

AN INTERPRETATIVE PHENOMENOLOGICAL
ANALYSIS OF THE EXPERIENCES OF HIV-POSITIVE
LAY COUNSELLORS WORKING IN VOLUNTARY
COUNSELLING AND TESTING SETTINGS

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ABSTRACT

The purpose of this study was to present and understand the experiences of HIV-positive lay counsellors working in Voluntary Counselling and Testing (VCT) settings. Specifically exploring and understanding the utilisation of personal experiences within counselling encounters, the practice of peer counselling within VCT, and the challenges experienced by HIV-positive lay counsellors within VCT settings. This study, employing a qualitative interpretative phenomenological methodology required a small sample of practicing HIV-positive lay counsellors, who were selected and interviewed on their experiences utilising semi-structured interviewing. Data was analysed for meaning units, which were interpreted inductively and hermeneutically, and categorised into super-ordinate themes. Three super-ordinate themes within the participants' experiences of providing VCT services were determined, namely: 'diagnosis and disclosure experiences', 'peer counselling', and 'challenges'. This research found that the experiences of providing peer counselling depended upon identification with their client's negative appraisal of their diagnosis experiences. Whether through empathic connections generated through the shared experience of discovering a seropositive status, or through countertransference reactions induced through their client's yearning for care and support. This required the counsellor to self-disclose within counselling encounters in order to provide personal experiences of living with HIV/AIDS. Successful implementation of peer counselling provided recently diagnosed individuals with knowledge surrounding HIV/AIDS, coping skills to manage the daily physiological and psychological challenges, facilitation and adherence to treatment, social assistance, ongoing relationships, inspiring hope, and the creation of positive appraisals. However the informal utilisation of task-shifting within lay healthcare cadres, and the lack of governmental recognition for the emotional labour provided within VCT indicated that HIV-positive lay counsellors require ongoing training, support and remuneration to limit potential occupational stress, resignation, and burnout.

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Chapter 1: Introduction

South Africa is the HIV/AIDS capital of the world, where 5.6 million South Africans are currently infected with HIV/AIDS (UNAIDS, 2010). The current challenge is twofold, reducing further infection in uninfected and infected individuals, and providing the necessary care, support and treatment the burgeoning HIV-positive population requires. The increasing realisation that processes of reducing further transmissions can only be achieved through behavioural modification is evident as an HIV-based cure and/or vaccine is currently unavailable (Kalichman & Simbayi, 2009; Kippax, 2006). However intertwined within the realisation of behavioural modification, is the inevitable truth surrounding behaviour change within voluntary counselling and testing processes, where providing access towards institutional supportive mechanisms is preferred over methods which directly manage issues of risky behaviours (Van Rooyen, Richter, Coates, & Boettiger, 2009). Furthermore assuming that simply modifying behaviours will result in decreased HIV prevalence does not recognise the debilitating affect of gender inequity, resistance towards behaviour change, and the belief of not being at risk of HIV-infection. The current challenge extends beyond affecting behavioural changes, but rather a recognition that HIV/AIDS intervention programmes must consider the structural barriers which reduce an individual's capacity to change.

The use of Voluntary Counselling and Testing (VCT) as a basis for reducing risky behaviours and as an entry-point to treatment is a crucial exercise in primary and secondary prevention (Van Rooyen et al., 2009). The South African government has emphasised the increase in availability of VCT services, as they believe that VCT is a crucial entry point for treatment and care (Hutchinson & Mahlalela, 2006). Although VCT is positioned to affect positive behavioural changes within uninfected populations, research indicates that VCT is either ineffective or inconclusive as a primary means of prevention (Grinstead, Van der Straten, & The Voluntary HIV-1 Counselling and Testing Efficacy Study Group, 2000; Richter, Van Rooyen, Solomon, Griesel, & Durrheim, 2001; Weinhardt, Carey, Johnson, & Bickham, 1999). However research examining the secondary preventative efficacy of VCT practices has evidenced positive behavioural affects within HIV-infected populations, whether through increased condom usage (Van Dyk & Van Dyk, 2003), reduction in risky behaviours (Hutchinson & Mahlalela, 2006), or adherence to Antiretroviral Treatment (ART) (Daftary, Padayatchi, & Padilla, 2007). While evidence suggests the efficacy of VCT as a secondary preventative strategy, the increasing HIV-positive population requires a variety of counselling and supportive services which are beyond refined research parameters. The

inclusion of peer counselling approaches within VCT has not been examined, therefore understanding the potential benefit of peer counselling practices within VCT as an alternative method of providing care and support to People Living with HIV/AIDS (PLHA) should be examined, yet limited research has focused on the utilisation of peer counselling within VCT services in South Africa.

Peer counselling is defined as a “one-on-one educational or counselling connection” between a recently diagnosed individual and an individual who has been living with HIV/AIDS for several years (Harris & Larsen, 2007, p. 844). A peer counsellor is an HIV-positive lay counsellor. The purpose of peer counselling includes emotional and social support, knowledge acquisition, coping skills, facilitation of access to treatment, risk reduction, developing positive appraisals, and the normalisation of seropositivity (Harris & Larsen, 2007; Messias, Moneyham, Murdaugh, & Philips, 2006; Schneider, Hlophe, & Van Rensburg, 2008). The most obvious benefit of such a relationship is the ability of transferring the lived experience of living with HIV/AIDS to those who desperately seek it (Harris & Larsen, 2007). Recently diagnosed individuals seek such experiences because of the realisation of their situation. Kylma, Vehviäinen-Julkunen and Lähdevirta (2000) state, individuals discovering their seropositivity encounter an extensive range of experiences and responses, including emotional distress, anxiety, fear, helplessness, hopelessness and suicidal behaviour. These responses have been experienced by peer counsellors, owing to the fact that they have lived through discovering their seropositivity, and in turn they are able to convey these experiences towards their clients. Harris and Larsen (2007) found that peer counsellors helped their clients change their lifestyles; changes included a reduction in risky behaviour through to eating healthier. The aim was to enable clients to “live longer and healthier lives with HIV” (Harris & Larsen, 2007, p. 850). Leading healthier lifestyles through the assistance of peer counselling with the result of reducing risky behaviours is a secondary means of prevention. Within South Africa this is particularly vital owing to the large proportion of HIV-positive individuals seeking care and support.

Research examining the benefit of peer counselling approaches are limited towards refined research endeavours and/or specific populations; for example, homosexual communities, or disenfranchised communities (Driskell et al., 2010; Gusdal et al., 2011; Harris & Larsen, 2007; Messias et al., 2009). However none of these projects have focused exclusively within a South African context, nor are they positioned within the field of VCT. The increasing pressure placed by the burgeoning HIV-positive population requires the utilisation of lay

healthcare cadres to assist and alleviate the burdens placed by HIV/AIDS. The formal utilisation of task-shifting endorsed by global organisations such as PEPFAR, UNAIDS, and WHO increasingly recognise the benefit of utilising lay healthcare cadres, particularly within primary healthcare systems which are critically short of professional healthcare personnel. However within South Africa the position of lay counsellors is not formally recognised as an aspect of primary healthcare (Van Rooyen et al., 2009). Furthermore lay counsellors have expressed concerns regarding the need for ongoing training, remuneration and recognition for the emotional labour provided during VCT services (Price & Binagwaho, 2010; Zachariah et al., 2009). In light of the sparse literature concerning peer counselling within South Africa, this research aims to understand the lived experiences of peer counselling practices within VCT settings in South Africa. Furthermore understanding the motivation for sharing personal lived experiences and how an HIV-positive status shapes the counselling process requires further inspection.

Interpretative Phenomenological Analysis (IPA) will be utilised to examine and understand the lived experiences of HIV-positive peer counsellors working within VCT settings in South Africa. Within IPA the endeavour is towards an interpretative commitment focusing on understanding the relationship between our involvement and position within the lived world (Smith, Flowers, & Larkin, 2009). Understanding the experiences of peer counsellors necessitates an understanding of their embodied position within the lived world of living with HIV/AIDS. IPA is a qualitative method of enquiry dedicated to the detailed examination of human lived experiences (Smith et al., 2009). This method of investigation places particular interest in the meanings that people ascribe towards their subjective experiences (Langdrige, 2007; Moustakas, 1994; Smith et al., 2009). In other words, experiences articulated in the participants own terms, as opposed to pre-existing conceptions of the experience. It is the investment of reflection that IPA is focused upon, in other words attempting to make sense of the participants own reflection of a particular experience that had specific significance for the participant (Smith et al., 2009). The commitment to examining how the phenomenon appears, and the recognition that the researcher is intimately connected to the interpretation and formation of the phenomenon, indicates the hermeneutic aspect of IPA. The double hermeneutic is an integral characteristic of interpretative phenomenological research, where the process of interpretation is central to IPA. It involves the researcher attempting to make sense of their participants making sense of their experiences (Smith et al., 2009).

The commitment towards an inductive approach within IPA expressly places the participant as the expert of the phenomenon under examination (Smith et al., 2009). An exploration of peer counsellors utilising their personal experiences in living with HIV/AIDS is consistent with the use of IPA. This is because peer counsellors would have the opportunity to reflect upon their lives regarding the lived experiences of living with HIV/AIDS. These experiences may include accepting a seropositive diagnosis, managing issues of disclosure, developing hope, symptom alleviation, adhering to treatment, behavioural changes, accessing social grants, and stigma management or resistance. Within the context of VCT, the peer counsellor has an opportunity to transmit valuable lived experiences of living with HIV/AIDS to recently diagnosed individuals. It is therefore important to understand the circumstances in which a peer counsellor decides to use their personal experiences within the counselling process. The use of a qualitative based methodology is particularly valuable in this setting because it allows an in-depth description of HIV-positive lay counsellors' experiences in living with HIV/AIDS both personally and in the workplace. The explicit utilisation of IPA allows an interpretative account of participant experiences within the context of their lifeworld, contrasted against descriptive phenomenological methods. The utilisation of semi-structured interviews is suited towards an examination of peer counsellor experiences, allowing the participants the opportunity to present thorough first-person accounts of their experiences articulated through their own terms (Smith et al., 2009).

The primary focus of this research project is to provide an in-depth interpretation of the experiences of HIV-positive peer counsellors counselling people with HIV within VCT services in South Africa. In addition, the utilization of personal experiences by the peer counsellor within the counselling process, as well as perceptions of credibility will be examined. Research regarding the benefit of peer counselling approaches indicates various benefits PLHA have when counselled by someone who has lived with HIV/AIDS for several years. These benefits included the provision of support, acceptance, empathy, the reconstruction of hope, changes in lifestyle, shared lived experiences and positive role-modelling (Harris and Larsen, 2007; Messias et al., 2009; & Gusdal et al., 2011). However the facilitation of personal experiences of living with HIV/AIDS within counselling processes is largely under researched. Towards this end three areas of investigation will be addressed: firstly what do the lived experiences of providing peer counselling mean in terms of the relationship between counsellor and client? Secondly how do an HIV-positive status and the utilisation of personal experiences shape the counselling process? Finally how do an HIV-

positive status and the utilisation of personal experiences shape mutual understandings of credibility within counselling processes?

Chapter 2: Literature Review

2.1 The sub-Saharan pandemic

The human immunodeficiency virus (HIV¹) which eventually progresses towards the acquired immunodeficiency syndrome (AIDS²) is the greatest epidemic affecting the world today, particularly for sub-Saharan Africa. Within sub-Saharan Africa, HIV/AIDS has reached critical levels, where over 23 million people are currently infected with HIV/AIDS (UNAIDS, 2010). This staggering figure coupled with HIV adult prevalence ranging from 5% to 30% poses serious problems and challenges in dealing with the epidemic. Yet, this is by no means the limit of the problem, as countless millions are also indirectly affected by the epidemic; especially through care-taking roles and perinatal transmission. The main mode of transmission in Africa is through heterosexual intercourse. Additionally the rate of new infections is highest among young women, and of the 23 million infected with HIV/AIDS, 60% are woman (Hodge, 2008; UNAIDS, 2010). Additionally HIV/AIDS impacts hardest on the productive core of a nation, which in turn affects those who rely on their resources and support (Hodge, 2008). The by-product of such a phenomenon has far reaching social, political and economic implications that are not only a primary health concern, but also a developmental, national security, and business sector concern (Omwami, Commins, & Keller, 2008). HIV/AIDS undermines human resources, as teachers, healthcare workers and civil servants are dying faster than they can be trained (Bing & Cheng, 2008). The resulting affect is social instability, the breakdown of familial and community support structures, hampered service delivery, and the risk of national security as military, police and other security forces are dying from AIDS (Bing & Cheng, 2008). What must be realised is that HIV/AIDS should not be viewed as a single isolated phenomenon affecting global health, but rather it is a multifaceted problem, which must be understood from the multiple dimensions in which it influences (Weeks, 1989).

South Africa is known as the HIV/AIDS capital of the world (Kauffman, 2004; Simon, Ho, & Abdool Karim, 2006) and currently has an HIV-positive population of 5.6 million, with HIV prevalence ranging from 15% to over 30% (UNAIDS, 2010). This figure, in comparison with the nation's total population of 47 million indicates a serious problem and proposes major challenges not only for those already infected with HIV, but also in preventing further

¹ Refer to p. 144 for Glossary of Terms

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transmission of the virus. The response to HIV/AIDS has two primary dimensions; firstly it must prevent further spread of the virus, and secondly care and support must be provided to those already infected. Appropriate governmental responses in such instances are of absolute necessity, owing to the nature of the virus. Typically in South Africa the period between HIV infection and death from AIDS or other opportunistic infection is 7 to 8 years (Phillips, 2004). Yet, because of the method of transmission and the slow leisurely character of the virus, an entire productive adult generation is increasingly requiring care and support (Phillips, 2004). The direct result is the loss of human capital, and the indirect result of which is an increasing orphan population (Lewis, 2004; UNAIDS, 2007). It is obvious from this that the problem of HIV/AIDS will continue to shape how South Africans deal with issues of sex, morality, and death.

2.2 South Africa's response

Mobilising AIDS awareness campaigns, mass condom distribution, sex education in schools, HIV-testing campaigns, voluntary counselling and testing (VCT³), HIV counselling and testing (HCT⁴), mother to child transmission (MTCT⁵) prevention programmes, home-based care (HBC⁶), lifeskills training programmes and peer education within communities, schools and workplaces are all examples of preventative measures which have been utilised to stop the spread of HIV/AIDS within South Africa (Peltzer & Phaswana-Mafuya, 2008; Phillips, 2004). These are all efforts at primary and secondary prevention. Primary prevention is the reduction of risky behaviours in uninfected individuals. Here prevention focuses on people who are not infected with HIV/AIDS but partake in activities which render them vulnerable to future infection (Hutchinson & Mahlalela, 2006; Kippax, 2006; West, Corneli, Best, Kurkjian, & Cates Jr., 2007). Activities such as sex without a condom, concurrent sexual relationships, and sharing needles for intravenous drug use increase the possibility of infection. Secondary prevention is the prevention of HIV-positive individuals infecting others; the aim here is to reduce risky behaviours in infected individuals which could infect others (West et al., 2007). An assortment of primary and secondary prevention strategies are suggested above. While many developed and developing nations have successfully

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implemented such intervention programmes, the South African governmental response to the epidemic has been fraught with political indifference, turmoil, disbelief, denialism, and sadly the deaths of hundreds of thousands of South Africans (Lewis, 2004; Nattrass & Kalichman, 2009; Van der Vliet, 2004).

2.2.1 Development of treatment policies

The development of comprehensive treatment programmes has been marred by several controversial positions held by representatives of the South African government (Van der Vliet, 2004). Most notably and widely documented are former president Thabo Mbeki and former Health Minister Manto Tshabalala-Msimang (Nattrass & Kalichman, 2009). The initial strategy to combat HIV/AIDS stemmed from collaborations between various stakeholders that culminated in the formation of the National AIDS Convention of South Africa (NACOSA) in 1992 (Van der Vliet, 2004). The aim of NACOSA was to develop comprehensive strategies to deal with the growing AIDS crisis. However the atmosphere that surrounded South Africa at that time was one of transition and uncertainty. HIV/AIDS was increasingly recognised as a national problem; however wider social and political issues such as education, housing, and employment required immediate attention; especially considering the history of South Africa under the apartheid system. The implementation of NACOSA as a presidential lead project coinciding with the election of Nelson Mandela in 1994 would lend credibility and legitimacy to government intervention programmes which stemmed from NACOSA (Van der Vliet, 2004). However the transition of National Government, acquiring the fragmented health system from the apartheid Government and the politicised nature that HIV/AIDS had acquired during the period of transition caused tension between local, provincial and national government. Tension concerning the allocation of financial resources, policy creation and reform, and programme initiation often resulted in the paralysis of implementation (Van der Vliet, 2004). Paralysis of action resulted in an increased prevalence rate after NACOSA was implemented, in 1992 HIV prevalence was 7.6%, by 1994 HIV prevalence was 14.2%; clearly the national AIDS plan outlined by NACOSA was not effective (Van der Vliet, 2004).

Resistance towards the provision of nevirapine to reduce MTCT, antiretroviral (ARV⁷) prophylaxis for rape survivors, and ARV treatment for HIV-positive individuals during the period of 1999 to 2003 caused bitter controversy and conflict between organisations catering

⁷ Refer to p. 144 for Glossary of Terms

towards the needs of HIV/AIDS populations and the South African National Government (Epstein, 2007; Van der Vliet, 2004). Marked by a series of controversies, the road towards the provision of antiretroviral treatment can be described as an extreme form of denialism from the highest levels of South African government. This is exemplified by the International AIDS Conference of 2000 held in Durban. The Presidential panel consisted of internationally recognised AIDS scientists and discredited dissidents, giving the illusion of fair representation and therefore legitimate scientific debate surrounding the scientific evidence supporting HIV as a cause of AIDS (Epstein, 2007; Natrass & Kalichman, 2009; Van der Vliet, 2004). President Thabo Mbeki was concerned about the aetiology of HIV/AIDS, and the initiation of scientific debate was intended to garner scientific discussion, rather than the political debate that currently surrounded HIV/AIDS in South Africa (Van der Vliet, 2004). However the politicised atmosphere surrounding HIV/AIDS in South Africa was the direct consequence of the government resisting credible scientific evidence supporting the link between HIV and AIDS (Natrass & Kalichman, 2009). From this, it is evident that governmental resistance towards the provision of nevirapine, Mbeki's reluctance to test for HIV and his support of dissident pseudoscientific opinions surrounding AIDS intended to support Mbeki's belief that AIDS research was greatly divided (Natrass & Kalichman, 2009). Although the intention was to initiate scientific debate, the direct result was confusion, doubt within South Africa, and the destabilisation of actions taken by organisations serving the needs of HIV-positive populations (Van der Vliet, 2004). The inactions of Thabo Mbeki and his ministers, his position surrounding HIV/AIDS, coupled with the fact that policy formation and creation hinges on his support, gave credence to many myths surrounding HIV/AIDS; a prime example is the absurd belief that having sexual intercourse with an infant girl would cure AIDS (Leclerc-Madlala, 2002; Van der Vliet, 2004). These and other similar conspiracy theories are particularly precarious in South Africa, not only because of the mass uncertainty created, but in addition it undermines the educational and medical information people have received (Van der Vliet, 2004). This irrational belief is the by-product of Thabo Mbeki not affirming the verifiable evidence that HIV causes AIDS.

The response to HIV/AIDS in South Africa is both complex and distressing. To solely blame Thabo Mbeki and cabinet for their inaction and position regarding HIV-causes-AIDS would be erroneous and only a partial piece of the tale. The political transition from apartheid to a democratic nation, the increased migration from rural areas to urban, the return of exiles, the racially differentiated effect of HIV-infection, political concerns with pharmaceutical

companies and toxicity levels of ARVs are all contributing factors which account for South Africa's current position on HIV/AIDS (Van der Vliet, 2004). It is unfortunate that the initiation of a scientific debate surrounding HIV gave credence to the dissident perspective that AIDS is a disease of poverty, rather than a sexually transmitted disease (Epstein, 2007). It undermines the reality of unequal sexual power between South African men and women, and the increased resistance towards behaviour change. Additionally it undermines the actions of those who have been providing the much needed services that HIV-positive individuals require (Van der Vliet, 2004).

2.2.2 Treatment is a single response

HIV/AIDS based organisations, doctors, and political leaders who actively campaigned for the provision of ARV treatment were the primary forces behind South Africa's current HIV/AIDS preventative treatment programmes (Deane, 2005). Fortunately by August 2003, the national government implemented a nationwide antiretroviral roll-out plan (Epstein, 2007; Van der Vliet, 2004). This effectively provided post-exposure prophylaxis (PEP⁸) treatment for rape victims, the prevention of MTCT and treatment for AIDS (Oppenheimer & Myers, 2007; Van der Vliet, 2004). The *National Strategic Plan on HIV & AIDS and STIs, 2007-2011* (NSP) specifically intends to provide 80% of the HIV-positive population with access to treatment, care and support (National Department of Health, 2007; Van Rooyen et al., 2009). However, it is estimated that approximately 275,000 of the current 2 million people qualified for treatment are receiving their treatment (Gosling, 2008). At present there is no cure or vaccine available for HIV/AIDS, and the only means of treatment is through antiretroviral therapy, which is both expensive and difficult to maintain (Hutchinson & Mahlalela, 2006). Additionally not all those who are infected have received treatment, as the rollout of ARVs has been hampered by poor service delivery, lack of antiretroviral treatment, limited financial resources, and poor governmental support (Skhosana, Struthers, Gray, & McIntyre, 2006; Van der Vliet, 2004). Very much work remains to be done considering the differing infrastructures of the provinces and therefore the difficulties in mobilising effective treatment strategies in those provinces (Deane, 2005). Research conducted by Mitchell, Kelly, Potgieter and Moon (2009) indicates that beginning ARVs is mediated by several interacting forces. Firstly, limited public knowledge surrounding HIV transmission, treatment

⁸ Refer to p. 144 for Glossary of Terms

and care constructs a limited understanding and value for antiretroviral treatment (ART⁹). Secondly, perceptions of ART being compatible with alternative traditional medicines conflicts with professional guidance, which advocates for ART only. Thirdly, knowledge concerning ART qualifications is present, but familiarity with long-term treatment adherence and management of side-effects is relatively unknown. Although the sample in Mitchell et al. (2009) research is not representative, the findings suggest that limited public knowledge concerning HIV-treatment reduces the belief in ART efficacy and utilisation.

Eligibility for ART in South Africa requires medical and psychosocial considerations an individual must qualify (Department of Health [DOH¹⁰], 2010b). Medical criteria include a CD4 cell count ≤ 200 cells/mm³ (Gosling, 2008) or a WHO stage IV disease; irrespective of CD4 cell count (DOH, 2010b). Psychosocial considerations include demonstrated reliability, no active alcohol and substance abuse, disclosure to at least one person, knowledge of HIV-infection and treatment consequences, acceptance of an HIV-positive status, and transportation to treatment services (DOH, 2010b). Recent developments by the World Health Organisation (WHO) (2010) have recommended increasing the qualifying requirements from ≤ 200 to ≤ 350 cells/mm³. However the *South African antiretroviral treatment guidelines 2010*, does not adhere to the recommendations outlined by WHO, instead they have increased the qualifying requirements for pregnant women and people who have a TB co-infection from ≤ 200 to ≤ 350 cells/mm³ (DOH, 2010b). Currently people living with HIV/AIDS (PLHA¹¹) have access to two treatment options; unfortunately if both options fail then the onset of AIDS is inescapable (DOH, 2010b). Individuals with such low CD4 cell counts are often unable to work and therefore unable to financially support themselves or their families. In such instances individuals are allowed to access a disability grant which must be certified by a medical officer (Leclerc-Madlala, 2006; Roberts, 2008). However it is becoming increasingly evident that individuals who are utilising ARVs could anticipate disqualifying for their disability grant owing to an increase in their CD4 cell count. The rationale is that an individual using ARVs would regain their health and therefore be able to work, however this premise is flawed because it assumes full employment in South Africa (Leclerc-Madlala, 2006). The conundrum is that a South African with advancing stages of HIV seeking treatment must contend with the choice of physical well-being or economic stability. This choice becomes complex when one considers high unemployment, poverty,

⁹ Refer to p. 144 for Glossary of Terms

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and the immediate need to provide sustenance for oneself and family (Leclerc-Madlala, 2006). The very notion that an HIV-positive individual experiencing advanced stages of HIV must decide between their own life and the physical well-being of their family is absurd. Nonetheless the practice of routinely changing ones ART regime to decrease CD4 cell count, and deliberately attempting to become HIV-positive to access or retain social assistance is becoming increasingly evident (Leclerc-Madlala, 2006).

The provision of ART is perceived to reduce negative attitudes of stigmatisation and prejudice held towards seropositivity. The rationale is a shift in perception regarding HIV/AIDS as a chronic manageable illness as opposed to a terminal illness; for those who manage to receive and adhere to ARVs (Burchardt, 2010; Jones, 2009; Kippax, 2006; Nwoye, 2004). Adherence to medicinal treatment is difficult in the context of poverty, lack of basic services such as housing, education, sustenance, and limited supportive services (Faubion, 2009). The fact that HIV infection is linked with promiscuous sex and drug use provides its own stigmatisation in societal perspectives (Daftary et al., 2007; Kalichman et al., 2005). Increasingly it is becoming apparent that in order to reduce the stigmatising attitudes towards HIV/AIDS, treatment and intervention strategies must aim towards normalising seropositivity. However, these strategies must consider the wider cultural forces in which they are operating, as the moral conservatism in South Africa surrounding sex and in particular patriarchal sexual culture will prove to be a substantial barrier (Mitchell et al., 2009; Robins, 2006). The notion that once an individual is infected with HIV they are subsequently immune to further infection of HIV is false. This indicates the possibility of dual or even superinfections is possible, and therefore suggests that the rate of AIDS progression is far more rapid in such instances (London, Orner, & Myer, 2008; Simon et al., 2006). In South Africa the stigmatising attitudes towards HIV/AIDS is a substantial barrier to testing (Hutchinson & Mahlalela, 2006). In light of this and the possibility of multiple HIV infections, and the difficulty with adherence, it is becoming increasing clear that treatment options will have scant effect if individuals who are HIV-positive are not aware and are concurrently practicing behaviours that render them vulnerable to further HIV infection.

2.3 Behavioural intervention

Providing treatment is only one facet of the response to HIV/AIDS, and must be coupled with educational programmes directed towards safe sexual practices. The fundamental fact is that

the only real means of prevention is currently through behavioural intervention (Kippax, 2006) as biomedical approaches have yet to demonstrate efficacy (Kalichman & Simbayi, 2009). The *National Strategic Plan on HIV & AIDS and STIs, 2007-2011* (NSP) specifically intends to reduce the number of new infections by 50% (National Department of Health, 2007). Considering that the main mode of transmission of HIV in South Africa is through heterosexual intercourse, both primary and secondary preventative strategies must focus on shifting individual and societal perceptions regarding safe sexual behaviours. Yet these strategies will only be effective if the principles of primary and/or secondary prevention strategies can be realigned with cultural norms and practices. This however, is not always possible, especially in South Africa where gender inequalities and resistance to behaviour change continue to shape the productive and reproductive lives of many young South Africans, particularly young women (Boesten & Poku, 2009; James, 2002; Van der Vliet, 2004; UNAIDS, 2007). Women in South Africa are particularly vulnerable to infection when societal and gender norms restrict reproductive choices which are based in a patriarchal system (Leclerc-Madlala, Simbayi, & Cloete, 2009). There is an increased need to develop methods which focus on gender relations as the vanguard to combating HIV/AIDS (Dworkin & Ehrhardt, 2007). The assumption that an individual's choice determines the practice of safe sexual behaviours is inaccurate, and disregards the gendered contexts in which people base their decisions (Dworkin & Ehrhardt, 2007).

2.3.1 Peer education

The transmission of HIV/AIDS-based education is an essential component of the response towards minimising further spread of HIV. The most dominant form of primary prevention in South Africa is the use of peer education programmes (PEPs¹²). The protocol of HIV peer intervention strategies typically involves the active training and support of individuals from a target group to effect behavioural change in their peers (Visser, 2007). The rationale is the transmission of educational and communications material to effect behavioural changes through knowledge of the epidemic (Campbell & Mzaidume, 2001; Hope, 2003; Sloan & Myers, 2005). The belief is that through re-educating individuals about the epidemic they become far more aware of the dangers of their risk behaviour, and consequently reassess their behaviour to promote healthy sexual practices (Cornish & Campbell, 2009). PEPs allow members of particular groups the opportunity to discuss and explore issues of risky

¹² Refer to p. 144 for Glossary of Terms

behaviours within a safe group setting. The active collaboration of group members in discussing the issues pertaining to their risky behaviour can lead to developments of new forms of behaviour created within the group, rather than attempting to persuade behaviour change through professionally given judgments (Van Dyk, 2005). This falls in line with the aims of primary prevention, which is the reduction of risky behaviours in uninfected individuals (Hutchinson & Mahlalela, 2006; Kippax, 2006; West et al., 2007). This point becomes particularly pertinent when one realises the potential for infection from risky behaviours such as concurrent sex partners, intravenous needle sharing and no condom usage (West et al., 2007).

The use of peer education programs are extensive the world over, however very few programs can claim reliable positive behavioural outcomes, in fact discovering no positive health effects is not an unusual result of PEPs (Cornish & Campbell, 2009). Biomedical approaches may produce positive behavioural outcomes within particular contexts with specific groups, for instance the increased condom usage among sex workers and their clients (Cornish and Campbell, 2009). However it is increasingly acknowledged that to effect positive behavioural change in historically marginalised groups requires an awareness and sensitivity to the particular social context of that group (Cornish & Campbell, 2009). Intervention programs must be designed to address and reduce the social problems which limit an individuals' capacity to practice safe sexual behaviour. Cornish and Campbell (2009) suggest actively involving community members in the design and implementation of educational prevention programs, attending to the wider social problems as a core tenet of the intervention program, thereby empowering community members involved. Within South Africa, resistance to behaviour change and gender inequality will prove to be substantial barriers to successful PEPs.

2.3.2 Barriers towards safe sexual behaviour

Within South Africa the practice of unsafe sexual behaviour is influenced by several interacting forces. Firstly, one must consider the personal forces influencing safe sexual behaviour, such as one's feelings towards safe sexual practices and HIV/AIDS. Individual factors such as attitudes towards condom use, monogamy, and sexual debut are all aspects which influence the personal practice of safe sexual behaviours (Niëns & Lowery, 2009). Secondly, the interpersonal and environmental context will influence an individual's ability to practice safe sexual behaviour. Interpersonal relationships are generally male-dominated in

South Africa, and this leads to the inability for women to safely negotiate sexual debut, condom use, and being able to discuss issues of sexuality with one's partner. Additionally one's environment also influences the ability to practice safe sexual behaviours, for example one cannot practice safe sexual behaviours if condoms are not easily accessible (Niëns & Lowery, 2009). Thirdly the influence of cultural factors such as traditions, roles, norms, shared beliefs and values, coupled with structural factors such as the legal, political, economic and organisational aspects fundamentally influence the practice of safe sexual behaviours (Niëns & Lowery, 2009). South African discourses that sustain the assumption of male dominance within interpersonal relationships are based on traditional cultural practices which assert patriarchal social traditions (Leclerc-Madlala et al., 2009). These practices assert male dominance within interpersonal relationships, and support unequal sexual power between South African men and women (Mathews, 2005; Mlay, Lugina, & Becker, 2008). Cultural norms and practices surrounding femininity and masculinity within South Africa are distinct and contribute towards placing individuals at risk of infection (Gupta & Weiss, 2009; Leclerc-Madlala et al., 2009). Yet these very beliefs limit the desire for or perception that prevention information is imperative. Men and woman born within such cultural ideological practices are frequently unable to recognise the debilitating effect their principles have on protecting themselves from HIV-infection. Men for instance are told that variety in sexual partners and assumed knowledgeable about sex is a recognisable male mode of behaving (Mathews, 2005; Mlay et al., 2008). Such beliefs will reduce the possibility of men seeking information on safe sexual practices, because their actions are and have been culturally sanctioned. The result is an increased probability of future infection owing to a lack of knowledge on safe sexual behaviour. The personal, interpersonal, and larger cultural influences on an individual often reduces one's ability to practice safe sexual behaviours (Niëns & Lowery, 2009). In light of this, intervention programmes aimed at reducing risky sexual behaviours must contend with these interacting forces, regardless of the context in which they are operating (Dworkin & Ehrhardt, 2007).

Gender inequalities within and not limited to South Africa, restrict the choices individuals have concerning safe sexual practices, and therefore reinforce norms and stereotypes which are major aspects of the South African pandemic (Kalichman & Simbayi, 2009; Mlay et al., 2008; Van der Vliet, 2004). In addition inequalities in the distribution of land and wealth continually place woman in vulnerable positions of forced sexual relationships to guarantee the continued existence of themselves and their children (Whiteside & Sunter, 2000).

Fundamentally it is an issue of negotiating safe sexual practices, but this is not always enforced or possible to enforce by those who have received HIV/AIDS-based education on safe sexual behaviours; assuming said individuals have had access to HIV/AIDS-based education (Gupta & Weiss, 2009). Women who are in abusive relationships for example, have less opportunity to practice safe sexual behaviours; owing to the fact that these women are required to seek permission from their partners to access such services (Christofides & Jewkes, 2010). In addition those who attempt to negotiate safe sexual practices must contend with the possibility of further violence, rejection, and the potential loss of their partner's financial support (Kalichman, Simbayi, Kaufman, Cain, Cherry, Jooste, & Mathiti, 2005; Makin, Forsyth, Visser, Sikkema, Neufeld, & Jeffery, 2008). Women in these circumstances who test HIV-positive are less likely to disclose their status owing to the possibility of further violence, discrimination, and the loss of financial support (Makin et al., 2008). Yet disclosure of a seropositive status permits access to social support and treatment opportunities, whereas nondisclosure restricts such opportunities (Gilbert & Walker, 2010). Mlay et al. (2008) and Skhosana et al. (2006) suggest the need to indicate the contribution men can make towards reducing further spread of HIV/AIDS in Africa; primarily through the use of couple-based voluntary counselling and testing, focusing on safe sexual practices.

Increasingly it is recognised that preserving out-dated cultural practices often counteracts the process of reducing further transmission of HIV/AIDS. Therefore it is important to recognise the effect such practices may have on test-seeking behaviour, but particularly in reducing risky behaviours that render individuals vulnerable to future infection. Gupta and Weiss (2009) and Jewkes (2009) state that prevention interventions must tackle gender inequalities to promote transformational change within gender roles and relationships which promote gender and health equity. However, dominate patriarchal sexual cultures within South Africa promote traditional masculine roles that sustain cultural practices of concurrency, and unprotected sex (Epstein, 2007; Robins, 2006). These hegemonic masculinities are increasingly challenged as programmes such as Khululeka Men's Support Group (Robins, 2006) redefine traditional constructions of masculinity. Members of Khululeka support group are attempting to bridge the gap in men participating in HIV-based prevention programmes, focusing on responsible sexual behaviours, living positively with their seropositivity, and supporting disclosure as a mechanism for acceptance (Robins, 2006). Preventative approaches such as the Khululeka Men's Support Group actively engage with local social knowledge surrounding masculine sexual norms and taboos to create gender equitable norms

and reduce violence against women. However the language surrounding AIDS is dominated by the discourse of Western science and policy, which frequently ignores local socially relevant belief systems (Posel, Kahn, & Walker, 2007). Furthermore such approaches have scant effect on modifying wider practices of concurrency. Theories of hegemonic masculine practices are useful to explain the gendered differences in beliefs concerning concurrency in South Africa. Kenyon and Zondo (2011) state that a substantial number of South Africans“, both men and women, do not prescribe and are resistant to practicing concurrent partnership. However, dominate ideologies such as hegemonic masculinities which aim to describe South African male behaviour sustain gender inequity and construct the belief of an inferior status for women. Prominent strategies for behavioural interventions in South Africa focus on the individual level, and may be ineffective at constructing wider cultural norms which object towards the practice of concurrency. Kenyon and Zondo (2011) advocate the necessity of insisting the dangers of concurrency through local organisations and key informants such as President Zuma, and the promotion of wider anti-concurrency campaigns as the centre point for HIV-prevention programmes.

