

**THE DEVELOPMENT OF A COUNSELLING INTERVENTION FOR PEOPLE  
LIVING WITH HIV AND AIDS EXPERIENCING STRESS-RELATED  
PSYCHOLOGICAL CONDITIONS IN THE EASTERN CAPE PROVINCE**

**N.V. TWAISE**

**2016**

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PSYCHOLOGICAL CONDITIONS IN THE EASTERN CAPE PROVINCE**

**NOMVULA VIRGINIA TWAISE**

**Submitted in fulfilment of the requirements for the Doctor of Philosophy Degree (Psychology) in the  
Faculty of Health Sciences at the Nelson Mandela Metropolitan University**

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**SUPERVISOR: PROF T.V. MAYEKISO**

**CO-SUPERVISOR: PROF D.S. ELKONIN**

## **DECLARATION**

I, NOMVULA VIRGINIA TWAISE, Student No. 21129181, hereby declare that the thesis for PhD (Psychology) to be awarded is my own work and that it has not previously been submitted for assessment or completion of any postgraduate qualification to another university or another qualification.

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**Nomvula V. Twaise**

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I would like to express my sincere appreciation to the following people for making this research project possible;

- First and foremost, I give thanks to God Almighty for giving me strength, favour, courage and determination to complete this project.
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### **Dedication**

This thesis is dedicated to people living with HIV and AIDS in South Africa.

## **Abstract**

People living with HIV and AIDS (PLHIV) suffer from a number of stress-related psychological disorders. The aim of this study was to develop an integrative intervention, which combined Cognitive Behaviour Therapy (CBT), Body-Mind Therapy and Multicultural perspectives to assist health care workers in identifying and treating stress-related psychological disorders among people living with HIV and AIDS. The study employed an intervention research design using both qualitative and quantitative methods. The quantitative data was collected from PLHIV attending HIV Counselling and Testing (HCT) and Anti-retroviral therapy clinics in the Buffalo City Municipality (BCM) of the Eastern Cape Province. The qualitative data was collected from the health care workers of the selected study sites. Purposive sampling was used to select the study sample. Instruments used included a biographical questionnaire, the Beck Depression Inventory-II (BDI-II), Medical Outcome Study- HIV (MOS-HIV) and focus group interviews to gather data for the development of an intervention model that would address reported stress-related psychological disorders. Findings showed that people living with HIV and AIDS endure stress in their lives on daily basis rather than episodes of severe or clinical depression. Many of the PLHIV are dealing with a number of psychosocial problems that compromise their quality of life and health status. In conclusion, the study illustratively interpreted and discussed the results in relation to the objectives of the study. The study recommends that PLHIV should be exposed to stress management programmes, and health care workers (HCWs) should be offered training in basic counselling skills, stress management and/or debriefing.

**Key words:** HIV and AIDS; stress-related psychological conditions; African worldview

## **Abbreviations:**

AIDS	-Acquired Immune Deficiency Syndrome
ART	-Antiretroviral Therapy
ARVs	-Anti-retrovirals
BDI-II	- Beck Depression Inventory -II
CBT	- Cognitive Behavioural Therapy
HBC	-Home-based carers
HCT	-HIV Counselling and Testing
HCW	- Health Care Workers
HIV	- Human immunodeficiency Virus
MOS-HIV	- Medical Outcome Survey - HIV
NMMU	- Nelson Mandela Metropolitan University
PLHIV	- People living with HIV and AIDS
PMTCT	- Prevention of Mother to child Transmission
REC-H	- Research Ethics Committee - Human
THP	- Traditional healing practitioner
TRE	- Trauma releasing exercises

## **Interchangeable terms**

‘Clients’ interchangeable with ‘Patients’

‘Health care workers’ inclusive of ‘Home-based carers’, Professional nurses, ‘Lay counsellors’ and ‘Social workers’

‘Participants’ inclusive of ‘HCW participants and ‘PLHIV participants’ or ‘client participants’

‘PLHIV clients’ interchangeable with ‘Client participants’

‘Counselling intervention’ interchangeable with ‘Intervention’

## TABLE OF CONTENTS

<b>DECLARATION</b>	III
<b>ACKNOWLEDGEMENT</b>	IV
<b>DEDICATION</b>	V
<b>ABSTRACT</b>	VI
<b>KEY WORDS</b>	VI
<b>ABBREVIATIONS</b>	VIII
<b>LIST OF TABLES</b>	XIII
<b>LIST OF FIGURES</b>	XIV
<b>CHAPTER 1: BACKGROUND TO THE STUDY</b>	
1.1. Introduction	1
1.2. Problem Statement	9
1.3. Rationale for the study	11
1.4. Research questions	12
1.5. Aims and Objectives of the study	12
1.6. An overview of the Research Methodology	13
1.6.1. Research setting	13
1.6.2. Research design- Intervention research design	13
1.6.3. Population and Sampling	15
1.6.4. Data Collection	15
1.6.4.1. Cross-sectional survey: Questionnaire	16
1.6.4.2. Psychological tests	16
1.6.5. Research Procedure	18
1.6.6. Delimitations	19
1.6.7. Data Analysis	19
1.6.8. Ethical Considerations	19
1.6.9. Layout of the study	20
<b>CHAPTER 2: LITERATURE REVIEW</b>	<b>21</b>
2.1. Introduction	21
2.2. An overview of psychological stressors	21
2.3. Fundamental facts about HIV and AIDS	24
2.3.1. Human Immune-deficiency Virus (HIV)	24
2.3.2. Acquired Immune deficiency Syndrome	24
2.4 Theories of the origin of HIV and AIDS	25



2.5. The epidemiology of HIV	26
2.5.1. Global epidemic	26
2.5.2. Sub-saharan Africa epidemic	27
2.5.3. South African epidemic	28
2.6. Types and sub-types of HIV	29
2.7. HIV transmission	30
2.7.1. Sexual transmission	30
2.7.2. Blood transmission	32
2.7.3. Mother-to-child transmission	33
2.8. Myths about HIV and AIDS	34
2.9. HIV and AIDS and Immune System	35
2.9.1. HIV infection Cycle	36
2.10. Managing HIV Infection and Antiretroviral therapy (ART)	37
2.11. HIV and AIDS Phases and Opportunistic Infections (OIs)	41
2.12. Psychosocial and emotional experiences among PLHIV	43
2.13. Stress-related psychological disorders and HIV and AIDS	43
2.13.1. Anxiety disorder and HIV and AIDS	45
2.13.2. Anxiety disorder	46
2.13.3. Acute stress disorder	47
2.13.4. Posttraumatic stress disorder (PTSD)	47
2.13.5. Depressive disorders	48
2.13.5.1. Depressive disorder and HIV and AIDS	50
2.13.5.2. Barriers to diagnosing depression in PLHIV	51
2.13.5.3. Depressive disorder treatment in PLHIV	51
2.13.6. Adjustment disorder and HIV and AIDS	53
2.13.7. Alcohol use disorder and HIV and AIDS	54
2.13.8. Stigma and Discrimination (S&D)	56
2.14. Rationale for psychological services for PLHIV	58
2.15. Conclusion	59
<b>CHAPTER 3: THEORETICAL FRAMEWORK</b>	60
3.1. Introduction	60
3.2. Integrative psychotherapy	60
3.2.1. Technical eclectic approach	62
3.3. Body-mind therapy	63

