor.
- You will receive a copy of this information and consent form for your own records.

Declaration by participant

By signing below, I agree to take part in a research study entitled, "Psychosocial care of people living with HIV: The case of Tzaneen, South Africa."

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) on (*date*) 2010.

.....
Signature of participant

.....
Signature of witness

Declaration by investigator

I (*name*) declare that:

- I explained the information in this document to
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that s/he adequately understands all aspects of the research, as discussed above
- I did/did not use a interpreter. (*If an interpreter is used then the interpreter must sign the declaration below.*)

Signed at (*place*) on (*date*) 2010.

.....
Signature of investigator

.....
Signature of witness

APPENDIX D: Informed consent for clients

**PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM
FOR HIV POSITIVE CLIENTS.**

TITLE OF THE RESEARCH PROJECT: PSYCHOSOCIAL CARE OF PEOPLE LIVING WITH HIV: THE CASE OF TZANEEN, SOUTH AFRICA.

REFERENCE NUMBER:

PRINCIPAL INVESTIGATOR: Mr. S.C. Mashele

ADDRESS: P.O. Box 463, Shiluvane, O873.

CONTACT NUMBER: 0827761712

You are being invited to take part in a research project, the details of which I will now explain to you. Please ask me any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Health Research Ethics Committee (HREC) at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good

Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

- The reason for doing this study is to understand how we can better help those attending ARV clinics to cope with their HIV positive status. We are especially interested in how to improve their mental health.

Why have you been invited to participate?

- *You have been invited because we know that people living with HIV experience many problems in their lives. You have been chosen because you attend this clinic and we believe that your experience as HIV positive client can assist us in discovering how to help you better.*

What will your responsibilities be?

- *Your responsibility in this study will be to participate in an uninterrupted interview for approximately one hour. Your honest responses will be greatly valued.*

Will you benefit from taking part in this research?

- *The study will help you to recognise sources of psychosocial support for yourself. The study recommendations improve training for lay counsellors and thus the services they provide.*

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

- *It is possible that taking part in the study could evoke sad feelings because being HIV positive is hard and sometimes feels difficult to bear. This is normal and talking through these feelings in the interview could help you to feel much better afterwards. Should it be necessary however, I can also help you be assisted by a mental health care nurse and/or psychologist.*

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

- *If you do not want to take part in the study you are still entitled to your usual ongoing counselling sessions and may request your lay counsellor to refer you to the services you require.*

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

- *In the event that you experience any **emotional distress** you will be referred to a mental health care practitioner for support.*

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

No, you will not be paid to take part in the study. There will be no costs involved for you, if you do take part.

Is there anything else that you should know or do?

- You can contact Mr. S.C. Mashele at 0827761712 if you have any further queries or encounter any problems.
- You can contact the **Health Research Ethics Committee** at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by your researcher.
- Should you require it, you will receive a copy of this information and consent form for your own record.

Declaration by participant

By signing below, I agree to take part in a research study entitled, "Psychosocial care of people living with HIV: The case of Tzaneen, South Africa."

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) on (*date*) 2010.

.....
Signature of participant

.....
Signature of witness

Declaration by investigator

I (*name*) declare that:

- I explained the information in this document to
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that s/he adequately understands all aspects of the research, as discussed above
- I did/did not use an interpreter. (*If an interpreter is used then the interpreter must sign the declaration below.*)

Signed at (*place*) on (*date*) 2010.

.....
Signature of investigator

.....
Signature of witness

APPENDIX E: Interview guide for lay counsellors (English)

INTERVIEW GUIDE FOR LAY COUNSELLORS

**Psychosocial care for people living with HIV: The case of Tzaneen,
South Africa.**

DEMOGRAPHIC DATA

Age:

Gender:

Name of clinic:

Highest grade passed:

1. Explain all the ways in which you personally support HIV positive clients at this clinic?
2. What social and emotional issues/problems do you help HIV positive clients with?
3. Provide examples of emotional problems that you assist HIV positive clients with on a daily basis?
4. Please explain how you assist clients with emotional problems?
5. Please explain how you assist clients with social problems?
6. Do you feel effective? Give examples.
7. Discuss barriers to assisting clients with emotional problems? Please provide examples.
8. Which HIV positive clients do you refer for further assistance?
9. Who do you refer them to?
10. Describe the training you received to provide counselling and assistance to HIV positive clients.
11. Do you feel you need more training and/or support to assist them? Be specific about exactly what you feel you need.

APPENDIX F: Interview guide for lay counsellors (Sotho)

SOTHO INTERVIEW GUIDE FOR LAY COUNSELLORS

Tsedimoso ya motho.

Mengwaga:

Bong:

Lebitso la kliniki:

Mphato wo o phasitsego:

1. ke ka tsela efe yeo wena thekgago balwetsi ba go ba le kokwana hloko ya HIV?
2. ke afe malwetsi a maekutlo le go phedisano ao o thusang balwetsi ba go ba phelago le HIV ka ona?
3. efa mohlala wa malwetsi a maekutlo ao o thusang balwetsi ba goba le HIV ka wona?
4. efa mohlala wa tsela eo o thusang balwetsi ba goba malwetsi a maekutlo le HIV ka yona?
5. efa mohlala wa tsela eo o thusang balwetsi ba goba malwetsi a phedisano le HIV ka yona?
6. O kwa o kgona ka o ba thusa ka kgonte? Efa mohlala.
7. ke eng dilo tseo di go thibelang go thusa balwetsi ka malwetsi a maekutlo?
8. O romelo balwetsi ba HIV kgo tswela pele ka thuso ya mathata a menagano/maekutlo,
9. O ba romela kae?
10. O hwetsitse hlahlo ya go thusa balwetsi ba menagano/maekutlo, ke hlahlo ya mufuta mang?
11. a kwa o sa hloka hlahlo le thekgo ye go e tseneletsego ya thusa ka malwetsi a menagano/maekutlo. Hlalusa go re ke hlahlo ya mufuta mang.