HIV/AIDS has both physical and social qualities that give people the impression that their set of shared values, beliefs and attitudes has been violated by the virus and this provides momentum for prejudice and stigmatisation. For example, the fact that HIV/AIDS is linked to socially unacceptable behaviours such as drug use and deviant sexual behaviour provides the impetus for stigmatisation (Brown, Macintyre, & Trujillo, 2003; Oppenheimer, & Bayer, 2007). Additionally the fact that HIV/AIDS is infectious, often causes visible and dehumanising effects on the body, and is incurable prompts the notion of a tarnished and immoral character which in turn causes stigmatisation (Oppenheimer & Bayer, 2007; Stanley, 1999; Tewksbury & Mcgaughey, 1997). The source of HIV/AIDS stigmatisation is a fear of the illness, fear of infection, and ultimately the fear of death associated with AIDS (Brown et al., 2003). Furthermore lack of knowledge concerning HIV transmission, treatment, and living with HIV bolsters stigmatisation surrounding HIV infection (Mbonu, Van den Borne, & De Vries, 2009; Wingood et al., 2008). These fears are often intertwined with other societal perceptions regarding seropositivity and stigmatised groups such as homosexuals and prostitutes (Brown et al., 2003). The result of these negative emotional responses can lead to prejudicial thoughts, behaviours and actions, which in turn have a negative effect on those who are HIV-positive (Brown et al., 2003). Individuals who experience discrimination often state the loss of employment, housing, rupture of familial and community membership, and

violence (Gilbert & Walker, 2010). The result of stigmatised perceptions vary and are context specific, however HIV/AIDS stigmatisation can have negative effects on test-seeking behaviour, willingness to disclose an HIV-positive status, mental health, positive health-seeking behaviour, and the quality of care and support received (Brown et al., 2003; Gilbert & Walker, 2010; Ncama, 2007; Wingood et al., 2008; Young, 2011). Wingood et al. (2008) found that significant experiences of stigma contributed towards depressive symptomatology, reduced quality of life, distressing episodes of posttraumatic stress, and resistance towards disclosure. These experiences are exacerbated when considering that black South African women are disproportionately infected and affected by HIV/AIDS (Wingood et al., 2008). These negative effects have far reaching implications for preventative strategies in South Africa as it will be increasingly difficult to reduce further transmissions if people are afraid of the connotations and realities of seropositivity. Furthermore in South Africa the extensive denial of HIV/AIDS for those affected and infected has resulted in perpetuating silence, shame and self-blame (Skhosana et al., 2006). HIV/AIDS stigmatisation will continue to provide a significant barrier towards successful educational and legislative endeavours (Wingood et al., 2008).

What has been suggested is that stigma reduction and eradication should form a component of all HIV/AIDS programmes in South Africa (Campbell, Foulis, Maimane, & Sibiya, 2005; Preston-Whyte, 2003; Wingood et al., 2008). Stigma reduction strategies such as: public HIV/AIDS education, community-based interventions addressing and reconstructing norms surrounding seropositivity, and legislative endorsement barring HIV/AIDS discrimination are not only necessary to normalise a seropositive status, but additionally as a public health objective to improve test seeking behaviours, disclosure practices, and the quality of life for PLHA (Wingood et al., 2008). Yet educational interventions at reducing stigma are limited and have shown little effect (Brown et al., 2003). Furthermore widespread stigma reduces the potential of enquiring about HIV testing and treatment opportunities (Mitchell et al., 2009). Jewkes (2006) however promotes the implementation of positive role modelling in care and support. This differs to the standardised practice of drawing attention to the negative aspects of stigmatisation and rather focuses on empowering discourses legitimised through the experiences of PLHA. The role of social support for PLHA is a vital process in eradicating stigma, the utilisation of positive role models reconstructing the lived experiences of living with HIV/AIDS is a crucial contribution to the empowerment of PLHA (Jewkes, 2006). However the position of peer counsellor providing positive role-modelling has received

limited attention in South Africa; the role of peer counselling will be discussed later in this chapter.

2.4 Voluntary Counselling and Testing (VCT)

2.4.1 Practice and procedure

The use of voluntary counselling and testing (VCT) or client-initiated counselling and testing (CICT¹³) services as a basis for reducing risky behaviours, and as an entry-point to treatment is a crucial exercise in primary and secondary prevention (Van Rooyen et al., 2009). Additionally, the South African government has emphasised the increase in availability of VCT services, as they believe that VCT is a crucial entry point for treatment and care (Hutchinson & Mahlalela, 2006). In South Africa the use of VCT is perceived to provide: a means of social intervention aimed at shifting individual behaviours to reduce risky behaviours (Kippax, 2006; Richter et al., 2001), is required for increased awareness of the magnitude of the HIV/AIDS epidemic in South Africa (Richter et al. 2001), promoting social and cultural values and norms aimed at reducing risky behaviour (Kippax, 2006; Richter et al., 2001), reducing the stigma surrounding seropositivity (Richter et al., 2001), and provide a means of entry into the medical system for treatment of HIV/AIDS through antiretroviral therapy (Hutchinson & Mahlalela, 2006).

VCT is a two-session format where a client receives pre-test counselling followed by a rapid HIV test, once the results of the test are known post-test counselling is given (Grinstead et al., 2000; Myers, Worthington, Haubrich, Ryder, & Calzavara, 2003; Uys, 2003). Essentially individuals are informed of the procedures of the HIV test and made aware of the potential of testing HIV-positive or negative and the consequences thereof. HIV-negative individuals are given advice on limiting their risk, as well as receiving HIV/AIDS based information to dispel false preconceived notions the client may have about contracting HIV. Protocols surrounding counselling HIV-positive clients specifically call for responsible methods of informing a seropositive status. Van Dyk (2005) promotes the practice that counsellors must ensure that their clients are adequately educated and prepared about the implications of testing HIV-positive. HIV-positive individuals are then subsequently given a referral to determine their CD4 cell count to establish whether they need to begin antiretroviral

¹³ Refer to p. 144 for Glossary of Terms

treatment, as well as to determine whether they may have a co-infection of tuberculosis (TB¹⁴). Individuals who are unable to work due to deteriorating health can apply for government assistance through the disability grant (Leclerc-Madlala, 2006). Additionally they are advised to attend support groups, and continue to practice safe sexual behaviours.

The pre- and post-test counselling process within VCT is generally conducted by a lay counsellor. Lay counsellors are typically trained by the non-governmental organisation (NGO¹⁵) they are affiliated to, and training consists of basic counselling, informed by the principles underlying Egan's Skilled Helper Model (Van Rooyen et al., 2009). They are also instructed on the ethics of counselling wherein confidentiality and the normalising of seropositivity are focal points (Uys, 2003). Training includes the acquisition and familiarisation of HIV-based knowledge, counselling skills, and holistic care typically implemented through role-playing, case studies and self study (Sanjana et al., 2009). In addition, they are required to develop extensive knowledge surrounding HIV/AIDS prevention, treatment, and care (Rohleder & Swartz, 2005). In South Africa, lay counsellors often provide more than the typical pre- and post-test counselling services offered through VCT. In addition to their responsibilities within VCT, they are expected to provide supportive and preventative services such as negotiating access to treatment, aid in disclosure, managing issues of stigma and prejudice, and financial support to name a few (Richter et al., 2001). However, the brief amount of training lay counsellors receive often restricts the effectiveness of lay counselling services, particularly concerning issues of intimate partner violence, gender inequity (Christofides & Jewkes, 2010), and dual management of TB and HIV treatment (Kigozi, Heunis, Wouters, Van der Berg, 2011). Lay counsellors provide services that can be described as "emotional labour" (Hochschild as cited in Grinstead et al., 2000, p. 639). Emotional labour is the act of providing support, care and hope to recently diagnosed individuals. The drawbacks however are increased stress, burnout, and resignation owing to the fact that lay counsellors frequently discuss sensitive issues such as sex, relationships, disclosure, death and dying (Grinstead et al., 2000; Rohleder & Swartz, 2005). Van Rooyen, Durrheim, and Lindegger (2011) caution towards lay counsellors asserting their moral predilections over cliental during counselling encounters, particularly concerning HIV risk behaviours. Instead they suggest adopting perspectives which assist with

¹⁴ Refer to p. 144 for Glossary of Terms

¹⁵ Refer to p. 144 for Glossary of Terms

responsible sexual behaviours rather than stressing blame and utilising moral outcomes as a basis for behaviour modification.

2.4.2 Barriers towards uptake

It is therefore apparent that the aims of VCT are aligned with the aims of primary and secondary prevention. However even if prevention programmes such as VCT are easily accessible, they fundamentally rely on the individual to come forward and test themselves. What has been suggested is mandatory testing, yet this option should not be viable as it directly contradicts a South African's right to decide to test. Additionally mandatory testing has the potential to further marginalise and stigmatise those already infected with HIV/AIDS (Kippax, 2006). Hutchinson and Mahlalela (2006) indicate several reasons that are associated with people not testing themselves for HIV/AIDS. These include the perceived notion that individuals are not at risk of infection, fear of seropositivity and the accompanying fear of stigmatisation and prejudice, and the lack of access to VCT (Hutchinson & Mahlalela, 2006). The availability of VCT centres within the Eastern Cape has increased from 52 to 403 sites as from 2004 (Hutchinson & Mahlalela, 2006). It is important to note that the period of publication to the researcher accessing the article written by Hutchinson and Mahlalela (2006) is over five years, therefore it is highly likely that additional VCT sites have opened after their publication. However the availability of counselling and testing services on primarily health-based localities in African health-care systems limits counselling and testing uptake, owing to staff shortages, poor management, and limited and poorly utilised resources (Asante, 2007). Attitudes concerning testing, the fear of testing HIV-positive, and the accompanying discrimination that is associated with seropositivity limit counselling and testing uptake. The fear of being discriminated for being HIV-positive, and the notion of not being at risk are primary forces behind minimal VCT uptake (Van Rooyen et al., 2009). Furthermore inadequate knowledge concerning HIV transmission, treatment and adherence reduces health-care seeking behaviours (Mitchell et al., 2009).

The accompanying fear of stigmatisation is warranted, where within South Africa incidences of violence have been directed towards those who are open about their seropositivity (Paxton, 2002). This is particularly salient for women in abusive relationships, who will experience additional barriers to utilising VCT services due to intimate partner violence (Kalichman et al., 2005). Christofides and Jewkes (2010) examined the feasibility of screening for intimate partner violence in VCT services. Results indicate that women respond positively to such

initiatives, but are concerned with broader social issues of gender inequality. What is required are interventions aimed towards reducing intimate partner violence, transforming gender roles and relationships, thereby increasing the number of women who undergo HIV testing. The unequal distribution of sexual power between South Africa men and women indicates that interventions aimed at reducing risky behaviour must first tackle the problem of sexual and gender inequality, before undertaking initiatives aimed at reducing risky sexual behaviours. However, lay counsellors are poorly equipped and frequently unable to resolve issues of gender inequality and the risk such inequity poses towards future infections (Christofides & Jewkes, 2010). Although lay counsellors are trained to address issues of sexual and gender based inequity, it would be erroneous to assume that such brief preparation could erode pre-existing attitudes of gender inequalities. Christofides and Jewkes (2010) suggest including knowledge of gender power inequalities and intimate partner violence into basic counsellor training to enable lay counsellors to effectively address issues of gender inequity.

2.4.3 Alternative testing services

Increasing uptake for HIV testing is fundamentally linked towards the reduction of HIV/AIDS (UNAIDS, 2007). Increasingly the need to implement a combination of counselling and testing services are required (Van Rooyen et al., 2009). Therefore alternative methods of providing testing services will be increasingly required considering that conventional methods of VCT are thus far ineffective as a primary means of prevention. Methods such as mobile VCT, routine offer of HIV counselling and testing (HCT), and home-based VCT are additional means of increasing uptake (Matovu & Makumbi, 2007). Mobile VCT involves HIV testing and counselling services operated from a vehicle that provides VCT to populations which are considered „hard to reach“, such as sex workers, and truckers (Matovu & Makumbi, 2007). The rationale of such practices is to provide testing services for populations which desire to be tested, but because of transportation issues are unable to due to the long travelling distance required for VCT. Criticisms of mobile VCT include perceived seropositivity owing to participation, where individuals who undergo testing are perceived by their communities as being HIV-positive (Van Rooyen et al., 2009).

The routine offer of HIV counselling and testing services are initiated by healthcare providers when individuals attend healthcare clinics, i.e. TB and STI clinics. Also known as provider

initiated counselling and testing (PICT¹⁶), testing in such instances is not mandatory, but forms part of the diagnostic process, and therefore allows for individuals to opt out of testing (UNAIDS, 2007). PICT has been shown to increase testing uptake, and identify previous undiagnosed infections (Van Rooyen et al., 2009). Home-based VCT involves lay counsellors providing VCT services within the clients' home. The benefits of home-based VCT are the increase in uptake among women who will not need to seek permission for transport and VCT participation, as well as minimising stigmatising attitudes in attending VCT (Matovu & Makumbi, 2007). However home-based VCT is less effective at affecting adolescents, where the arrival of lay counsellors garners speculation from family members, which reduce the number of adolescents accessing counselling and testing services (Van Rooyen et al., 2009). Although the above mentioned alternative VCT testing services have been suggested, Matovu and Makumbi (2007) have stated that the effectiveness of such practices is as of yet difficult to determine. This is because efficacy in many cases has been influenced by research settings and is not examined in a „business as usual“ setting (Matovu & Makumbi, 2007). Additionally, client and counsellor encounters are limited owing to rapid testing and counselling procedures (Roberts, Grusky, & Swanson, 2008). This limitation may have repercussions for later care and support for those individuals who do test HIV-positive. What is therefore required is a thorough examination of alternative VCT practices which are not influenced by research agendas, but ultimately focus in a work as usual context.

2.4.4 VCT efficacy

Advocates of VCT assert that VCT services are both feasible and effective at reducing risk behaviours in developed and developing nations (Mathews, 2005). Yet many researchers (Grinstead et al., 2000; Richter et al., 2001; Weinhardt et al., 1999) have found that VCT is either ineffective or inconclusive as a primary means of prevention. The Voluntary HIV-1 Counselling and Testing Efficacy Study Group conducted research in Kenya, Tanzania and Trinidad found that VCT is ineffective as a primary means of prevention (Grinstead et al., 2000). In other words VCT is not an effective means of preventing uninfected individuals from becoming infected. Within South Africa, research on the efficacy of VCT has indicated that couples who test together are more likely to have significant behavioural change, as opposed to individuals undergoing counselling and testing services (Van Rooyen et al., 2009). However, less than 1% of South African couples have tested together (Kippax, 2006).

¹⁶ Refer to p. 144 for Glossary of Terms

Kippax (2006) states that there is a growing disillusion that people who are aware of their serostatus will act in a responsible and rational manner such that they will not endanger another person(s) or themselves to further transmit HIV/AIDS; i.e. they will not engage in behaviours that increase the risk of HIV infection. Consequently, there is an increasing awareness that those who test HIV-negative continue to practice risky sexual behaviours, as the stress and anxiety surrounding HIV-testing and the possibility of testing HIV-positive is not a strong enough motive to engender behaviour change (Van Dyk & Van Dyk, 2003). Efficacy studies on VCT in developing countries generally focus on professional counsellors, and/or settings with well devised research parameters (Rohleder & Swartz, 2005). This limits the credibility of VCT as a whole, considering that a vast majority are run by lay counsellors (Rohleder & Swartz, 2005). However, evidence suggest that behaviour change is most noticeable when sero-discordant couples, where one partner is HIV-positive and one is HIV-negative, are tested together, and with HIV-positive individuals (Grinstead et al., 2000; Weinhardt et al., 1999). Unfortunately less than 1% of couples in Africa have concurrently tested; low uptake is attributed to reluctance in disclosure (Van Rooyen et al., 2009).

The two-session counselling model has been criticised for reducing the number of people who are able to test or receive treatment, owing to service delivery hold-ups created by clients moving between testing and counselling components of VCT (Van Rooyen et al., 2009). Additionally the extent of the epidemic and the differing target groups that require counselling and testing in South Africa indicate that one overriding model of counselling and testing is ineffective. Alternative counselling and testing approaches are required to affect the necessary behavioural change needed (Van Rooyen et al., 2009). Young (2011) indicates that shortened post-counselling procedures cannot adequately confront problematic appraisals of receiving a sero-positive status. This however does not rule out the feasibility or efficacy of secondary prevention within VCT, as many researchers (Daftary et al., 2007; Kippax, 2006; Richter et al., 2001; Rohleder & Swartz, 2005) have publicised the effectiveness of VCT as a secondary means of prevention. This includes increased condom usage from HIV-positive individuals with long-term and casual sexual partners (Van Dyk & Van Dyk, 2003), reduction in risky behaviours (Hutchinson & Mahlalela, 2006), and adherence to antiretroviral treatments (Daftary et al., 2007).

VCT has been and is currently positioned to best confront the ever increasing challenges of HIV/AIDS prevention within South Africa (Hutchinson & Mahlalela, 2006). However as a primary preventative strategy VCT is increasingly labelled as being ineffective or uncertain at

reducing risk behaviours that render individuals vulnerable to future infection. Coupled with divergent infrastructural, economic, and political capacities within South African provinces, this indicates that VCT cannot be positioned as the epicentre of HIV/AIDS prevention. Other strategies such as peer-based education, utilising media resources, reduction of MTCT, and alternative counselling and testing methods must be utilised in conjunction with varied VCT models to prevent further future transmissions. Van Rooyen et al. (2009) suggest adopting a risk-reduction model of counselling over the current Egan model. The risk-reduction model is structured to achieve behavioural change, critical to reducing further transmission, whereas the Egan model is less focused on behaviour change. Within the last two decades, the focus within HIV/AIDS prevention in South Africa is the reduction of further transmissions. However considering the ever increasing HIV-positive population and their increasing need for extensive care and support, VCT is best positioned to provide such services. What has been proposed by many researchers is the need to understand methods of care and support for those already infected with HIV/AIDS (Harris & Larsen, 2007; Sherman & Ouellette, 2000; Uys, 2003). In developing countries where HIV/AIDS prevalence rates are often greater than 15% (UNAIDS, 2007) there is a serious need to develop models of care and support which can facilitate people living with HIV/AIDS. To this end, VCT services are best positioned to impart information, support, and care to HIV-positive populations (Rohleder & Swartz, 2005).

2.5 Increasing need for care and support

South Africa currently has an HIV-positive population of over 5 million people (UNAIDS, 2010). The provision and subsequent adherence to antiretroviral treatment is believed to increase the length of time HIV progresses to full-blown AIDS and death. Yet this timeframe is uncertain for most who actively manage to adhere to treatment, and increasingly, those that do gradually develop AIDS are requiring intensive care and support (Harris & Larsen, 2007; Kippax, 2006). It is therefore evident that comprehensive care must be afforded to those living with HIV/AIDS, particularly those who are in the advanced stages of AIDS progression. What is increasingly recognised is the need for physiological, social, and psychological care within the financial and medical reality of the individual (Seipel, Sorenson, & Roberts, 2007). The fact that a majority of those infected with HIV/AIDS in South Africa will be unable to access treatment, the provision of palliative care is the only

current means of ensuring that PLHA can enjoy an increased quality of life before death (Seipel et al., 2007). Additionally the reliance on governmental social assistance can aid in alleviating some of the difficulty in living with advancing stages of HIV. Yet the conundrum of utilising treatment or forfeiting social assistance inevitably directs those living in poverty to pick the state grant (Leclerc-Madlala, 2006). In order to understand the magnitude of what is required, it is important to understand the physiological and psychological implications of being HIV-positive. Towards this end, it is paramount that an understanding of the experiences from discovering an HIV-positive status to acquiring full-blown AIDS is thoroughly examined, including disclosure decisions, disability, appraisals, and the provision of HBC.

2.5.1 Psychological impact of living with HIV/AIDS

Individuals discovering their seropositivity experience a wide range of psychological responses, including emotional distress, anxiety, fear, helplessness, hopelessness, loss of self-esteem, suicidal behaviour (Kylma et al., 2000; Van Dyk, 2005), surprise, disbelief, and shock (Hult, Maurer, & Moskowitz, 2009). These psychological responses and the accompanying uncertainty experienced are expected characteristics of experiencing an illness. The unpredictable nature and course of AIDS progression causes fear of the unknown (Worthington, Myers, O'Brien, Nixon, & Cockerill, 2005). Uncertainty about disclosure and responses to seropositivity, treatment for HIV/AIDS and opportunistic infections (Brashers, Neidig, & Goldsmith, 2004), ensuring economic survival, managing and resolving seropositivity within intimate relations (Burchardt, 2010) are factors recently diagnosed individuals must consider. What is recommended is the assessment of the consequences of uncertainty, and the corresponding emotional responses (Brashers et al., 2004). In other words, understanding the consequences and associated emotional responses to uncertainty will motivate psychological and behavioural activities directed towards managing uncertainty (Brashers et al., 2004). For example, individuals who perceive their uncertainty as a threat may actively or passively seek information to reduce anxious emotional responses. The act of information seeking is linked towards acquiring knowledge that benefits the individual and their experiences of living with HIV/AIDS (Brashers et al., 2004).

It is the management and development of strategies to counteract these uncertainties that assist diagnosed individuals to continue to live normally within the context of a seropositive status. Suspended in such uncertainty, PLHA are confronted with the realisation that their

lives have changed in inextricable terms. People are faced with the challenge of maintaining health to impede the onset of AIDS, and the anxiety of looming death (Burchardt, 2010). Experiences of diagnosis rupture perceptions of normality, and drive individuals towards a multiplicity of methods in regaining control of their lives (Burchardt, 2010). Burchardt (2010) suggests that PLHA characterise their experiences of seropositivity through self-identification with HIV-infection. Personal transformation, seeking and providing support, and striving for normality are interwoven between the “making” and “unmaking” of HIV-positivity as mechanisms for self-identification (Burchardt, 2010, p. 19). PLHA may develop strategies which directly remove them from treatment and support opportunities, as their motivation towards normality involves a disconnection with identification as someone living with HIV/AIDS. Conversely other PLHA may readily identify as HIV-positive to assist in the therapeutic healing process. Burchardt (2010) emphasis the variety of ongoing processes people engage to cope with and deal with their seropositivity. Whether these engagements manifest as active commitments to managing and dealing with HIV is dependent upon the individual’s identification with their seropositivity and the level and form of social support received (Burchardt, 2010). This therefore implies that individuals can choose to disassociate with being HIV-positive, to reject the notion that their seropositivity is a facet of their identity (Stanley, 1999). The decision to incorporate or disassociate with a seropositive status are strategies at reconstructing or avoiding stigmatising discourses relating to seropositivity.

Moskowitz and Wrubel (2005) examined the experiences of 57 HIV-positive gay men to comprehend the varying processes of coping and the accompanying emotional responses individuals’ experience in appraising their seropositivity. The notion of prescribing a single process of adjustment fails to recognise the multiple and complex process of achieving well-being in living with HIV/AIDS (Moskowitz & Wrubel, 2005). Personal characteristics, individual circumstances and cultural interpretations of illness and health intertwine and inform an individuals’ experience of living with HIV/AIDS. Moskowitz and Wrubel (2005) found that some individuals’ pursue practices and behaviours which are not necessarily conducive to positive affects and positive health behaviours; this indicates that the objective of creating positive appraisals is not valued by all individuals living with HIV/AIDS. In addition this indicates that such individuals are less likely to practice safe sexual behaviours and access healthcare services promptly (Moskowitz & Wrubel, 2005). Undeniably individuals overwhelmed by their seropositive experiences may consciously avoid negative and positive emotions related to an awareness of their seropositivity. Whereas other

individuals may consciously derive positive affects through the mobilisation of support. Burchardt (2010), Moskowitz and Wrubel (2005) elucidate towards the complex and diverse processes individuals experience in appraising, coping and disclosing their seropositivity. The implication of such divergent practices affects processes of well-being, healthcare seeking behaviour and safe sexual practices. Moskowitz and Wrubel (2005) suggest that healthcare providers be aware of their client's method of appraisal to tailor their counselling encounters appropriately. Yet such suggestions do not account for VCT encounters, where lay counsellors are prescribed basic counselling skills which may assist in developing positive appraisals, but are not designed to be tailored towards specific and or difficult cliental.

2.5.2 Physiological impact of living with HIV/AIDS

The progression of HIV to death from full-blown AIDS in South Africa can last between 7 to 8 years (Philips, 2004). Without a doubt, the physiological effects of HIV/AIDS limit functional activities thereby reducing Health-related Quality of Life (HRQoL¹⁷) for those living with an HIV-positive status (Van As, Myezwa, Stewart, Maleka, & Musenge, 2009). Research conducted by Van As et al. (2009) indicates that South Africans living with HIV/AIDS experienced impairments of: mental functioning, such as lack of energy, sleep deprivation, and emotional distress; cardiovascular, haematological, immunological, and respiratory functioning. HIV infection is recognised as a multisystemic disease affecting multiple systems within the body (Worthington et al., 2005); and mobility as a prerequisite in functioning in ones environment. The physical symptoms of HIV/AIDS vary from individual to individual, and include weight loss, cough, fever, poor appetite, and diarrhoea (Lavy, 2007). But, most distressingly, HIV/AIDS counteracts an individuals' intrinsic immunity thereby rendering them vulnerable to opportunistic infections (Simon et al., 2006). In South Africa the most prevalent opportunistic co-infection is tuberculosis, with 60% of those infected with TB having a co-infection of HIV (Daftary et al., 2007). Owing to the fact that no vaccine or cure is currently available for HIV/AIDS, the only treatment means is through antiretroviral treatment, which is lifelong (Nwoye, 2004; Simon et al., 2006). It is therefore apparent that individuals who wish to lead healthier lives must adhere to continuous ART. Inadequate adherence to ART can result in increased HIV replication, high viral loads, and medicinal resistance (McInerney et al., 2008). However adherence to ART is described as the most demanding, inflexible, and stringent of oral medications (Nwoye, 2004). Additionally

¹⁷ Refer to p. 144 for Glossary of Terms

ART is highly complex and inconvenient, often with over 20 pills to take with stringent timetables that often incite visible side effects (Peretti-Watel et al. 2006). The provision of palliative care is increasingly required when access to ART is restrained due to wider socio-economic-political factors. Within South Africa, of the 711,000 people who require HIV/AIDS treatment only 225,000 people receive ART in South Africa (Dorrington et al., as cited in Daftary et al., 2007).

2.5.3 Disability

The provision of comprehensive combination antiretroviral therapy shifts the perception of HIV/AIDS from a terminal illness towards a chronic manageable disease for those who manage to have access and adhere to treatment (Jarman, Walsh, De Lacey, 2005; Kippax, 2006; Nwoye, 2004). Yet the development of a comprehensive framework for understanding the disabling effect of living with HIV/AIDS has only recently been developed (O'Brien, Bayoumi, Strike, Young, & Davis, 2008). O'Brien et al. (2008) developed the Episodic Disability Framework as a means of understanding the multifaceted health-related challenges that PLHA experience on a day-to-day basis. Disability is understood as both multidimensional and episodic (O'Brien et al., 2008). The dimensions of living with HIV/AIDS include symptoms and impairments, difficulties in carrying out daily activities, problems with social participation and erratic uncertainty on a daily basis (O'Brien et al., 2008). Each dimension is interrelated and occurs in varying frequencies over the course of living with HIV/AIDS. Experiences of disability are therefore affected by major life-events and the contextual factors associated with that event (O'Brien et al., 2008). For example, an individual living with HIV/AIDS may experience an increased feeling of disability and uncertainty when they begin antiretroviral therapy. The experience of disability may be exacerbated by discriminatory events such as unhelpful, methodical medical personnel, and may be alleviated through positive experiences of social support from friends, family or adherence counsellors. Extrinsic factors of social support involving practical and emotional support can alleviate experiences of disability, while factors of stigma are exacerbated through discrimination (O'Brien et al., 2008). Similarly intrinsic factors such as coping strategies are behaviours, attitudes, and beliefs individuals implement as a means of sustaining control over living with HIV/AIDS. However these strategies are limited or augmented through personal characteristics such as age, co-infection, and mental health (O'Brien et al., 2008). Significant events relating to living with HIV/AIDS typically illustrate major episodes of disability, and include: receiving an HIV-positive diagnosis, beginning or

changing antiretroviral treatment and the death of friends or relatives from HIV. However experiences of living with HIV/AIDS are not homogenous and indicate the varying levels of uncertainty in living with HIV/AIDS (O'Brien et al., 2008). It is important to note that although the experiences of living with HIV/AIDS are not homogenous, there remains an increased need to provide the multifaceted aspects of support for PLHA.

2.5.4 Home-based Care

HBC is defined as care given within the home of an individual living with HIV/AIDS. This method of providing palliative care is becoming increasingly utilised as primary and secondary healthcare facilities are frequently unable to deal with and manage the increasing HIV-positive population (Van Dyk, 2005). Care is generally given by a family member who is additionally supported by multidisciplinary team of counsellors, volunteers, social workers, and health care practitioners. The increasing HIV-positive population will strain the services that primary and secondary healthcare facilities routinely offer. If care and support of PLHA is increasingly recognised, methods such as HBC should be utilised, not only to reduce the strain on primary and secondary healthcare services, but to provide care and support to PLHA (Kabore et al., 2010). In light of such developments, there is an increased dependence on volunteer caregivers as the numbers of HIV-positive individuals increasingly require care and support (Akintola, 2008). HBC is an avenue in which lay counsellors routinely offer emotional supportive services to PLHA, over and beyond the counselling and supportive services offered through VCT. The primary benefits of HBC are empowerment and the reduction of dependence on primary healthcare services (Van Dyk, 2005). The provision of HBC is intended to supplement the services provided by primary healthcare packages, and recognition of the need to enhance the quality of supportive services beyond clinic settings (Kabore et al., 2010). These may include disease management, psychosocial support, and ARV guidance. People who are given the opportunity to care for members of their own family can provide good holistic care, thereby reducing the strain on provincial and national healthcare budgets, and simultaneously create awareness surrounding HIV-infection within their community. The drawbacks of utilising HBC are the associated discrimination and stigma surrounding seropositivity, and the difficulties construed around managing and dealing with a seropositive status, such as difficulties with ART adherence, disclosure decisions, and a lack of knowledge about HIV-infection (Akintola, 2008). Orner (2006) found that caregivers sought ongoing systems of support that acknowledged the difficulty in caring for PLHA. Financial, material and emotional support were deemed the most necessary

systems of support that were either unavailable or badly disseminated. Multidisciplinary teams of counsellors, social workers and healthcare practitioners must provide ongoing systems of support and care for these caregivers to minimise burnout and exhaustion (Van Dyk, 2005). Within the context of VCT this indicates the need for ongoing supportive services to lay counsellors who either provide HBC, or support home-based carers.

2.5.5 Disclosure

Receiving an HIV-positive diagnosis presents challenges which extend beyond medical effects, and directly relate to processes of identity crises for those infected (Young, 2011). Typically disclosure of a seropositive status is understood as an analysis of potential benefits and risks (Frye et al., 2009). The benefits of disclosure involve access to institutional treatment and support opportunities for PLHA (Norman, Chopra, & Kadiyala, 2007), conversely the risks of disclosure revolve around the stigmatised attitudes and perceptions regarding seropositivity (Gilbert & Walker, 2010; Paxton, 2002) and the potential loss of relationships occurring from disclosure (Jarman et al., 2005). The complexity of disclosure is evident when one considers acts of silence as safeguards towards possible stigma, yet such beliefs are problematic when disclosure of HIV necessarily precludes social support (Paxton, 2002; Poindexter & Shippy, 2010). The necessity and difficulty with disclosure and the sensitivity required determining whom, how and when disclosure is appropriate, are complex continual decisions PLHA must consider. Norman et al. (2007) describe disclosure decisions as fluid processes which may have multiple rather than one inevitable outcome. Such decisions are often beyond the control of PLHA, and are a product of their life circumstance; such as HIV progression, demand for social support, and treatment adherence (Poindexter & Shippy, 2010).

PLHA disclosing as a means of confronting stigmatised attitudes, face potential ostracism, prejudice, termination of relationships, verbal and physical abuse, and violence (Gilbert & Walker, 2010). However such risks are necessary for the mobilisation of support and treatment, which requires public disclosure, whether in group settings to access support groups or individual settings to access counselling and treatment opportunities (Poindexter & Shippy, 2010; Skhosana et al., 2006). Classifications of disclosure extend beyond external behaviours which relate to support and treatment opportunities, and encompass methods of social interaction mediated by personal experiences and internalised disclosure decisions (Poindexter & Shippy, 2010). Poindexter and Shippy (2010) examined disclosure experiences

of a cohort of men and women, and found that disclosure behaviours could be separated into categories of stigma management and stigma resistance. Stigma management involves identification or denial of HIV-infection, identification is a well thought-out disclosure to someone who may be significant to the individual's life; for example members of a support group, counsellor, or social worker. Denial involves the concealment of a seropositive status to reject external forms of stigma by not identifying as someone living with HIV. Stigma resistance is the voluntary disclosure of a seropositive status, which aims to deconstruct prevailing negative beliefs surrounding seropositivity (Poindexter & Shippy, 2010). Stigma resistance as acts of social defiance allow PLHA the opportunity to reclaim control of their lives and how their infection defines them, as opposed to socially constructed notions of seropositivity (Poindexter & Shippy, 2010).

Research conducted by Jarman et al. (2005) indicates how psychological mechanisms of protection may impede a women's decision to disclose her seropositivity. The necessity of protecting oneself psychologically is a mechanism at reducing feelings of seclusion and otherness related to being HIV-positive. Concealment of a seropositive status reduces the risk of revealing a stigmatised identity, yet such strategies limit discussions around lived experiences and the sharing of emotional difficulties experienced by PLHA. Jarman et al. (2005) found that women in partner-relationships where their HIV-status is known and or is shared had reduced experiences of anxiety concerning psychological protection of the self. However, experiences of living with HIV necessarily include experiences of relational connectedness with friends, family, and their community. Where non-disclosure reduces the availability of social support and amplifies the need to develop and maintain psychological protection against feelings of isolation and otherness. Disclosure approaches have typically examined the benefits and risks associated with physiological and psychological processes, where disclosure allows an infected individual the opportunity to receive treatment and share in the lived experiences of being HIV-positive, whilst non-disclosure is linked to opportunities of future infection but are understood as mechanisms against external forms of stigmatisation. There is a need to understand the relationship between psychological protection and partner-relationships relating to disclosure approaches, how such connections can reduce experiences of isolation and otherness, but similarly facilitate non-disclosure (Jarman et al., 2005; Leonard & Ellen, 2008; Skogmar et al., 2006). Kalichman and Simbayi (2009) suggest providing PLHA the opportunity to determine the advantages and disadvantages of disclosure within their personal context and framed within cognitive decision-making structures. The

purpose of cultivating disclosure decision-making procedures is to imbue confidence and critical assessment of the circumstances in which disclosure is safest and effective (Kalichman & Nachimson, 1999). The intention of recognising disclosure decision-making processes is to emphasise the complexity of internal disclosure decisions framed within South Africa, rather than presuming the rational choice of disclosure as it facilitates institutional support and treatment opportunities (Kalichman & Simbayi, 2009).