3.4. Cognitive Behavioural Therapy (CBT)	69
3.4.1. The use and limitations of CBT	73
3.5. Multicultural Approach	74
3.5.1. African worldview on mental illness	75
3.5.1.1. God and ancestors as causal agents of illness	76
3.5.1.2. Implications of external causation of illness for HIV and AIDS	77
3.5.2. Multicultural competencies and standards	78
3.6. Conclusion	79
<b>CHAPTER 4: RESEARCH METHODOLOGY</b>	<b>80</b>
4.1. Introduction	80
4.2. Research aim and objectives	80
4.3. Research design	80
4.3.1. Quantitative research method	81
4.3.2. Qualitative research method	82
4.4. Research setting	83
4.5. Population and Sample	86
4.5.1. The sample for phase one	87
4.5.2. The sample for phase two	88
4.5.3. The sample for phase three	90
4.6. Research Instruments	90
4.6.1. Biographical questionnaire (Bio)	90
4.6.2. Medical Outcomes Study- HIV (MOS-HIV)	90
4.6.3. Beck Depression Inventory (BDI)	91
4.6.4. Focus Group Discussions (FGD)	92
4.7. Research procedure	92
4.8. Data collection	97
4.8.1. The development of the counselling intervention model	97
4.8.1.1. A review of literature	97
4.8.1.2. An integration of the theoretical framework guiding the research	98
4.8.1.3. Biographical questionnaire and psychological assessments	98
4.8.1.4. Focus group interviews with health care workers	98
4.8.1.5. Pilot Study	99
4.8.2. The implementation of the intervention model	100
4.8.2.1. Training of health care workers	100

4.8.2.2. The implementation of the intervention by HCW	101
4.8.3. Preliminary evaluation on the implementation of the intervention model	102
4.9. Ethical considerations	102
4.10. Data Analysis	103
4.11. Conclusion	104
<b>CHAPTER 5: RESEARCH FINDINGS</b>	<b>105</b>
5.1. Introduction	105
5.2. The development of the intervention findings	105
5.2.1. Quantitative data findings	106
5.2.2. Qualitative data findings	125
5.3. The implementation of the intervention feedback findings	134
5.3.1. Processing of outcomes of the implementation	134
5.3.2. Summary of benefits	142
5.3.3. Summary of challenges	144
5.3.4. Summary of Identified themes	146
5.4. Preliminary Evaluation of the implementation of the intervention model findings	150
5.4.1. Qualitative data findings: Feedback from health care worker participants	150
5.5. Summary of all findings	153
5.6. Conclusion	155
<b>CHAPTER 6: DISCUSSION OF THE FINDINGS</b>	<b>157</b>
6.1. Introduction	157
6.2. Discussion of the development of the intervention model	157
6.2.1. Discussion of the quantitative research findings	157
6.2.1.1. Biographical questionnaire data findings	158
6.2.1.2. MOS-HIV Health Survey data findings	159
6.2.1.3. Beck Depression Inventory –II data findings	161
6.2.2. Discussion of the qualitative research findings	162
6.3. Discussion of the implementation of the intervention model findings	163
6.3.1. Discussion of the training of health care worker participants	163
6.3.1.1. Body-mind therapy – trauma –stress releasing exercises	164
6.3.1.2. Cognitive behavioural therapy techniques	166
6.3.1.3. Exploration of multicultural healing processes	167
6.3.2. Discussion of the implementation of the model with PLHIV participants	168
6.3.2.1. Discussion identified themes	169

6.3.2.2. Discussion of the depressive disorder among PLHIV	172
6.3.2.3. Discussion of stress as experienced by both HCW and PLHIV participants	172
6.3.2.4. Discussion of the African traditional healing perspective	174
6.4. Discussion of the evaluation of the implementation of the intervention	175
6.5. Conclusion	176
<b>CHAPTER 7:</b>	
<b>SUMMARY, LIMITATIONS, CONCLUSION AND RECOMMENDATIONS</b>	<b>177</b>
7.1. Summary of the study	177
7.2. Conclusion	180
7.3. Limitation of the study	181
7.4. Recommendations	182
7.4.1. Recommendations on the use of the counselling intervention	182
7.4.2. Recommendations for future research	184
<b>8. REFERENCES</b>	<b>186</b>
<b>9. APPENDICES</b>	<b>230</b>
Appendix A: The Integrative Intervention	230
Appendix B: Research Ethics Committee –Human Letter	242
Appendix C: Permission letter from Sophumelela Centre	243
Appendix D: Permission letter from the Eastern Cape Department of Health	244
Appendix E: Permission letter from Amathole District Municipality	245
Appendix F: Informed consent form	246
Appendix G: Letter to Health Care Worker participants	247
Appendix H: Letter to PLHIV participants	248
Appendix I: Biographic questionnaire sample questions	250
Appendix J: BDI-II questionnaire	251
Appendix K: MOS-HIV sample questions	254
Appendix L: Focus group interview sample questions	255
Appendix M: Cognitive Restructuring worksheet example	256
Appendix N: Stress quiz	257
Appendix O: TRE photos	259

## List of Tables

Table 1: Classification of ARV drugs in South Africa	40
Table 2: Biographical information sample of PLHIV participants	87
Table 3: Distribution of the sample of HCW from both research sites	89
Table 4: Distribution of the pilot study sample by designation and gender	99
Table 5: PLHIV participants' level of education	107
Table 6: Periods when PLHIV participants tested HIV positive	108
Table 7: Person counselling PLHIV participants for HIV	110
Table 8: Fearful of testing HIV positive	110
Table 9: Support group membership	110
Table 10: Period when PLHIV participants started taking ARVs	111
Table 11: Profile of client participants on ART by gender	112
Table 12: Measures that help participants cope with fear of taking ARVs	113
Table 13: PLHIV participants' description of their health status	114
Table 14: Severity of bodily pains in the past 4 weeks	115
Table 15: Limitations of participants to do certain activities	116
Table 16: Participants' limitations by pain to do daily activities	116
Table 17: Participants' inability to work due to ill-health	117
Table 18: Participants' general feelings in the past 4 weeks	117
Table 19: Participants' feelings about their health in the past 4 weeks	118
Table 20: Times participants felt negative emotions because of their health	119
Table 21: Ratings of participants' health status	120
Table 22: Quality of participants' life in the past 4 weeks	120
Table 23: Levels of depression of the participants as measured by the BDI-II	121
Table 24: Biographical information sample of HCW at Sophumelela Centre	125
Table 25: Biographical information sample of HCW at Nontyatyambo Clinic	125