APPENDIX G: Interview guide for lay counsellors (Tsonga)

TSONGA INTERVIEW GUIDE FOR LAY COUNSELLORS

Psychosocial care for people living with HIV in Tzaneen, South Africa.

Vuxokoxoko bya munhu:

Malembe:

Rimbewu:

Lebitso la kliniki:

Ntanga leyi nga pasiwa:

1. Xana wena u va pfuna njhani lava nga na HIV?
2. Hi swihi swipiqo swo hanyisana na ku tsikeleleka ka mihleketo leswi u pfunaka vavabyi hi swona?
3. Nika xikombiso xa swipiqo xa swa mahanyelo leswi vavabyi va taka na swona?
4. Hlamusela hi laha u pfunaka vavabyi lava nga ku vaviseka emoyeni ha kona?
5. Hlamusela hi laha u pfunaka vavabyi lava nga na swiralanganya swa mahanyelo ha kona?
6. U twa u swi kota nyika swikombiso?
7. I yini swi ku kanganyisaka ku pfuna vavabyi hi ku vaviseka emoyeni? Nyika swikombiso.
8. Hi vahi vavabyi lava nga na ku vaviseka emoyeni u va rumelaka eka vativi?
9. U va rumela ke va mani?
10. hlamusela ku letela loku u ku nyikiweke ku pfuna vavabyi lava nga na HIV?
11. Xana u twa u lava ku leteriwa ko tatisa kumbe ku seketeriwa ku va u ta kota ku pfuna vavabyi?
Nyika swikombiso swa ndzetelo lowu u wu lavaka

APPENDIX H: Interview guide for clients (English)

INTERVIEW GUIDE FOR HIV POSITIVE CLIENT

Psychosocial care of people living with HIV: The case of Tzaneen South Africa.

DEMOGRAPHIC DATA

Genogram:

Name of clinic:

Current employment:

Highest grade passed:

1. What was it like when you first heard you are HIV positive?
2. How does it feel to be HIV positive?
3. Have these feelings changed over time? How much time?
4. What quality of assistance did you get from the clinic?
5. Who assisted you, what did they do?
6. What kind of help/support have you received from outside the clinic?
7. Do you have a counsellor that works here at the clinic and if so, how is your relationship?
8. Please tell me about the help you get from the counsellor and how you feel about that?
9. Are there any other people who help and support you?

If on antiretroviral therapy (ART)

10. What is it like to take ART?
11. Where and from whom do you get the most support?

12. Did you require a lot of help when you started ART and who provided this?

APPENDIX I: Interview guide for clients (Sotho)

SOTHO INTERVIEW GUIDE FOR HIV POSITIVE CLIENT

Psychosocial care of people living with HIV: The case of Tzaneen, South Africa.

Lenaneo la maloko

Tsedimuso ya motho.

Lebitso la kliniki:

O direla mang:

Mphato o pasileng:

1. Go be o le bjang ge o kwa lamatomo gore o "HIV positive"?
2. Ke maekotlo afe a o na go le ona mapapi le go ba o le "HIV positive"?
3. Maekutlo a fetogile le nako? Ke nako e kana kang?
4. Ke thekgo ya mufuta mang eo e hwetsang kliniki?
5. Ke mang ao felego thuso, o dirile eng?
6. O ile wa hwetsa thuso/ maele afe ntle ga kliniki?
7. O na le mokhanselara yo a berekago mo kliniki, le gwerana bjang?
8. O na le mokhanselara mo kliniki le gona le somisana bjang?
9. Gona le batho bao ba go thusago le go go thekga?

Go bao ba hwetsago di dipilisi tsa "HIV".

10. Go bjang go tsea dipilisi tsa "HIV"?
11. Ke kae le gona go mang mo o hwetsago thekgo ye ntsi?
12. O nyakile thekgo e ntsi ge o thoma di ART le gona ke mang a o filego yona?

APPENDIX J: Interview guide for clients (Tsonga)

INTERVIEW GUIDE FOR HIV POSITIVE CLIENTS (Tsonga).

Psychosocial care of people living with HIV: The case of Tzaneen, South Africa.

Nongonoko wa maxaka

Vuxokoxoko bya munhu:

Vito ra kliniki:

Vito ra mutorhi:

Ntanga leyi nga pasiwa:

1. A ti twe njhani ro sungula loko u twa leswaku u na HIV?
2. U ti twa njhani hi ku va u ri na HIV?
3. Ku ti twa loku ku ncica ku ya nkharhi? Nkarhi wo leha njhani?
4. I ku pfuneka ka njhani loku u ku kumaka ekliniki?
5. I mani a ku pfunaka, u endla yini?
6. I ku pfuneka ka njhani kumbe nseketelo lowu u wu kumaka e handle ka kliniki?
7. U na mukhanselara laha, vuxaka bya nwina byi njhani?
8. Ndzi byele hi ku pfuniwa loku u ku kumaka aka khanselara na swona u ti twa njhani ha kona?
9. Kuna a vanwana vanhu lava ku pfunaka no ku seketela?

Loko u teka maphilisi

10. Swi njhani ku teka maphilisi
11. Hi kwihi na swona I mani a ku seketelaka ku teka maphilisi?
12. Xana u lave ku seketeriwa ko tala ku teka maphilisi, u ku nikiwile hi mani?