Research regarding disclosure of a seropositive status to gain entry into institutional support and treatment opportunities effectively describes half of the potential benefit of disclosure practices. Research conducted by Norman et al. (2007) reveal that disclosure decisions often serve to unburden the internalised stigma regarding seropositivity. Paxton (2002) describes the liberating experience of disclosure when confronting AIDS-related discrimination. Acts of self-disclosure not only provide access towards institutional support structures, but additionally facilitate community involvement to support other PLHA, by providing a platform towards public disclosure and stigma eradication (Norman et al., 2007). The use of positive role models, specifically HIV-positive individuals advocating for the rights of PLHA, to confront issues of stigmatisation are increasingly recognised as a means to reconstruct the realities and discourses surrounding the lived experiences of PLHA (Gusdal et al., 2011; Jewkes, 2006; Norman et al., 2007). The provision of support through individual or group counselling approaches is necessary to foster self-efficacy in disclosure. Furthermore Kalichman and Nachimson (1999) advocate practicing a range of scenarios to develop and build self-efficacy for disclosure decision-making; including role plays, imagery, and other behavioural rehearsal techniques.

2.6 Peer counselling

The idea of utilising peer counselling as a prevention opportunity should be considered in South Africa. Firstly, because of the high HIV/AIDS prevalence rate, but additionally as a means of normalising seropositivity, this may shift societal perceptions from stigmatisation to acceptance. Peer counselling can be defined as a “one-on-one educational or counselling connection” between a recently diagnosed individual and an individual who has been living with HIV/AIDS for several years (Harris & Larsen, 2007, p. 844). The purpose of peer counselling includes emotional and social support, knowledge acquisition, coping skills, facilitation of access to treatment, risk reduction, positive appraisals, and the normalisation of

seropositivity (Harris & Larsen, 2007; Messias et al., 2006; Schneider et al., 2008). The most obvious benefit of such a relationship is the ability of transferring the lived experience of living with HIV/AIDS to those who desperately seek it (Harris & Larsen, 2007). At this point it is important to clarify the difference between a lay counsellor and a peer counsellor. A peer counsellor is an HIV-positive lay counsellor; the use of the term „peer“ refers to an individual who is living with HIV/AIDS. Recently diagnosed individuals seek such experiences because of the realisation of their situation. Kylma et al. (2000) state, individuals discovering their seropositivity encounter an extensive range of experiences and responses, including emotional distress, anxiety, fear, helplessness, and suicidal behaviour. These responses have been experienced by peer counsellors, owing to the fact that they have lived through discovering their seropositivity, and in turn they are able to convey these experiences towards their clients. Harris and Larsen (2007) found that peer counsellors helped their clients change their lifestyles; changes included a reduction in risky behaviour through to eating healthier. The aim was to enable clients to “live longer and healthier lives with HIV” (Harris & Larsen, 2007, p. 850). Leading healthier lifestyles through the assistance of peer counselling with the result of reducing risky behaviours is a secondary means of prevention. As stated above, secondary means of prevention is the prevention of further spread of HIV/AIDS through HIV infected individuals. In South Africa this is particularly vital owing to the large proportion of HIV-positive individuals. In addition the use of VCT services could provide an avenue for the use of peer counselling.

2.6.1 Peer Support

South Africans living with HIV/AIDS must not only contend with the increased impairments in their physiological and psychological well-being, but must also maintain treatment, reduce risky behaviours to minimise further infection, decide on disclosure, and indirectly manage issues of stigmatisation and prejudice linked to their seropositivity. Considering the difficulties and challenges that PLHA must contend with, avenues of care and support are increasingly required. Towards this end, VCT should be considered as an appropriate setting, not only as an effective secondary means of prevention, but also as an avenue for the provision of palliative care as a means to access support groups, emotional, physiological and spiritual care, caring for children, and restructuring self identities (Seipel et al., 2007; Roberts, 2008; Uys, 2003). Peer support, most commonly referred to as support groups in South Africa, differs from conventional counselling as they are often informal and less structured, with a group facilitator focused on directing the conversation as opposed to

leading it. Typically peer support is structured around PLHA sharing their experiences in living with HIV/AIDS (Molassiotis et al., 2002; Roberts, 2008). The provision of social support is important for psychological adaptation to living with HIV/AIDS, and as a potential mechanism towards personal growth (Barskova & Oesterreich, 2009). In addition, Molassiotis et al., (2002) and Seipel et al. (2007) state that the benefits of peer support, apart from sharing experiences to conveying empathy, is the reinforcement of coping skills, social networks, and self esteem. Support is provided through: informational support, practical information about HIV/AIDS, emotional support, empathic and comforting support, and instrumental support, practical assistance in living with HIV/AIDS (Roberts, 2008). These benefits help PLHA manage uncertainty in living with HIV/AIDS (Brashers et al., 2004) by actively encouraging living hopefully and dealing with death and dying on an intrapersonal and interpersonal level (Molassiotis et al., 2002). Commitment and dedication towards minimising uncertainty can improve the feeling of control (Stanley, 1999), this is critical as external forms of control over HIV only exist through medicinal means. Additionally such active commitment by HIV-positive individuals restructures the experience of self, from an individual perception towards an experience of self as crucially connected to others (Stanley, 1999). Such perceptions promote the utility of social support networks, not only as systems of support, but additionally as a means of reconstructing psychological realities which reflect the lives of PLHA, rather than socially constructed norms that are typically assumed to represent the experiences of living with HIV/AIDS.

The provision of social support is envisioned to enable a client to move from a state of denial towards acceptance of their seropositive status (Leonard & Ellen, 2008). However empirical evidence suggests that this assumption is inconsistent with the practice of support group participation. Leonard and Ellen (2008) found that their participants attended support groups initially but discontinued owing to refusal to engage in issues typically discussed in support groups; fundamentally they found discussing topics related to HIV/AIDS depressing. The benefit of support group participation is the provision of an enabling environment where a recently diagnosed individual can disclose and come to terms with their new serostatus. Yet experiences of support group participation typically ignore discourses surrounding nondisclosure decisions and the effects such beliefs may have on support group membership and the perceived fulfilment experienced from active participation. In addition the certainty that disclosing will provide social support does not reflect the lived experiences of disclosure decisions which are fluid and alter over time (Leonard & Ellen, 2008). The implications of

Leonard and Ellen's (2008) research, indicates that studies concerning disclosure decisions represent the dominant narratives within biomedical research and do not reflect the complex processes involved in disclosure decisions. In addition those who typically access social support are disenfranchised and unable to communicate in a language other than the discourses prescribed by western biomedicine (Leonard & Ellen, 2008).

In the context of VCT in South Africa, support groups are commonly led by a lay counsellor, and meetings are held at the VCT centre or other neutral venue. Culturally sensitive and relevant norms and beliefs are represented and accounted for when counsellors reside within the cultural boundaries of their communities (Kabore et al., 2010). In addition to providing information about HIV/AIDS and the sharing of lived experiences, support groups focus on other subjects such as family planning and safe sexual behaviours such as condom usage (Mantell, Scheepers, & Abdool Karim, 2000; Molassiotis et al., 2002), empowerment strategies and the opportunity to reconstruct and personalise seropositive identities (Stanley, 1999). Roberts (2008) examined normative support as a function of support groups, where PLHA develop group norms which enable the creation of positive self identities that challenge dominant stigmatising discourses relating to seropositivity. Positive living is emphasised as a means of dealing with a seropositive status and actively encourages accessing healthcare services (Roberts, 2008). The reformation of a positive self identity intends to empower and counteract the debilitating effects of external stigmatisation which PLHA experience (Gilbert & Walker, 2010; Schneider et al., 2008). The provision of informational, emotional and instrumental support allows PLHA the opportunity to redefine their identity by constructing norms relevant and applicable to them, as opposed to the stigmatised identity that typically represents a seropositive status (Roberts, 2008).

Kabore et al. (2010) investigated the benefit of receiving community-based support services against clinical outcomes assessing treatment adherence, HRQoL, and CD4 cell count in resource-limited sites. Participants who received community-based supportive services such as HBC, treatment guidance, prevention education, psychosocial support, assistance with governmental grants and referral to counselling and testing services had significantly improved their CD4 cell count, improved their HRQoL, and attained higher levels of adherence to treatment (Kabore et al., 2010). This study highlights the need to provide PLHA levels of social support which facilitate and expand upon services offered by primary healthcare. The focus of such support is beyond exclusive medical outcomes, but rather indicates the need to provide holistic palliative services to an increasing HIV-positive

population. However, participation in social support necessitates public self-disclosure which can be problematic owing to stigmatised attitudes and beliefs surrounding HIV, yet non-disclosure and social isolation limits the potential benefit of social support (Flowers et al., 2006).

2.6.2 Restoration of hope

Of the available literature none focused on the practice of peer counselling in VCT services in South Africa. Existing literature concerning peer counselling was available but scarce, and does not focus specifically on the context of VCT or South Africa but rather HIV/AIDS community-based organisations in western Canada (Harris & Larsen, 2007), a community-based program in the south-eastern United States (Messias et al., 2009), a HIV prevention study assessing the acceptability of peer counsellors in the United States (Driskell et al., 2010), and an examination of peer counsellors facilitating adherence to ART in Ethiopia and Uganda (Gusdal et al., 2011). In their research Driskell et al. (2010), Harris and Larsen (2007), Messias et al. (2009) and Gusdal et al. (2011) discovered various benefits PLHA have when counselled by someone who has lived with HIV/AIDS for several years. These benefits included the provision of support, acceptance, empathy, the reconstruction of hope, change in lifestyle, shared lived experiences and positive role-modelling. What is particularly relevant here is the reconstruction of hope in terms of experienced hopelessness in living with HIV/AIDS. PLHA experience an extensive range of psychological distress as a result of discovering their seropositivity, this distress can lead to a diminished survival rate and potentially manifest as hopelessness or “losing one’s grip and sinking into narrowing existence” (Kylma et al., 2000, p. 764). Hopelessness can be further described in three dimensions, affective such as lack of hope, motivational such as giving up, and cognitive such as having no future hope (Kylma et al., 2000). Harris and Larsen (2007) found that peer counselling and peer support were able to reconnect and facilitate hope. This rekindling of hope was made possible through the relationships developed between the HIV-positive counsellors and their HIV-positive clients (Messias et al., 2009). In addition it shows an active engagement by PLHA for constructive action in changing their lives. Constructive action as Kylma et al. (2000) state is hope that is good for a person based on their situation, and it is taking action in spite of the situation.

The development of honest, open, and nonjudgmental relationships is crucial to the successful implementation and practice of peer counselling (Driskell et al., 2010; Messias et

al., 2006). Developing sound relationships between peer counsellors and their clients is a necessary step towards recognising concerns in living with a seropositive status. In addition the relationships developed, facilitate the use of personal experiences, in virtue that recently diagnosed individuals seek assistance, and are provided knowledge acquired through experience (Messias et al., 2009). Furthermore within such therapeutic relationships peer counsellors must engender to balance the acknowledgement of the cruel realities of seropositivity, while maintaining the development of meaning, hope and purpose for their client; this includes the realisation of the difficulties associated with HIV/AIDS, without rejecting support and love provided through friends and family (Cartwright & Cassidy, 2002). However, it would be erroneous to assume that experiences of seropositivity are homogenous across all contexts. Within South Africa it is well established that HIV/AIDS is experienced differently across provincial boundaries, and even within provincial territories (UNAIDS, 2007). These experiences are further differentiated between men and women, owing to longstanding gender inequalities within South Africa. Yet, there are experiences in living with an HIV-positive status which could be cross-culturally relevant. Experiences concerning diagnosis, treatment, and care are all anxieties which peer counsellors have experienced, and would be able to transfer as a useful means of living with HIV/AIDS. Obviously within experiences such as diagnosis, treatment and care there will be fundamental differences, for example people may have difficulties with disclosure, which would in turn affect opportunities for care giving via friends and family (Ncama, 2007), and other individuals may have difficulties with treatment and may want to attempt alternative therapies as opposed to ART. What is therefore required, are peer counsellors able to adapt their own personal experiences to cater towards the specific needs of individuals, and not use their own experiences as a template for universal care for HIV-positive individuals (Messias et al., 2009). Ongoing supervision and training would be required if peer counsellors are expected to provide such services. Without which counsellors are likely to experience exhaustion, psychological distress and possibly burnout (Schönnesson & Ross, 1999).

2.6.3 Personal experiences and countertransference

Peer counsellors incorporate their own lived experiences into providing recently diagnosed individuals with examples to live by (Messias et al., 2009). The practice of utilising personal experiences within traditional counselling practices is often frowned upon (Driskell et al., 2010; Maroda, 2001). This is exemplified through notions of psychodynamic countertransference, which can be defined as the broad range of reactions counsellors

experience from their clients, which stem from the counsellors' unresolved issues (Hofsess & Tracey, 2010; Kaplan & Sadock, 1996). Counsellors experiencing countertransference reactions are taught to consult other therapists or their supervisors on how to deal with their reactions (Teyber, 2000). Within psychoanalytic therapy the counsellor is taught to remove such barriers towards the counselling process (Maroda, 2001). This classical definition of countertransference originated through Freud advocates against the therapeutic value of countertransference. Totalistic descriptions of countertransference refer to all the therapists' reactions to their client, emphasising the study of all reactions to benefit therapeutic relationships. Complementary descriptions of countertransference perceive the therapists' reactions as a complement to the client's method of relating, emphasising the client's interpersonal method of relating thereby allowing the development of effective therapeutic interventions. Relational descriptions of countertransference perceive countertransference as reciprocally constructed by the counsellor and client, where both the client and counsellor's unresolved conflicts contribute to the materialisation of countertransference (Hayes, Gelso, & Hummel, 2011). However, classical, totalistic, complementary and relational descriptions of countertransference are frequently used interchangeably, and often in contradiction of one another. Hayes et al. (2011) endorse an integrative description of countertransference, emphasising the inevitability of countertransference, but advocating the therapeutic benefit of such reactions beyond the counsellor's reaction and encompassing all clinically pertinent information.

The implication of multiple viewpoints on countertransference produces confusing and contradictory practices relating to resolving such experiences (Hayes et al., 2011). Yet not all forms of therapy follow such strict procedures; the constructionist approach to therapy calls for active use of reflexive practices (Monk, Winslade, Crocket, & Epston, 1997), these reflexive practices actively utilise the counsellor's own personal experiences within the counselling process, and this is achieved through active collaboration with the client during counselling (Monk et al., 1997). Within the practice of peer counselling, utilising a client's transference may be a useful means of assessing what the counsellor should attempt to deal with first or next. This may concern issues of acceptance, treatment, how to manage symptoms, leading healthier lifestyles, accessing social grants or social support. For an HIV-positive lay counsellor, they may have countertransference reactions towards their clients' narrative concerning diagnosis, disclosure, treatment, and care (Schönnesson & Ross, 1999). The transference may evoke mixed emotions concerning the counsellors' own initial

experiences in confronting such issues. The sharing of such experiences can facilitate the desire for knowledge, support and care that recently diagnosed individuals require.

Lay counsellors, as discussed, are given basic training in counselling (Van Dyk, 2005). The procedures and methods of the counselling process are generally influenced by traditional counselling techniques. These traditional counselling methods often place the counsellor/therapist as the expert of professional knowledge (Payne, 2007). The possession of such knowledge enables the counsellor to identify and thereby correct issues that the client brings to therapy (Payne, 2007). However, the professional realm of therapeutic practice is generally beyond the scope of most that practice lay counselling. In addition, principles that underlie the core mechanisms of their training can only be briefly touched upon. For example, individuals who undergo basic counselling for VCT are given instructions to avoid the disclosure of personal experiences. The rationale centres on the principles under which their training is based, whether cognitive-behavioural therapy or a client-centred approach. This is problematic, considering the brief explanations they are given for not utilising personal experiences. Additionally there is potential for countertransference reactions occurring between a HIV-positive counsellor and a recently diagnosed individual. Yet the benefits of such experiences are set aside as counselling procedures dictate the methodologies under which lay counsellors may counsel. The use of direct self-disclosure in the counselling process is prohibited, yet situations in which an HIV-positive lay counsellor experiences countertransferential emotions to her client's reaction to discovering a seropositive status are possible. The brief amount of training invested into dealing with such issues is problematic, considering that such experiences are increasingly probable. The primary goal of lay counselling is the transmission of information to reduce an individual's risk of contracting HIV, and the development of emotional acceptance and growth stemming from a seropositive status (Van Dyk, 2005). Yet the increasing need for care and support for the burgeoning HIV-positive population calls for approaches that actively utilise personal experiences, whether in the context of peer counselling or peer support.

Research concerning countertransference is typically focused on the harmful and negative aspects rather than the potential therapeutic value (Hayes, 2002; Hayes et al., 2011; Hofsess & Tracey, 2010; Maroda, 2001). Countertransferential experiences of contagion, death, denial and mortality are recurrent experiences occurring in professional therapeutic practice, which require ongoing supervision and support (Cartwright & Cassidy, 2002). Counsellors who actively engage with countertransferential reactions intentionally invoke and or allow

personal experiences that in some way relate to their clients' experiences, and make use of such experiences therapeutically (Schroeder as cited in Hayes, 2002). The benefit is the possibility of deep empathic understanding, honesty, compassion and humility drawing upon the counsellors personal experiences epistemically. However the potential for abuse and misuse are abundant, and suggests that utilising personal experiences must directly benefit the client and not provide a platform for counsellors to self-indulge (Hayes, 2002; Van Dyk, 2005). However research conducted by Cartwright and Cassidy (2002), Hayes et al. (2011) focus on professional therapeutic practice, limiting the extent in which lay counsellors can effectively cope with countertransference reactions. This is particularly salient for peer counsellors who will experience some form of countertransference from their clients' experiences of diagnosis, disclosure, treatment, and care (Schönnesson & Ross, 1999). Furthermore reserving countertransference experiences within professional therapeutic practice fails to recognise the potential of countertransference reactions within lay cadres of the healthcare system, and assumes that such experiences are only probable within professional therapeutic practices.

Hayes (2002) states that recognition of the counsellors own woundedness is critically significant for the utilisation of the self as an instrument of healing. An awareness of the woundedness of peer counsellors necessitates a prescription of problem awareness, yet the conditions under which personal experiences are utilised extend beyond a fixation of crises, and encompass an awareness and willingness to resolve one's own issues. Continuous motivation to resolve one's own issues reduces the possibility of countertransference reactions, and increases the epistemic value of personal experiences within therapeutic practice (Hayes et al., 2011). Within therapeutic practice the utilisation of personal experiences must be adapted to suit the needs of cliental, Hayes (2002) cautions at the utilisation of resolutions successful to the counsellor, which may not engender success in cliental. Furthermore theoretically managing episodes of countertransference are ineffectual, and suggest that the counsellors' awareness of their countertransference reactions including theoretical knowledge is pivotal to successful therapeutic utilisation of countertransference (Hayes et al., 2011). Although Hayes (2002) specifically relates his article to professional therapeutic practice, the implications for lay counselling are evident in his prescriptions. Firstly the utilisation of personal experiences must directly benefit the client, to recognise the potential for extended life beyond the normative construction of a limited life following an HIV-positive diagnosis (Van Dyk, 2005). Secondly counsellors must acknowledge their inner

conflicts and continuously work to resolve them to improve accessing epistemic experiences. Thirdly counsellors must endeavour to adapt their personal experiences to directly benefit their cliental (Hayes, 2002). Finally recognition of countertransference experiences occurring in lay cadres of healthcare must be validated with ongoing institutional support.

2.6.4 Necessity

It is apparent that peer counselling and the use of peer support among HIV-positive individuals has valuable applications in terms of providing care and support to the ever increasing HIV-positive population. The benefit of transferring lived experiences, from an individual who has lived with HIV for several years to an individual who has been recently diagnosed, is valuable in coming to terms with a seropositive status, developing modes of coping, dealing with the anxiety of beginning and maintaining ART and the corresponding effects of utilising ART, and other modes of personal and social support (Gusdal et al., 2011; Harris & Larsen, 2007). The use of peer counselling and peer support within VCT is suitable in relation to the philosophy of secondary prevention. However the feasibility and application of such a solution will face significant barriers to successful implementation. For instance, the stigmatising and prejudicial perceptions surrounding seropositivity in South Africa will be a fundamental barrier towards the active use of such services (Mbonu et al., 2009). Individuals may be aware that there is an HIV-positive counsellor available for consultation, but may be reluctant to procure their services for fear of being victimised as someone with HIV/AIDS.

The use of personal experiences between a peer counsellor and a recently diagnosed individual may require the direct self-disclosure of the counsellor's HIV-positive status. This may be a necessary step if the uses of personal experiences are utilised in the counselling process. The reasons for direct self-disclosure must primarily focus on how such an act can directly benefit the client (Van Dyk, 2005). The act of direct self-disclosure should aid the client in focusing on their concerns, directing energy towards examining and understanding their condition, rather than the counsellor burdening the client with his/her problems. One cannot expect the client to readily accept testimonials about living with HIV if the counsellor cannot express that they are living with HIV. Yet the notion of publically disclosing an HIV-positive status directly relates towards fears of AIDS-related stigma (Paxton, 2002). Individuals are less likely to publically disclose their HIV status for fear of being discriminated as someone who is living with HIV/AIDS (Paxton, 2002). The act of publically

disclosing an HIV-positive status should be given practical and emotional support, as a means of normalising seropositivity (Paxton, 2002). Increasingly it is apparent that disclosure of a seropositive status is important in creating consciousness about living with HIV/AIDS, but fundamentally as a mechanism to normalise seropositivity and potentially reduce the stigmatising attitudes surrounding HIV/AIDS (Ncama, 2007).

Examining HIV-positive peer intervention approaches provides an opportunity to understand the feasibility and validity of peer counselling approaches. However the study conducted by Driskell et al. (2010) focuses on the experiences of gay and bisexual men, where acceptance of the intervention program was largely dependent upon counsellor demographics. Participants who were allocated peer counsellors found that the age of their counsellor either assisted or hindered the initial process of developing relationships with their counsellors. Additionally participants who were allocated professionally trained prevention case managers found that the gender of their counsellors hindered the initial process of developing a relationship with their counsellor. The implications of such barriers indicate that the acceptance of prevention intervention programs are largely determined by the groups for whom the interventions are developed (Driskell et al., 2010). Yet developing contexts such as South Africa are plagued with a shortage of professional medical staff, thereby presenting a significant difficulty with intervention implementation (Zachariah et al., 2009). In response various global organisations have advocated the employment of PLHA within the formal healthcare system (WHO, PEPFAR, UNAIDS, 2007).

The fact that VCT services are not uniform across South Africa and vary in terms of service delivery and expertise will reduce the effectiveness of such a service, especially in resource-poor settings. The demand for care and treatment may be uniform across the country, but the supply of such services and medication is often varied and unreliable (Poku & Sandkjaer, 2007). Gender inequality and the perception of male dominance within intimate relationships, will reduce the number of woman who may be seeking such services, but are unable due to financial restrictions, potential abuse from their partner(s) or spouse, and long travelling distances to clinics. HIV-based stigma and the pervasive denial of those affected and infected will additionally reduce VCT uptake (Van Rooyen et al., 2009). However these barriers should not reduce the feasibility and usefulness of peer counselling and peer support within VCT, especially considering that developing comprehensive methods for care and support for HIV-positive individuals are increasingly required (Seipel et al., 2007). However in South Africa lay counsellors are not recognised as a part of the public health system, rather they are

perceived to provide a minor role with regard to the technician approach to primary health care (Peterson & Swartz, 2002; Schneider et al., 2008; Van Rooyen et al., 2009). This approach clashes with the preventative and supportive services that counsellors provide. One solution provided by Rohleder and Swartz (2005) is to determine the effectiveness of counsellors in work as usual settings in VCT. This means that understanding the psychological and emotional aspects of lay counsellors should provide an avenue into understanding the effectiveness of lay counsellors in VCT. Evaluating the effectiveness of counsellors in VCT may only be possible if the counsellors themselves are regarded as “part of the formal employment structure of the public health system” (Rohleder & Swartz, 2005, p. 398). The fact that lay counsellors are not regarded as part of the formal healthcare structure should not indicate their ineffectiveness.

Van Rooyen et al. (2009) indicate the need to officially recognise the position of lay counsellors within the formal healthcare system, as well as confront issues of compensation and the provision of ongoing supervision and training. This position is supported by studies conducted by Gusdal et al. (2011) where peer counsellors served as important facilitators towards adherence to ART through positive role modelling within their communities. Yet because these peer counsellors are not recognised within their formal healthcare system, they pointed out issues concerning the lack of support and remuneration (Gusdal et al., 2011). Price and Binagwaho (2010) and Zachariah et al. (2009) states how unofficial utilisation of task-shifting may result in vague and overlapping responsibilities within lay and primary healthcare cadres. Task-shifting is defined as the systematic relocation of responsibilities in patient care typically from specialised to less specialised providers (WHO, 2006). This is particularly salient for peer counsellors who assume the function of counsellor within VCT, but are required to additionally provide multiple supportive services within the field of HIV care, and are not adequately supported nor compensated for their additional services. There remains a necessity to determine the role of lay cadres within the formal healthcare system, particularly addressing issues of remuneration, supervision and support (Sanjana et al., 2009; Schneider et al., 2008; Zachariah et al., 2009). Although Zachariah et al. (2009) states the possibility of lay counsellor resignation owing to lack of remuneration and support. The perception that lay counsellors will seek alternative forms of employment because of a lack of institutional support assumes the availability of abundant employment. However this assumption fails to recognise the limited availability of employment opportunities, and the

reality of securing employment within the context of a seropositive status in South Africa (Leclerc-Madlala, 2006; Schneider et al., 2008).

The local Department of Health in the Eastern Cape have explicitly stated that adherence counsellors, local PLHA assisting with treatment adherence, are not recognised within the healthcare system as “anything but volunteers” (Evensen & Stokke, 2010, p.164). The implication of such statements have far reaching implications for the practice of peer counselling, particularly because local governance (DOH) refuses to recognise the benefits of such practice and rather perceives any services offered as purely voluntary. Additionally this indicates that community health workers (CHW¹⁸), an umbrella term encompassing community and lay workers within the healthcare system, are accountable to clinic staff, facility managers, and supervisors, but are an exploited workforce without occupational benefits, adequate support and recognition (Schneider et al., 2008). A severe lack of clarity in national policies concerning task-shifting implies that formal recognition of such practices is unlikely (Evensen & Stokke, 2010). Yet the utilisation of CHW both globally and locally to balance the strain on primary healthcare are well established. Additionally CHW entrenched within large-scale unemployment are more likely to remain embedded within healthcare services as the incentive of regular remuneration is far more desirable than unemployment (Schneider et al., 2008).

In virtue of the fact that a peer counsellor is essentially a lay counsellor with an HIV-positive status, it must be assumed that the message of their lived experiences supersedes those of their HIV-negative counterparts. The assumption that an HIV-positive counsellor is more able and credible to counsel a recently diagnosed individual as opposed to their HIV-negative counterparts has rarely been examined. Existing research conducted by Messias et al. (2006) regarding notions of credibility, affirm the assumption that peer counsellors are more credible to impart information and support to recently diagnosed individuals. In addition research conducted by Gusdal et al. (2011) demonstrates that peer counsellors appeared to appreciate and relate to their client’s personal concerns better than their professional counterparts; adherence nurses. Research surrounding peer counselling have emphasised the ability of peer counsellors to empathically connect with clients who are also HIV-positive (Harris & Larsen, 2007; Messias et al., 2009). Notions of credibility have rarely examined the differences in the effectiveness of VCT counselling from the perspectives of lay and peer counsellors.

¹⁸ Refer to p. 144 for Glossary of Terms

Conceptions concerning HIV/AIDS counselling effectiveness have consistently assessed the value and success of intervention programmes, where a reduction in risky behaviours is considered successful (Daftary et al., 2007; Kippax, 2006; Richter et al., 2001; Rohleder & Swartz, 2005). Credibility is established in virtue of efficacy studies on VCT, therefore lay counsellors are assumed to be credible in light of the secondary preventative successes of VCT. In this regard, peer counsellors could be regarded as being more credible to convey a seropositive test result, in virtue of their unique position as people living with HIV/AIDS and the fact that they are lay counsellors. Yet, notions of the credibility of peer counselling operating from VCT services within South Africa have not been examined.

The experiences of work related stress and occupational burnout in HIV/AIDS care and counselling, have frequently focused on nurses, doctors and lay counsellors who are HIV-negative. It is widely understood that HIV/AIDS care and counselling is negatively associated with the devastating nature of HIV/AIDS. The fears of association, contagion, and discrimination relating to HIV/AIDS have increased the need to understand the difficulties in counselling and caring for people living with HIV/AIDS (Miller, 2000). It must be noted that peer counsellors face unique stressors and difficulties in providing VCT services (Poindexter, 2006). Apart from the emotional difficulties in providing counselling and testing services, and supportive community based services, peer counsellors will have additional difficulties in relation to their seropositivity. For instance, they may require additional ongoing support for adhering to ART, dealing with their own experiences of living with HIV/AIDS, managing conflicting emotions regarding their clients' experiences in living with HIV/AIDS, intense identification with their clients' experiences, managing the increasingly difficult field of treatment and the accompanying uncertainties surrounding long-term use of antiretrovirals, and dealing with stigmatising and prejudicial attitudes towards seropositivity (Poindexter, 2006). In addition to managing HIV-related concerns, Poindexter (2006) points out the mutual role of consumer and provider within peer counselling, where HIV-positive peer counsellors may have child-rearing and intimate partnering responsibilities which may aggravate and or alleviate experiences of work-related stress. The role of peer counsellor does not imply an exclusion from supportive services, yet the nature of peer counselling entails an individual who provides supportive services and requires such services simultaneously (Poindexter, 2006).

Research conducted by Poindexter (2006) indicates that peer counsellors in the Massachusetts area frequently felt unsupported in areas concerning the realities of living with

a sero-positive status. If an organisation aims to employ seropositive counsellors, then issues concerning their experiences of vulnerability, reduced health and emotional state must be considered an aspect of that individuals' appointment. The plight of these counsellors is regrettable and unfortunately echoes the experiences of many peer counsellors in South Africa. Not formally recognised within the healthcare system, and dually living with a sero-positive status within the fragile healthcare structure of South Africa, introduces a myriad of daily challenges. Literature concerning improved quality of life for those living with HIV/AIDS has been documented (Harris & Larsen, 2007; Messias et al., 2009), yet little research has focused on the experiences of peer counsellors working within VCT in South Africa. The aim of this research is to broaden conceptions regarding peer counselling within VCT in South Africa, specifically the Eastern Cape. Towards this end the use of personal experiences and issues of credibility will be examined from the perspectives of peer counsellors. The meanings ascribed by the peer counsellors with regard to the use of their personal experiences and notions of credibility are the focal points behind this research. It is hoped that findings from this project will shed light on the difficulties of such practices, and the ongoing need for supervision, training and care that peer counsellors may require, over and above the fact that they are living with HIV/AIDS.

Chapter 3: Methodology

As indicated in the previous chapter, this research project aims to understand the experiences of HIV-positive peer counsellors working in VCT centres in Grahamstown and Port Elizabeth; both in the Eastern Cape. The unique phenomenon of having an HIV-positive peer counsellor, who has lived with HIV/AIDS for several years providing valuable lived experiences of living with HIV/AIDS, will shed insight into the lived experiences of living with HIV/AIDS and working with people living with HIV/AIDS; particularly within the context of VCT.

3.1 Research questions

The primary focus of this research project is to provide an in-depth exploration of the experiences of HIV-positive peer counsellors counselling people with HIV. In addition, the utilization of personal experiences by the peer counsellor within the counselling process, as well as perceptions of credibility will be examined. Towards this end, the following questions were addressed:

- *What do the lived experiences of providing peer counselling mean in terms of the relationship between counsellor and client?*
- *How do an HIV-positive status and the use of personal experiences shape the counselling process?*
- *How do an HIV-positive status and the use of personal experiences shape mutual understandings of credibility in the counselling process?*

3.2 Research framework

This purpose of this research is twofold. Firstly, this research aims to understand the phenomenal impact of peer counselling within VCT settings, through an analysis of a small cohort of HIV-positive lay counsellors working within VCT. Secondly, this research aims to expand upon the need to provide additional methods of care and support to those who are HIV-infected in South Africa. The practice of peer counselling has received minimal research interest within the context of VCT, as far as the researcher is aware. There remains a need to

understanding the experiences of HIV-positive lay counsellors working within the domain of lay HIV-care and –counselling.

3.2.1 *Philosophical underpinnings: phenomenology*

Interpretative Phenomenological Analysis (IPA) is a qualitative method of enquiry dedicated to the detailed examination of human lived experiences (Smith et al., 2009). IPA is informed by three philosophical principles, phenomenology, hermeneutics and idiography. Phenomenology is the study of human experience influenced by the philosophical writings of Husserl, Heidegger, Merleau-Ponty, and Sartre (Smith et al., 2009). Husserl, widely considered the father of phenomenology, posited that examinations of everyday experiences required a move away from the „natural attitude“ towards a „phenomenological attitude“ characterised through the adoption of „phenomenological reduction“ (Shinebourne, 2011). The methodical process of „phenomenological reduction“ involves redirecting ones phenomenological vision away from the unreflective immersion in experiences of the world towards a focus on “how the object appears to consciousness” (Shinebourne, 2011, p. 17). This process necessitates the bracketing, or *epoche*, of elements not essential towards the examination of the experience. This allows the generation of new consciousness surrounding the phenomena, as opposed to consciousness influenced through the interference of prior knowledge and beliefs surrounding the phenomena (LeVasseur, 2003). The success of *epoche* allows the emergence of the „transcendental ego“, which is consciousness necessary to examine the pure phenomenal experience (LeVasseur, 2004). For Husserl, consciousness is always conscious of something, this something refers to the object of which we are conscious, thus there is an *intentional* relationship between an object and one’s awareness of it, whether this is made manifest through the perception of a „real“ object in the world or through an act of memory or imagination (Smith et al., 2009). Ultimately Husserl was concerned with establishing the „essence“ or „*eidōs*“ of experiences, determining the essential features of the experience beyond the particular circumstances of their appearance (Smith et al., 2009). Although Husserl was interested in discovering the „essence“ of experiences, IPA attempts to capture particular experiences as experienced for particular individuals.

Within IPA the adoption of Husserl’s „phenomenological attitude“ allows the systematic and attentive reflection of everyday lived experiences. However in contrast to Husserl’s method of *epoche*, IPA recognises the limited nature of knowing in advance the preconceptions which may affect the research process, and insists that the process of determining

preconceptions may only be possible within, during and/or after processes of interpretation (Smith et al., 2009). Heidegger rejected the possibility of pure reflection as posited within Husserl's prescriptive state of consciousness, „transcendental ego“, stating that all consciousness is an inextricable part of the external world that an individual inhabits, „being-in-the-world“ (Lopez & Willis, 2004). Therefore consciousness can never be uninvolved or separated from the world (LeVasseur, 2003). IPA recognises individuals as embodied and imbedded within a world of “objects and relationships, language and culture, projects and concerns” (Smith et al., 2009, p. 21), particularly within historical, social and cultural contexts (Shinebourne, 2011). Therefore for IPA the commitment is towards an interpretative position within the lived world focusing on understanding “the perspectival directedness of our involvement in the world” (Smith et al., 2009, p. 20)

3.2.2 Philosophical underpinnings: hermeneutics

Within IPA the endeavour is towards an interpretative commitment focusing on understanding the relationship between our involvement and position within the lived world (Smith et al., 2009). This interpretative process necessitates the practice of hermeneutics, where hermeneutics are a prerequisite to interpretative phenomenological enquiry (Smith et al., 2009). Hermeneutics is the theory of interpretation, originally designed to interpret religious texts (Shinebourne, 2011). Hermeneutics involves processes and methods which elucidate and make manifest the discourse of intersubjectivity, recognising that meaning is not made explicit but requires illumination (Lopez & Willis, 2004). Within IPA the process of interpretation recognises the intersubjective process of meaning making between the researcher and participants (Unger, 2005). Heidegger refers to the term „co-constitutionality“ which relates to all meanings derived through interpretation which are a mixture of meanings articulated by both researcher and participant (Lopez & Willis, 2004). IPA considers phenomenological investigations as an interpretative process, in contrast to the descriptive phenomenological endeavours advocated by Husserl and Giorgi (Pringle, Drummond, McLafferty, & Hendry, 2011). Thus rather than focusing on descriptive accounts of the real perceived world through participant narratives within descriptive phenomenology, interpretative phenomenology is focused on describing the meanings of the participant „being-in-the-world“ and how such meanings influence the social realities of the individual (Lopez & Willis, 2004).