## List of Figures

Figure 1: The Intervention Research Model	14
Figure 2: Global estimate adults and children living with HIV- 2013	26
Figure 3: Comparison of the Sub-Saharan Africa HIV prevalence, 2013	27
Figure 4: HIV prevalence by province (15-49 years) South Africa 2012	28
Figure 5: HIV prevalence by age and sex, South Africa, 2012	29
Figure 6: The HIV Structure	35
Figure 7: HIV Life Cycle diagram	36
Figure 8: The Psoas muscle	68
Figure 9: Eastern Cape Province population, 2011	84
Figure 10: Summary of the research process	85
Figure 11: Diagrammatic presentation of the intervention	94
Figure 12: Data Analysis process of Qualitative research method	103
Figure 13: Participants' Marital status	108
Figure 14: Marital status vs. years of testing HIV positive	109
Figure 15: PLHIV participants who received ART counselling	112
Figure 16: Anxiety over taking ARVs	113
Figure 17: Interference of bodily pain with participants' normal work in the past 4 weeks	115
Figure 18: Participants' current physical and emotional status compared to 4 weeks ago	121
Figure 19: A comparison of males and females on feelings of discouragement	122
Figure 20: Comparison of participants' feelings of guilt with years of living with HIV	123
Figure 21: Comparison of participants' self-perception with support offered	123
Figure 22: Comparison of participants' feelings of discouragement and years living HIV	124
Figure 23: Participants who rated their health status versus feelings of discouragement	124

## **CHAPTER 1**

### **BACKGROUND TO THE STUDY**

#### **1.1. INTRODUCTION**

People living with HIV (PLHIV) continue to experience a number of stress-related problems in spite of years of research and interventions which have resulted in little improvement in their psychological well-being (Dalmida, Koenig, Holstad, & Wirani, 2013). There is an increasing number of PLHIV in South Africa, but there is a paucity of research regarding the psychological consequences of an HIV positive diagnosis on their mental health. There exist limited data on how PLHIV cope with psychological risk factors caused by the diagnosis of HIV and the treatment thereof. There is even less evidence of the link between stress-related psychological illness and HIV in developing countries. Such research is crucial in order to inform the provision of HIV care services in these settings. By implication, the studies have fallen short in addressing the fundamental psychological disturbances that PLHIV face daily. Although PLHIV accept their HIV positive diagnosis, due to a number of social, emotional and physical challenges including stigma which surround them they tend to experience stress-related psychological illnesses, which sometimes go unnoticed or misdiagnosed. This delay in recognising such disorders may result in a rapid progression of their condition until such time it becomes very late to help them (Breet, Kagee & Seedat, 2014). This means strategies to address these conditions are also limited, more especially in resource-poor settings.

The burden of HIV and AIDS brought with it an increasingly heavy workload in the health care system more especially for health care practitioners. Additional to this heavy workload health care workers are faced with integrating mental health care into the already overburdened health care system and this has proved to be far too difficult for the health care system to manage (Lê, Morgan, Bestall, Featherstone, Veale & Ensor, 2016). The result is a less than optimal delivery of mental health care. To try and address this gap there came a demand to use lay health workers such as lay counsellors and home-based caregivers to deal with this workload in the HIV and AIDS treatment, care and support programmes (Chibanda, Cowan, Verhey, Machando, Abas & Lund, 2016). Due to increasing workload and new

responsibilities in the health care system, even lay health care workers are struggling to meet the needs of mental health care among PLHIV.

An integrative intervention is proposed in this study to assist health care workers to help PLHIV cope with stress-related challenges in their daily life. This intervention could also enable health care workers to relieve stress and burnout in their own lives including their family members or communities. By so doing the heavy burden on health care workers could be reduced and PLHIV can cope better with stress using this self-help intervention.

First of all it is in order to give a brief background into what HIV is all about. HIV was discovered to be a virus different from any virus previously known. Van Dyk (2012) explains that viruses cannot reproduce on their own because they do not have such 'mechanisms' in their core to do so. They are parasites in the sense that they need to use the biochemical faculties of living cells, such as those of human cells, to reproduce and are called 'retroviruses'. These viruses attach themselves to specific receptor sites on the host cell, and when they get the key to unlock the host cell receptor site, the immune protective system of the host cannot function. Denner (2014) argues that retroviruses are usually very simple viruses, but the HI virus is very complex because it can change itself so quickly that different variants of the virus can be found in a single infected individual. It also has the extraordinary ability to evade the immune system of the host.

The HI virus is mainly found in bodily fluids of the human organism and enters the body through three modes of transmission namely; unprotected sex with an HIV positive person, HIV positive blood contamination, and either peri- or post- natal mother –to- child transmission (Shukla, 2014). It attacks the white blood cells called CD4 cells or T-helper cells that help protect the body against numerous illnesses and weaken the immune system gradually by destroying these cells and replacing them with virus-loaded cells. This process continues until there is a great volume of the virus in the bloodstream than CD4 cells and the body eventually gives in to opportunistic infections including the common co-infections with HIV such as TB (Tuberculosis) and STIs (Sexually Transmitted Infections). At this stage the person starts developing what is called, Acquired Immune Deficiency Syndrome (AIDS). If treatment is not prescribed early enough, these opportunistic infections could resist treatment and the immune system becomes completely destroyed, eventually leading to death (Brey, Seybold, Kollan & Bogner, 2016).



HIV and AIDS have been with mankind for over thirty years but neither a vaccine nor a cure has yet been developed. Some developments have been made by many international and national organisations, including some in South Africa. Antiretroviral drugs (ARV's) have been developed to allow those living with HIV and AIDS to live longer (Van Dyk, 2012). The use of ARVs has significantly extended the life of the infected individual so that HIV infection can be seen as a chronic disease, rather than a fatal infection. As a result more and more people are surviving with HIV (Liamputtong, Haritavorn & Kiatying-Angsulee, 2015).

UNAIDS (2013) estimated that globally 35.0 million [33.2 million–37.2 million] people were living with HIV at the end of 2012. The recently recorded HIV prevalence rate in South Africa of (12,2%) or 6,4 million people living with HIV, represents a quarter of the burden of HIV infections in Sub-Saharan Africa and 18% of the global burden (HSRC, 2012). The 2012 figure is 1.2 million more people living with HIV and AIDS (PLHIV) than in 2008 (10.6% or 5.2 million people).

The Eastern Cape where this study is set, is generally seen as one of the poorest provinces in South Africa, with an unemployment rate of more than 45%, a high rate of poverty and slow economic growth rate, all of which are important drivers of the HIV and AIDS pandemic. In the recent research done by HSRC (2012), the Eastern Cape reflects an estimated HIV prevalence of 11,6%, with Buffalo City Municipality (BCM) recording 13,6%. The study suggests that this increase is due to the combined effects of new infections and a successfully expanded Antiretroviral Therapy (ART) programme. The latter has increased the survival range among HIV-infected individuals (Simbayi et al., 2014).

The impact of HIV is significant for every individual but it also impacts on the families, friends and the wider community of those infected and affected. Antiretroviral treatment (ART) allows PLHIV to maintain their health and often allows them to lead relatively normal lives. However, not PLHIV in South Africa have access to this kind of treatment and this means that HIV and AIDS deaths are still one way or the other increasingly high throughout the country. As far back as in 2004, a survey conducted by South Africa Advertising Research Foundation (SAARF), found out that South Africans spent more time at funerals than at weddings and birth ceremonies (Myer, Seedat, Stein, Moomal & Williams, 2009). Although AIDS-related deaths have declined due to the

introduction of ARVs, the number of HIV infections is still increasing in South Africa. In addition to this is psychological suffering on individuals and at community level, where the HIV and AIDS epidemic has had a substantial impact on the country's overall social and economic progress (Whitside & Sunter, 2005).

Harrison, Angarola, Forsyth and Irvine (2016) noted that more than 450 million people worldwide have mental health disorders according to the world health organisation. Studies attribute this burden, in part, to the chronicity of the illness and the lack of, or limited access to, mental health services around the world (WHO, 2008). This limited access has become more noticeable in the context of the HIV and AIDS epidemic. However, with the expansion of ART initiatives there also lies an opportunity for the integration of mental health care into HIV and AIDS treatment (Bachireddy et al, 2014).

Research has highlighted the impact of HIV and AIDS on the psychological health of infected individuals, mainly in Europe and North America, showing that HIV infection is associated with an increased incidence of common psychological conditions such as anxiety and depressive disorders (Gardner et al., 2016). Psychological health care has been integrated into HIV and AIDS programmes in more affluent countries for many years as a result of substantial evidence of the linkages between psychological health and HIV. Studies from these countries suggest that PLHIV often suffer from depression and anxiety disorders as they adjust to the diagnosis, struggle with the meaning of a positive HIV test result, adapt to life with a chronic life-threatening illness, anticipate and receive news of the disease's advance, and witness the death of friends and family. According to Sayegh et al., (2016) the relationship between HIV infection and the risk for depressive disorders, indicated that PLHIV are nearly twice as likely to have had a recent episode of a major depressive disorder when compared to HIV negative individuals.

Depression can also reduce the motivation to seek health care. It can impair compliance and adherence to treatment, reduce condom use when having sex, decrease the quality of life, and increase mortality (Morrison et al., 2014). The neuropsychiatric effects of the virus can lead to dementia and motor disorders that further affect the quality of life. Psychological illness can also be a risk factor for PLHIV. Certain psychological conditions, including substance abuse, increase vulnerability to HIV infection. In North America, the HIV risk among people with major psychological conditions has been associated with lack of

condom use, multiple sexual partners, and injection drug use (Simbayi, et al., 2014). The social exclusion that often accompanies life with a severe psychological illness may also increase vulnerability to infection, leading to the exchange of sex for money or goods and an increase in coercive sexual encounters. Cognitive deficits associated with certain psychological conditions may impair judgment and the ability to negotiate safe sexual encounters, (Freeman, Patel, Collins & Bertolote, 2005).

While there is increasing attention paid to the medical needs of HIV-infected individuals in Sub-Saharan Africa, there is less attention paid to the psychological needs of PLHIV (Collins, Holman, & Freeman, 2006). In settings of high prevalence such as South Africa, where a large proportion of the population live with HIV, the scope of this need is substantial (Myer, Seedat, Stein, Moonal, & Williams, 2009).

In South Africa the notion of psychological conditions is engulfed with stigma, where people with psychological conditions are treated differently and are often isolated. It is important to note that persons living with HIV and AIDS and psychological conditions are subjected to a double stigma: being HIV positive and with a psychological disorder (Sharer, Cluver & Shields, 2015). Additional to this is the stigma associated with some of the opportunistic diseases accompanying HIV, such as TB, which have carried stigma for many years (Pethlu, 2005). Due to stigma, some families would even take their sick family members living with HIV and AIDS to traditional healers, where they are sometimes considered to be possessed by ancestral spirits or evil spirits (like being bewitched), (Cumes, 2013; Mkhize, 1998).

The BCM area where the study was conducted is serviced by only one psychiatric ward situated at the Cecilia Makhiwane Hospital, where patients and clients from all rural, peri-urban and urban areas of BCM and even those from other poorly resourced district municipalities are referred. This over utilisation results in poor assessment and treatment because many clients are not adequately observed or treated (Petersen et al., 2015). There are few beds to admit these clients for further psychological/psychiatric assessment. Clients who do not exhibit violent behaviour are treated and sent home even though they might need a more thorough psychological assessment. The expansion of HIV and AIDS treatment initiatives in resource-poor settings provides an opportunity for integrating mental health care into HIV and AIDS treatment programmes (Petersen et al., 2015). The World Health

Organisation Report (2008), recommends that attention to the psychosocial needs of PLHIV should be an integral part of HIV and AIDS care. This includes assistance with employment, income, housing, informed decision-making, coping with illness, stigma and discrimination, prevention and treatment of mild and serious psychological conditions.

Psychological theories provide evidence-based explanations for why people think, behave and feel the way they do. Personality factors, family history, early experiences and interpersonal relationships are seen as important factors to consider when evaluating psychological disturbances in people (Comer, 2010). Unlike biology, psychology is not truly a unified field. There are still many disagreements within the field as to what subject matter is important to focus on, and what methods are best to use for studying the subject matter. Consequently, different schools of thought within psychology have developed their own theories as to why, for example, someone becomes depressed (Van Dyk, 2012). As a result even with HIV and AIDS many theories have been employed. Some have been used more than others but there is still uncertainty as to which best explains the behaviour of PLHIV. Cognitive Behavioural Therapy (CBT) has been widely used by many psychologists in this field (Tshabalala, 2008). The Multi-modal Transactional intervention has also received attention as has Psychodynamic Theory. However, with the complexities of HIV and AIDS, therapists and health care workers in general are forced to be more creative in their interventions.

In its quest for a theoretical framework, this study explored integrative psychotherapy as a guideline to develop an intervention that will assist PLHIV, cope with stress-related illnesses. Integrative psychotherapy is the fusion of different schools of psychotherapy and interventions to bring together the affective, cognitive, behavioural and physiological systems within a person (Beutler, 2005). However, Corey (2015) cautions that in attempting to integrate, one should guard against merging concepts that are very diverse such as a classical psychoanalytic approach and radical behaviourism. However, despite such divergence in theories, there are possibilities for a creative synthesis among some interventions. Exploring and developing a therapeutic intervention that integrates socio-economic, spiritual and cultural factors would benefit both PLHIV and health care workers.