3.2.3 Philosophical underpinnings: idiography

Idiographic approaches focus in-depth on the particular with a commitment towards detailed analyses of particular experiences, contrasted against nomothetic approaches which focus on the general (Smith et al., 2009). Within IPA there is an idiographic focus on the detailed examination of particular instances and the recognition that individuals can provide unique insight and perspectives on their involvement in a particular phenomenon (Shinebourne, 2011). Interpretative phenomenological methods of investigation place particular interest in the meanings that people ascribe towards their subjective experiences (Langdridge, 2007; Moustakas, 1994; Smith et al., 2009). In other words, experiences articulated in their own terms, as opposed to pre-existing conceptions of the experience. This is particularly useful when one aims to engage with the significance that people place upon their experiences. IPA is specifically interested in this significance, and individuals who place importance upon such experiences have invested extensive amounts of reflection, thought, and emotion into the meaning of the experience (Smith et al., 2009). It is the investment of reflection that IPA is focused upon, in other words attempting to make sense of the participants own reflection of a particular experience that had specific significance for the participant (Smith et al., 2009). The analytic process involves a detailed analysis of each transcription towards a careful examination of potential shared similarities and differences across cases to produce thorough accounts of patterns of meaning and reflections on shared experiences (Shinebourne, 2011; Smith et al., 2009).

3.3 Research design

The commitment towards an inductive approach within IPA expressly places the participant as the expert of the phenomenon under examination (Smith et al., 2009). An exploration of peer counsellors utilising their personal experiences in living with HIV/AIDS is consistent with the use of IPA. This is because peer counsellors would have the opportunity to reflect upon their lives regarding the lived experiences of living with HIV/AIDS. These experiences may include accepting a seropositive diagnosis, managing issues of disclosure, symptom alleviation, adhering to treatment, behavioural changes, accessing social grants, and stigma management or resistance. Within the context of VCT, the peer counsellor has an opportunity to transmit valuable lived experiences of living with HIV/AIDS to recently diagnosed individuals. It is therefore important to understand the circumstances in which a peer

counsellor decides to use their personal experiences within the counselling process. Therefore understanding the experiences of peer counsellors necessitates an understanding of their embodied position within the lived world. The use of a qualitative based methodology is particularly valuable in this setting because it allows an in-depth description of HIV-positive lay counsellors' experiences in living with HIV/AIDS both personally and in the workplace. The commitment to examining how the phenomenon appears, and the recognition that the analyst is connected to the interpretation and formation of the phenomenon, indicates the hermeneutic aspect of IPA. The double hermeneutic is an integral characteristic of phenomenological research, where the process of interpretation is central to IPA. It involves the researcher attempting to make sense of their participants making sense of their experiences (Smith et al., 2009).

3.3.1 Sampling

Sampling methods for IPA are influenced by idiographic principles that focus on the particular; contrasted against other psychological endeavours which are influenced by nomothetic approaches (Smith et al., 2009). IPA studies specifically offer in depth, nuanced analyses of particular cases of lived experiences (Smith et al., 2009). IPA specifically calls for small homogenous samples which are able to provide rich contextualised data about a particular shared experience (Smith et al., 2009). Four participants were purposively selected from the participating VCT centres. Two participants were located in Grahamstown, the other two participants were located in Port Elizabeth. In order to maintain confidentiality, pseudonyms will be utilised in place of the participants' names. The VCT centre in Grahamstown was used in the researcher's pilot study on the experiences of HIV-positive peer counsellors. The VCT centre in Port Elizabeth was located using *AIDSbuzz* (<http://www.AIDSbuzz.org>, 2011) an online directory of non-profit organisations offering care, support, and treatment for families and individuals affected by HIV/AIDS. Participants were located by assessing whether any lay counsellors had used direct self-disclosure with their client in the counselling process. If the counsellors had disclosed their seropositivity, they would therefore be more likely and willing to participate in a research project concerning their experiences of counselling people with HIV/AIDS and the use of personal experiences. Counsellors who were HIV-positive, but had never self-disclosed were unwilling to participate in the research project. Permission to conduct research was approved by a Rhodes University Ethics Committee, by the respective directors of the VCT centres, and later from the counsellors themselves (See Appendix 1). Inclusion criteria were HIV-

positive lay counsellors of any gender who have been working as HIV/AIDS lay counsellors for at least a year in a VCT centre. A minimum of one year of practice was deemed a necessary inclusion criterion, as inexperienced counsellors would not be able to elucidate the desired rich contextualised data that is required. Additionally, proficiency in English as well as being able to actively engage with the researcher about their experiences concerning HIV counselling and testing was required. HIV-negative lay counsellors were excluded from the study, as the focus is on the experiences of HIV-positive lay counsellors. Participants were informed of the procedures of their participation in the research project, and were informed that participation was voluntary, anonymous and confidential. All participants agreed to have their interviews recorded with a digital recording instrument (See Appendix 1).

The two participants, Zinhle (Z), Nora (N), from the Grahamstown VCT centre are both female and have been practicing lay counselling for more than five years, each. The organisation was founded in 1999 and is located in Grahamstown. It is credited with initiating the now routinely available VCT services within Grahamstown and the surrounding rural areas. Core activities include VCT, support groups for people infected and affected by HIV/AIDS, providing access to treatment, mother-to-child prevention programs, and disseminating HIV-educational material within their communities. The two counsellors have matriculated, all are utilising antiretroviral treatment, and only one counsellor has children. The two participants, Thandi (T) and Laura (L), from the Port Elizabeth VCT centre are both female and have been practising lay counselling for no less than five years, each. The organisation was founded in 1995 and is located in North End in Port Elizabeth. Core activities include VCT, HBC, support groups for people infected and affected by HIV/AIDS, identifying and supporting orphaned and vulnerable children (OVC), assistance in accessing social grants, and disseminating HIV-educational material within their communities. The two counsellors have matriculated, one counsellor is utilising antiretroviral treatment, and one counsellor has children.

3.3.2 Interview design

The interview schedule comprises of six core questions directed towards exploring the experiences of HIV-positive peer counsellors. Each question aims to elucidate experiences surrounding the counselling process (See Appendix 2). The design of an interview schedule requires the researcher to have thorough knowledge concerning the topic under investigation. Kvale (2007) states that an awareness of the topic allows the researcher to focus the study and

determine the aims of the research endeavour. This process allows the researcher to identify the themes within the topic, which are pertinent to the direction of the interview design, process, and implementation. The first step in this process is therefore an exploration of the literature concerning peer counselling, lay counselling practices within VCT settings in South Africa, and the experiences of living with HIV/AIDS in South Africa. The process of „thematizing“ within the literature (Kvale, 2007) is necessary to ground the researchers understanding of peer counselling. The aim of this research was to explore and understand the experiences of providing counselling services as an HIV-positive lay counsellor within VCT services. The research design is therefore exploratory in nature, which requires minimally structured methods of data collection, semi-structured interviews, focusing on allowing the participant to direct the flow of the interview process (Kvale, 2007).

3.3.3 Semi-structured interviews

Phenomenology posits that the experiences of an individual are a useful means for extracting knowledge about the meaning of a phenomenon in the world (Shinebourne, 2011). Recognising that individuals can only be examined within the context of their embodied and embedded position in the world, suggests a socially constructed and perceived reality (Smith et al., 2009). Therefore meaning is located within the private domain of the individual, and thus understanding the meaning ascribed by individuals necessitates the examination of personal narratives as a source of knowledge. IPA is interested in human experiences and maintains “a theoretical commitment to the person as a cognitive, linguistic, affective and physical being and assumes a chain of connection between people’s talk and their thinking and emotional state” (Smith & Osborne, 2003, p.52). Therefore the utilisation of semi-structured interviews is suited towards an exploration and understanding of the experiences of HIV-positive lay counsellors working within VCT settings. Allowing the participants the opportunity to present thorough first-person accounts of their experiences articulated through their own terms (Smith et al., 2009). It is important to recognise the hermeneutic aspect of data collection, as processes of „co-constitutionality“ between researcher and participants (Lopez & Willis, 2004). The semi-structured interview is a discursive style of interviewing, which does not follow a rigid schedule but recognises that the interview process is a communicative event where both researcher and participant co-construct the knowledge produced (Kvale, 2007).

3.4 Data analysis

All interviews were recorded with a digital audio recording device, and transcribed verbatim by the researcher. The process of analysis follows the recommendations outlined by Smith et al. (2009). The method followed is not a sole prescribed system of analysis, where flexibility and creativity is frequently encouraged during the analytic process. The iterative process of analysis involves flexible engagement with the data, utilising different modes of thinking as opposed to maintaining a rigid analytic system (Smith et al., 2009). Fundamentally the analytic focus is directed towards the participants' trying to make sense of their experiences. The first step involves reading and re-reading of the transcriptions, this process of repeated reading allows for a representation of the overall interview structure to develop. Appreciation of this superstructure allows the researcher to understand the connections between narratives within the interview; additionally the repeated reading ensures that the participant is the focus of analysis (Smith et al., 2009).

The second step involves noting anything of interest within the transcriptions, not only to develop familiarity with the text, but additionally to understand how the participant frames their experiences of living with HIV/AIDS. The use of exploratory comments was divided into three discrete methods, descriptive, conceptual, and linguistic commenting. Descriptive comments highlight the objects that represent the participant's experiences; these are the experiences that make up the lifeworld of the participant (Smith et al., 2009). For example, from an interview, the descriptive comment „HIV a terminal illness“ is generated from the sequence of text around „we just heard there was this HIV, and it is a killing disease“. Through further reading and noting, descriptive comments such as „HIV a terminal illness“ may be linked to other comments such as „bedridden“ and „seeking support“. These connections between descriptive commenting may be linked to conceptual ideas regarding the experiences of being HIV-positive, such as „diagnosis transforms the self“. Conceptual comments are focused on engaging with the text on an interrogative form (Smith et al., 2009). This involves moving away from directly describing the context of the participant's experiences towards focusing on the overarching understandings across and present in the narratives of the participant's experiences. Linguistic comments highlight the language used, and may include taking note of repetition, laughter, pauses, tone, and fluency. Metaphors are a particularly dominant component of linguistic commenting, as it is a linguistic device which links descriptive comments to conceptual notes (Smith et al., 2009). For example „you can take a cow to drink water, but you can't make it drink“ is a metaphor for describing how

providing care and support is routinely provided by peer counsellors, yet they can do little if their clients are unwilling to accept such supportive services. The right-hand margin of each hardcopy of the transcriptions was utilised for initial noting, a blue pen was used to indicate descriptive comments, a purple pen was used to indicate linguistic comments, and a green pen was used to indicate conceptual comments.

The third step is the development of emergent themes through analysing exploratory commenting (Smith et al., 2009). This process involves identifying the connections and interrelationships between exploratory notes (Smith et al., 2009). Fundamentally the themes should reflect the participant's own thoughts and words of the experience under examination, but additionally include the researcher's own interpretation of the participants' experiences. For example the emergent theme „diagnosis transforms the self“ is extrapolated from exploratory comments „discovering seropositivity“, „disbelief“, „uncertainty“, and „the lost self“. This theme indicates the difficulty the participant had in accepting her seropositivity, but additionally it is linked towards the content of the participant's experiences, which is the difficulty in understanding the changes in herself and her identity following an HIV-positive diagnosis. Although the participant is never explicit about the difficulties in accepting her new identity, it is nevertheless implicit in what the participant says about her experiences in discovering her seropositivity. Therefore the theme „diagnosis transforms the self“ encompasses a range of understandings related to both participant and researcher. For the participant it relates to the difficulty in accepting a seropositive status and the meanings that have formulated as a result of those experiences. For the researcher, the theme „diagnosis transforms the self“ relates to the initial experiences of discovering a seropositive status implicit in the participants' accounts, but also the overarching meanings ascribed to an HIV-positive status in South Africa.

The fourth step is identifying patterns between emergent themes to develop super-ordinate themes which encapsulate the participants' experiences (Smith et al., 2009). Abstraction and polarization were used as methods of identifying and linking patterns between emergent themes. Abstraction involves linking similar conceptual ideas across emergent themes (Smith et al., 2009). For example, an extract of the experiences of diagnosis for one participant produced emergent themes of „hopelessness“, „diagnosis transforms the self“, and „life-changing“. These emergent themes were clustered together to form the super-ordinate theme „HIV-positive diagnosis experiences“. Polarization involves examining the transcriptions for oppositional relationships across emergent themes, where the emphasis is

on noting differences as opposed to similarities (Smith et al., 2009). For example, in one participant's transcript the theme „diagnosis transforms the self“, the initial negative aspects of diagnosis underlie the theme. Yet included are a set of themes which relate to the positive aspects of diagnosis, these are evidenced in the themes „long-term goals“ and „positive thinking“. This set of themes would later be clustered together into the super-ordinate theme „peer counselling“.

The fifth step in IPA involves moving away from the first case, and repeating steps one to four for each subsequent transcribed interview (Smith et al., 2009). The difficulty in this process is removing the influence of analyse from the first and later cases in each interview. Smith et al. (2009) suggest systematically following the outlined steps to ensure that themes drawn from subsequent cases emerge from those cases, this ensures rigour and allows each case to speak on its own terms. After steps one to four are completed for each transcribed interview the final step can be undertaken.

The sixth step of IPA involves seeking connections across cases (Smith et al., 2009). Here super-ordinate themes are compared between cases, where themes directly related to a particular case may be shared as a higher order concept between cases. For example the super-ordinate theme „disclosure“ is shared between all the participants, yet for one participant their attitude surrounding disclosure differs to the beliefs that the other participants have about disclosure, yet the concept of disclosure is an important theme that permeates across all the interviews. This indicates the dual quality of IPA research, where there are specific idiosyncrasies of a particular case that share higher order concepts between cases (Smith et al., 2009). In this case the concept of disclosure in the context of living with HIV/AIDS has relevance for all participants, yet the meanings ascribed by participants provide different implications during counselling and for disclosure. A table of super-ordinate themes is presented in the results chapter.

3.5 Validity

Assessing the validity and quality of IPA research requires a move away from criterion that typically defines a valid and reliable quantitative research endeavour. Throughout the research process the guidelines outlined by Yardley (2000) have been utilised to ensure sensitivity and rigour. Yardley (2000) proposes four broad principles to assess the quality of

qualitative based enquiries; additionally Smith et al. (2009) have applied these principles to assess the quality of IPA research. The first principle is maintaining sensitivity to context throughout the research process (Smith et al., 2009); this includes an awareness of the socio-cultural context surrounding HIV/AIDS research in South Africa, providing relevant and substantive literature surrounding the experiences of living with HIV/AIDS in South Africa, and ensuring that analytic claims are substantiated through verbatim extracts of the participants' experiences. The second principle is commitment and rigour throughout data collection, analysis and the write-up process (Yardley, 2000). Within IPA, commitment refers to ensuring that the researcher is attentive to the participant during data collection, and thorough throughout the analysis of each case (Smith et al., 2009). The commitment to an idiographic approach places importance on individual experiences and the meanings ascribed to those experiences. Therefore commitment is demonstrated through the development of competence in utilising IPA, where engagement and empathic exploration with the topic moves beyond simple descriptive explanations towards interpretative meaning making (Smith et al., 2009). Rigour refers to thoroughness of the analytic process, where sample selection is meticulously selected for their ability to engage with the topic, and data collection and analysis follow a systematic process to ensure thoroughness. The third principle is transparency and coherence (Yardley, 2000). Transparency refers to the clearness in which the entire research process has been described (Smith et al., 2009). Towards this end a reflexive journal has been included to detail the rationale of the researcher, but additionally to indicate how the researcher's own assumptions, beliefs, intentions and actions have affected the results of the research (Yardley, 2000). Coherence refers to a fit between the research question and the methodology used to answer that question (Yardley, 2000). The focus of this research is an exploration of the experiences of HIV-positive lay counsellors, towards this end the use of IPA is appropriate and consistent to the subject matter. The final principle is impact and importance, which refers to the relative value of the research (Yardley, 2000).

3.6 Ethics

All psychological research endeavours are required to be guided by ethical principles. Additionally the American Psychological Association stipulates that examinations of the human condition should be utilised to promote human welfare (Kvale, 2007). Ethical considerations are paramount to qualitative enquiries as the process of in-depth interviewing

involves the explication of an individual's private life towards the public domain. Therefore the researcher is responsible for ensuring that the process is conducted with respect for the participants' well-being. The process of ensuring strict ethical practices began prior to data collection, throughout the data collection process and during data analysis. In accordance to Rhodes University ethical requirements and qualitative researchers (e.g. Kvale, 2007; Smith et al., 2009), the ethical protocol was constructed prior to data collection in anticipation of the ethical issues related to researching HIV-positive individuals. The researcher anticipated that questions regarding diagnosis and disclosure experiences would likely cause some level of distress, and therefore free debriefing sessions were provided to participants through the Rhodes University Psychology Clinic after the interview process. Prior to the interview process, participants were provided with information regarding the topic of the research project, the possible benefits and risks pertaining to participation, and their rights as research participants. These rights are articulated in the consent form (see Appendix 1), and include the voluntary nature of participation, the participant's right to decide what to disclose during the interview process, and the participant's right to withdraw from participation from the study. Participants were invited to raise concerns and / or questions before the interview process, subsequently written agreements were signed by both participants and researcher prior to each interview.

Chapter 4: Results

The use of personal experiences from HIV-positive peer counsellors working in VCT has not been examined within a South African context. Towards this end this project aims to understand: how the use of peer counselling shapes the relationship between counsellor and client, how a seropositive status and the use of personal experiences shape the counselling process, and how a seropositive status and the use of personal experiences shape mutual understandings of credibility in the counselling process. Thorough analysis of the participant's transcriptions has revealed several key themes in the use of peer counselling and personal experiences, as well as notions of credibility. Understanding how the use of peer counselling shapes the relationship between counsellor and client, it is first important to understand the boundaries in which personal experiences are used within the counselling process. The basis for the use of personal experiences within VCT appears to be dependent upon the counsellors' decision to disclose her serostatus. Throughout the transcriptions a recurring theme is the issue of disclosure, this is a major factor all individuals who live with HIV/AIDS must eventually contend with. This issue permeates throughout the transcriptions as a precursor towards the use of peer counselling, and furthermore the use of personal experiences. Therefore understanding the constraints and experiences surrounding disclosure of an HIV-positive status, will provide the explanation towards understanding how seropositivity and the use of personal experiences shape the relationship between HIV-positive peer counsellors and their clients. The super-ordinate themes are listed on the left side of the table below, the right side indicates the themes attached to each super-ordinate theme found throughout the transcriptions (Figure 1). The extracts utilised are firmly rooted in what the participants are actually saying, and therefore the use of lengthy verbatim quotations is necessary to substantiate the findings and implications of peer counsellor experiences (Pringle et al., 2011; Smith et al., 2009).

Diagnosis and Disclosure Experiences	<i>Counsellors' experiences of Diagnosis and Disclosure</i>
	<i>Diagnosis Transforms the Self</i>
	<i>Counselling experiences of Diagnosis and Disclosure</i>
	<i>Self-Disclosure as a prerequisite to Peer Counselling</i>

Peer Counselling	<i>Practice and Procedure</i>
	<i>Multiple Roles</i>
	<i>Interacting Partnership Managing Uncertainty</i>
Challenges	<i>Peer Counselling Challenges</i>
	<i>Confidentiality</i>
	<i>Youth Specific Challenges</i>

Figure 1: Super-ordinate Themes

4.1 Diagnosis and disclosure experiences

4.1.1 Counsellors' experiences of diagnosis and disclosure

Discovering one's serostatus was described by Laura as a "life-changing" event. The process is made more difficult when prejudice and stigma discourage individuals from disclosing their illness. HIV-positive individuals have a difficult task of deciding when and to whom they should disclose their seropositivity. Within the context of intimate partnering, women have further difficulty with disclosure owing to social and gender norms which restrict their behaviour. The experiences of diagnosis and disclosure for Thandi and Laura are framed from a sero-discordant standpoint. In both instances the difference in serostatus produced a volatile relationship, structured around mistrust and uncertainty. This is exemplified through the experiences of Thandi and Laura; Laura found the task of disclosure as daunting as accepting her new serostatus, while Thandi altered her decision of nondisclosure when her husband's previous romantic partner passed.

L: "Honestly speaking I didn't think that I was going to be or I can have HIV...I told my husband the very same day I was coming from the clinic that I am HIV-positive, and he was like where did you get it, and how did you get it? And I didn't have all those answers, because I didn't know really where I got it, because he was the man I slept with...I couldn't think of how, I couldn't answer that question, it totally changed my life, you understand. So when I told him that I am HIV-positive, it's where everything started you know unhappiness in the house. But I couldn't tell anybody outside like my mother or his family,

because it was like a taboo, if by then they were saying that this disease is for people that who is sleeping out, who is not faithful, so that shame inside me, how am I going to say that I am HIV-positive”

T: “I was talking with my husband, and we decided to go and test before we get married. Unfortunately I was coming positive...I didn’t open up with my family till we finally decided we can be open up with our status, but he doesn’t want me to be open, I decided to sit down with him and telling him the consequences of not disclosing on our families, because there was one thing that I was scared, and that was if they can known this without my acceptance, my knowledge, they will certainly be angry...as I was loving my husband I didn’t go to tell them till his late girlfriend passed away. Ever since then I decide to tell my parents, it was 2001...after I told them, he wasn’t honest for me, we started fighting and everything”

The emphasis on the negative aspects of diagnosis and disclosure are highlighted through the above excerpts. Sero-discordant couples not tested together cannot achieve the benefits of couples-based counselling approaches. The first excerpt highlights the difficulty in disclosure when couples are not concurrently tested. Here Laura struggled to comprehend the magnitude of her situation. Exacerbated by her husband’s questioning and positioning as a potential victim of her infection. The second excerpt highlights the fear of unintentional disclosure, where Thandi indicates her desire to personally disclose, contrasted against the perception that knowledge about her status without her consent could result in prejudice. Yet Thandi’s fear of unintentional disclosure appears to represent her husband’s fear of being identified as being involved with someone living with HIV/AIDS, as opposed to Thandi dreading identification as a PLHA. Thandi and Laura’s experiences of diagnosis are punctuated with difficulties of sero-discordance, mistrust and fear of being associated with an HIV-positive status. Increasingly there is a need to facilitate sero-discordant couples not concurrently testing for HIV, especially concerning issues of disclosure and ongoing preventative behaviours, such as safe sexual practices. The difficulty in disclosure is intensified when PLHA consider the implications their diagnosis could have on existing social relationships, as evidenced by Thandi and Laura’s experiences. Nora emphasises the difficulty in disclosure decisions, where women are frequently blamed for infecting their partners, emphasising the complexity of disclosure.

N: “...when you are diagnosed that you’re HIV positive there’s three things, they think about other people, what are other people gonna say about you, they gonna maybe they gonna say that you are sleeping around, that is why you having this virus. Secondly, they think maybe about the boyfriend, what is the boyfriend cause most of the time it’s us [women] who are firstly diagnosed that you are HIV positive, although our boyfriends are negative ne. So she think

that, how can she explain this to her boyfriend. Thirdly it's about the family you see"

The reality of seropositivity juxtaposed against the social construction of HIV transmission creates the impression of opportunities to vilify an HIV-positive individual as immoral. Thandi expressed great difficulty in managing the reality of her sero-discordance with her husband. Such situations create volatile circumstances when uninfected partners refuse to protect themselves. Additionally it places infected individuals in quandaries over safe sexual responsibility and the responsibility of providing within intimate relationships.

T: "...I told the doctor that I have got a problem, but my husband doesn't want to take this problem [HIV-infected], he [doctor] want to know what is happening. I said that I am HIV-positive, and ever since then if my husband want to be with me, he didn't even give the foreplay, nothing, he just do what he want to do, and after I finished to sleep with him, I don't feel comfortable, because the doctor said I am supposed to protect myself, but I don't want to lose my husband, I don't want to lose my marriage. So instead of running after my value, I running after his marriage...you must be careful, because these guys are not loving us, they are just playing us. It's worse if your partner knows you are HIV-positive, he took a lot of advantage"

The above excerpt emphasises the necessity of providing supportive services to assist sero-discordant couples. Additionally it draws attention to the need to provide skills and knowledge which empower women's reproductive rights within counselling and testing procedures. Uncertainty surrounding an HIV-positive diagnosis is a constricting experience, which must be assisted by empathic and respectful counselling. Assistance with disclosure as a standard principle of counselling and testing procedure is necessary, considering the great difficulty PLHA have in deciding to whom and when they disclose their status. Zinhle's experience of diagnosis and disclosure was not accompanied by post-counselling, ultimately resulting in a prolonged period of denial, secrecy, social isolation and struggle.

Z: "She ask me when did I diagnose, then I told them very soon, because I diagnose on the 12th of this month, and it was the 14th of February that time...I told her that I don't have the results, but the sister who was talking with me at the hospital is the one who told me that I'm HIV-positive...Then, they want me to stay here at the centre, but because I was very early for me to tell other people that I'm HIV positive, I told my mother and I told my mother because I trusted her and also she told other people because she want to help me. And then I regret to stay here at that day, because there were lots of people I think there were thirty people at that time here and in this corner someone talking about AIDS, in that corner someone talking about AIDS, in that corner someone talking about AIDS. Which is I don't, I still in denial in that word AIDS"

Zinhle's experiences indicate how her initial exposure to supportive services enhanced rather than reduced feelings of isolation. Consistent reminders concerning one's seropositivity may aggravate experiences of uncertainty. However, all counsellors indicated that participation in support groups dedicated towards providing support and care to individuals living with HIV/AIDS, vastly improved the process of accepting their seropositivity. The provision of educational, emotional, and instrumental support facilitates the process of disclosure, treatment, and acceptance. Membership and involvement in social support reduced many of the initial uncertainties that were experienced upon diagnosis.

L: "...The sister [nurse] advise me that I must go to the support group...so I started to mix with this support group in 2002, it's whereby I could get all the information...I was curious, I wanted to know more about this HIV, because I didn't really know anything"

N: "I was much interested to listen more to HIV, because I didn't know everything about HIV, I was interested in information because I was HIV-positive. I wanted to know the truth about HIV/AIDS, so I was gaining more information every time. I was starting to get relieved that I know that I am not going to die if I treat myself the way they taught me"

T: "...I met the support group of Hope World Wide by 2001, ever since then I feel comfortable about my status, because as soon as I started to attend the support group there were people living with this stuff (HIV/AIDS) since 1994, late late, earlier than me, so ever since then I feel comfortable"

There is unanimous consensus that participation in social support played a pivotal aspect in relieving many of the uncertainties in discovering and living with a seropositive status. The opportunity to exchange valuable life experiences of living with HIV/AIDS in an empathic and respectful environment substantially improves the rate of healing and acceptance. The provision of social support through informational, emotional, and instrumental processes provided the counsellors an opportunity to reconstruct their lives through discourses which empower and offset societal prejudices regarding seropositivity, and assists the transition towards acceptance. However, participation in social support is accompanied by public self-disclosure, which can inhibit rather than assist the process of acceptance. This is particularly salient where PLHA refuse to accept their diagnosis because of socially constructed associations connected to being seropositive. The extract below indicates Zinhle's experiences of social withdrawal for fear of being identified as someone with HIV/AIDS.

Z: "But because I was still in denial we are come here half past eight until four o'clock, we are going all of us we are going out, but I refuse to go with other people because in my mind I knew that other people outside in the street or in

town they know that these people are the people who are having AIDS, so I didn't want other people to see me walking with them"

The participants noted that their experiences of receiving a seropositive diagnosis and the process of post counselling lacked experiential weight. In the context of HIV counselling and testing, the desire to communicate with an HIV-positive individual stems from the counsellors own experiences in discovering their seropositivity. Although many of these experiences occurred over a decade ago, they still have relevance in highlighting the need of such services for recently diagnosed individuals. Zinhle, Laura, and Nora are hopeful that their experiences of diagnosis and their position as counsellors will reduce the occurrence of powerlessness and hopelessness experienced in counselling and testing services.

L: "...each and every time when I'm thinking about what happened, I wish I could by then do something, and things were not like now, because right now things are much better, there are counsellors, there are people who available themselves, there are NGOs ...if you need something they can help you out with groceries and all that"

Z: "...especially for us on those days, because there were no people who were HIV-positive standing in front of us in those days. I can say they are better them, because they have people like me, who can say I am HIV-positive, just look at me"

N: "... it was so difficult for me to cope with the status because in those days there was a stigma attached... at the Centre we get the results right now... there you get the results after three weeks... the caregivers are gonna tell you that you are HIV-positive just go to the support group... I didn't get proper counselling... I didn't know that the shingles you can get it from the first stage, I thought that the shingles is for the last stage. So I was stressed thinking that I'm gonna die"

The experiences of these peer counsellors indicate the lack of experiential knowledge within their post counselling experiences. Although their experiences of receiving a seropositive diagnosis occurred during a tumultuous period within South African history, the necessity of providing relevant, sensitive, and insightful counselling is still an important aspect of VCT. The lack of insight into the lived experiences of HIV progression, stigma attached to a seropositive status, and minimal institutional supportive assistance are indicative of the period in which the counsellors received their diagnosis. The current standard procedure of determining CD4 cell count and referral to support groups is necessary, but increasingly there is a need to provide experiential knowledge within the post counselling process; especially for those receiving a HIV-positive diagnosis.

4.1.2 Diagnosis transforms the self

Receiving an HIV-positive diagnosis inescapably alters one's life, future aspirations disappear, while past mistakes are over evaluated and amplified. The participants expressed immense anxiety and uncertainty about their diagnosis experiences. Before antiretroviral treatment became readily available to PLHA, an HIV-positive diagnosis was inextricably associated with death, dying and an immoral character tarnished by socially deviant behaviour. Zinhle and Laura's experiences signify the difficulty of receiving a seropositive diagnosis within South Africa's period of HIV dissonance.

Z: "Those times, 1999 when I was diagnosed there was nothing, even at hospitals, they said they don't know what you can do. If you are sick you know they don't have cure for yourself, we don't have treatment for you, we don't know what we can do"

L: "...what happened is that I started to get sick, I had a nervous breakdown, and they admit me at provincial, they said that I have depression, so I started the depression tablets. But because of that I couldn't cope at work, because I was working at the old age home, I have to bath the old people, I had to take care of them, whereas I couldn't because I've got this thing inside me, its haunting me and I've got nobody to talk to about this...believe me, things were hectic by then, because with my new status, I'm sick, my husband also died, and I've got this child of mine...So, it was really, it was a big change in my life...I had a stroke, I had meningitis, [and] my family couldn't understand what was going on, they were thinking that maybe I was witched, whereas I knew what was happening with me, you understand, but I can't talk out"

Receiving a seropositive diagnosis is inseparably linked towards uncertainty, Zinhle's experiences focus on the inability of healthcare personnel to alleviate and assist recently diagnosed individuals. Laura's excerpt centres on the severity and restrictive experience of uncertainty, emphasising the depressive, hopeless and limiting experience of attempting to accept a seropositive diagnosis. The transition from hopelessness towards a construction of a positive self identity in living with HIV/AIDS requires ongoing psychosocial support. Zinhle's experience of acceptance exemplifies the necessity of providing ongoing supportive services to recently diagnosed individuals. The compassion and concern Zinhle received, allowed her to move beyond the process of denial.

Z: "I already told you that I was in denial ne? I came in here in the morning and have my breakfast and go to sleep. Then they woke up me for lunch and go to sleep and then they woke up me at four o'clock so that I can go home, every day I was doing that thing. And then because there is staff here, there's other staff here at that time and they nominating me to answer the phones. So that I forgot about sleeping, so it was only this phone, this phone at that time so I

must run from that side to this side to answer the phone, while they are in the meeting on upstairs. So that thing, it makes me to wake up at least every now and again”

Zinhle’s experience indicates how the transition from hopelessness towards acceptance can manifest as a process of personal transformation. The simple act of focusing Zinhle’s energy beyond her self-imposed isolation provides refuge and a sense of responsibility. Removed from the processes which sustained her denial, Zinhle is given an opportunity to regain control of her life. The commitment towards constructive positive action to manage the experiences of uncertainty following a seropositive diagnosis can manifest in a variety of approaches. Nora projected a long-term approach to dealing with her new serostatus. This approach transformed her belief of imminent death in living with HIV/AIDS, towards a future of possibilities, structured around the belief that HIV would not result in impending death. However upon the availability of treatment opportunities Nora empowers her rejection of the lethality of the virus towards an opportunity to create a life and future for her children,

N: “I told myself I will wait until cure, I never said treatment, I said I will wait until cure comes, I won’t die until that...I never thought that I am going to die, I am going to die. That time I didn’t even have job when I was diagnosed, I didn’t have a job. Even my parents were not working, my mother was not working, we only depend on the grant...If I say I want to raise my kids, because I didn’t think anything about furthering my education, because I know that for now I don’t have money, it will be stressing me to think about education, because it is something that I can’t do. Thinking about possible things that you can do, like raising my kids, I can stay, I can live for my kids, I can raise my kids, until I see that they are educated...So that is positive thinking, not to say yoh I am HIV-positive I am dying, there is nothing I can do, I can’t work, I can’t do anything”

The motivation towards restructuring one’s life post diagnosis is the desire to regain control, to re-establish an identity beyond their seropositive status. The above excerpts highlight personal transformation and the struggle to regain normality as mechanisms towards achieving control over one’s life following an HIV-positive diagnosis. The perception of a reduced life and limited opportunities are rectified when there is a conscious drive towards producing a life structured around hope. Yet Nora’s decision to deny the lethality of HIV is a daily reinforcement of her beliefs, treatment merely expands and assists her conviction. Laura shared in this vision of creating a future for her son, her determination empowered through participation in social support.

L: “...I wanted to take care of myself, because I wanted to live, my son was only six years old by then, so I had to live for him now...But, honestly

speaking, if you have kids you have to live for them, it is the only thing that helps, you understand”

Zinhle’s experiences of diagnosis and internalised stigma provided the impetus towards her desire to assist and campaign for the rights of PLHA, but fundamentally as a method to normalise and rectify assumptions relating to living with HIV/AIDS within her community. The transformation from hopelessness towards activism can be seen as a progressive process reinforced by continuous practice, which over time creates an empowered HIV-positive identity.