An integrative approach to psychological intervention ensures that practitioners attend not only to clients' cognitions and behaviours, but also to their diverse cultural and spiritual

pathways (Wilber, 2007). In the context of South Africa, the integrative approach would allow more focus on other types of healing such as traditional healing practices, acknowledging the complex ways in which socio-cultural context, body, mind, and emotions continually interact and influence an individual's well-being. According to the WHO (2008), 90% of people of African origin still seek traditional healing practices. Therefore to ignore this important aspect in dealing with PLHIV in Africa, would be to ignore an important aspect in the lives of these individuals.

According to Norcross and Goldfried, (2005) integrative psychology includes the often marginalised study of spirituality, intentional consciousness, body-mind therapy, meditation, biofeedback, imagery, somatic practices, creativity and expressive arts, human ecology, postmodern gender and cultural psychologies and their application in clinical settings. At the same time the Integrative psychotherapy field values mainstream psychological interventions and emphasizes research based on systems theory, human sciences and integrated methods.

The Integrative approach suggests that its elements are part of one combined approach to theory and practice. The most recent edition of the Handbook of Psychotherapy Integration by Norcross and Goldfried, (2005) recognises four routes to integration: Common Factors, Technical Eclecticism, Theoretical Integration and Assimilative Integration (Norcross & Goldfried, 2005). These are discussed extensively in Chapter three.

Body-Mind Therapy has also been widely used to develop alternative approaches to therapy. One example is Trauma/Stress Releasing Exercise (TRE) developed by David Berceli (2008). He has used this technique for the past twenty years in different countries with different cultures and with different experiences of trauma/stress. He has worked with soldiers, earthquake survivors, child abuse and sexual abuse survivors as well as PLHIV, (Berceli, 2008). According to Berceli, (2005) people store many traumas in their bodies with no outlet to release this pent-up negative energy. They keep on adding stress and trauma and the body keeps on storing this history from childhood and adolescence to adulthood until such time as these experiences manifest themselves through psycho-physiological illnesses. Berceli, (2008) argues that unlike animals, human beings have locked away their natural way of releasing trauma/stress, as it happens, by blocking neurological tremors that occur in the body as a way of releasing that particular trauma. This blockage is caused by ego defense

mechanisms that prevent individuals from being their authentic selves (Berceli, 2008). By trembling, human beings are able to release the toxic build-up of stored chemicals, which makes them stressed and eventually ill. David Berceli devised a simple-to-learn exercise programme that quickly releases trauma or stress in one's body. This restores the body to its natural state of balance and deep relaxation. This exercise works very well when combined with other psychological interventions such as Cognitive Behavioural Therapy (CBT).

Cognitive-behavioural therapy was primarily developed through a merging of behaviour therapy with cognitive therapy. There is empirical evidence that CBT is effective for the treatment of a variety of problems, including mood, anxiety, personality, eating disorders, stress, substance abuse and psychotic disorders (Butler, Chapman, Forman & Beck, 2006). The cognitive-behavioural treatment varies according to a client's needs. CBT is usually brief and most clients are able to complete their treatment in a few weeks or months. However for clients requiring more attention the therapist may offer long-term therapy (Weisberg & Magidson, 2014; Bea & Tesar, 2002).

As previously indicated people of African origin have never stopped consulting traditional healers, therefore this study will incorporate the traditional healing perspective in understanding the belief system of PLHIV who are experiencing stress-related psychological conditions. An exploration of the traditional healing perceptions on HIV and AIDS would assist in a holistic understanding PLHIV. Bodibe, (1988) argues that traditional healing, or the African world view, can contribute to a positive paradigm shift in the delivery of therapy services in South Africa. He continues by arguing that the African world view is not impervious to change, and is indeed, also informing the process of change. Therefore, western therapists, in collaboration with traditional healers, can zero-in on therapeutic approaches that operate within a holistic paradigm (Edwards, 2014). With the use of the integrative psychotherapy approach, three elements in this study are combined namely: cognitive behavioural therapy, body-mind therapy and recognition of multicultural therapy. This combination allows the counsellor to explore the client holistically rather than focusing on one dimension of the individual. It also challenges the counsellor to explore the issues which relate to the social, cultural and spiritual well-being of the client.

The review of literature which follows in chapter two explored stress-related psychological conditions affecting PLHIV, which is used to guide the development of an

appropriate psychological intervention that will deal with this challenge. The wealth of research (both theoretical and empirical) that exists on HIV and AIDS, stress-related psychological conditions and to some extent, psychological health and HIV and AIDS, will guide this study.

The extensive literature review included a number of clinical conditions associated with HIV infection from a mental health perspective, such as anxiety, depression, acute and post-traumatic stress disorders, adjustment disorder, and substance use disorders, as well as socio-economic, cultural, and spiritual factors that bring stress to PLHIV. The subject of HIV and AIDS is widely discussed in the literature review chapter. A significant body of literature on the psychological dimensions of HIV and AIDS has contended that the problem of comprehensive psychological assessment and treatment, lies in the lack of adequate mental health centres and appropriately trained practitioners, to investigate and treat these conditions properly, especially in the Sub-Saharan countries including South Africa (Myer, Seedat, Stein, Moomal & William, 2009; Prince et al, 2007). The African traditional perspective on mental health problem has been examined in Chapter three.

## **1.2. PROBLEM STATEMENT**

There is significant evidence that shows that PLHIV are particularly vulnerable to stress-related disorders such as acute stress reactions, anxiety, depression, substance and/or alcohol use disorder (Gardner et al., 2016). They experience acute stress reactions on being diagnosed as HIV positive and have to deal with this diagnosis for the rest of their lives. On receiving their HIV positive diagnosis, PLHIV deal with emotional reactions like anger, guilt, denial, despair and when engulfed by these negative emotions may isolate themselves or even abuse alcohol but often will not seek help immediately. In some instances they do not receive the care needed to keep them in the health care system for observation, due to poor health services in hospitals and clinics. These individuals end up with undetected psychological problems until such time as their health has deteriorated to the point of requiring hospitalisation or they die (Peltzer 2012).

A number of theories and interventions have been used to understand the psychological well-being of PLHIV (Linke & Pekmezi, 2013). Most studies have been conducted in countries other than South Africa. The study conducted in South Africa by a

team of researchers at the University of Cape Town's psychiatry and mental health department argue that even though mental health disorders, such as depression, anxiety, and alcohol use, are commonly associated with HIV, they remain largely under diagnosed. They maintain that the main reasons for under-diagnosis of mental health disorders are lack of human and financial resources (Joska, Stein & Flisher, 2008).

In 2005 a study at the University of the Witwatersrand in Johannesburg, which surveyed 302 PLHIV clients attending four ARV clinics in Gauteng and Limpopo, found that one out of five HIV-positive persons suffered from depression or anxiety disorders. As a result they adhered poorly to treatment, stopped going for check-ups and had higher risks of morbidity and mortality (Joska, Stein & Flisher, 2008). Depression also contributes to the deterioration of immune system and depressive HIV positive people as a result require more intensive health services, will need more hospitalisation and have a poorer quality of life (Joska et al., 2008). Although mental health screening is theoretically part of the Department of Health's (DoH) HIV treatment guidelines, public health care providers are unable to routinely screen for mental health disorders (Prince, Patel & Saxena, 2007).

The management of psychological reactions to a HIV positive diagnosis is based on pre- and post-test counselling (Van Dyk, 2012). Clinics and hospitals, where people go for HIV counselling and testing in South Africa, have inadequate systems to detect early signs of stress-related psychological conditions. This makes it difficult for these individuals to recognise or understand what they are going through or know how to seek help elsewhere.

For this reason, it would be helpful to have an intervention appropriately designed to help PLHIV. In a country like South Africa where both HIV and AIDS and psychological conditions are seen as shameful diseases, it becomes imperative that people are educated about the risks associated with neglecting people living with these diseases (Petersen & Lund, 2011). In order to be able to educate people, an initial in-depth investigation of the extent of the risks is very important.

The new 2030 Agenda for Sustainable Development includes a target to achieve universal health coverage including access to quality, essential health care services (Lê, Morgan, Bestall, Featherstone, Veale & Ensor, 2016). This implies aligning human and financial assets with provision of the right care at the right time in the right place to prevent



waste and maximise scarce resources. However, such an integrated health system, although making sense to minimise waste expenditure, might not yield the desired results when it comes to health care practitioners as the burden will be placed on the shoulders of the health care practitioners who are already overloaded with the present health care work.

Psychological effects on men and women might differ and therefore the study also sought to explore sex differences in processing and accepting the life of being HIV positive under stress. There have been a significant number of studies on how women in Africa are dealing with HIV and AIDS but less documentation on how men handle the diagnosis and the psychological progression of the disease. There are a number of factors affecting men and women differently in dealing with HIV and AIDS for example many studies identify females as highly vulnerable to HIV and AIDS (Tshabalala, 2008). Women also have to deal with conflicting cultural norms that enable men to have multiple concurrent sexual partners. This inevitably contributes to the increased rate of HIV infection in South Africa (Soul City, 2004).

A study of health care workers including doctors, nurses and volunteer caregivers showed that they experienced symptoms of physical, emotional, relational and behavioural stress (Akintolo, Hlengwa & Dageid, 2013). They are required to handle clients who are also stressed, without any skills to handle psychological conditions. These emotions sometimes go undetected on both sides resulting in behavioural outbursts and more health deterioration. It is from this background that this study seeks to develop an intervention that will assist both health care workers and their clients to be able to handle stress.

### **1.3. RATIONALE FOR THE STUDY**

The imbalance of power socially, culturally and economically, renders women and girls more vulnerable to HIV infection. The relationship between poverty and HIV and AIDS with each reinforcing the other, is another contributing factor. Sexual behaviour is, to a large extent, determined by people's economic, social and cultural circumstances. Those living in poverty may engage in sex work, migrate to urban areas in search of work, have unprotected sex with new partners, have no access to health care resources and information about sexual health and thus may not know how to protect themselves and their partners from HIV. On the other hand, HIV increases poverty in that breadwinners who fall ill may lose their income, or

need to spend more money on health needs. Girls may be forced to leave school to take care of ill parents or other family members and be denied education, while pensioners may spend their pensions on caring for their orphaned grandchildren (Cluver, Operario, Lane & Kganakga, 2011).

In an effort to identify how these conditions affect HIV infected and affected individuals, the study examined stress-related psychological conditions specifically manifested in PLHIV. A literature review was first utilised in order to identify the findings of how PLHIV have previously coped with HIV and AIDS and the stress that goes with this condition.

Likewise, the researcher believes that the findings of the study will help all government and non-governmental organisations dealing with HIV and AIDS in the Eastern Cape to integrate mental health care appropriately, from a research point of view. They will now be aware of what they are dealing with and therefore hopefully respond appropriately.

#### **1.4. RESEARCH QUESTIONS**

The study sought to answer the following questions:

1. What are the stress-related psychological conditions experienced by PLHIV?
2. How can health care workers assist PLHIV with stress management?
3. What should inform the development of a counselling intervention that can be applied effectively by health care workers working with PLHIV?
4. How should the counselling intervention be applied effectively?

#### **1.5. AIM OF THE STUDY**

The main aim of this study was to develop a counselling intervention using an integrative approach that would be used by health care workers to help PLHIV manage stress-related psychological conditions experienced in daily life. In so doing health care workers working with PLHIV will understand different behaviours individuals living with HIV tend to exhibit and why they do so.

The objectives of the study were to:

1. To determine the psychological conditions experienced by PLHIV.
2. To develop a counselling intervention to be applied by health care workers managing PLHIV.
3. To implement the counselling intervention
4. To conduct a preliminary evaluation of the efficacy of the counselling intervention.

## **1.6. AN OVERVIEW OF THE RESEARCH METHODOLOGY**

### **1.6.1. Research Setting**

The study was conducted in the Buffalo City Municipality (BCM). The BCM is situated relatively centrally in the Eastern Cape Province, which is bounded to the south-east by the long coastline along the Indian Ocean. The Eastern Cape Province has the third largest population of 6 562 053 million people (Census, 2011), which is 12.7% of the South African population. The BCM is one of the newest metropolitan municipalities established in South Africa after the 2011 Local Government elections. The focal point of the study was two health care facilities, namely Sophumelela Centre (a non-governmental health facility) and Nontyatyambo Clinic (a governmental health facility). These health facilities were chosen because they both offer HIV counselling and testing (HCT), antiretroviral therapy, care and support.

### **1.6.2. Research Design**

The study employed an intervention research design as proposed by Rothman and Thomas (1994) frequently used in research in the social development professions. They outlined the systematic development of interventions, which included six phases, namely: Problem analysis and project planning; information gathering and synthesis; intervention design; early development and pilot testing; evaluation and advance development; and dissemination. Gilgun and Sands (2016) purport that although Rothman and Thomas (1994) present these phases sequentially, the process tends to be nonlinear and recursive.

According to Rothman and Thomas (1994) one important aim of the intervention research is to create means for improving community life, health and well-being. The intervention research traditionally focuses on testing an approach or intervention designed to maintain or improve the functioning of an individual or group. The ultimate goal is to test and refine a given intervention or programme in order to disseminate it to a wider population. The six phases of the intervention research are illustrated in figure 1 as outlined by De Vos, (2006).