Z: “I think for me because my own opinion, before I was a counsellor I wanted to help people, because in our days people they do not know what is HIV, they do not know what is AIDS. They take that if someone is having this virus, they thought that it’s AIDS. Secondly I wanted to help community, because other people they point fingers to other people that one is having AIDS, that one is having AIDS. I wanted to show the community that even if you have the AIDS you can live the long long [life], you are like other people, you have a right to say what is right or what is wrong, especially for you who are living with the virus”

The desire to facilitate the process of acceptance stems from Zinhle’s diagnosis experience. She felt isolated and alienated and feared identification as someone living with HIV/AIDS. The mobilisation of social support, and activism allowed Zinhle the opportunity to reframe her experiences of diagnosis. Her identification as someone who is HIV-positive legitimizes her desire to reconstruct notions of seropositivity within her community, but additionally it provides other PLHA within her community, the opportunity to live beyond constrained societal notions of what it means to live with a seropositive status. Participation in counselling and testing programmes and community activism empowers Zinhle as she is able to restructure the realities and discourses surrounding the lived experiences of PLHA. Thandi’s process of acceptance occurred during participation in social support, empowered to lead a constructive and positive lifestyle she began work as a lay counsellor.

T: “...ever since then I feel comfortable [since] 2005 when I started my job here at [VCT centre]...The people that took me to that place, there were people that were open up for me and give me the right choice. Ever since then I take myself as someone who know how to living healthy life, and I decided to be open about my status and help other people, this is when I am starting to be a lay counsellor”

4.1.3 Counselling experiences of diagnosis and disclosure

Counselling recently diagnosed individuals is challenging for both counsellor and client. The counselling process follows a set of standard procedures that directs recently diagnosed individuals towards avenues of care and support. The desire for emotional support and the ability to provide such supportive services is a critical feature within the counselling process. The use of „positive thinking“ and „positive counselling“ is utilised as a mechanism towards accepting a seropositive status. Nora emphasises the importance of fostering hope through positive thinking processes “positive thinking is thinking that I will focus on my dreams”.

Z: “Positive counselling for them, I just tell them that as you are HIV-positive, it doesn’t mean it is the end of the road for you. I can say it means you are in a new life, you must change your lifestyle...I ask them to do is the CD4 count...the CD4 count is going to tell that particular person that you need to take the ARVs...also asking them to eat the proper food, proper food it doesn’t mean you must have the huge money in your pocket, just have a small garden in your home...So I ask them to do those things, mostly to think positive things because they are positive, not negative things.”

T: “Firstly what I used to say to them, he mustn’t take this as a death sentence, he must take it as a turning point on their lives, because some of them discover this when they are sick, but it is not nice to discover this when you are sick, because firstly it takes all your strength, but if you are not sick, just take this and try to gauge a way forward. This is where I am supposed to pull up my socks, because certainly it is not easy to tell someone to pull up their socks when you discover that you are positive...you have discovered that you are positive, don’t kill yourself, think about your future, and don’t feel down and give up for your plan, because everybody has a plan, and everything is happening on purpose”

N: “Positive thinking...that you were HIV-positive since that time when there was nothing, there was no hope, there was nothing, but I survive from that time”

L: “...if you have dreams maybe you want to be a teacher or want to work somewhere one day, you can continue with your dreams, not to say I’m HIV-positive I can stop going to school, I can continue with my life... I have the experience of what I am saying”

Negative thoughts and emotions directed towards discovering seropositivity are perceived as a common response, but overall unhelpful in acceptance. The peer counsellors advocate for a positive outlook in living with HIV/AIDS, firstly through acceptance of the virus, and then by applying thought and energy into living positively with HIV/AIDS. Positive living is emphasised as opportunities to re-engage with life through particular positive approaches, the

counsellors“ stress the benefit of treatment and social support, but also promote dietary and behavioural practices which empower PLHA.

Z: “...sometimes they can think that why am I stupid, why am I sleeping with that guy or that lady, why this virus come to me. They can think those questions, they can ask them those questions, but I ask them to be coming on end for those questions, because they won’t help them, because the virus is there and there is no cure for the virus, it can’t go away by thinking and asking themselves those questions”

N: “The way you think, it will lead you to where you want to go. If you want to die, the way you think negative, that is you are going to die. If you think positive you will survive”

4.1.4 Self-Disclosure as a prerequisite to peer counselling

The anxiety and uncertainty of discovering a seropositive status can be reduced through the provision of experiential knowledge in living with HIV/AIDS. Experiential knowledge is the ability to communicate the lived experiences of living with HIV/AIDS in a constructive and helpful manner that can assist recently diagnosed individuals. The use of peer counselling not only follows the procedures of post counselling, but in addition the experiential knowledge of living with HIV/AIDS has legitimate experiential authority when utilised by an HIV-positive peer counsellor. Peer counsellors are able to provide personal accounts of their experiences with diagnosis and living with HIV/AIDS to recently diagnosed individuals.

L: “There are those who get too much emotional when they hear about their status, so when the situation is like that, it’s whereby you advise, I’ve been through this you know, what helped me was ABC, you understand, so some of the counselling sessions of mine I do use my experiences of that, how did I feel, and what helped me to be standing on my feet up till now”

N: “So if the person knows that you also HIV-positive, so that person is starting to ask you questions, he is free to talk to you. So when did you know your status, how did you do so that you are still alive, and then you start talking you start talking, then the person will start listening to you. Because saying that you can do this you can do this, you don’t know he can do that, how do you know that will help her? But if you say that help me also, so you can try it, it is helping”

T: “I wanted to show you that you are not alone there were lots of people who are living with this virus [HIV/AIDS] so I don’t want you to take this as a sentence as a death sentence. You can live even more life”

Z: “...when they are coming to from sister (nurse) ne, you see that the client is crying or you see that the eyes of the client are red in colour. Which is she or he is not accepting this thing, but after I told that person that I’m also HIV positive, I’m maybe eight years or six years at that time, like this year I’m eight

years with this virus. Then that person try to smile and continue asking me questions that when do you diagnose? What things are you doing now? Why are you like this? So I told them about the support group I told them about myself, I told them maybe about other [HIV-positive] people”

The standard procedures of HIV counselling are still adhered within peer counselling, yet clients who respond poorly to their diagnosis often evoke the counsellor’s diagnosis experience. This anxiety they experienced is part of the process of coming to terms with ones seropositivity. For these counsellors it reflects a personal experience in which they themselves had to overcome. The participants stated that they maintained calm and collected attitudes during the counselling processes, but underlying this demeanour was a definitive concern they felt for their clients, frequently compelling the counsellors towards assisting their cliental.

T: “Yes it such a stressful career... the only thing you have to do is just do your work properly, and after four o’clock just leave each and every problem in the office and then just come again in the morning, facing that problem, because it’s gonna stress you if you gonna think of the problems that you are dealing with in the office... as I mentioned previously that at night it’s whereby the thing, everything come in your mind. So I can act as if I don’t care about that thing [client’s seropositivity], okay I leave it at this desk and go back home, but at night I’m going to be thinking about that thing [client’s seropositivity]”

Z: “...you can feel especially when that person is very worried, you see moos, you see the face is not the face I just see before he or she went there [nurse], you can see. And you feel, you have the heart, the pain heart for that person, sometimes it can lead you to think back on your own, when you were diagnosed...especially when my first saw positive [HIV-positive], I was crying because I take that, that the results that lady [results] remind me my results”

N: ”I think as a counsellor, if somebody came with the positive results, you are doing [what] is called the referral to the evidence of the past... because you know what was happening to you, so right now what is really happening. So I think of that person and having worried that oh my God, you know. I know my first day when I having the results [I] couldn’t sleep. So what about this person, how is she gonna do, so [I] try by all means to convince that person... explain further to that person... that she or he is clear about what is the illness about”

L: “I think for us to explain further to that person...is she or he clear about what is the illness about. Trying to show that person all the stages that she or he might not stress herself about. Think of the dead. It’s difficult, it’s difficult because sometimes the tears could fall, sometimes we don’t know where to start. But we make sure that, I make sure that when other people are staying there at the waiting area are not going to see that person crying, I’m gonna make sure that I’m going to convince her up until we came out from the door laughing. Ya not think about that thing and we did what is called having the

contact with that person. I'm gonna give her my cell number and she is going to give me hers, so that I can call her at night or sending an SMS. Trying to take that thing away because I know that the bad times whereby everything came in your head, so yes I know that that is going to be happening, so I use to SMS anything that is going to make her laugh so that she can't think about that because I know so painful"

Frequently these countertransference reactions provide the impetus towards the use of personal experiences and self-disclosure. The counsellors react towards the emotional consequences of delivering a seropositive diagnosis, and these reactions typically reflect the counsellors own experiences with their diagnosis experience. Intense identification with their clients' experiences compels Zinhle, Nora and Laura to utilise their personal experiences as a means of facilitating acceptance, empathy and understanding. Yet it appears that the use of personal experiences is dependent upon the counsellor's observation of the counselling process. If the counsellor feels that the use of personal experiences will help reduce the experienced uncertainty and anxiety in post counselling, then the counsellor may disclose their serostatus as a means of indicating solidarity and support. Additionally there are situations in which clients are only seeking confirmation of their serostatus.

Z: "...it's not easy to disclose their status in their clients. It depends to that person if they want. Even me, sometimes I disclose, sometimes I am not. It depend on the situation of this person, because sometimes you disclose because you see that this person is very worried, it's crying, and she don't know what she is going to do after here [counselling] end. You just don't want that particular person to maybe do suicide when it's outside there, so this is the reason I am disclosing for them. Sometimes I'm not disclosing because other people they are HIV-positive, they don't even want you to do post counselling. It depends on them, their feelings, and whether or not they want to hear. Sometimes what we are having at this office, maybe they come here and they know they are HIV-positive, but they just want to confirm...after they come from sister [nurse] to do the post counselling, they just tell you that I know I am HIV-positive, I just want to confirm"

L: "...so it's not each and every session, or each and every someone who enters the room you conduct the counselling that you just disclose, no it's not like that at all. You see the situation, and when you see this person is thinking that it is the end of the life, or you will die tomorrow if you hear your status now. So you have to be like, at least creative, motivating the way and just advice you know"

The use of personal experiences appears to be dependent upon the counsellor disclosing his/her serostatus to the client, and whether or not the client is inclined to listen to the counsellors' personal accounts. Affirming if necessary that surviving and living with HIV/AIDS is possible in virtue of their lived experiences and personal accounts. Counselling

procedures are strictly maintained, but not all counselling sessions warrant the use of personal experiences. Thandi however was adamant that the use of personal experiences contravened against the training they had received. In this case personal experiences were not used because Thandi believed that publically disclosing her serostatus would somehow negatively affect the VCT centre she worked for. This may stem from the perception that Thandi did not want to be identified as living with HIV/AIDS, fearing the possibility of bringing her organisation into disrepute. Therefore the decision to not utilise personal experiences, may express deeper issues relating to Thandi's stigmatised perception regarding PLHA. Although Thandi acknowledges the benefit of support group participation, she actively disassociates her identity as someone with HIV within counselling protocols. Her professional identity as a lay counsellor conflicted with her identity as an individual living with HIV/AIDS. Thandi states "If a client is telling you their story, then you also tell the story, it's not proper, it's not professional".

T: "I am not using to see I am also positive, what I am saying to her if you can become positive, there is a programme of people who are living with the virus, because what is happening on our company you mustn't disclose for the clients...I have to be professional for my work"

Thandi's refusal to utilise her personal experiences allies with client-initiated counselling and testing protocols of counsellors not disclosing. However, Laura who has received identical training and is employed by the same organisation frequently utilises her personal experiences within counselling and testing processes. The role of peer counsellor is not recognized within the primary healthcare system, thereby adding confusion to the role of peer counselling within healthcare services. This indicates the disparity between training scenarios and daily counselling sessions held on a business-as-usual setting. During training, lay counsellors are discouraged from utilising personal experiences, but frequently counselling sessions actively call for the use of personal experiences. Yet withholding personal experiences and providing minimal rationale for such procedures results in conflicts between the need to remain professional, and the need to support a recently diagnosed individual. This is particularly salient where individuals are struggling to comprehend their seropositivity, and where countertransference emotions steer the counsellor towards disclosure and the use of their personal experiences. Yet it is within such scenarios that the desire to provide emotional support opposes the professional practice of non-disclosure and the self-imposed withholding of experiential knowledge. Despite this, Zinhle, Nora, and Laura advocate for the use of personal experiences within post-counselling procedures. Their rationale for using personal

experiences appears to be a desire to facilitate recently diagnosed individuals with their difficulties of acceptance.

N: “They told us that personal experiences, you can’t tell someone. All the workshops tell that you can’t share your problem. If someone came here and tell you the problem, you can’t say if you James saying I have this and this and this, and yoh you know I also had this and this...if you try their opinions, how they taught you to talk to the client, and if you see that is not working you can share your experiences, so that the person see that he or she is not alone at that time, because she is with you”

L: “...they did say that don’t, you must not use your personal experiences. With that, you know we had a huge discussion, because as a person who knows what happens, I just told them how it goes, you understand, it s better for us people who are HIV-positive...it is better to open up to someone who knows that I have been through here, you understand...and I said to them I won’t promise anything, but when I see that the client is thinking that they are going to die tomorrow or today, I have to do something to help the client, to draw him back from the grave, you understand. So, they did tell us that, but it is not working, because honestly speaking, when you do that, and you see now there is the client, and the client is now busy trying to kill himself or herself, for a thing that I know I could do something more”

The procedures of VCT strictly maintain the adverse consequences of utilising personal experiences; such insight informed through processes of professional therapeutic practice forfeits the potential benefit of self-disclosure practice. The assumption that a counsellor would abuse processes of post-counselling to indulge in narcissistic tendencies disregards the lived realities of counsellors who have undergone similar experiences of receiving a seropositive diagnosis. Laura and Nora state that the procedural practice of VCT is often inadequate at assisting clients accept a seropositive status. Both counsellors advocate for the use of personal experiences as a means of assisting the process of acceptance. Laura’s experiences indicate that she has attempted to bridge the divide between counselling procedures and the utilisation of personal experiences. It is evident that the use of personal experiences is dependent on the counsellor disclosing his/her seropositive status. However not all counselling sessions with recently diagnosed individuals begin with disclosure. The decision to disclose is based on the counsellors’ sensitivity and observation towards their clients’ diagnosis experience. In other words only in certain situations are personal experiences utilised within the counselling process, yet the factors that determine such uses are dependent upon identification with their client’s diagnosis experiences and observation of their client’s reaction to discovering their serostatus. Therefore the practice of peer counselling as a basis for transferring lived experiences of living with HIV/AIDS can only

occur in situations where the counsellor has disclosed their serostatus to their client. This is exemplified through Laura's experiences of utilising her personal experiences, yet she stressed the importance of maintaining a professional identity within counselling and testing practices. The implication is not to undermine the utilisation of personal experiences, but rather the use of personal experiences, from Laura's perspective, should be a component and standard practice of counselling and testing procedures. The objective is the facilitation of acceptance through identifying lived experiences applicable to the client, rather than placing additional burdens generated through the counsellors' experiences.

L: "...but when you are out there, you put yourself aside that is my personal stuff, what is bothering me at home. Now I need to be in the same level"

Laura's position on maintaining her professional identity remains fixed within a counselling and testing encounter. The gravity of delivering a seropositive status must be accompanied with respectful and insightful counselling. Laura maintains the use of personal experiences, despite the insistence on remaining professional and ergo not self-disclosing. Thandi's reluctance at utilising personal experiences reflects her desire to remain professional within counselling processes, ergo not self-disclosing. Refraining from self-disclosure supports Thandi's belief regarding the benefits of utilising institutional and informal support structures.

T: "The person is confused, and then you just trying to calm the person, it is better to know your status, because at least you will sleep. Even if you know that you are HIV-positive, that will pass, even if you are HIV-negative you will be relieved, than thinking I wonder if I do have it, I don't have it. You don't relax, you don't know what is going to happen. But, even if you don't test, if it [HIV] is there it won't go away, you will just get sick, and then maybe it will be impossible for you to get help. But, if you come now and get tested that will help you, so that you can get help earlier."

Thandi's stance on not utilising personal experiences and self-disclosure practices in VCT are within counselling and testing protocols. Her decision of nondisclosure extends beyond explanations of HIV-related stigma, and relates to issues concerning the maintenance of her professional identity as a lay counsellor. Thandi is reluctant at comprising her professional role as a lay counsellor, asserting that practices of self-disclosure and the sharing of personal experiences extends beyond the provision of VCT.

4.2 Peer counselling

4.2.1 Practice and procedure

All peer counsellors were professionally trained in various educational institutions across South Africa. Training typically focuses on the core skills required in providing basic counselling and testing services, additionally counsellors are required to develop basic counselling skills such as confidentiality, empathy, and respect directed towards providing a comprehensive and sensitive counselling experience.

Z: “Yes, firstly I was having here at Rhodes for five days, secondly at Livingstone for ten days, thirdly at East London for five days, twice at East London. At Rhodes it was VCT, at Port Elizabeth it was VCT and at East London also it was VCT and again at East London it was data forms”

L: “...I went to ATTIC, training in Port Elizabeth, it was basic counselling, and then they sent us also in Port Elizabeth, University of Port Elizabeth for VCT counselling”

T: “Lots of training, firstly it was the psycho-stress support, we call it SPSS, from then it was HIV and AIDS basic counselling, from then it was structured group therapy”

In addition all counsellors practice a set protocol which they utilise with their clients. The standard two-session model of client-initiated counselling and testing is employed, and these protocols are standard within VCT, yet differ in practice depending on the clients’ serostatus. Thandi’s professional standpoint is reflected in her practice of lay counselling, where she emphasises the provision and utilisation of available resources for PLHA, as opposed to employing her personal experiences. Zinhle discusses her role within counselling and testing procedures as a platform to disclose her serostatus, to indicate solidarity and support.

T: “We are doing a VCT, which means its voluntary counselling and testing. We are starting with the pre-test counselling... we are telling the people what is HIV... it’s up to the client if she or he want to continue this... So we are explaining to the client everything about HIV... after pre-test counselling... we take that client to sister [nurse], then from sister to you again for post counselling. Even if the results are negative [HIV-negative], we suppose to do a post counselling. You do a post counselling under the conditions of telling the client that take care of yourself, use a condom... come after three months, for a window period. Maybe the virus is in your blood but because is not appearing now, so you must come after three months... the positive one [HIV-positive] is the one you’re supposed to tell everything, because he or she done the first step to come to do a VCT. The second step we gave them a referral to their nearest clinics to do a CD4 count, to do TB screening and also support for treatment”

N: “My role now here I am a VCT counsellor, which means voluntary counselling and testing...So I am waiting for the people who are coming from outside, Rhodes students, all the areas in town, in my community, the rural areas, they are coming here. So I am waiting for them to come, and then doing pre-counselling with them, explaining what is all about HIV/AIDS, because some of them they don’t the difference between HIV and AIDS, so we just explain, starting from the start. After that I send them to sister [nurse] and then after that come to me again for post-counselling”

Z: “Maybe I am counselling someone, if the person is HIV-negative there is no stress on that...I told them, if you are HIV-negative you could be HIV-positive the next time if you don’t protect yourself. So, it is important, if you are HIV-negative now, protect yourself until you come back, and then you continue using condom...But, with people who are HIV-positive, it is difficult sometimes to talk and saying, because they think you don’t know what you are talking about, you don’t feel what they feel, you never felt, you never be in that position...Those times, 1999 when I was diagnosed there was nothing...So now they are shocked that I am survive since that time until now. Then they ask some questions, how did you do [that], and I told them that I follow instructions...I told them that is why I am still alive”

The procedure of counselling enables a client the opportunity to understand what a seropositive or seronegative status entails, and the necessary actions which should be taken pending the client’s serostatus. The counsellors’ accentuate the difficulty people experience in accepting their reality of testing seropositive, expressing unease and the difficulty in communicating empathic understanding. According to Zinhle, clients receiving a seropositive diagnosis are concerned that their counsellors have no experience in the daily challenges of living with HIV/AIDS, and therefore are unable to empathically connect to the lived reality of testing seropositive. It is within these circumstances where the counsellors may disclose their seropositivity to indicate solidarity, support and empathy. The sharing of preventative methods is intended to protect the client, but in addition reduce the possibility of further transmission through behavioural intervention.

N: “We promote to not forget about the disease [HIV/AIDS], but to change their lifestyle, especially sexual lifestyle. Also the way of eating and thinking”

Z: “You can continue with your life, but you have [to] change some stuff, if let’s say change your behaviour, if maybe you had five boyfriends or girlfriends, at least come down to one, because it will also help the person who is HIV-positive”

Nora and Zinhle attempt to reduce risk behaviours their client’s may practice, yet the training they received for VCT is not focused on risk-reduction protocols. Ill equipped to manage issues of risky behaviour, advocating for a reduction of such behaviours is simply the only

means the counsellors have of attempting to affect behavioural change. The counsellors“ advocate for active participation in support groups, as noted, Thandi advocates for participation in social support. Zinhle confirms her belief in the benefit of support group participation, noting how her participation assisted in her progression towards acceptance, and how such facilitation allowed her to move beyond her harsh diagnostic experience.

T: “So to me it’s very nice, we advise them, especially the HIV [positive] ones, advise them to come to meet other people who are also HIV positive”

Z: “...as a new person who diagnosed today ne, it’s nice to have other people, experiences of other people. I told them about the support group that we are having here because I found the strength in this support group myself”

Disclosing a seropositive status in an environment where people are experiencing similar difficulty with their diagnosis can alleviate feelings of restriction and burden. Yet Nora noted how her initial experiences of support group participation created a stressful environment. The transition from denial towards acceptance in support group membership is poorly understood. Nora’s experiences indicate that PLHA who are recommended to attend support groups to aid in acceptance are frequently placed in situations in which the discourses utilised are not theirs, but reflect a biomedical understanding of disclosure and support group experiences.

N: “When I was diagnosed...other people of the support group were stressing me, because they had families that were providing for them at home. With my grant I can buy a box of bananas, and I said hey I can’t do that, how can I survive if I can’t use fruit, I only eat starchy food at home... the main things is how you think...Because I thought that I must eat what I have, and I had a little garden of spinach...So I thought from my side, you can eat whatever you have, if you have samp you can eat samp, if you have samp and beans you can eat samp and beans. As long as you are eating, as long as you have energy to do your work, exercise, doing all that stuff... sometimes people will stress you, telling you this, telling you this, but if you focus to what you want, you know what you want, that will help”

Nora noted her initial difficulty in support group participation, citing that her economic situation exacerbated the experience of uncertainty. She emphasises that conviction and the development of self-esteem, knowing what she wanted in relation to what she had, improved the process of accepting her seropositivity. Upon reflection Nora notes how participation in social support resulted in the development of confidence and knowledge, which are powerful mechanisms for reducing stress. Fundamentally Nora believes that individuals must extract for themselves the relevance of any type of support provided, even though such experiences

may appear overwhelming. Nora's experiences of support group participation firstly as a client, then as a facilitator emphasises how support groups are suited towards providing educational, emotional and instrumental support to PLHA. Yet the discourse underlying such support is framed within a context which may not represent the experiences of those attending the support group, but rather the dominate discourse surrounding care and support in HIV/AIDS. Nonetheless, Nora emphasises how support groups are able to convey educational material which may not have been available during counselling procedures.

N: "...when I came here I was a client and now I am a counsellor. So it is important to collect everything that people are giving you, don't choose anything. Like, now I'm a counsellor, but I started to be a client because I was interested in everything, and also sometimes I just read. Maybe I see the pamphlet, I read, then I say this is important, and because I know I must share it with them. Like domestic violence, I never attend workshop about domestic violence, and where to report it, and what is it. They didn't even understand financial abuse, they never know that there is financial abuse, but if, even if your family, your sister, even your boyfriend they can't demand your money...I was doing example with me"

The facilitation of social support allows a divergent range of topics to be discussed in the context of living with a seropositive status. Although counsellors may be untrained to discuss issues beyond post counselling protocols, as evidenced by Nora's experiences. The provision of social support may assist in the dissemination of additional educational material, which endeavours to empower PLHA. When conducting counselling with recently diagnosed individuals, counsellors are required to follow procedures that facilitate treatment for HIV/AIDS through ART, and any other potential opportunistic infection.

Z: "...the positive one [HIV-positive] is the one you're supposed to tell everything, because he or she done the first step to come to do a VCT. The second step we gave them a referral to their nearest clinics to do a CD4 count, to do TB screening and also support for treatment"

T: "...now the second step I must go to the clinic and take the supplements they going to give me, and check my CD4 count, how is my CD4 count, so that if my CD4 count is below 200 then I can start the antiretrovirals earlier, so that I not go to be ill, or with full-blown with AIDS"

The availability of treatment indicates that counsellors are required to have experiential knowledge concerning treatment, possible negative side-effects, and adherence difficulties. The ability to transfer lived experiences of utilising and managing ARVs is a fundamental aspect of peer counselling. Yet antiretroviral treatment is the most stringent oral medication to adhere to. Zinhle stressed the difficulty she experienced in managing and adhering to ART.

Z: “So we are convincing ourselves... the ARVs is the chocolate, because we know that we are going to take them for the rest of your life... so that thing [ARVs] is going to be stressing you, so just a Kit-Kat (laughs), because you gonna be stressed. Ya, think oh my God the tablets, oh what is going to happen to me... I’ve got a friend we are both on ARVs so we used to speak about those things”

Laura’s experience of beginning treatment was shadowed by her experiences of contracting meningitis. The negative experiences of utilising treatment were reduced by the assistance of her colleagues.

L: “I had meningitis this year...I was not on ARVs, I was not on any antibiotics since 2001 up till 2010, so when I went to the hospital, they took my CD4 count, but they said the symptoms is like meningitis, so they don’t lumber puncture on my back. The results came back, and it said I got meningitis. The doctors state you as stage 4, whereas you can walk. On that case, when my CD4 count came back, it was 196, so I had to start on the ARVs, so they done all the processes like the screenings, and the education, and I was using Nevirapine, so I reacted on this Nevirapine, and I was like someone who was burnt, my whole body...it is like blisters, it’s really painful thing. So, I was admitted at the hospital, my dear I couldn’t do anything, I was like someone who had been burnt with boiling water, my tongue was pink pink, I couldn’t eat, I couldn’t drink...I suffered a lot, I was a whole month in hospital...but you know what helps me a lot, it’s to see my friends, and at church they know me also, my church members and colleagues. There were two here at work who were really helpful on me, because they have to come each and every day to come and bath me...through that I recovered very quickly”

Such difficulty with treatment indicates the need to assist counsellors in their experiences of adherence and management of treatment side-effects. This is a necessary process as counsellors will encounter counselling situations in which their experience of utilising antiretrovirals facilitates their client’s desire for practical and experiential knowledge concerning treatment and adherence. The management of HIV-related symptoms is an additional avenue in which personal experiences can assist clients. Zinhle frequently encourages the utilisation of alternative remedies to boost immune system functioning; but similarly Zinhle does not compromise the importance of utilising ART.

Z: “...sometimes when you are HIV-positive you are developing things in your skin...I give them the recipes that I know. For an example, if you have blisters...sometimes the blisters are coming especially this part [torso], all over this part; its swollen like maybe this side or this side. So I ask them to mix the green pepper, the garlic, the ground ginger, the cucumber...I ask them to mix them, they must chop them those things, and then you boil it...then after that you just strain it and drink that water...you drink that water, it boost the immune system, especially if the CD4 count is below maybe 200, let’s say 250, it increase the CD4 count.”

4.2.2 Multiple roles

In addition to the roles and responsibilities of providing voluntary counselling and testing services, all the participants have additional portfolios that they manage alongside that of their counselling roles. These additional tasks involve active community engagement with individuals and families infected and affected by HIV/AIDS. Laura's position within the organisation extends beyond counselling protocols, and actively entails engagement with individuals, and families infected and affected by HIV/AIDS, through HBC, provision and facilitation of support groups, and support with treatment. Nora's provides counselling services for HIV-testing, and facilitates and supports the support group run at the VCT centre. Thandi's staunch approach towards providing support is evident in her position as director of multiple support group programmes. Zinhle stressed the difficulty she had at managing different roles within the organisation, she believed if she was hired specifically for lay counselling then that was her responsibility, instead she was given limited direction on her performance, and was expected to perform tasks and responsibilities beyond her position.

L: "...what I am doing I am not only a counsellor, I am a peer educator, I am a motivational speaker, I am the coordinator of the support group, I go to churches, we've got the grannies club...So, there is a lot that I am busy doing, this same person who is HIV-positive"

N: "My duty is to talk to somebody who came for HIV-test...they duty me downstairs for the support groups, to do topics with, facilitating with the support group...helping with the kitchen. Because it's only two of us, I have to make sure that there is food for the clients, I have to make sure that clients are busy with some stuff. They are doing what I was doing, to encourage them"

T: "I am overseeing programmes; I am running the Kids Club and the she support group...My support group is the grannies support group, it is where the grannies are looking after their grandchildren, because their daughters and sons are passed away because of HIV/AIDS. I have six support groups, six programmes...I started with 23 people, it was coming dome the area where I am staying, because I am staying at [Port Elizabeth].

Z: "I'm alone, ne, she want to do me maybe five different types of work, why we are five counsellors here. So I can't manage all that work, you see. To my mind she supposed to say to me you must stop doing the VCT, you must doing oversee. But now they told us that the oversee is a part time job, since when, you see, since when it's a part time job?"

These additional tasks stretch the supportive and counselling capabilities of the counsellors. Even though many of the additional portfolios engage with HIV-positive communities, it is an added stressor when one realises that these counsellors are not only providing the

necessary counselling services for recently diagnosed individuals in VCT, but are also providing supportive services to those already living and affected with HIV/AIDS within their surrounding communities. It is within the practice of these procedural services that the use of personal experiences may additionally be utilised. Educational and experiential material which the counsellors themselves have disseminated can be reiterated to ensure continuous exposure to positive ways of living with HIV/AIDS. Zinhle notes how the allocation of multiple positions caused distress in relation to remuneration and responsibility. Zinhle's experiences emphasise the difficulty of working within an informal task-shifting environment, stressing the difficulty of defining her role within the organisation. She felt that her position as an HIV-positive employee working in the field of HIV-care prompted exploitation. Furthermore the informal utilisation of task-shifting produces ambiguous boundaries between counsellor and client, fostering dependence in clients that are unfamiliar with therapeutic relationships. Yet, Zinhle expressed the joy she experienced in discussing issues surrounding HIV/AIDS, where she advocates for safe sexual practices, but in addition the adoption of healthy life-style behaviours. However along the same thread Zinhle notes how the undefined role of lay counselling has created situations in which clients expect their counsellors to resolve their issues, as opposed to directing them towards avenues in which social support could be afforded.

Z: "I can say it's my daily bread... because, some of them they are coming to me to find advices. Like, I'm also working with, I'm also a volunteer for [organisation]"

Z: "...I think it's very difficult because they expecting you to do everything for them, especially the, our client here. They expecting you to do everything like, to give them clothes, to give them money if you have, to give them everything

The counsellors actively lead lifestyles which promote living positively with HIV/AIDS. Zinhle embodies the role of a positive role model within her community, through provision of social support and the sharing of lived experiences in VCT, as well as the facilitation of institutional support and treatment. Although Zinhle actively assists in the utilisation of support, the indistinct role of peer counselling and the socio-economic circumstance of many of her clients, manifest as an expectation to resolve many of their difficulties. Zinhle expresses the great difficulty in fulfilling her clients' expectations, noting how certain clients have demanded financial assistance. Yet despite the difficulties of exerting therapeutic boundaries within resource constrained settings as a counsellor, Zinhle's willingness to

provide multiple levels of social support necessitates her decision to disclose, to identify as someone living with HIV.

Z: "...there's a one lady, my neighbour, she always told me that there are other people that see you as a role model, I say no, [she says] no you are a role model, especially to me, because there are many people who died because of this HIV-positive, they didn't talk out. Then you are talking, each and every day when I see you, you are beautiful...so I can say I am a role model"

N: "...we promote people must not use alcohol, you must not smoke, we must not change partners, or if you change partners you must use a condom. So I don't drink, I don't smoking, I don't have a partner, maybe I choose to abstain because I don't think of partner."

Zinhle fundamentally believes in the benefit of disclosure, her conviction is steadfast despite the potential harm she could experience from publically disclosing. Yet her decision to remain vocal indicates her commitment towards providing PLHA platforms in which to similarly disclose, and reconstruct perceptions surrounding seropositivity. Although Nora does not elucidate towards the benefits of disclosure, she utilises self-disclosure practices within counselling encounters to facilitate acceptance of a seropositive status. Clients will have difficulty absorbing and extracting what is relevant for their lives, especially in the context of receiving and accepting their seropositive status. Peer counsellors in such situations will be able to communicate their experiences of diagnosis, treatment, disclosure, and behavioural change that will facilitate the desire for emotional support and experiential knowledge. Yet the transfer of such lived experiences is dependent upon the relationship between counsellor and client.

4.2.3 Interacting partnership managing uncertainty

Peer counselling is described as a one-on-one educational and counselling connection between a recently diagnosed individual and an individual who has been living with HIV/AIDS for several years. Yet the counsellors are adamant that counselling involves more than just transferring HIV-based education, rather it involves active collaboration between both counsellor and client focused on empowerment. A pivotal aspect of the counsellor client relationship is the reduction of uncertainty, which includes uncertainty in illness progression, treatment, disclosure, and social assistance. Laura emphasises the role of counselling as a partnership between counsellor and client, similar to narrative therapeutic approaches, contrasted against psychoanalytic therapy with structured boundaries of expert and client. Thandi emphasises the guiding nature she employs as a counsellor.

L: "...in the counselling session, it's not an education, it's different, you can't educate, it's the interacting, you understand, you understand, you ask back, okay you are in this situation, what do you think we should do...you can't lecture, you are just there to guide, you understand. So how do you think we should do to make this right? Or how do you think? back to her, because it's another thing. You must always know that when you are a counsellor, there is a difference between educating and counselling, so you just let the person speak more, or you will ask is there anything maybe you need me to explain more, to elaborate of what we are meaning when we say this and that"

T: "...you show this woman that if she can becoming positive what can happen, but if she is negative what can happen. On my side, I used to say you can take it by the right choice or bad choice. Because what is happening, if you go and test, maybe you can be positive, maybe you can't be positive...there is treatment now, firstly there was no treatment, but you have to show that one, if you go and do this what you can do for her, because you have to be guiding for this person"

Laura and Thandi's differing approach towards post-counselling procedures reflects their identification with their own seropositivity. Laura's experiences have directed her towards creating a counselling environment conducive to the sharing of lived experiences. Whereas Thandi's experiences creates a counselling environment focused on engaging with systems of social support which facilitate the sharing of lived experiences. Peer counsellors perceive themselves as active partners within the counselling process. Yet the success or failure of such a relationship is perceived to be dependent upon the client's own resolve. Frequently counsellors employ a strategy of transparency and honesty in their experiences of living with HIV/AIDS. The act of disclosure in these counselling sessions not only indicates solidarity but additionally facilitates a more comfortable and empathic relationship between counsellor and client. However it must be noted that not all counselling processes are accompanied by the counsellor self-disclosing.

Z: "...one time there was a lady she was very young, she was crying, and then I told her that no you can cry maybe because of the shock, you are worried now, but as time goes you will be fine. Because as you see me now in front of you I was diagnosed in 1999, and then she get shocked and look at me and stop crying now, and then telling her that you can continue living life as before...If you've got someone who's [HIV] positive...I prefer to disclose so that she can get shocked and look at me, I got so many years living with HIV"

N: "... I love to speak especially the one who are coming inside for doing the testing, especially those who are HIV-positive. I told them that I'm also HIV-positive, they can see me that I'm still fine, I'm still okay... when you are telling people that your HIV-positive, they don't believe that you're HIV-positive... but its true... then they starting asking me that what are you doing?"

Why are you... right? Which things are you doing so that you can be healthy like this?"

L: "...you know it helps a lot to tell people about yourself, like if you disclose, to let the people know that there is still life, as like myself you see, I'm ten years living with HIV, but nobody knows, unless I am telling you that, you understand. So if the client seems like it's the end of the world, I have to draw him back, I don't have a choice there...it is better to live open with your status, so that you can get to help left, right, and centre, because it doesn't help to keep things to yourself, you won't get help if you are just there keeping everything for yourself, thinking that you know, whereas you don't know, you understand, it does help, really if does help"

T: "What is happening for me as lay counsellor, firstly the doctor state that you are positive, at your own what do you want to do about yourself? What do you want me to do for you? Are you willing to accept yourself? Because firstly before you accept your status, you have to accept yourself. Don't take yourself as someone who do wrong things, take you as someone who can be challenged from God and from you"

Zinhle, Nora and Laura's experiences of counselling recently diagnosed individuals indicates that acts of self-disclosure can be utilised as a mechanism to assist acceptance. Providing recently diagnosed individuals with a living example of living with HIV/AIDS may present the momentum towards acceptance. Yet Thandi's experiences of counselling recently diagnosed individuals does not involve acts of self-disclosure, instead she perceives seropositivity as a challenge one must overcome. Thandi stresses the importance of accepting oneself as a process of accepting a seropositive status. She perceives her role as a lay counsellor as a facilitator towards supportive services, providing such support through her personal experiences, yet insofar as indicating their effectiveness. Despite the differences in their counselling approaches, Thandi and the other counsellors offer their clients a space in which to discuss their issues. Affording avenues in which clients can voice their concerns and gain experiential knowledge is a valuable contribution towards reducing and managing uncertainty in diagnosis and in living with HIV/AIDS. One aspect that is reiterated throughout the transcriptions is the practice of positive thinking as a mechanism to reduce uncertainty. Positive thinking directed towards long-term goals facilitates the reconstruction of hope. The fostering and maintenance of hope is regarded as essential in living with HIV/AIDS. This is demonstrated by the fact that the participants actively sought to improve upon themselves, and this in turn reflected their idea that one's seropositivity does not limit one's life. All the counsellors promote the practice and principle of positive thinking within their own lives as well as their clients. This mode of thinking and behaving is a mechanism

through which HIV-positive individuals are able to reconstruct their lives in living with HIV/AIDS.

T: "...firstly I can say for me it is better to speak about something that you know you are living with it...I told myself ya I do have this problem, this virus, firstly I was taking it as a problem, but now I am taking it as something that lift me up"

Z: "For an example, you can mention the years that you have this virus, and then sometimes they say no you are lying, because they can't see the virus. You can make yourself not the virus lead you to whatever, not to make you sick, to develop some blisters, some shingles, some rashes, you can manage those things especially"

Thandi's statement indicates that experiential knowledge is a pivotal aspect of providing relevant and sensitive counselling experience. Yet Thandi does not utilise her personal experiences, instead she draws her confidence from her experiences as a veteran lay counsellor. Zinhle emphasises the importance of experiential knowledge, conversely to Thandi, Zinhle actively utilises her personal experiences to facilitate support. The shift in perception of HIV/AIDS as an illness that can be managed, that can be overcome is the key principle in living positively with HIV/AIDS. Yet this perception requires concerted effort by both counsellor and client. If the client is unwilling to change his or her behaviour, is unwilling to accept a seropositive diagnosis, or if they are unwilling to change their own perceptions regarding HIV/AIDS, then positive thinking and the use of personal experiences will have scant effect on such clients. It is the collective effort between a counsellor who has regained hope, and a client who is willing and seeking to restore hope that shapes the nature of the counselling relationship. Zinhle and Thandi stress the difficulties in managing clients who admit that they will infect others, despite attempts at changing behaviours or providing avenues to access social support.

T: "...but there are those who say no man I won't make it, you can take a cow to drink water, but you can't make it drink you understand...when the situation is like that, you feel like you could do more, but there is nothing that you can do. It start with the person"

Z: "...the other people, that saying, that I won't die alone. I will give this disease for, to others. So which means that if you won't die alone, which means that you are not using a condom. And they are those who are drinking, like they are drinking in the shabeens, I think you understand what happen in the shabeen when others are drink ne. So it's happen like that. So I think disappointed, even here at the support group when you are teaching them about the condom, other people they say they won't use a condom because you can't eat a sweet with a wrapped paper [laughs]. Others they say they don't know

how to use, then we use a demonstration for them, others they say they won't use a condom. They got this virus because they didn't use a condom, so what is the use of using a condom, but we explain to them that...I used to explain, I used to give them an example of a pregnant woman. When you are pregnant, you won't get pregnant while you are pregnant, but when you are HIV positive, you can get the HIV even tomorrow, even now, especially when you are not using a condom, which means you are re-infect yourself by not using a condom”

It is evident from the above excerpts that additional training is required for peer counsellors to affect positive behavioural changes in clients who are unwilling to change behaviours which render them vulnerable to future infections. Although the counsellors advocate for behavioural change, protocols underlying counselling and testing in VCT are predominantly directed towards empowerment and the utilisation of institutional and informal supportive resources, as opposed to protocols which specifically focus on risk-reduction. The counsellors can only advocate for behavioural change, rather than specifically target behavioural problems which render individuals vulnerable to future infection. Yet Nora stated that she accomplished her responsibility by purely conveying what was required of her in VCT protocol. Whether or not her clients changed their behaviours or accepted their seropositivity was entirely up to them. Nora perceives her role as a facilitator towards support and treatment services, nothing more and nothing less.

N: “It depends to individuals, because you can say to you use condoms, to help yourself then you will use it, and then I will say to someone else, and then she didn't, so it depends how people believe... some change, some don't”

Stress and the inability to reduce stressful life events are attributed to a diminished survival rate for PLHA. The counsellors maintain the necessity of positive thinking mechanisms, but additionally endorse practices of a “stress free” lifestyle. For Laura, her troubled relationships with men resulted in her decision to live a life free of intimate partnering with men.

L: “...what I heard from the knowledge that we get from the trainings and the workshops, is that if you stress free you can live longer, because if you are in a relationship by itself is a stress, because you have to answer where you have been, why are you coming late, why are you and all that. When you are on your own, at least you can manage yourself, you understand, and yes you are going to have stress, but it will be a little, because you know you have to be home at six, I have to do this and that, you understand. You know you are on your own, unlike you got this second person now, this boyfriend, he will need you more, whereas you got a kid you got to take care, or your job”

Laura's decision indicates her desire to live a life removed from the stress of maintaining intimate relationships. However her choice may reflect broader issues of female

empowerment. Laura's sero-discordant experience motivated her choice to be removed from intimate partnering. Her decision distances her from potential stress, yet it reflects a belief that intimate partnering does not provide psychological protection from HIV/AIDS. Instead as stated above, Laura believes in the benefit of social support, and actively promotes leading a "stress free lifestyle".

4.3 Challenges

Peer counsellors experience a multitude of challenges in providing emotional and supportive services to communities and individuals affected and infected with HIV/AIDS. The counsellors indicated a variety of difficulties they experienced as HIV-positive peer counsellors. The primary anxieties concern the difficulties in providing counselling and testing services as HIV-positive counsellors within the stigmatised field of HIV work in South Africa. The lack of ongoing support for countertransferential experiences is increasingly recognised, but as of yet no systems of support are available for such reactions. The dual role of providing supportive services and simultaneously requiring support indicates that current practices within VCT do not account for peer counsellor needs.

4.3.1 Peer counselling challenges

The emotional labour provided by peer counsellors comprises of emotional and supportive services which aim to facilitate the counselling and testing process. The difficulty in discussing sensitive topics concerning sexual activity, mortality, and disclosure presents opportunities for occupational stress, burn-out, and resignation. Coupled with intense identification with their clients' experiences concerning diagnosis, treatment and support, peer counsellors require ongoing support to minimise the effect of occupational stress, and the stress of living with a seropositive status. Laura admitted that her position as an HIV-positive peer counsellor, coupled with the additional responsibilities of HBC and support group co-ordination required "ongoing counselling" as a means of coping and dealing with the difficulties in providing VCT services.

L: "You know I have been through a lot, so it really helps me when there are people who helps me like with ongoing counselling, take care of carers, at least at work they organise us a wellness clinic, so if you feel like you are not okay, you just go to them"

Laura and Thandi are fortunate to receive ongoing counselling services. Yet the experiences of Zinhle and Nora indicate that restraints towards providing ongoing supportive services required their own internal support group to relieve the daily pressure of HIV work, and living with a seropositive status.

Z: “But we are the counsellors of [VCT centre], we speak with our problems in this room, if you’re having a problem we share it amongst each other so that you can’t put that burden over your shoulders, you have to overcome it.”

Counsellors maintain the difficulty and stressfulness in counselling recently diagnosed individuals in a VCT context. Laura noted how her experiences of counselling men proved difficult, as she believed that women were more open about discussing issues pertaining to their seropositivity, as opposed to men whom they found tended to “bottle up” their experiences.

L: “...we get a lot of challenges, most especially on guys, you know males are not like us, you know a female, we like to share you understand, you just enter a room, there are other ladies, you just make a space, you know what, yesterday I experience something, guys are not like that and they like to bottle up, and they die very quickly, its whereby you hear someone heard about his status last week, after two weeks the person is dead, it’s because they like to keep things in themselves. As the bible said, a male is the head of the house, they are using that even in the HIV things, whereas it is not helping them, because they are the ones who are dying very quick”

These experiences indicate the difficulty in counselling men, particularly those who do not recognize the benefits of receiving counselling. Such difficulties and experiences often led counsellors of one VCT centre towards actions that relieve stress to improve upon their performance; in addition this allows the counsellors to continue counselling people with HIV/AIDS. Zinhle stated the joy and benefit of helping recently diagnosed individuals, but debriefing was considered an essential aspect to maintain moral and overall job performance.

Z: “... at some stage she [director of VCT centre] might take us to the debriefing, so that we can at least relieve our stresses. But the problem, I think it’s a funding, ya she doesn’t have enough money to take us there, because it’s so expensive to get those massages”

Peer and lay counsellors are not officially recognised as part of the formal health care system, additionally a large majority of VCT services are provided by lay counsellors working for NGOs which are primarily funded through international donors. Providing a means to generate income and skills is an effective empowerment approach. However, Nora notes that

limited financial resources have resulted in the reduced effectiveness of the support group programme facilitated through the VCT centre.

N: “They are doing what I was doing, to encourage them. But now it is different, there are financial problems, so I can’t do everything with them...we are struggling to do handwork, to keep them busy so that they don’t think too much about their status, because of the [lack of] finances we are only doing the gardening”

Limited financial resources to sustain and effectively manage support groups merely indicate the difficulty peer counsellors encounter as a result of their status within the healthcare system. Zinhle, Laura and Nora’s experience of becoming a lay counsellor could be described as a fortunate circumstance. Laura’s experience of diagnosis is punctuated with difficulties with unemployment; she struggled to comprehend how she would support her child without a husband and a job. Nora similarly shares in Laura’s difficulty and states how she survived with constrained resources until she became a practicing lay counsellor. These experiences highlight how the availability of treatment improves an individuals’ capacity to work, yet opportunities for employment are not abundant in South Africa. The following extracts are placed within the context of employment in VCT, the experience of relief at discovering a possible route out of potential poverty can be an alleviating process when one considers the context of securing employment post HIV-positive diagnosis.

L: “...luckily what happened after three month of the workshop and the training that I attend, this lady was getting married...So as a person who was a helper, because I was volunteer now freely, because I wanted to know about this thing [HBC], so they said to her that, can you bring the lady that is helping you with the home visits and do the education on the bench, we want to see her, because we think we are going to use her, because this lady was now going to Cape Town, she is going to work on that side, so they needed now someone who is going to help here in Port Elizabeth. So, I was lucky, because it was only three month since I got this workshop and training. So when I came in on that Monday, they said to me that we need you, we think we are going to employ you, but you have to get more skills, so do you want to work with us, and I said yes I would like to work with them, because honestly I was not working, and I was not getting any money from the government”

Z: “So [director] asked me to help other lady who was very sick at home, so I volunteer myself to help that lady. I go to that lady early in the morning, help her to wash her baby, because she was having a baby which is I think she was that little one was eight months nine months at that time. I tried to wash the child, clean the child everything and tried to clean the house if there’s something that I want to clean up. And then take her with her child at the centre every day. So maybe they [director] saw that I’m a right counsellor, and then

all of them all of them the staff and Jabu agree that I must be one of them, I must be in that staff. And then, at the first of June I was employed here”

Laura and Zinhle share in the fortune of becoming lay counsellors from volunteering as home-based caretakers. Provided an opportunity these counsellors subsequently became highly versatile counsellors who frequently utilised self-disclosure in counselling sessions to indicate support, but additionally practice public self-disclosure to mitigate the stigmatised perception regarding PLHA. However they are not acknowledged within the formal healthcare system and Zinhle indicated the stressfulness of potentially losing employment owing to organisational financial constraints.

Z: “...when I was in PE for VCT training again, when I came here I heard that it’s gonna only me whose gonna, whose going to work here, for others there’s no work for others, which is I’m new remember I’m new and those who are old they were chasing out, ne. That is why they were very cross, because they said we are nominating him, her to be the member of us, but now it’s her who stay here we are chasing out us, you see. That is why we were fighting. Not because they were chasing out, it’s because the funders they need the one who having the VCT. So it was only me who have the training of a VCT, not them”

The reality of limited opportunities for employment in South Africa may explain Thandi’s reluctance at utilising personal experiences during counselling processes. Maintaining a professional boundary preserves the impression of professionalism inherent in therapeutic relationships. Yet the informal utilisation of task-shifting in lay cadres of the healthcare system limit counselling sessions as counsellors are expected to fulfil a mandatory quota of cliental, in addition facilitate and engage with treatment, HBC, and financial and subsistence assistance. Located within such expectation the opportunity to share lived experiences are limited, and the emphasis on utilising systems of social support appear to favour practices of sharing personal experiences over counselling and testing encounters.

4.3.2 Confidentiality

Confidentiality is a core mechanism towards providing relevant, sensitive and empathic counselling services. Lay counsellors are expected to ensure that their client’s serostatus remains confidential throughout the counselling and testing procedure. Zinhle noted how the issue of confidentiality is paramount to the counselling experience, where her experiences of clinic based counselling and testing services, indicates the serious lack of confidentiality that exists in such settings.

Z: "...there are if I am not mistaken, seven clinics who are doing the VCT, but the disadvantage of them is that they have one day in a week. So, maybe if you are not there maybe Monday...at [clinic] I think it's Tuesdays, so if you are not there, they just send you here. Actually, most of the people they want to come here...because they say this place, is a quiet place, because at the clinics you can hear that all those for VCT most come this side, and there are lots of people waiting, maybe with the sickness, other checkups, and waiting for the results. So they are going to see that okay James, he went that side for VCT, now we going wait and see how he is going to be when he is out, to see when he coming out there in that office. If they see that you have the red eyes, they know that you are HIV-positive. So they say, yes the confidentiality is there inside the office, but outside it is not."

These experiences may limit the number of people who voluntarily test themselves for HIV, owing to the lack of confidentiality that exists in the waiting areas of busy public clinics. The same counsellor noted that confidentiality must be maintained throughout counselling and testing procedures.

Z: "...because remember confidentiality. If you see that person first time, even not first time, if you are the counsellor, and then he or she just gets inside, you are his/her counsellor. The pre- and the post- [counselling] are supposed to be done by you for that particular [person]. If she wants to speak to the other person who is HIV-positive like her or like him. If he or she agree with you, then you can refer that person to the other counsellor, maybe he is HIV-positive. Remember the confidentiality, you can't break the confidentiality"

The implication of this statement indicates that counsellors are not willing to expose their client's or other counsellor's serostatus in the hope that such encounters could provide the client with valuable lived experiences. The client's serostatus and the necessity to keep it confidential override any circumstance which aim to facilitate the use of personal experiences. Nora reflected on circumstances in which a commitment to confidentiality placed others in jeopardy of infection, these situations produced particularly difficult positions for the counsellor.

N: "Firstly in 2002 when I was started to be a counsellor, there's a people who are coming from one of the farms...unfortunately we didn't know that there is a couples there, maybe fortunately for me I counselled the lady and I counselled the man. But I didn't know that they're couple then I separate them, unfortunately for the lady was HIV positive, fortunately for the man was HIV negative and he asked me about the results of the lady and she also told me that she do have another lady in this group and the results of that lady is negative, she showed him that the results is negative, so this one didn't show the results then I told them that it's not my fault, if she want, if she do not want to show you the results it's her right to not show you the results. Here I'm producing confidentiality, I can't tell you about the results of someone else. So, it was like that, but the same couple I saw the same couple in the street, then the lady was,

she told me that I must not tell the boyfriend, and I obeyed her opinion. Then I was very, I don't know what happened to me that time, I was very very angry in my side when I saw them together, and then she came to me, the lady came to me, because the man I know the man more than the lady, then she came to me and saying to me that please don't tell him. I say to her that I won't tell him, I won't tell him anything but be sure that you are using a safer sex. And then she told me that how, because maybe he gonna think she's HIV positive, because they didn't use a condom before, so it's very very difficult to tell him that you must use a condom now"

The challenge of confidentiality extends beyond the clinical settings of counselling and testing practices. Frequently sero-discordant couples place counsellors in positions of uncertainty and difficulty. Predominantly in situations where couples are not concurrently tested, and where sero-discordance evokes fears of stigma and prejudice linked to seropositivity. Zinhle advocated and encouraged couples-based counselling, yet similarly admitted the difficulty she experienced with sero-discordant HIV test results.

Z: "I think it's very nice and good to come with the couples, so that they can see what is going on between them. Although sometimes you find negative and positive, you see, but it's a right thing...at the same time it's difficult"

4.3.3 Youth specific challenges

All the participants stated that they struggled to affect positive behavioural changes in young people, specifically concerning the practice of safe sex. Zinhle disheartened at her efforts at affecting positive behavioural changes in young people is uncertain of what actions would prompt change. The debilitating aspects of seropositivity does not provoke behavioural change, in fact youths appear to regard claims of seropositivity as failed attempts to incite behavioural change.

Z: "...the only thing I wish, especially for the youth, they still don't understand that this virus is really killing. I'm afraid, I'm afraid because they want to experience things, you can say that please just have a boyfriend after you finish with your studies, and please marry, but before you do that come and do the VCT. They going to say, especially on my age, maybe I have a child, they are going to compare ages, my age and her age, then she going to tell you that...you delivered me when you were sixteen, why are you stopping me from doing what I want to do, you see. They have, they do have comparison between their ages and their parents' ages. So, it's very difficult, I don't know what we are supposed to do, so that they can see that this thing [HIV/AIDS] it is really killing, it's a problem...because yes they are scared but at the same time they are not, because as you see that I am not sick, there is nothing that you can see on your own that I am HIV-positive. When I am telling them that I am HIV-positive, they don't believe me, so it seems as if I am lying to them...they are not scared of people who are HIV-positive. As I said they want to experience

things, and they don't want to use a condom, because they said you can't eat sweets covered"

The difficulty in affecting behavioural change in youths indicates that the preventative approaches the counsellors utilise are ineffective, or appear irrelevant to youths. Such difficulty with preventative modification may stem from youthful sociocultural perceptions of living with HIV/AIDS. The perception of not being at risk of infection, the perception that PLHA should appear unwell owing to the debilitating effects of living with HIV/AIDS, and the perception that safe sexual behaviours are not culturally relevant. Thandi expands on this notion of cultural relevance by demonstrating how her attempts at instilling cultural values and norms applicable to her generation, often conflicts with youthful interpretations of cultural practice.

T: "...because what is happening now it wasn't happening on their age. For instance, I don't have children, I am raising my sister's children, but my life and his life it's not a common. Because I was raised by my mom, my mom was a priest, a priest at the church, but what she told me if I can taught my sisters kids now, it can be difficult, because they can say look this was happen at your age, now we are living at our age"

Thandi's background experiences were largely dictated by religious practices which may conflict with current youthful perceptions surrounding sexual behaviour. Zinhle and Thandi's belief at being ineffectual at convincing youths surrounding the dangers of unprotected sex, and the realities of HIV reflects the constrained role of lay counselling within South Africa. Whether the responsibility to modify youthful perceptions surrounding safe sexual practices is within the domain of VCT, peer counsellors require ongoing systems of support to facilitate and determine how and what is culturally relevant for youths.

Chapter 5: Discussion

Peer counselling as defined by Harris and Larsen (2007) is an educational and counselling connection between a recently diagnosed individual and an individual who has been living with HIV/AIDS for several years. Within the context of counselling and testing services in South Africa, the practice of peer counselling has received minimal research interest. This chapter explores the lived experiences of being an HIV-positive peer counsellor working in VCT services in the Eastern Cape of South Africa. In addition the implications a seropositive status may have on the counselling relationship, the use of personal experiences, and perceptions surrounding credibility will be elucidated. An exploration of peer counselling entails an understanding of the lived experiences of the participants' experiences of diagnosis and self-transformation; from hopelessness towards a reconstruction of a positive self-identity in living with HIV/AIDS. An awareness of the participants' lived experiences of living with HIV/AIDS provides an opportunity to understand the counselling processes and practices they propagate. Additionally the informal utilisation of task-shifting within lay cadres of healthcare services without adequate remuneration and ongoing support increases experiences of occupational stress, limiting the potential benefit of counselling encounters owing to the reality of being over-extended within a healthcare system critically short of professional healthcare personnel. The implications of multiple HIV-care positions and the informal utilisation of task-shifting will elucidate the current challenges and concerns that peer counsellors experience within the field of HIV -care, counselling and support.

5.1 Counsellors lived experiences

5.1.1 Diagnosis experiences

The experience of receiving a seropositive diagnosis significantly alters an individual's perception of self and places infected individuals over quandaries over issues concerning disclosure, treatment, and self-identity (Burchardt, 2010). All participants noted the emotional difficulty and struggle to comprehend their new serostatus. Experiences of denial, shame, anxiety, hopelessness, isolation and social avoidance are typical responses towards receiving a seropositive diagnosis (Kylma et al., 2000) and were articulated by the participants. These psychological responses indicate the difficulty in accepting a seropositive diagnosis. Once infected, individuals are presumed to represent the deviant behaviours which

resulted in their seropositivity. The social construction of HIV-infection linked to promiscuous sexual behaviour and groups such as prostitutes and intravenous drug users support the construction of a stigmatised identity (West et al., 2007). Yet such conclusions do not account for the socioeconomic context of those who are infected, nor does it consider resistance to behaviour change as a contributing aspect of the epidemic.

Women, as discussed, are particularly vulnerable to HIV infection owing to gender and societal norms which restrict women's reproductive rights (Leclerc-Madlala et al., 2009). Yet women are frequently blamed for transmitting HIV to their partners (Jewkes, 2009) owing to biological aspects of vulnerability, where an HIV-positive woman is more likely to transmit HIV to men, as opposed to an HIV-positive man transmitting it to women. However, biological explanations cannot account for the patriarchal structure in which relationships are based. Women may present resistance towards male hegemonic discourses concerning intimacy and the role of women within intimate partnering, but fundamentally femininity is presented as subordinate to male authority (Jewkes, 2009). Thandi's experience of receiving a seropositive diagnosis coupled with her husband's insistent practice of no condom usage highlights the structural inequalities which define gender inequity within South Africa. Her inability to practice safe sexual behaviours is not an issue of nondisclosure, but her husband's deliberate act of defiance against the notion of being at risk for HIV-infection. Her compliance encourages the practice of patriarchal control, and minimises the opportunity to practice safe sexual behaviours. Laura's experiences of sero-discordance are punctuated with victimisation and blame, her husband insisting that her infection is the result of her immoral behaviour, culminating in experiences of social isolation, shame and self-blame. These experiences signify the necessity of providing women with empowering discourses focusing on their reproductive rights within counselling and testing procedures (Jewkes, 2006). In addition the provision of disclosure assistance is required to assist couples not concurrently testing and where sero-discordance causes internal struggles and conflict for those infected and affected.

Laura and Thandi's experiences of receiving a seropositive diagnosis are aggravated by difficulties with sero-discordance. Recently, counselling and testing protocols have advocated for the utilisation of couples-based counselling approaches (Mlay et al., 2008; Skhosana et al., 2006). However, Kippax (2006) states that less than 1% of South African couples have concurrently tested for HIV, indirectly creating an environment of mistrust, where abuse and violence may occur. The implications of such developments can hinder opportunities for

disclosure and thereby affect support and treatment endeavours. Examining the gendered realities of living with a seropositive status entails a prescription of hegemonic discourses, which endorse the normative belief of a dominant patriarchal society (Kenyon & Zondo, 2011; Posel et al., 2007). This perspective attempts to understand the limited and often confrontational nature of sero-discordance and gender inequity of the HIV/AIDS pandemic in South Africa. However such prescriptions must allow the possibility and generation of discourses which refute, support or propagate other discussions surrounding the gendered nature of South Africa's pandemic. Members of the Khululeka Men's support group attempt to redefine traditional constructions of masculinity in light of the HIV/AIDS pandemic (Robins, 2006). Thandi's experience of sero-discordance and the subsequent termination of her relationship may not indicate a homogenous experience for all sero-discordant couples in South Africa, but her experiences indicate that additional voices are being articulated which challenge the hegemonic discourse which is understood as a normative experience of sero-discordance.

5.1.2 Disclosure experiences

Experiences of diagnoses are compounded when decisions to disclose are influenced by socially constructed beliefs surrounding a seropositive status. Societal perceptions surrounding the immoral characteristics of HIV transmission inhibit decisions to disclose (Gilbert & Walker, 2010), which in turn affects opportunities for social support and treatment. Furthermore within South Africa the widespread denial of HIV/AIDS for those affected and infected perpetuate acts of silence, self-blame and social isolation limiting opportunities for treatment and social support (Skhosana et al. 2006). The challenge for recently diagnosed individuals extends beyond medical outcomes and directly relates to processes of identity management (Burchardt, 2010). The reality of testing HIV-positive challenges an individuals' conception of self, and directly relates to processes of self-identification with their new HIV-infection. However individuals are less likely to identify themselves as living with HIV/AIDS owing to the prevailing stigmatising attitudes surrounding HIV-infection and transmission.

Disclosure experiences are typically understood as processes of stigma management and stigma resistance (Poindexter & Shippy, 2010). Stigma management techniques are processes of psychological protection and are understood as a continuous progression of identification or denial of HIV-infection. Denial experiences of HIV-infection are understood as

mechanisms towards avoiding stigmatising discourses, but particularly as a process of dissociating with being identified as someone with HIV. Stigma resistance are processes of voluntary disclosure directed towards deconstructing prevailing stereotypes surrounding the lived experiences of living with HIV/AIDS. The experience of Zinhle emphasises this disassociation through mechanisms of denial and social avoidance. Her initial decision of nondisclosure allowed her to avoid the connection between her and other PLHA, as well as reduce feelings of seclusion and otherness associated with being HIV-positive. Denial as a mechanism of psychological protection provides temporary sanctuary from stigmatising experiences, whether actualised or internalised, but in addition reduces opportunities for social support and the provision of treatment (Jarman et al., 2005). Yet the desire to regain a semblance of normality through denial processes often prevents constructive action towards positive health behaviours. Although the diagnosis experience of this counsellor occurred over a decade ago, the importance of providing support for disclosure decisions is evident in her diagnosis experiences (Kalichman & Simbayi, 2009).

Prior to their participation in social support programmes the counsellors¹¹ indicated the difficulty in disclosing their HIV-positive serostatus to family, friends, and intimate partners. All the participants, following their diagnoses, disclosed their serostatus to at least one individual. Laura and Thandi disclosed to their partners, but distressed at disclosing to members of their immediate family. Zinhle and Nora disclosed to their mothers, but agonised over disclosing to other individuals, infected or not. Within South Africa, disclosure of an HIV-positive status frequently results in ostracism, prejudice, termination of relationships, verbal and physical abuse, and violence (Gilbert & Walker, 2010). Whether these experiences are actualised or internalised owing to prevailing constructions surrounding seropositivity indicate the significance and complexity of disclosure decisions. Wingood et al. (2008) found that significant experiences of stigma contributed towards depressive symptomatology, reduced quality of life, distressing episodes of posttraumatic stress, and resistance towards disclosure. These experiences are exacerbated when considering that black South African women are disproportionately infected and affected by HIV/AIDS (Wingood et al., 2008). Zinhle¹²'s reluctance at participating in social support emphasises the overwhelming experience of internalised stigma. Fearful of identification as an infected individual through associating with other PLHA, and the associated connection to an immoral character, Zinhle¹³'s determination at remaining isolated further entrenches and sustains her belief of being shameful regarding her seropositivity, ultimately resulting in extended episodes of

stress and anxiety. Laura's experiences signify the severity of internalised stigma, fearful of the associations to HIV, her infection and powerlessness to disclose culminated in perpetuating acts of silence and self-blame. Similarly Nora emphasises the prevalence of stigma following her diagnosis experience, noting her belief in an imminent death connected with a seropositive status. Disclosure decisions are complex and fluid processes, which must be understood beyond accessing support and treatment opportunities, Norman et al. (2007) emphasise the multiple rather than singular outcome inherent in disclosure decisions.

5.1.3 Social support experiences

The process of transformation from mechanisms of denial, rejection, shame and hopelessness towards self-identification as someone living with HIV/AIDS requires empathic, respectful psychosocial support (Poindexter & Shippy, 2010). The participants noted how their interest in acquiring knowledge surrounding HIV was their primary motive for support group participation. Furthermore observing individuals cope with their HIV infection in positive approaches and identifying the similarities in experiences substantially improves feelings of uncertainty and anxiety (Burchardt, 2010). Molassiotis et al., (2002) and Seipel et al. (2007) state that the benefits of peer support, apart from sharing experiences to conveying empathy, is the reinforcement of coping skills, social networks, and self esteem. The participants advocate for active participation in social support programmes, to identify with other HIV-infected individuals creating an environment conducive towards sharing lived experiences. Nora states how her experiences of inadequate post-counselling resulted in further confusion and anxiety, and because treatment opportunities were non-existent, her only means of relief was through support group participation. Thandi's experience of sero-discordance and lack of support within her marriage propelled her towards avenues of care and support, where upon identification and participation in social support she expressed acceptance of her seropositivity. However, not all HIV-infected individuals will progress towards processes of self-identification, owing to internal psychological protection decisions which appear more favourable to actions of disclosure. This is particularly salient for woman in abusive relationships, where attempts at practicing safe sex may directly result in disclosure of a HIV-positive status, whereas nondisclosure exposes a non-infected sexual partner to potential infection (Kalichman & Nachimson, 1999).

Self-identification as a process of stigma management involves acts of disclosure to individuals relevant to the infected party. These may include individuals capable of providing

support and treatment opportunities including CHW, friends, family members and or current sexual partner(s). All the participants noted how active participation within social support structures significantly reduced experiences of anxiety and uncertainty related to accepting their seropositivity. The benefit of social support allows access to educational, emotional, and instrumental support processes (Roberts, 2008). These allow PLHA an opportunity to redefine their identity through construction of norms applicable to PLHA, as opposed to the normative stigmatised identity that typically characterizes a seropositive status (Roberts, 2008). The provision of support reduces experiences of anxiety by alleviating experiences of uncertainty surrounding HIV progression, treatment, sexual behaviour, and feelings of isolation. Social support membership entails self-disclosure practices in virtue of participation. Yet decisions to disclose a seropositive status are complex and intertwined with perceptions of self, and the societal perception of HIV-infection. Processes for determining the benefits and risks of disclosure are understood as opportunities to access support and treatment, and do not include evaluations of personal context (Kalichman & Simbayi, 2009). Economic variables such as financial security and socio-political aspects of gender inequity may aggravate and/or alleviate decisions to disclose. Understanding stigma through discourses of identification, denial and resistance allows the recognition of behavioural patterns which inform participation within systems of support and treatment. However underlying this system is the acknowledgment of the prevailing nature of HIV-based stigma. Stigma management as a system of understanding disclosure decisions is inexorably connected to discourses of stigmatisation and prejudice. Jewkes (2006) suggests that processes of social support should be understood from an empowering perspective, rather than dominate negative discourses which typically reflect systems of dealing with stigma.

The provision of social support is believed to reduce the experience of isolation and otherness associated with a seropositive status (Leonard & Ellen, 2008). Yet the experiences of Nora indicate that the discourses typically implemented in social support can amplify feelings of isolation and uncertainty. Leonard and Ellen (2008) found that systems of social support are dominated by dialogues which focus on assistance with disclosure as a means of accessing support and treatment opportunities. Yet individuals utilising these supportive services ceased after initial participation owing to the emotional difficulty of discussing a topic which now encompassed their very existence (Leonard & Ellen, 2008). Normative functions of social support disregard the nuanced experiences of accepting a seropositive diagnosis, and assume that experiences of acceptance stem primarily through involvement and membership in social

support approaches. Nora's socioeconomic position throughout her diagnosis experience indicates her difficulty with maintaining health, particularly considering her limited financial position and the lack of treatment opportunities. Additionally Nora constructs a normative belief surrounding her experiences of a stigmatised identity, reducing her capacity for acceptance. Nora's experience is not an isolated phenomenon and indicates that the provision of social support assumes homogeneity across experiences of receiving a seropositive diagnosis. The benefit of receiving and participating in systems of social support involve access towards treatment opportunities and the provision of emotional, educational and instrumental support. Yet the reality of many women living with HIV/AIDS subsumes wider socioeconomic and gender difficulties which aggravate experiences of uncertainty that hinder processes of acceptance. Nora's experiences indicate that disenfranchised populations encounter additional difficulties which are enhanced by experiences of receiving a seropositive diagnosis. Indeed within such conditions daily concerns may supersede those generated by HIV/AIDS, although such concerns may be improved by the provision and adherence to treatment.

5.1.4 Transformation experiences

The creation of positive appraisals following a seropositive diagnosis is an essential aspect of peer support and peer counselling. Typically individuals who discover their seropositivity are confronted with the realisation of their own mortality, and are unable to construct positive outcomes owing to prevailing normative conceptions of living with HIV/AIDS; particularly concerning impending death, embodiment of immorality, and deviant behaviour (Burchardt, 2010). It is evident from Nora and Zinhle's transcripts that systems of social support can often distort this process and undeniably create further uncertainty and anxiety. Nora's experiences indicate divergent discourses surrounding support group participation, emphasising how the normative structure of social support can inhibit rather than improve experiences of uncertainty. Furthermore within such circumstances the opportunity to perpetuate negative appraisals is possible when discussions relate solely to disclosure as an opportunity to access treatment. Zinhle's experiences indicate that individuals may disassociate with their HIV-infection by avoiding social situations with the purpose of fostering mechanisms of psychological protection. Zinhle's experiences of isolation are linked to her avoidance of being identified as an individual with HIV within systems of social support. Although Nora and Zinhle's experiences signify the difficulty of acceptance directly following a seropositive diagnosis, the provision of systems of support, whether institutional

and or informal are necessary to cultivate and construct positive appraisals of living with HIV/AIDS. Furthermore social support contributes towards psychological adaptation of living with HIV/AIDS through mechanisms of personal growth (Barskova & Oesterreich, 2009), and the realisation that experiences of the self are significantly connected to others (Stanley, 1999).