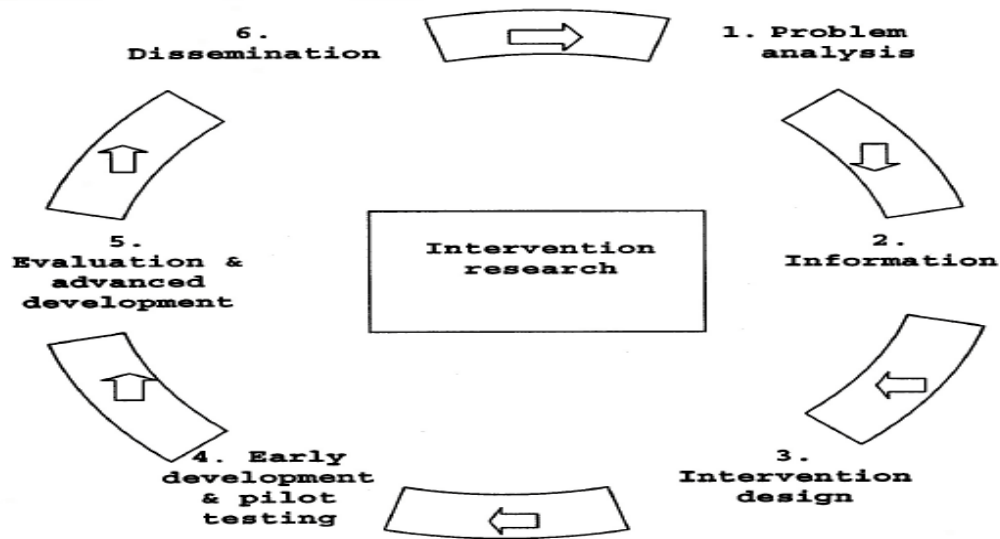


Figure 1 Six phases of intervention research

Figure 1: Source: De Vos, 2006

The problem was identified and analysed with the involvement of participants in the process. Information was gathered through a number of existing information sources identifying functional elements of successful models. The data was gathered using a number of data collecting methods, interpreted to develop the intervention. The intervention was developed, piloted and eventually implemented to its intended population. The study dealt with analysing the results and evaluating the implementation of the intervention.

The dissemination phase of the intervention research involves several operations such as choosing a brand name, establishing a price, identifying a market of potential adopters for community intervention, creating demand and setting standards for the intervention use and all these aspects require a good budget. In this study dissemination was not conducted by the researcher as this was not required by this particular study. However, recommendations of the

study indicated how this intervention could be disseminated. This has also been put forth as the limitation of this study.

The research design of this study used both qualitative and quantitative research methods using the triangulation technique where questionnaires, interviews and focus groups as data collection techniques were utilised. The triangulation technique is used to gain advantage on the weaknesses of each data collection technique utilised.

### **1.6.3. Population and Sampling**

This study consisted in total ninety-eight (98) participants participating at different stages of the study. Out of 98 participants there were twenty health care workers and (seventy-eight) 78 client participants who are PLHIV from two health care centres. The researcher had aimed at 120 participants in total which she obtained at the recruiting stages of the research but due to reasons beyond control the number decreased before commencing the study. Some participants had transport challenges and some had domestic problems especially those from Nontyatyambo clinic. The majority of the participants were women and black Africans. Their biographical information is illustrated in chapter four.

The researcher used purposive sampling. Purposive sampling is one of the selective methods that focused on the purpose of the study. Purposive sampling in its nature starts with a purpose in mind, where the sample is selected to include people of interest and excludes those who do not suit the purpose. It allows the researcher to choose individuals or the setting based on what is required. It is believed that individuals possess useful information for the purpose of the study. The sampling procedure involved a three-stage process in which PLHIV complaining about stress or stressful conditions and health care workers were selected.

### **1.6.4. Data Collection**

Data was gathered by means of a number of data-collecting techniques. The researcher collected data from adult men and women living with HIV and AIDS who attended one governmental and one non-governmental HIV and AIDS health facilities in the BCM area in the Eastern Cape Province. The study included people aged 18 years and above. The target population for the study was the health care workers at Sophumelela and

Nontyatyambo health care centres and clients living with HIV and AIDS in the same facilities.

#### **1.6.4.1. Cross-sectional survey: Biographical questionnaire**

Data was obtained via a biographical questionnaire to gather information on age, gender, location, marital status, family information, how and when they knew about their sero-positive status and how they reacted to the results, whether they were attending counselling sessions or not, as well as their Anti-retroviral treatment status. Additional to the quantitative data, qualitative questions were asked as a follow-up to the quantitative-type questions. Seventy-eight (78) questionnaires were administered to selected participants.

#### **1.6.4.2. Psychological Tests**

Over and above the cross-sectional questionnaires and semi-structured focus group interviews conducted, psychological assessments such as the Medical Outcomes-HIV questionnaire (MOS-HIV) and Beck Depression Inventory (BDI-II) were administered to assess the impact on daily life of HIV and AIDS as a chronic illness.

The MOS-HIV is a comprehensive health measure that has been used extensively in studies of HIV and AIDS. Developed in 1987, the MOS-HIV was one of the first disease-targeted measures for the population of HIV positive people and is widely used in clinical trials and other research and evaluation studies. The MOS-HIV has nine subscales: cognitive, physical, social, role and mental health functioning, general health perception, pain, fatigue, health distress, health status transition and quality of life (Wu et al., 1991). Due to its wide use, the MOS-HIV validity and reliability have been cleared, and is considered valid and reliable quality of life (QoL) measure for PLHIV.

- **MOS-HIV Reliability**

Data from numerous studies support the internal consistency and reliability of the multi-item scale in the MOS-HIV. In most cases, Cronbach's alpha coefficients exceed 0.70, suggesting adequate reliability for group comparisons. Cronbach's alpha coefficients for the physical health summary scores range from 0.90 to 0.92 and the coefficients for the mental health summary scores ranged from 0.91 to 0.94 across different samples (Wu, et al., 1991).

- **MOS-HIV Validity**

Multi-trait analyses support the convergent and discriminant construct validity of the scales, and suggest that they measure distinct aspects of health across different stages of illness. There is a large body of data on the relationship of the scale scores to concurrent indicators of health. As expected, MOS-HIV scores are moderately and significantly correlated with scores on established health status instruments, symptom indices, performance measures, and clinical and examination findings. According to Wu et al., (1991), people with asymptomatic HIV and AIDS illness have consistently demonstrated higher scores on MOS-HIV than those in the later stages of the illness.