The reinforcement of positive cognitions is vital to construct a positive identity in living with HIV/AIDS. Individuals may decline to identify as being HIV-infected, whether to reduce experiences of stigma, or disregard the realities of seropositivity through processes of defiance. Burchardt (2010) emphasises the variety of forms of making and unmaking of seropositivity as methods of self-identification. Zinhle's experiences of social isolation as a desire to disassociate with her HIV-infection, indicates the extent individuals will endure to deny their HIV-positive status. Non-disclosure and social isolation practices limit the potential benefit of social support (Flowers et al., 2006). Furthermore, individuals entrenched within avoiding discourses are less likely to access healthcare seeking behaviours (Moskowitz & Wrubel, 2005). Following Zinhle's initial disbelief of receiving a seropositive diagnosis and her aspiration for volunteering, HIV/AIDS encompassed her very existence beyond her diagnosis experience. Zinhle's transition from stigma management towards stigma resistance embodies her desire to transform the experience of receiving a seropositive diagnosis. The making of seropositivity as a self-identifying aspect necessitates her practice of self-disclosure within VCT. She aims to reconstruct the norms which define PLHA by actively participating in community-based initiatives and counselling and testing protocols aimed at normalising a seropositive status. Furthermore Zinhle's acts of public disclosure within counselling procedures, as a peer educator and public speaker are directed towards legitimising her position in the world as an HIV-positive person. The focus is on constructing applicable norms for PLHA articulated by an individual living with HIV/AIDS. The construction of positive role-models is vital in creating additional nuanced conceptions of living with HIV/AIDS (Jewkes, 2006); particularly in developing contexts. Zinhle embodies the conception of positive living and positive thinking mechanisms, which encourages the utilisation of healthcare services for the provision of treatment, but additionally Zinhle advocates for participation in social support structures over and beyond counselling endeavours. Zinhle's position as a peer counsellor and activist campaigning for PLHA indicates her conviction in challenging existing normative beliefs surrounding the lived experiences of PLHA.

Laura's experiences of sero-discordance and subsequent experience of self-blame and social isolation indicates the difficulty of creating positive appraisals following a seropositive diagnosis, particularly when social support is not afforded by family and friends and internalised stigma prevents open discussion surrounding a seropositive diagnosis. Although Nora's experiences of social support signifies the divergent discourses which represent difficulty and struggle within social support participation, Laura's experiences indicate the benefit of peer support as an opportunity to reappraise negative experiences of HIV-positive diagnoses. Seipel et al. (2007) state that the benefits of peer support encompass the reinforcement of coping skills, social networks of seropositive individuals, and self esteem. Laura's participation in support groups provided the conviction for directing her focus on providing a meaningful life for her child, which indicates her aspiration for living within her seropositive reality, contrasted against her initial reaction of self-blame, shame and non-disclosure. Similar to Zinhe's adaptation, Laura's transition from stigma management to stigma resistance indicates her desire to transform the normative construction of living with HIV/AIDS. Laura's acts of public disclosure within VCT, as a home-based carer, and public speaker legitimise her position as an individual infected with HIV. Laura's determination to utilise personal experiences within counselling is not a defiant approach against the processes of VCT protocol, but rather her resolve to ensure that post-counselling encounters are sensitive, culturally relevant, and insightful.

Nora's experience of social support indicates the difficulty individuals may have in identifying and relating to other infected individuals. Nora's experience signifies that recently infected individuals may struggle to navigate and assimilate the multitude of HIV-related information disseminated within systems of support, particularly concerning the applicability of suggestions and recommendations that appear unfeasible. Although Nora's initial experience of social support indicates the difficulty in creating positive appraisals within support group participation, Nora's transition from a state of uncertainty suggests that personal conviction and transformation can be powerful mechanisms for developing positive appraisals of living with HIV/AIDS. Her steadfast belief in the development and provision of an HIV-based cure maintains her desire to provide a meaningful life for her children. Nora's extreme identification with her HIV-infection is a personal method at regaining control over her life. Her belief in the development of a cure should not be perceived as naive confidence, but rather her belief legitimises her intention of leading a long and fulfilled life; contrary to the limited life believed to represent an HIV-infection. Nora's practice of self-disclosure

within VCT is directed towards reconstructing the normative construction of living with HIV/AIDS, defying the notion of a limited life following a seropositive diagnosis. However her resolve differs from Zinhle and Laura's purpose, where Zinhle and Laura aim to redefine the normative beliefs surrounding the lived experiences of living with HIV/AIDS, Nora purposely denies the lethality of HIV-infection and opts to promote living in preparation for a cure. Recapturing the potential for future possibilities is an attempt to regain a semblance of normality, shattered through experiences of receiving a seropositive diagnosis. Nora's position as a peer counsellor and support group facilitator indicates her desire to facilitate processes of developing positive appraisals within counselling and supportive structures. Although Nora maintains that effective behavioural transformations are reliant on the client's resolve and the counsellor's facilitation.

Thandi's experience of sero-discordance is punctuated with experiences of unprotected sex, and her husband's defiant disregard for her desire to protect him from HIV-infection. Through disclosure within support group participation, Thandi found empathic connection and refuge in the experiences of individuals living with extended HIV-infection. Empowered to lead a healthy and positive life and presented with opportunities to practice lay counselling she secured some financial stability and removed herself from a relationship not conducive to safe sexual practices. Thandi's experiences with social support, subsequent acceptance of her seropositive status within social support, and her position as a lay counsellor empower her conviction to provide similar experiences to recently diagnosed individuals. Facilitating multiple support group programmes, Thandi assists grandparents who have inherited grandchildren from departed sons and daughters. Her self-disclosure within support group facilitation and as a public speaker attempts to empower infected and affected individuals. Although Thandi refuses to self-disclose within VCT encounters, this indicates the significance of ameliorating the plight of affected individuals within her community. Her desire to remain professional as a lay counsellor necessitates non-disclosure practices, where she insists on the benefit of support group participation. Thandi's intention is to reconstruct the normative belief surrounding seropositivity through self-disclosure in public forums.

Zinhle's transformation from a state of denial and social avoidance towards a positive appraisal of her infection required continuous effort and social support. Zinhle's denial of her infection and her sustained practice of social avoidance necessitated a simple act of external responsibility, in this case the simple task of answering a telephone, which gradually removed her reliance on social avoidance and isolation. Similarly, Laura's appraisal of her

infection was dominated by experiences of shame and self-blame, which were alleviated through the provision of external responsibilities of HBC and participation in social support. In addition Laura realised that although her life had changed inextricably, this catalysed and amplified her motivation to structure her life towards ensuring a future for her child. Akin to Laura's resolution, Nora purposefully decided to live for her children, assimilating and emphasising the importance of developing self esteem and personal conviction within systems of social support. Thandi's experiences indicate that participation in social support allowed her to construct a positive image of living with HIV/AIDS through recognising the potential to lead a fulfilled life through the experiences and reflections of individuals who had been living with HIV/AIDS for several years. Thandi's experience of support group participation indicates that participation in social support contributes towards psychological adaptation of living with HIV/AIDS. The development of hope through constructive action indicates that PLHA are actively engaged with attempting to change their lives despite the realities of living with a seropositive status (Kylma et al., 2000). Yet underlying this realisation is the awareness that processes of acceptance require social support, moreover commitment and dedication towards minimising uncertainty improves feelings of control (Stanley, 1999).

The peer counsellors' transition from service user towards service provider highlights the increasing reliance and utilisation of lay cadres within healthcare systems (Sanjana et al., 2009; Zachariah et al., 2009). Laura and Nora elucidate towards their financial struggle during the period of discovering their seropositivity. Zinhle highlights her period of struggle in accepting her seropositive diagnosis, and signifying her desire to minimise negative experiences of receiving a seropositive diagnosis. Thandi's negative experience with sero-discordance and subsequent acceptance through peer support additionally highlights her determination to provide similar systems of peer support to recently diagnosed individuals. The participant's experience of acceptance and personal growth following their diagnoses prompted their resolve to provide similar systems of support to reduce experiences of hopelessness in counselling encounters with recently diagnosed individuals. The provision of counselling and supportive services intends to reduce detrimental experiences of receiving a seropositive diagnosis, but fundamentally to ensure that support is supplied where necessary. However assuming that the counsellors' sole intention is the provision of supportive services does not consider the economic reality of such facilitation. Although the counsellors endeavour to minimise negative experiences during counselling encounters, owing to their

familiarity in living with HIV/AIDS, the reality of limited opportunities for employment in South Africa, compels the counsellors to remain embedded within the field of HIV-care. Furthermore rooted within such practice is the informal utilisation of task-shifting, ensuring that peer counsellors abundant with personal experiences are far more versatile and functional to impart personal experiences within the multidimensional field of HIV-care, rather than simply limiting their potential benefit to counselling and testing processes.

5.2 Peer counselling

5.2.1 Practice and procedure

Protocols which underlie counselling and testing procedures strictly prohibit the sharing and utilisation of personal experiences (Driskell et al., 2010). The basis of such practice centres on avoiding additional burdens which the counsellor may invoke during counselling and testing processes; particularly considering the ramifications of a seropositive diagnosis. Although recently diagnosed individuals will ultimately contend with various issues relating to their seropositivity, the challenge of counselling and testing procedures is not to amplify such concerns, but to assist and alleviate experiences of uncertainty in managing such problems. The supposition that sharing personal experiences within counselling procedures will result in the amplification of uncertainty is probable, yet does not account for the potential benefit of such practices. Furthermore the standard model of counselling and testing facilitates access towards institutional support and knowledge acquisition, but does not assist in developing positive appraisals of seropositivity. The sharing of personal experiences in managing and living with HIV/AIDS, directed towards empowering and facilitating recently diagnosed individuals should be considered an option for developing alternative methods of providing care and support to HIV-positive populations. Particularly for recently diagnosed individuals who are struggling to comprehend and accept their seropositive diagnosis.

Voluntary counselling and testing procedures are intended to provide entry for the utilisation of support and treatment opportunities. Lay counsellors as representatives of VCT are required to provide access towards such opportunities, while exhibiting extensive knowledge surrounding HIV transmission, reduction in risk behaviours, and treatment (Hutchinson & Mahlalela, 2006). Thandi's reluctance at utilising personal experiences supports the standard procedural practice within VCT. Her motivation relates to the construction of a counselling

identity which conflicts with utilising personal experiences. Furthermore the role of lay cadres within the healthcare system produces vague and overlapping responsibilities (Zachariah et al., 2009), which maintain professional therapeutic boundaries, yet fail to afford ongoing supportive counselling for countertransference experiences. The dichotomy between training and practice within VCT indicates that the role of lay cadres requires scrutiny regarding the utilisation of personal experiences, and ergo the practice of self-disclosure as a mechanism for assisting in acceptance of a seropositive diagnosis. Prohibiting personal experiences because of the potential burden disregards the potential benefit of self-disclosure within VCT. Additionally it implies that peer counsellors may be incapable of respecting the boundaries of counselling procedures, and as a precautionary measure the decision to remain imbedded within professional therapeutic practice must include procedural practices of non-disclosure. However the experiences of Zinhle, Laura, and Nora indicate the discrepancy between training and daily practice of VCT, where routinely these counsellors self-disclose to identify with their clients to facilitate the sharing of lived experiences of living with HIV/AIDS.

5.2.2 Self-disclosure

The utilisation of personal experiences within counselling and testing practices requires acts of self-disclosure. This necessary step is evident from Zinhle, Laura and Nora's transcripts, where the utilisation of personal experiences is preceded by self-disclosure of a seropositive status within counselling encounters. Van Dyk (2005) states that self-disclosure practices must benefit the client by focusing towards an examination and understanding of their seropositivity. Yet the challenge of self-disclosure directly relates towards normative constructions of stigmatisation (Miller, 2000). The paradox of self-disclosure within the context of VCT relates to the potential benefit of sharing lived experiences, versus the risk of identification as someone living with HIV/AIDS in South Africa. Although confidentiality as a core structure of counselling protocols are strictly maintained by counsellors, their cliental may inadvertently or consciously disclose their counsellors HIV-status to others, potentially placing their counsellors in precarious situations. The practice of self-disclosure centres on the participant's identification to their clients' diagnoses experiences. Particularly in encounters where their clients are struggling to comprehend their new serostatus.

HIV-positive peer counsellor may have countertransference reactions towards their clients' narrative concerning diagnosis, disclosure, treatment, and care (Schönnesson & Ross, 1999).

Contemporary classifications of countertransference would dispute such experiences within lay therapeutic practice. However, Hayes et al. (2011) state that countertransferential reactions are inexorably linked with therapeutic relationships. This is evidenced throughout the counsellors' recounting experiences of post-counselling recently diagnosed individuals. However within the procedural practice of VCT the utilisation of personal experiences are forbidden. Yet simply prohibiting the sharing of personal experiences as a method of professional therapeutic practice serves little cause when one considers acts of non-disclosure as procedural etiquette, and yet no counselling or supportive service for countertransference experiences are provided. Although Zinhle, Laura and Nora promote and actively utilise personal experiences in counselling situations in which they believe are required. The routine practice of internal support group participation is inadequate at easing their experiences of countertransference. Furthermore Laura and Nora specifically state how open discussion within their organisation surrounding the utilisation of personal experiences have merely resulted in the reinforcement of standard VCT practice, rather than re-evaluating the potential benefit of utilising personal experiences as a facilitator towards accepting a seropositive diagnosis.

5.2.3 Countertransference reactions

Zinhle and Laura's experiences of counselling recently diagnosed individuals emphasise the ease at which identification during counselling encounters can result in countertransferential experiences; predominantly concerning the difficulty of accepting a recent seropositive diagnosis, but also include experiences of disclosure, and beginning and adhering to treatment. The experience of conveying a seropositive diagnosis frequently evokes the counsellors' past experience of receiving their seropositive diagnosis (Schönnesson & Ross, 1999). Providing personal accounts of the expected difficulties, possible solutions, coping strategies and positive cognitions are valuable contributions towards reducing the expected uncertainty and anxiety experienced post diagnosis. The simple courtesy of self-disclosure to demonstrate empathy and acknowledgment during counselling encounters may assist with acceptance. It is important to clarify the distinction between an empathic connection and a countertransference reaction during post-counselling in VCT. A countertransferential reaction compels a counsellor towards alleviating the experienced difficulty in accepting a seropositive diagnosis. Participants experiencing countertransferential reactions embody personal unresolved conflicts which direct counselling processes towards sharing particular personal experiences. An empathic connection is a counselling connection which recognises

the inherent shared experiences of diagnosis, treatment and care, where the provision of personal experiences is utilised to facilitate acceptance but ultimately to convey empathy and solidarity. This distinction is a necessary clarification as counselling encounters where personal experiences are utilised does not necessarily indicate that a countertransferential reaction has or will occur. Rather within particular counselling encounters where clients invoke the yearning for care and counsellors who have struggled to resolve their conflicts in receiving care are countertransferential reactions likely to occur.

Nora states that identifying with her clients' experiences of diagnosis through self-disclosure practices creates a counselling environment conducive to sharing personal experiences. Furthermore through identifying as an individual living with HIV/AIDS the participants are perceived as being credible to convey their knowledge owing to their lived experiences of diagnosis and subsequent acceptance. Messias et al. (2006) found that peer counsellors are better suited towards imparting information and support to recently diagnosed individuals. In addition research conducted by Gusdal et al. (2011) established that peer counsellors are better able to relate to their clients' personal concerns. Yet the counselling encounters which cultivate the utilisation of personal experiences are dependent upon identification with their clients' reactions towards receiving a seropositive diagnosis. Laura and Zinhele state that although they actively encourage the utilisation of personal experiences within counselling encounters, not every counselling session with a recently diagnosed individual engenders the utilisation of personal experiences and self-disclosure. The counsellors maintain that the use of personal experiences is reliant on their clients' negative appraisal of their seropositive diagnosis. This aspect seems particularly apparent, yet there are counselling encounters where clients are merely confirming their assumption of being infected. An examination of the utilisation of personal experiences indicates that counselling encounters where the participants identified with their clients' experiences of struggle and hopelessness often results in the utilisation of personal experiences. Within such practices the participants recognized specific avenues in which their personal experiences could be adapted towards supporting recently diagnosed individuals. Assistance with acceptance, positive cognitions, disclosure, treatment, and social support are frequently presented as avenues in which personal experiences are most valuable.

5.2.4 *Developing hope*

Accepting a seropositive diagnosis challenges an individual's conception of self and directly relates towards managing an identity perceived as being tarnished by immoral behaviour. Furthermore such experiences shatter perceptions of normality and compel individuals towards regaining control of their lives (Burchardt, 2010). Kylma et al. (2000) emphasise psychological distress as a consequence of receiving a seropositive diagnosis, which can result in a diminished survival rate and reduced HRQoL. Hope, despair and hopelessness can be interpreted as moving along a continuum with regards to living with HIV/AIDS, these dimensions of hope are influenced by factors such as uncertainty and one's emotional state. Uncertainty is an aspect of life in general, it is however far more pronounced if one has a chronic illness such as HIV/AIDS. Research regarding uncertainty has limited their findings towards negative results; this however does not indicate that uncertainty has no positive aspects. Kylma et al. (2000) found that uncertainty and fear is associated with despair and hopelessness, whereas uncertainty and aspiration is associated with hope. Living with HIV/AIDS increases the awareness of uncertainty surrounding one's life (Brashers et al., 2004), peer counselling and peer support are not void of uncertainty. On the contrary peer counselling and peer support groups have evidenced uncertainty when members become ill or die (Messias et al., 2009). Therefore uncertainty is a factor in which people living with HIV/AIDS must contend with daily. Hope however is an outlet through which PLHA can create meaning and purpose in their lives; it allows them the opportunity to dream, and to have future expectations (Harris & Larsen, 2007)

The experiences of hopelessness can manifest as affective, motivational and cognitive responses, each contributing towards reduced acceptance of a seropositive status (Kylma et al., 2000). Affective hopelessness is described as a lack of hope, motivational hopelessness is described as the abdication of hope, and cognitive hopelessness is described as forfeiting future hope. Hopelessness experienced as a consequence of receiving a seropositive diagnosis irreparably affects the response towards managing an HIV-positive identity. Furthermore hopelessness extends beyond counselling encounters and relates to disclosure decisions, treatment access and adherence, and illness appraisals (Poindexter & Shippy, 2010), affecting an individual's motivation to disclose and thereby gain access towards supportive systems. Within such impenetrability the participants will draw attention to their extended period of living with HIV/AIDS. The motivation is to indicate that HIV is not associated with impending death, and that behaviour and lifestyle modification are required to live positively

with an HIV-infection. In addition the participants highlight the importance of fostering long-term commitments and aspirations, focusing on the development of hope perspectives. The promotion of positive counselling mechanisms throughout counselling and testing procedures allows a recently diagnosed individual the opportunity to realise that their HIV-infection is not a terminal experience, where treatment opportunities reduce the debilitating effects of infection, while supportive services are available to assist with daily challenges.

5.2.5 Treatment experiences

The lived experiences of beginning and adhering to ARVs provide recently diagnosed individuals an opportunity to recognise the value of experiential practice; particularly concerning the difficulty with treatment adherence and management of treatment side-effects. In addition providing knowledge concerning eligibility criteria for ART is essential, considering the low levels of familiarity with HIV/AIDS knowledge in the Eastern Cape (Mitchell et al., 2009). Prior to beginning treatment counsellors will inform of qualifying criteria, which includes disclosure to at least an individual, or participation in support groups, cessation of alcohol and substance use and or abuse, acceptance of a seropositive status, and transportation to treatment services (DOH, 2010b). Nora emphasises the importance of discarding behaviours adverse to health, such as smoking and alcohol consumption, and the adoption of constructive behaviours conducive to well-being, condom usage, treatment adherence, and acceptance of a seropositive status. Laura's assistance with transportation within facets of HBC significantly relieves difficulties of accessing treatment. Mitchell et al. (2009), state that observation of the experiences of ART adherence can significantly improve knowledge surrounding treatment and adherence behaviours. Counsellors utilising HIV treatment may transfer their lived experiences to individuals uncertain of beginning treatment, thereby facilitating the process of beginning and maintaining treatment regimes. However, Zinhle and Nora's experiences of ARVs indicate the continuous difficulty of adherence and management of treatment side-effects. In addition limited institutional support has directed Zinhle and Nora to create an internal supportive structure to discuss and alleviate their difficulties of HIV treatment, managing treatment side-effects, and treatment fatigue. These experiences signify the need to provide assistance and training for treatment adherence, not only for counsellors' struggling with adherence, but their cliental too. Laura's ability to assist with transportation needs is fortunate, but indicates the reality of ARV provision in South Africa, where only selected clinics provide treatment and a serious shortage of medical personnel impedes service delivery (Mitchell et al., 2009).

5.2.6 Conviction

The participants, notably Laura, Zinhle and Nora, state that although the utilisation of self-disclosure and personal experiences may alleviate difficulties with acceptance, ultimately their cliental must be willing to adapt and modify their behaviours accordingly. The metaphor Thandi utilises emphasises the reality of behaviour modification within lay cadres of the healthcare system, where lay counsellors are untrained to facilitate behavioural change while focusing on providing access to institutional and informal support (Van Rooyen et al., 2009). Similarly, Nora's experiences of providing HIV counselling indicates that individuals apathetic to their infection may not readily accept testimonials of lived experiences of living with HIV/AIDS. Within the context of receiving a seropositive diagnosis in VCT, coupled with strict protocol surrounding self-disclosure and the utilisation of personal experiences, counsellors who decide to disclose to indicate solidarity and provide emotional support may struggle with cliental who appear resistant to behaviour change and acceptance of their seropositivity. Furthermore the protocols which underlie counselling and testing are not focused on developing positive appraisals nor are they focused on behaviour modification, rather the emphasis is on accessing supportive systems (Van Rooyen et al., 2009). The challenge is affecting positive transformations in clients who demonstrate initial resistance. Yet the lack of procedural practice concerning difficult cliental and the restriction on utilising personal experiences creates counselling encounters where counsellors resign to affecting change. Zinhle's experiences of counselling difficult cliental indicates the dangers of apathy, where cliental resistant to acceptance have expressed their intent to infect others. Nora shares in this struggle indicating that her determination to affect positive behavioural changes in recently diagnosed individuals, particularly concerning safe sexual practices, have minimal affect on those who are resistant to accepting their seropositivity. Additionally the procedural practice of referring difficult cliental to external sources of support may not assist with conveying safe sexual practices. Resistance towards developing positive appraisals may be attributed to the complex nature of illness appraisal experiences, influenced by personal characteristics, provision of social support, individual circumstances and culturally embedded modes of experiencing illness and health (Moskowitz & Wrubel, 2005).

5.3 Counselling relationship

The relationship developed between counsellor and client within client initiated counselling and testing is paramount for reducing experiences of anxiety and uncertainty. Counselling sessions where personal experiences are utilised to indicate solidarity and empathic support assists with difficulties of accepting a seropositive diagnosis, developing positive appraisals and coping techniques (Harris & Larsen, 2007; Messias et al., 2006; Messias et al., 2009). The circumstances in which personal experiences and the practice of self-disclosure are utilised centre on the peer counsellors' identification towards their client's response of receiving a seropositive diagnosis. Within such therapeutic relationships the opportunity to receive and disseminate valuable lived experiences to affect behavioural change, aid in disclosure decisions, access treatment, and the construction of a positive identity in living with HIV/AIDS is paramount. The intention is to ensure that clients are fully aware of the consequences of testing seropositive. The counsellor's who share personal experiences emphasises the empathic connection to their client's diagnosis experience, drawing attention to their experiences of expected challenges, successes, and knowledge, additionally facilitating access to institutional support and treatment services (Messias et al., 2009).

Counselling relationships which promote the utilisation of personal experiences, ergo self-disclosure practices, immeasurably affects experiences of post-counselling. Successful implementation of peer counselling provides recently diagnosed individuals with knowledge surrounding HIV/AIDS, coping skills to manage the daily physiological and psychological challenges, facilitation and adherence to treatment, social assistance, ongoing relationships, inspiring hope, and the creation of positive appraisals (Driskell et al., 2010; Gusdal et al., 2011; Harris & Larsen, 2007; Messias et al., 2006; Messias et al., 2009). Within such endeavours peer counsellors are able to convey their personal experiences and provide lived examples through their narratives of undergoing similar experiences (Harris & Larsen, 2007). The participant's experiences support the findings of Messias et al. (2009) where counsellors' embodied work included serving as role-models, maintaining relationships, and encouraging hope in other HIV-positive individuals. Additionally willingness to share personal experiences was expressed as essential to helping recently diagnosed individuals. Harris (2006) emphasises the positive outlook of peer counsellors, indicating the resilience and motivation to create mutually supportive relationships with PLHA. The value of peer counselling is evident from the transcriptions, mirroring findings surrounding the beneficial practice of sharing personal experiences within counselling encounters (Driskell et al., 2010;

Harris & Larsen, 2007; Messias et al., 2009). Through the provision of VCT services, HBC, and public speaking the peer counsellors reveal what is often a hidden experience. The stigma and fear of being HIV-positive, particularly for HIV-positive women, can be transformed through individual and collective empowerment (Messias et al., 2009).

Although the rapid nature of VCT (Roberts et al., 2008) does not necessarily suit the practice of self-disclosure and the sharing of personal experiences, counselling encounters which strictly follow procedural practice may be less likely to produce clients that have positively appraised their diagnosis experience. Furthermore the initial reluctance of individuals to participate in support groups points towards the assignment of behavioural modification modules in VCT services to facilitate unwilling and defiant clients (Van Rooyen et al., 2009). Although Zinhle, Laura, and Nora endeavour to utilise their personal experiences in post-counselling encounters, the undefined role of lay cadres within the healthcare system, and the multiple responsibilities required of HIV-positive CHW may produce constrained and superficial counselling encounters. The practice of informal task-shifting indirectly results in rapid post-counselling processes, reducing the likelihood of self-disclosure practices to encourage sharing personal experiences. Thandi's reluctance at utilising personal experiences may extend beyond simple preservation of a professional counselling identity, and indicate that the rapid nature of VCT is embedded within an informal task-shifting environment, thereby limiting the potential utilisation and benefit of sharing personal experiences in counselling encounters. However her encouragement of support group participation indicates the only available method to assist PLHA, and should be promoted within time-limited counselling encounters (Messias et al., 2009).

5.3.1 Providing and requiring support

Prior to becoming practicing lay counsellors, the participants indicated their desire to facilitate and support recently diagnosed individuals. The motivation to help others is a pinnacle theme in research concerning women living with HIV/AIDS, where upon knowledge acquisition and disease management HIV-positive women are compelled towards social assistance (Moneyham et al., 1997). The motivation to assist recently diagnosed individuals is engendered through the participants' personal experiences, emphasising the credibility of their prescriptions through self-disclosure practices. The participants noted the importance of facilitating one-on-one counselling and support within VCT, but additionally emphasise the necessity of connecting recently diagnosed individuals with existing

supportive systems, including health, social and economic resources. Messias et al. (2009) note the relevance of prior experiences of CHW, accentuating the importance of ongoing peer counsellor training on the eligibility, availability and access to existing supportive structures. The participants indicated the necessity of training concerning assistance with disclosure decisions, particularly amongst sero-discordant couples, apathetic cliental threatening to infect others, and assistance with counselling men. The necessity of ongoing training is to encourage positive living approaches, which emphasise treatment access and support group participation. Without current applicable knowledge, the prescription of counselling guidance may further aggravate experiences of anxiety and uncertainty following a seropositive diagnosis.

The concurrent practice of providing support and seeking support in peer counselling creates complex challenges which require ongoing systems of support, particularly concerning remuneration, ongoing training and supervision (Poindexter, 2006; Zachariah et al., 2009). Consider the lived reality of a seropositive status juxtaposed against ensuring positive experiences of living with HIV in other recently diagnosed individuals. Peer counsellors possess a wealth of lived experiences, but are required to constantly check against their utilisation within VCT. Yet countertransference reactions are highly probable owing to the shared experience between a peer counsellor and a recently diagnosed individual, especially concerning acceptance of a seropositive status, diagnosis experiences, disclosure decisions, and accessing treatment and support opportunities (Schönnesson & Ross, 1999). Hayes et al. (2011) suggest that therapists motivated to resolve their issues reduce the likelihood of countertransference experiences, while increasing the epistemic value of personal experiences. However the professional realm of therapeutic practice is beyond daily peer counselling practices. In addition experiences of diagnosis and the daily challenges of living with HIV/AIDS are continuously adapted, refined and adjusted (Burchardt, 2010; Moskowitz & Wrubel, 2005). Assuming that simply resolving internal struggles will alleviate experiences of countertransference does not consider the difficulties in conveying a seropositive diagnosis, nor does it consider the pervasive nature of managing a seropositive identity. Furthermore the methodologies which underlie VCT protocols are unambiguous concerning self-disclosure practices and therefore the utilisation of personal experiences. Moreover VCT procedures are rapid and focus on ensuring that cliental are aware of the implications of their seropositivity, and are directed towards institutional support

programmes to facilitate with acceptance and positive appraisals. Such counselling encounters reduce the possibility of fostering ongoing relationships with cliental.

5.3.2 Maintaining ongoing relationships

Laura's experiences with sero-discordance and limited support following her seropositive diagnosis motivated her objective of providing empathic and respectful counselling experiences. Zinhle's experiences of denial and social isolation following her seropositive diagnosis motivated her intention of providing an avenue for disclosure, mitigating the harmful effects of silence and social isolation. Thandi's negative experience with sero-discordance and subsequent acceptance following support group participation motivates her intention of providing similarly meaningful support to recently diagnosed individuals. The participants desire to limit experiences of psychological distress following a seropositive diagnosis, through the provision of lived experiences concerning the development of positive appraisals and coping techniques in living with HIV. The creation of a platform for clients to voice their concerns creates a counselling relationship of peers, as opposed to traditionally defined therapeutic roles of professional counsellor and client. Laura emphasises the interacting partnership of the counselling relationship, where the provision of personal experiences coupled with the clients' willingness to assimilate are paramount for successful development of positive living. The development of honest, open, and non-judgemental relationships is crucial to successful implementation of peer counselling (Driskell et al., 2010; Messias et al., 2006). However the rapid nature of VCT ensures that counselling encounters are brief and rushed (Roberts et al., 2008). This is problematic as post-counselling encounters endeavour to assist with negative appraisals of receiving a seropositive diagnosis, but are incapable owing to the expectation of hastening through counselling protocols (Young, 2011). Furthermore the rapid nature of counselling encounters and the requirement of processing a requisite quota of cliental limit the potential benefit of fostering long-term relationships between counsellor and client. Instead clients are requested to attend support groups to facilitate the development of relationships with other HIV-positive individuals. Thandi's reluctance at utilising personal experiences within VCT encounters encourages the benefits of support group participation, strengthening her resolve of remaining professional, but additionally indicating her confidence in developing positive appraisals of HIV-infection within support groups.

Laura's determination to improve experiences of diagnoses provides her momentum to develop ongoing relationships with her cliental beyond VCT. Remaining in constant contact serves to reinforce the coping skills, positive appraisals and positive counselling approaches disseminated in VCT. Similarly Thandi expresses an inherent concern for her clients beyond VCT, indicating that the notion of separating professional responsibilities outside of VCT is often unfeasible, owing to shared experiences and the knowledge that acceptance of a seropositive status is fraught with emotional difficulty. The challenge for peer counsellors extends beyond their role within their organisation and encompasses daily interactions within their communities as HIV-positive CHW. Opportunities for rest and recuperation are limited if communities in which HIV-positive counsellors are based are consistently expecting peer counsellors to provide support, knowledge and care over and beyond their work-related responsibilities. The addition of multiple assortments of HIV-based work the participants are expected to accomplish ensures that daily interactions with HIV-positive cliental are cultivated, yet a lack of professionally defined therapeutic boundaries is evident. Zinhle's experiences of assisting recently diagnosed individuals indicate the difficulty in establishing therapeutic boundaries within the context of community-based programmes. The provision of HBC, assistance with procuring treatment, financial and subsistence support represents opportunities to engage with HIV-positive CHW. The challenge is the construction of positive role models to ensure positive behavioural and psychological adaptation in living with HIV/AIDS versus the expected role communities anticipate from their CHW; especially peer counsellors. The intention is not to foster dependency in their cliental, but to empower their cliental to act on their own account. Similarly this indicates the necessity of providing peer counsellors with guidance in facilitating and providing support, focusing on the divergent responses individuals' experience whilst limiting the potential for developing dependency (Messias et al., 2009).

5.3.3 Multiple roles

The informal utilisation of task-shifting within HIV-based lay healthcare cadres without remuneration and social support is problematic and increasingly recognised as a potential for resignation, burn-out and demoralisation (Sanjana et al., 2009; Schneider et al., 2008; Zachariah et al., 2009). All the participants practice VCT, and are expected to provide ongoing systems of support within support groups, HBC, and peer education. Within such commitments are the transmission of HIV/AIDS-based education, assistance with treatment literacy, and accessing governmental social assistance. These additional tasks are positioned

within the field of HIV-based work, yet the experiences of Zinhle indicate that organisations who hire HIV-positive individuals often disregard the reality of being an HIV-positive counsellor. Poindexter (2006) highlights the duality of peer counselling, where counsellors facilitate accessing systems of social support, but simultaneously require access to systems of support. This is particularly salient for experiences of countertransference, where the utilisation of personal experiences is prohibited, but no structure of ongoing counselling or support are provided for counsellors who experience countertransferential reactions from counselling recently diagnosed individuals. In addition therapeutic boundaries exist in professional discourses of counselling, yet within the realm of lay healthcare cadres, coupled with high expectations from cliental to affect economic and health-based change, the boundaries between peer counsellor and client are often blurred and indistinct. Zinhle's experiences of providing counselling and testing services indicates a high level of expectation from her cliental, including the provision of financial and subsistence support. The informal utilisation of task-shifting coupled with ongoing care provided to cliental reduces therapeutic boundaries, thereby increasing the likelihood of occupational stress, yet a lack of institutional support and the socio-economic realities of infected lay counsellors compels them to remain imbedded within such environments (Schneider et al., 2008).

A lack of governmental clarity on task-shifting and the consistent delay in recognising the benefit of utilising lay healthcare personnel to offset the increasing pressure on primary healthcare services is increasingly recognised (Evensen & Stokke, 2010; Sanjana et al., 2009; Zachariah et al., 2009). The Department of Health's apathetic position on lay healthcare personnel further entrenches informal practices of task-shifting (Evensen & Stokke, 2010; Schneider et al., 2008). Directly resulting in an increase in the quantity of work and potentially reducing the quality of counselling encounters, without adequate compensation, recognition, and ongoing support (Sanjana et al., 2009; Schneider et al., 2008; Zachariah et al., 2009). This is particularly prominent in adherence counselling, counselling difficult and apathetic cliental, and experiences of countertransferential reactions. Messias et al. (2009) indicate that the success or failure of peer intervention programmes is largely dependent upon the mobilisation, ongoing training and support of local individuals. Without the requisite support and training required to implement successful intervention programmes, one cannot assume the direct benefit of such practices. Unfortunately the experiences of Zinhle, Nora, and Laura indicate the lack of governmental support, citing their ongoing need for remuneration, training, support and recognition (Messias et al., 2009; Zachariah et al., 2009).

5.3.4 Challenges

The peer counsellors indicated several challenges in providing VCT services as HIV-positive lay counsellors. A severe lack of institutional support concerning their experiences of countertransference, a lack of clearly defined therapeutic boundaries between counsellor and client creating dependency relationships, and affecting behavioural change in defiant cliental. Furthermore embedded within the field of HIV-care and counselling the participants highlighted their difficulty in affecting behavioural changes in youths, particularly concerning safe sexual practices. Thandi's experiences in peer education with youths indicates that culturally defined modes of sexual activity are frequently cited as a right to unprotected sex, thereby reducing the potential benefit of peer education programmes aimed at reducing risky behaviours, rendering youths vulnerable to future infections. Additionally Zinhle notes how self-disclosure practices within peer education and public speaking citing the lived realities of living with HIV/AIDS does not engender behavioural changes in youths. The utilisation of CHW in affecting behavioural changes within their communities is a critical aspect of increasing knowledge concerning HIV/AIDS transmission, treatment and care. However the experiences of the counsellors indicate that a single prescribed method of peer education is ineffectual at modifying risky behaviours, particularly in youths.

Confidentiality is a core aspect of voluntary counselling and testing encounters (Uys, 2003), yet the experiences of the participants indicate that the virtuous aspect of confidentiality often conflicts with preventative attempts at reducing risky behaviours. Zinhle notes how her experiences of counselling sero-discordant couples frequently results in conflict between maintaining her client's serostatus, versus exposing a client's seropositivity to protect a seronegative partner from potential infection. The dilemma is amplified when seropositive cliental insist on non-disclosure, fearing potential ostracism and violence emanating from self-disclosure practices. Peer counsellors are unprepared to sacrifice their position as lay counsellors by violating their counselling agreement with their cliental. Yet the act of silence potentially exposes an individual to HIV-infection, owing to difficulties in discussing and negotiating safe sexual practices in relationships which have forgone the utilisation of condoms owing to an acknowledgement of exclusivity in their relationship. This indicates a need to provide counsellors with ongoing training to negotiate the benefit of self-disclosure practices within sero-discordant relationships in counselling and testing encounters. Developing and fostering the importance of support and safe sexual behaviours in sero-discordant couples. Fundamentally the single prescribed method of counselling and testing is

ineffectual at affecting behavioural changes, whether in uninfected or infected individuals, and indicates the necessity of utilising additional counselling and testing methodologies (Van Rooyen et al., 2009).

5.4 Credibility

Research examining the benefit of peer counselling approaches focus on disenfranchised (Gusdal et al., 2011; Messias et al., 2009) or specific populations (Driskell et al., 2010; Harris & Larsen, 2007). However day-to-day practices of peer counselling within South Africa are beyond refined research parameters, and encompass daily challenges, constrained finances and limited support (Zachariah et al., 2009). Although the development of comprehensive care programmes for PLHA is increasingly required and recognised, the scarcity of professional medical personal to implement such programmes are alarmingly evident (Sanjana et al., 2009; Schneider et al., 2008). Furthermore the recognition of the utilisation of lay cadres within the healthcare system to alleviate the burdens placed by HIV/AIDS on primary healthcare is increasingly recognised (Sanjana et al., 2009; Schneider et al., 2008; Zachariah et al., 2009). Increasing evidence suggests the effectiveness of peer counselling approaches in affecting positive health outcomes in PLHA. Messias et al. (2006) found that peer counsellors appeared more credible to impart information and support to recently diagnosed individuals. Additionally Gusdal et al. (2011) discovered that PLHA recognised the experiential weight of peer counsellor recommendations, particularly concerning the empathic connections fostering positive health outcomes of treatment adherence behaviours. Yet the focus on specific populations and the general nature of South Africa's HIV pandemic suggest more evidence is required to determine the credibility of peer counselling approaches in South Africa.

The participants embody the individual Jewkes (2006) describes as embedded within the field of HIV care and counselling, creating an enabling environment fostering disclosure not only to access support and treatment, but also to deconstruct normative constructions of living with HIV/AIDS. Replacing preconceived beliefs and norms through lived experiences legitimised through an individual living with extended HIV infection. The participants experience deep empathic connections towards their clients' diagnosis experiences, and the facilitation of personal experiences intends to reduce the expected psychological distress of receiving a seropositive diagnosis. Zinhle, Laura, and Nora state how cliental frequently state

disbelief in counsellor prescriptions because of a lack of lived experiences in living with HIV/AIDS. Within such conditions the participants self-disclose to indicate solidarity, but fundamentally to create opportunities for empathic relationships utilising personal experiences. Clients recognise the inherent value of disclosure as it challenges their conception of stigmatised silence in living with HIV/AIDS. The participants, notably Zinhle, Laura and Nora, state that the use of self-disclosure allows access to using personal experiences, creating a relationship of mutual understanding, where clients appear more willing to adjust towards and accept their seropositivity, owing to the lived experiences of their HIV-positive counsellors. Thandi's reluctance at utilising personal experiences does not diminish the value or credibility of her counselling prescriptions, rather her method legitimises the utilisation of social support programmes, which focus on sharing personal lived experiences of living with HIV/AIDS.

Chapter 6: Conclusion, Limitations and Recommendations

6.1 Conclusion

The practice of peer counselling within the context of VCT services in South Africa has received minimal research interest. This research expands on literature concerning the practice of peer counselling, but additionally informs on the utilisation of CHW in mobilising care and support for the burgeoning HIV-positive population. The provision of peer counselling fosters an empathic connection between counsellor and client. The focus of these counselling relationships is the development of acceptance of a seropositive status, promoting positive appraisals, positive behavioural modifications, assistance with beginning and adhering to ART, support in accessing governmental social assistance, and knowledge acquisition. Although counselling and testing procedures are rapid, the counsellors endeavour to reduce the hopelessness experienced in discovering a seropositive diagnosis. The intention is to emphasise the availability of treatment and supportive services, but fundamentally to indicate through personal experiences that the initial struggles of acceptance are vastly improved through active development of self-efficacy and participation in social support. The circumstances in which personal experiences are utilised depend on the counsellors' identification towards their client's struggle in accepting their seropositive diagnosis. Cliental may invoke unresolved issues within their counsellors, or the empathic connection of sharing an experience may manifest as a process of sharing personal lived experiences. Irrespective of the means, the process of sharing lived personal experiences of living with HIV/AIDS is explicitly prohibited within VCT services. However three of the four interviewed participants adamantly stated that they frequently utilised their personal experiences within counselling encounters which they deemed required such provision.

Counselling relationships which promote positive thinking mechanisms attempt to reduce the debilitating experience of diagnosis, and emphasise the development of hope perspectives. Although the importance of developing positive appraisals is significant, the socioeconomic reality of many infected individuals subsumes wider issues of inequity, particularly in relation to gender inequality. Peer counsellors may endeavour to affect positive behavioural changes in their cliental, but woman in abusive relationships may be unable to practice positive health-seeking behaviours, owing to the likelihood of experiencing further abuse, financial lose, and violence. This draws attention to the need to provide training for intimate partner violence, and discourse which empower women's reproductive rights. Additionally

cliental who are resistant to behaviour modification and indicate their desire to infect others signifies that counsellors require additional training to facilitate defiant cliental, rather than the procedural practice of referring to other CHW; where the potential for further infection is highly likely owing to the client's unchanged attitude concerning safe sexual practices. Furthermore widespread financial inequality is likely to produce cliental who insist on their counsellors resolving their multiplicity of issues. The lack of professionally defined therapeutic boundaries in VCT is evident in community health work, where the participants have experienced high demands from their cliental, over and beyond the allocated facilitation within VCT.

The diverse and complex process of accepting a seropositive diagnosis is influenced by individual, cultural and contextual variables, frequently beyond the training protocol received by lay counsellors. Peer counsellors may strive towards maximising the potential to positively appraise a seropositive diagnosis, but in circumstances where training is unhelpful, the participants resign to affecting transformation. This supports results from Van Rooyen et al. (2009) research, which emphasises the importance of developing alternative counselling and testing approaches. The current Egan influenced counselling and testing model appears to be ineffectual in engendering behaviour change in defiant cliental. Furthermore untrained to determine individual risk practices to minimise future infection, the participants can only advocate for health-seeking behaviours motivated through personal experiences. There is an increasing need to include behaviour modification modules into VCT training. The general nature of South Africa's pandemic does not indicate that experiences of diagnosis, treatment and care are homogenous, indeed the findings of this research indicates the divergent socio-economic positions of seemingly homogenous groups, such as HIV-positive lay counsellors, affects the lived experiences of living with HIV/AIDS.

Research examining the credibility of peer counselling approaches as a secondary preventative strategy has indicated the applicability and feasibility of peer counselling in resource constrained settings (Gusdal et al., 2011; Messias et al., 2009). Additionally the increased reliance on CHW occupying the roles and responsibilities of primary healthcare personnel to offset the increasing pressure of HIV/AIDS on primary healthcare is evident. Therefore the inclusion of peer counselling approaches as an alternative method of providing care and counselling to the escalating HIV-positive population should increasingly become utilised. However the structural limitations of VCT are evident in the experiences of the participants, particularly concerning ongoing training, remuneration and psychosocial support

(Sanjana et al., 2009; Zachariah et al., 2009), which must be addressed to clearly define the role of peer counselling within VCT services. Simply prohibiting the sharing of personal experiences under the assumption that counsellors will utilise counselling and testing encounters to indulge in narcissistic practices, disregards the potential benefit of sharing personal lived experiences of living with HIV/AIDS. Additionally it undermines the practices of peer counsellors who utilise self-disclosure practices and share their personal experiences on a daily basis within South African VCT services. Jewkes (2006) and this research advocate the utilisation of peer counsellors as active role-models within their communities, reconstructing norms, beliefs and attitudes concerning seropositivity, expressed and legitimised through an individual living with HIV/AIDS.

6.2 Limitations

The commitment towards an inductive approach in IPA places the participant as the expert of the phenomenon under examination. The researcher and participants co-constructed the reflexive experiences of the counsellors accepting seropositive diagnoses, personal transformations, disclosure decisions, counselling processes, and treatment. The double hermeneutic is evident where participants are attempting to make sense of their experiences, while the researcher attempts to make sense of the participant's reflexive examination of their experiences. The participants were able to elucidate their lived experiences, although articulated in their second language, English. A limitation exists within the interpretation of experiences not articulated in the participants preferred language, Xhosa. For example questions regarding the potential benefit of sharing personal experiences may have been construed towards assessing the participants work performance, and therefore answers could have reflected the social desirability aspects of wanting to appear competent and professional. Although the question is not particularly guiding towards critical self evaluations of work performance, the lack of employment opportunities within South Africa, coupled with securing stable income may potentially have compelled the participants to answer in a socially desirable manner. However the utilisation of such questioning is necessary and appropriate for assessing the lived experiences of providing VCT services. Furthermore embedded within the field of HIV care and counselling, the participants are equipped with discourses propagated within the field of HIV care and counselling, and may not necessarily reflect the lived experiences of the participants, but rather rehearsed dialogues perpetuated

throughout counselling encounters. The notion that discourses reflect lived experiences are continuously challenged by discursive psychological endeavours (Shinebourne, 2011).

The utilisation of only female participants could be construed as a potential research limitation. Although all counsellors within VCT are trained to implement a particular counselling protocol, the female participants expressed specific concerns relating to counselling men and affecting behavioural changes in youths. This concern may not translate to male peer counsellors who may experience difficulties in counselling woman, although no male counsellors were willing to participate in this research project, and therefore the challenges affecting HIV-positive male counsellors is as yet unknown. The implications from this research may not reflect the lived experiences of HIV-positive male peer counsellors, indeed the experiences of living with HIV/AIDS must not be construed as homogenous.

All HIV-positive individuals require care and support, the experiences of accepting a seropositive diagnosis are influenced by cultural, individual and socio-economic circumstances. The majority of participants through their diagnosis experiences were compelled towards sharing personal experiences within counselling processes. However one participant was reluctant at utilising her personal experiences as it conflicted with the preservation of her professional counselling identity. The counsellor who refrained from self-disclosure practices may reflect the broader practice of VCT in South Africa, where the practice of sharing personal lived experiences conflicts with processes of VCT protocol. The utilisation of four participant's experiences of living with HIV/AIDS and working within the setting of VCT does not reflect all lived experiences of HIV-positive CHW. Smith et al. (2009) recommend at least six participants for novice research endeavours. However the nature of a seropositive status intimately connected to stigmatisation and prejudice, reduced the number of participating HIV-positive lay counsellors. Therefore the implications of the experiences of four HIV-positive lay counsellors does not elucidate towards generalisability, rather the focus is widening the conception of the lived experiences of such individuals within particular VCT contexts.

6.3 Recommendations

Examining the credibility of recommendations transmitted via an HIV-positive lay counsellor versus an HIV-negative lay counsellor requires additional research. The peer counsellors

frequently utilised their personal experiences to facilitate and support recently diagnosed individuals. The counsellors claimed the benefit of their prescriptions through personal lived experiences, citing their past experiences as the impetus towards their desire to limit the experienced anxiety and uncertainty in post-counselling. The researcher recommends examining how clients experience self-disclosure practices within VCT processes in South Africa, how sharing personal experiences may reduce or amplify experiences of uncertainty. Furthermore the inclusion of male peer counsellors may elucidate the benefits and challenges of such practices, as the focus on female counsellors indicates how issues of gender inequity permeate throughout counselling encounters, where male clients appear resistant towards accepting the prescriptions of HIV-positive female lay counsellors.

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Appendix 1

Rhodes University Department of Psychology Agreement Between Student Researcher and Research Participant

I (participant's name) _____ agree to participate in the research project of (researcher's name) _____ on the experiences of HIV-positive lay counsellors' working with people with HIV.

I understand that:

1. The researcher is a student conducting the research as part of the requirements for a/ an (Honours/ Master's/ PhD) _____ degree at Rhodes University.
2. The researcher is interested in the relationship between being both HIV-positive and a lay counsellor in relation to the counselling services provided in VCTs, especially with regard to counselling people who are HIV-positive.
3. My participation will involve an interview which will take approximately 90 minutes. With the possibility of a follow-up interview which will take approximately 30 minutes.
4. All interviews will be digitally recorded, and I agree to have my interview recorded.
5. I will be asked to answer questions of a personal nature but I can choose not to answer any questions about aspects of my life which I am not willing to disclose.
6. I am invited to voice to the researcher any concerns I have about my participation in the study and to have these addressed to my satisfaction.
7. I am free to withdraw from the study at any time – however I commit myself to full participation unless some unusual circumstances occur or I have concerns about my participation which I did not originally anticipate.
8. The report on the project may contain information about my personal experiences, attitudes and behaviours, but that the report will be designed in such a way that it will not be possible to be identified by the general reader.

Signed on (Date):

Participant:

Researcher:

Appendix 2

I would like to thank you for taking the time to participate in my research project! This project is interested in understanding the experiences of being an HIV-positive lay counsellor working in a VCT centre. Additionally I am interested in understanding your experiences of providing personal experiences within counselling. You will be asked questions concerning: your experiences in providing counselling services to both HIV-positive and negative clients; your experiences in using personal experiences within counselling; and your views on using personal experiences within counselling. At this point I want to reiterate that participation is completely voluntary and your name will not be used in any part of the research process.

- Please tell me about yourself and how you came about working as a lay counsellor at the VCT centre.
- What sort of training have you received for VCT?
 - What type of counselling method were you taught?
 - Could you please describe your typical day at work?
 - Do you think that VCT is effective at reducing HIV/AIDS?
 - Besides counselling people who come for an HIV-test, what other duties do you have at...?
 - What are your experiences counselling HIV-negative clients?
 - What are your experiences counselling HIV-positive clients?
- How do your experiences (of being HIV-positive) shape the relationship between you and your clients?
- Have you ever used your own personal experiences within the counselling process?
 - Could you please give me examples of situations in which you would use your own personal experiences?
 - What are your impressions on the use of personal experiences?
 - When you underwent training for VCT, what did they tell you about the use of personal experiences?
- Do you think that because you are HIV-positive you have more credibility to counsel someone who has just received an HIV-positive test result, as opposed to an HIV-negative counsellor?
 - Do clients who have been recently diagnosed as HIV-positive ever request a counsellor who is HIV-positive?
- Is there anything else you would like to add?

Glossary of Terms

AIDS – Acquired Immune Deficiency Syndrome

ART – Antiretroviral Treatment or Therapy

ARV – Antiretroviral

CHW – Community Healthcare Worker

CICT – Client Initiated Counselling and Testing

DOH – Department of Health

HBC – Home-Based Care

HCT – HIV Counselling and Testing

HIV – Human Immunodeficiency Virus

HRQoL – Health-Related Quality of Life

IPA – Interpretative Phenomenological Analysis

MTCT – Mother-to-Child Transmission

NGO – Non-Governmental Organisation

OVC – Orphaned and Vulnerable Children

PEP – Post-Exposure Prophylaxis

PEPs – Peer Education Programmes

PICT – Provider Initiated Counselling and Testing

PLHA – People Living with HIV/AIDS

TB – Tuberculosis

VCT – Voluntary Counselling and Testing

Reflexive Journal

This reflexive journal follows the experiences, beliefs, attitudes and perspectives of the researcher during his study of the experiences of HIV-positive lay counsellors. The intention of this journal is to highlight the reasons why the researcher focused on the particular aspects surrounding this research endeavour. Researching HIV/AIDS carries a real sense of urgency and necessity. Millions are directly and indirectly affected by the pandemic. Narrowing and filtering through the vast research spectrum surrounding HIV/AIDS is challenging. Deciding on a topic of choice even more so, considering the range of options, from vaccination trials to counselling bereaved survivors. Interpretative Phenomenological Analysis requires a thorough explanation for the choice of focus. In this research project, the experiences of HIV-positive lay counsellors working with people living with HIV/AIDS, represents a unique phenomenon. Individuals who are living with HIV/AIDS are counselling people about their new condition, providing guidance and personal experience towards someone who may have little to no knowledge about their ailment. The choice to focus on the experiences of HIV-positive lay counsellors is influenced by the fact that firstly no research has been conducted on such a phenomenon within South Africa, and secondly because such a phenomenon can have direct benefits for the increasingly large HIV-positive population; specifically regarding the provision of care and support. Additionally this research may have implications concerning the difficulties experienced in such a phenomenon, and therefore shed insight into what HIV-positive lay counsellors may require beyond their need for care and support for their ailment.

Literature Review

The literature review is influenced by articles concerning current practices surrounding HIV/AIDS prevention, the history of HIV/AIDS in South Africa, and literature concerning HIV/AIDS in Africa. Literature concerning peer counselling practices were included but did not focus within VCT services. Literature which focused exclusively on a South African context was given priority, as a thorough understanding of the cultural milieu would provide good contextual background. There is a need to understand the scale of the pandemic, and while quantitative studies focusing on statistics surrounding HIV-prevalence, rate of progression, and number of infected are an important contribution to the field, one must in addition understand the wider cultural forces which affect the decisions that people can or

cannot make. Gender inequality and resistance to behaviour change present serious challenges for conventional methods of prevention. The power differences between South African men and women are culturally imbedded within traditionally bounded modes of being South African. The union of prevention philosophies and safe sexual behaviours are crucial to reducing the pandemic, yet shifting cultural perceptions surrounding unequal power differences will require substantial effort and care. These social problems within and not limited to South Africa will inevitably affect the method of intervention programmes implemented. Recognising the affect of inequity related issues is the first step towards affecting positive behavioural changes to reduce further HIV transmissions.

An exploration of treatment policies for HIV/AIDS in South Africa provides the opportunity to examine the reasons behind the lack of ARV provision prior to 2003. It is unsurprising that a large body of literature concerning the ARV debacle in South Africa is available for review. Throughout the literature concerning the South African Governments lack of support for providing treatment for HIV/AIDS, there is the increasing impression that a substantial proportion of blame should be directed towards specifically Thabo Mbeki, former South African President, Dlamini-Zuma, and Tshabalala-Msimang, former South African Health Ministers. It is widely believed that the actions of Thabo Mbeki undermined the huge strides that organisations, professionals, scholars and lay individuals made prior to the provision of ARVs. Actions such as alliances with dissident perspectives surrounding the aetiology of HIV/AIDS, lack of support for reducing MTCT, support for hoax cures, reframing real social responses as attacks on patriotism are all examples of the types of actions the South African government initiated, rather than constructive actions to reduce HIV/AIDS. Strong governmental support to effect policy change is an absolute necessity; a prime example is that of President Abdou Diouf of Senegal who together with religious organisations, civil society and governmental resources maintained HIV-prevalence at below 2%. Although the focus of this particular research surrounds the experiences of HIV-positive lay counsellors, one must take note of the fact that the participating lay counsellors currently practicing lay counselling experienced their diagnosis during the period of Thabo Mbeki's Presidency. His lack of support for the provision of ARVs had a direct effect on their lives. It is therefore apparent that any examinations into HIV/AIDS prevention include discussions surrounding the development of treatment policies within South Africa. Not only to highlight the result of a lack of governmental support, but also to indicate that positive change requires commitment to fundamentals, such as agreements on transmission, prevention, and care.

The provision of ART is expected to reduce the debilitating effects of a compromised immune system. The provision of governmental assistance is expected to support individuals incapable of maintaining employment due to their deteriorating health. However these macro-level policies implemented to support and treat HIV-infected individuals often fails to recognise the structural limitations of their prescriptions. South Africa is plagued with widespread issues of unemployment. Additionally the prevailing stigma surrounding a seropositive status and the alienation of those infected with HIV/AIDS reduces the already limited opportunity of employment for HIV-positive individuals. The extensive practice of temporarily stopping ART to decrease CD4 cell count, and deliberately becoming infected to access governmental assistance are indicative of wider issues of inequity. However the ongoing support of governmental policies, attitudes, and beliefs is necessarily required to develop positive role-models. Yet the position of South Africa's current President, Jacob Zuma, particularly surrounding the practice of safe sex and concurrent sexual relationships propagate attitudes and beliefs which are not conducive towards health-seeking behaviours. This is problematic as preventative strategies will have scant effect on reducing further transmissions if the actions of Jacob Zuma are perceived as sanctioning unprotected sex, and the practice of concurrent relationships. The necessity of staunch governmental assistance both politically and personally is necessary to align the practices of primary and secondary prevention with cultural practices. Although Jacob Zuma does not sanction unprotected sex within South Africa, his practices of unprotected sex sanctions the belief of not being at risk of infection. This is a problematic issue for peer education practices which typically advocate abstinence, monogamy, and condom usage. Although this research project is interested in the experiences of HIV-positive lay counsellors, the cliental that undergo VCT may be in sexual relationships which do not utilise condoms, or individuals may be practicing concurrent relationships. Such individuals will prove challenging particularly when VCT protocol is specifically designed to provide assistance with accessing supportive services, rather than affecting behavioural changes. The need to formally include behavioural modification modules into VCT training is paramount within the literature, and the experiences of the participants.

What projected itself most strongly within the literature was the need to assess modes of care and support for an ever increasing HIV-positive population. This aspect is particularly pertinent within South Africa, and is discussed within the literature review. Although there is a strong sense of urgency surrounding the need to develop comprehensive means of care and

support, it is strange that no additional governmental support exists for the practice of peer counselling within VCT, especially if VCT is perceived to be critical in the reduction of secondary transmissions. The phenomenon of peer counsellors working in VCT can be dissected into smaller components. The term peer counsellor refers to an HIV-positive lay counsellor. The term peer is given to indicate experiential connectedness; the counsellor and his/her client are connected in virtue of their shared experience in discovering their seropositivity. The prevailing characteristic of such a relationship indicates the sharing of lived experiences, a blueprint of the counsellors' life, and what the client can expect in living with HIV/AIDS. One must be cautious to presume that experiences of living with HIV/AIDS are homogenous, although the utilisation of peer counselling engenders the sharing of personal experiences, counsellors must navigate through their experiences and glean what they deem is necessary for their clients, rather than assuming that their experiences of HIV/AIDS are homogenous and therefore applicable to all recently diagnosed individuals. An additional difficulty is marrying the notions of peer counselling within VCT. A peer counsellor in this sense refers to an individual who on some level has publically disclosed their seropositivity. This public self-disclosure on some level is necessary if lived testimonials of the counsellor's experiences are to be accepted. This phenomenon presents itself as particularly unique, considering that in most instances individuals who have publically disclosed in South Africa have met with mixed but often violent responses. What this indicates is the need to normalize an HIV-positive status. The fact that an individual who wants to aid his/her people in living with a life-threatening, debilitating illness may face scrutiny from self-disclosure is unacceptable. The continuous stigmatising attitudes that individuals place on those living with HIV/AIDS reduces efforts at normalizing seropositivity. In addition, lack of governmental support for peer counselling may reduce the effectiveness of VCT, for example lay/peer counsellors may be overworked, resulting in burnout and/or resignation, VCT centres may be understaffed, resulting in burnout/or resignation.

Literature concerning the experiences of peer counsellors is limited towards specific research endeavours and/or specific communities infected and affected by HIV/AIDS. The available research indicates the potential benefit of utilising peer counselling during VCT encounters, particularly where individuals are struggling to comprehend the magnitude of their infection. However no specific research refers exclusively on the experiences of HIV-positive lay counsellors practicing within VCT settings in South Africa. Therefore the inclusion of

literature concerning the experiences of diagnosis, acceptance, disclosure, support and transformation experiences is necessary to understand the counselling processes propagated within the context of South Africa. The rationale centres on understanding the lived experiences of living with HIV/AIDS in South Africa. The researcher does not claim that such experiences are homogenous, but rather the focus is on widening conceptions regarding the lived experiences of living with HIV/AIDS through the participant's experiences of diagnosis, acceptance, support, and transformation. It is hoped that an appreciation of the counsellors lived experiences will provide insight into the utilisation of personal experiences, and how a seropositive status affects processes of counselling, particularly in counselling encounters where counsellors experience empathic or countertransferential reactions, which may direct the counsellor towards sharing their personal lived experiences. The purpose of this research was to broaden conceptions surrounding peer counselling practices within VCT settings in South Africa, to appreciate the nature of sharing personal lived experiences within counselling processes, as well as determine notions of credibility generated between a HIV-positive lay counsellor and their recently diagnosed client. Additionally understanding the structural limitations and restrictions surrounding lay counselling will elucidate the compounded challenges faced by peer counsellors. Where peer counsellors experience the daily challenges of living with HIV/AIDS, while working within the complex field of HIV-care and –counselling.

Data Collection

Interpretative Phenomenological Analysis requires small homogenous samples able to provide rich contextualised data about a shared experience. This research was interested in the shared experiences of living with HIV/AIDS, and practicing as an HIV-positive lay counsellor. The researcher had to ensure that the participating lay counsellors had at some point within their careers as lay counsellors or as individuals publically disclosed their seropositivity. This is a necessary step as the researcher cannot ethically ask when said counsellor was first diagnosed with HIV/AIDS. Therefore only lay counsellors who had publically disclosed and were willing to participate were included into the research. Two participants were found in Grahamstown. Permission to conduct interviews had been obtained from the director of the VCT centre. It was hoped that additional participants could be found utilising snowballing methods. However there is only one NGO funded VCT centre

within Grahamstown, and the inclusion criteria for participation, exclusively calls for individuals who are currently working as a lay counsellor, therefore individuals involved in specifically care-taking roles were not considered. Initially three participants agreed to be interviewed, however one counsellor resigned prior to data collection. It is interesting to note that the VCT centre in Grahamstown did not have contact details for other VCT centres in the surrounding regions of the Makana municipal district.

The next two participants were found in Port Elizabeth, utilising an online search engine www.AIDSbuzz.org, specifically locating VCT centres within the Eastern Cape, but particularly geographically closer to Grahamstown; owing to the researchers' lack of transportation. Permission to conduct interviews was given by the director of the centre, and the manager of the lay counsellors. Initially five interviewees agreed to participate, however one participant was an HIV-positive peer educator and had not practiced lay counselling, and was therefore excluded. The other two participants had a change of heart and declined to be interviewed after initially agreeing. The five participants from Port Elizabeth were particularly difficult to locate for several reasons. Firstly, the sustained stigma attached to HIV/AIDS still poses major issues for disclosure practices. For example, one NGO was approached in Port Elizabeth, the director expressed that several individuals would probably be interested to participate in the study. However after consultation not one individual was willing to participate, possibly due to the perceived stigma resulting from participation in a study exclusively utilising HIV-positive individuals. Secondly, VCT centres and other organisations catering towards HIV-positive individuals and communities are typically geographically located to assist particular communities. Therefore reducing the likelihood of communication between organisations, and reducing the possibility of successful snowballing techniques. Thirdly, not all VCT centres have HIV-positive lay counsellors, or at the minimum lay counsellors who had publically disclosed their seropositivity, thereby reducing the likelihood HIV-positive lay counsellors participating. Although the prescription for novice research endeavours for Interpretative Phenomenological Analysis are six participants, the nature of HIV/AIDS stigma and the persistent denial and silence surrounding seropositivity in South Africa reduced the possibility of high participant numbers.

The utilisation of in-depth semi-structured interviews allows the extraction of rich contextualised data surrounding the lived experiences of HIV-positive lay counsellors. This method of data collection is compatible with IPA, and the use of semi-structured interviews is necessary to allow the participant the opportunity to dictate the direction of the interview, as

IPA specifically places the participant as the expert of the phenomenon under investigation. Establishing rapport between interviewees and the researcher is paramount to data which is rich rather than a superficial description of the experiences being investigated. The researcher conducted preliminary interviews with the participants from Grahamstown, these interviews were a fulfilment of the researcher's Honours degree, and informed on the interview schedule subsequently designed for this research project. A total of eight interviews were undertaken, where each participant was interviewed twice. The Grahamstown participants were initially interviewed to determine the effectiveness of the interview schedule. After determining the inclusion and exclusion of particular lines of questioning, the researcher conducted final interviews with the Grahamstown participants. Similarly the Port Elizabeth participants were interviewed with the revised edition of the interview schedule. All participants agreed to examine the interview schedule prior to data collection, where participants consequently agreed with the lines of questioning. The second round of interviews focused on expanding threads of discussion which were not probed in the first interview encounter.

Data Analysis

The process of data analysis follows the guidelines outlined by Smith, Flowers, and Larkin (2009) in their seminal text surrounding Interpretative Phenomenological Analysis. The process of analysis is flexible allowing creative engagement with the process of interpretation, rather than following a strict prescriptive method of analysis. The difficulty in IPA centres on removing the researchers developed beliefs, norms, and interpretations generated through analysing each subsequent transcription. This process is intensified when experiences of diagnosis and disclosure appear to reflect similar shared traits and characteristics among transcriptions. However the researcher must ensure that each transcription is given the appropriate energy and rigour required, rather than presuming that one participant's experiences are transferable to another. This process was particularly difficult for several reasons. Firstly, the limited literature concerning the practices and experiences of peer counsellors working within a VCT setting required an examination of experiences of living with HIV/AIDS in South Africa. This examination informed the basis for understanding the shared and explicit experiences which informed experiences of living with and working with an HIV-infection. This process is inevitably influenced by characteristics of the South African pandemic, specifically regarding the continued discussion

surrounding the stigmatised nature of HIV-infection, ongoing issues of gender inequity, and the perception of not being at risk of HIV-infection. These particular characteristics are not only experienced by South Africans infected with HIV/AIDS, but these features affect the nature of investigating experiences of living with HIV/AIDS in South Africa. Secondly, the available literature on peer counselling focuses on particular localities and/ or specific population groups beyond the context of South Africa, and indeed beyond the context of VCT, thereby reducing the transferability of their findings and interpretations. Although all infected individuals require care, support and treatment, the experiences of diagnosis, disclosure, reconstructing hope, acceptance, and personal transformation are imbedded and embodied within the context of the infected individual.

The progression from HIV diagnosis towards acceptance and employment within the field of HIV-care and counselling was a shared characteristic of the participant's experiences. These shared experiences amongst the participants informed the layout of the results and discussion chapter. It must be noted that the results chapter is grounded within the participants' accounts, but the analytical interpretation of these experiences may go beyond the participant's own interpretation and conceptualisation of their experiences. The lengthy verbatim raw data utilised within the results chapter reflects the experiences of the participants, beginning with the confrontational nature of disclosing a serostatus after recently discovering their seropositivity, towards a construction of a positive identity in living with HIV/AIDS, and finally culminating in the experiences of providing VCT services following acceptance of their seropositive diagnosis. The transition from hopelessness towards a positive outlook in living with HIV/AIDS is a crucial aspect of living positively with HIV-infection. However the experiences of the participant indicate that their experiences of post-counselling lacked experiential weight. The recognition that other recently diagnosed individuals may experience similar levels of hopelessness and anxiety during counselling processes, directed the participants towards endeavours to reduce the devastating experiences of discovering a seropositive status within VCT services. Whether these processes included the utilisation of personal experiences or directing recently diagnosed individuals towards avenues of care and support is irrespective of the fact that the participants endeavoured to reduce the negative experiences of discovering a seropositive diagnosis. The progression from hopelessness towards a reconstruction of hope and the construction of a positive outlook in living with HIV/AIDS is a shared feature of the participant's experiences. Yet the explicitly differing interpretations in which the experiences are articulated and reflected by

the participants indicate the convergent and divergent levels of seemingly similar shared experiences. The inclusion of particular participant accounts reflected within the result chapter signifies the shared nature of the experience, but underlying this recognition is the explicitly differing manner in which shared experiences are interpreted by participants. The idiographic focus within IPA is a crucial aspect of phenomenological research, providing detailed analyses of divergence and convergence across cases, allowing detailed and rich descriptions of each of the participant's experiences. Although the shared characteristic of the participants experiences are utilised as a structural preference, this does not indicate that the shared nature of the experiences signifies a homogenous experience amongst the participants.

Discussion

The structure of the discussion chapter follows the participant's progression from HIV diagnosis towards acceptance and employment within the field of HIV-care and counselling. Additionally this includes an examination of the structural limitations which influences the process of counselling within VCT, such as the lack of formal recognition for lay counselling practices within primary healthcare, the informal utilisation of task-shifting within lay healthcare cadres, and the challenges of providing VCT as HIV-positive individuals. The discussion chapter centres on the researcher's interpretation of the participant's experiences, where the results chapter focuses exclusively on participant accounts, the discussion chapter focuses on the infusion between participant accounts and the available literature concerning lay counselling practices within South Africa, and global research endeavours surrounding the practice of peer counselling. As stated, the available literature concerning the practice of peer counselling is focused on particular and/or marginalised populations, beyond the context of VCT settings in South Africa. Available literature concerning peer support, and adherence counselling is available but does not focus exclusively within the context of counselling, nor is it focused within the realm of VCT services. Therefore attempting to understand the experiences of HIV-positive lay counsellors requires an examination of experiences of living with HIV/AIDS in South Africa. The difficulty with navigating through the vast spectrum of lived experiences of living with HIV/AIDS is removing the researcher's newly informed beliefs, attitudes and biases generated through an examination of the literature prior to data collection, during data analyses, and the discussion write-up. Particularly when limited

literature directs the research process towards an examination of contextualised experiences which are not transferable within the domain of qualitative research projects.

The utilisation of personal experiences between peer counsellors and their cliental allows the development of acceptance of a seropositive status, positive appraisals, and the reconstruction of hope. However the available literature does not focus on the circumstances in which personal experiences are utilised, instead the benefits of empathic connections are stressed as an important variable within peer counselling, and elucidate towards the rationale for sharing personal lived experiences of living with HIV-infection during counselling encounters. However during the analytic process the affect of countertransferential reactions appeared to present as an alternative explanation for the utilisation of personal experiences during VCT. An empathic connection which engenders the utilisation of personal experiences or, the sharing of personal experiences as a consequent of the counsellor's unresolved inner conflicts presents an interpretation beyond the participant's reflexive narrative. The participants perceived the utilisation of their personal experiences as a consequence of conveying a seropositive diagnosis, where their cliental are visibly experiencing immense psychological distress which directs the counselling process towards sharing personal experiences. However this explanation does not consider the lived realities of the participant's negative experiences of diagnosis, which compelled the participants towards providing counselling and supportive services aimed at reducing the debilitating experiences of receiving a seropositive diagnosis. The possibility that the participant's negative experiences of diagnoses represent their unresolved inner conflicts, where the lack of support permeated throughout their experiences of accepting their seropositivity, may present an explanation for the utilisation of personal experiences within VCT; particularly when cliental implicitly express a desire to be cared and nurtured, which engenders a countertransferential reaction which compels the participants towards providing care and support through sharing personal experiences.