- **BDI-II Validity**

The BDI-II is a series of questions developed to measure the intensity, severity, and depth of depression in client participants with psychiatric diagnoses. Its long form is composed of 21 questions, each designed to assess a specific symptom common among people with depression. A shorter form is composed of seven questions and is designed for administration by primary care providers. This test was first designed by Aaron T. Beck, a pioneer in cognitive therapy (Beck, Rush, Shaw, & Emery, 1979).

The BDI-II has been extensively tested for content validity, concurrent validity, and construct validity. The BDI content validity was constructed from a consensus among clinicians about depressive symptoms displayed by psychiatric participants. At least 35 studies have shown concurrent validity between BDI and such measures of depression as the Hamilton Depression Scale and the Minnesota Multiphasic Personality Inventory-D (MMPI-D). Tests for construct validity have shown the BDI to be related to medical symptoms, anxiety, stress, loneliness, sleep patterns, alcoholism, suicidal behaviours and adjustment among youth (Beck, Steer & Garbin, 1988).

- **BDI-II Reliability**

The BDI-II has also been extensively tested for reliability. Internal consistency has been successfully established by over 25 studies in many populations. The BDI-II has been shown to be valid and reliable with results corresponding to clinician ratings of depression in more

than 90% of all cases, (Steer, Ball, Ranieri & Beck, 1997). It has also shown to have test retest reliability (Moore, Neale, Silberg & Verhulst, 2016) in several studies.

#### **1.6.4.3. Focus Group Interviews**

A focus group is a form of qualitative research method of collecting data in which a group of people are asked about their perceptions, opinions, beliefs and attitudes towards a particular subject. Focus groups are a powerful means to evaluate or test new ideas. They are basically interviews of between 6 -10 people at the same time in the same group in an open-ended discussion (Gillham, 2005). Focus group in this study were those of health care workers and focussed on their perceptions, opinions and observation of PLHIV and how they assist them to cope with psychological conditions and stress, as well as suggestion which may assist their intervention. Data was gathered through semi-structured questions.

#### **1.6.5. Research Procedure**

The research procedure after information gathering phase, followed the three phases of the intervention research namely; intervention design through collecting data to develop the intervention, pilot testing of the intervention and refine it and its implementation, and the evaluation of the implementation of the intervention as explained in Chapter four.

Focus groups interviews with health care workers were conducted. Questionnaires were administered to client participants. Data collected was analysed. Thereafter, a draft intervention was compiled and piloting of the biographical questionnaire was done among the health care workers living positively with HIV and AIDS. After revising the questionnaire instruments through pilot testing, data was collected by the researcher together with research assistants. The information from focus groups was analysed to establish themes that would guide the development of the intervention and questionnaires were analysed using SPSS.

The intervention was then developed. The researcher, with the assistance of a counselling psychologist colleague assisted with pilot testing with four PLHIV health care workers through conducting at least three sessions of the intervention. After these sessions the intervention was refined with minor changes and health-care workers at Sophumelela centre and Nontyatyambo clinics were trained on the intervention as explained in Chapter four.



The implementation of the intervention was done by thirteen health care workers through conducting three intervention programme sessions with client participants. After three intervention sessions each, a process evaluation session with health care workers was conducted to give feedback and reflections on how they had experienced the intervention. Input from all these stages was put together, analysed and the findings are discussed in chapter five and six.

#### **1.6.6. Delimitations**

The study was delimited to the development, implementation and process evaluation of the intervention for PLHIV who experienced stress-related psychological conditions. The study was confined to health care workers as the primary target group for all the focus group interviews and PLHIV as secondary target group for quantitative data collection and implementation of the intervention. The reason for using health care workers continuously through the study was to maintain continuity, as health care workers were likely to remain in their employment for at least an approximate period of three years or for the duration of this research, unlike PLHIV who might not be available when the researcher went back for the post-test interview.

#### **1.6.7. Data Analysis**

Data Analysis is a process of inspecting, cleaning, transforming data with the goal of highlighting useful information, suggesting conclusions and supporting decision-making (Rubin & Rubin, 1995). Data for this study was analysed using the Statistical Package for Social Science (SPSS). Specific statistical analyses were determined by the type of questions asked and responded to by respondents. The cross-tabulations and frequencies as illustrated in chapter five with tables and pie-charts have been used. Qualitative data was analysed using themes and presented verbatim. A diagram showing qualitative data analysis process is shown in chapter four.

#### **1.6.7. Ethical Considerations**

The research proposal was submitted for approval to the Nelson Mandela Metropolitan University Human Ethics Committee before the commencement of the study. After approval by the Committee, permission to conduct the study at Nontyatyambo clinic

was obtained from the Eastern Cape Department of Health and from the District Manager of Amathole District. For the Sophumelela centre, permission to conduct the study there was obtained from the Managing Director of the centre. Participation was voluntary with informed consent signed by willing participants (both PLHIV and health care workers). Records of the participants were safely stored in the researcher's office lockable cabinet to ensure confidentiality in accordance with the law and in a manner that permits compliance with the requirements of the research ethical code.

## **1.7. LAYOUT OF THE STUDY**

This chapter has offered an introduction to the study. In Chapter 2, relevant literature in the field of HIV and AIDS and stress-related psychological conditions has been reviewed. Chapter 3 presents the theoretical framework for the study. In Chapter 4 the research methodology is outlined along with the analysis of data collected and ethical considerations. This chapter also divides the collection of data process in three phases, namely, the development of the intervention, the implementation of the intervention and the evaluation of the implementation of the intervention. Chapter 5 presents the findings of the study as per the three phases already mentioned in Chapter 4. In Chapter 6 the findings of this study are discussed and finally Chapter 7 deals with the summary of the study, limitations of the study, conclusions and the recommendations for the implementation of the intervention as well as the contribution to new knowledge and for future research.

## **CHAPTER 2**

### **REVIEW OF LITERATURE**

#### **2.1. INTRODUCTION**

This chapter focuses on a review of literature as it relates to the stress-related psychological conditions among PLHIV. It gives an extensive discussion on the fundamentals of HIV and AIDS including: theories of HIV origin, epidemiology, transmission HIV life cycle and structure and available treatment. This chapter also elaborates on stress-related psychological conditions as they affect PLHIV.

#### **2.2. AN OVERVIEW OF PSYCHOLOGICAL STRESSORS AMONG PLHIV**

People living with HIV and AIDS may suffer psychological distress as a result of the many physical, social, and economic effects of the disease in their lives. Among the various stressors are chronic physical pain, physical disfigurement, possibility of infecting others, stigma, discrimination, abuse, and the loss of fundamental human rights (Orne-Gliemann, et al., 2015). Other challenges include changes in lifestyle to accommodate the illness itself and the financial burden that treatment brings for oneself and one's family (Slomka, Gripshover & Daly, 2013). PLHIV often face loss of independence, physical, social, and emotional isolation, uncertainty concerning the timing and nature of treatment and disease progression and uncertainty in their personal and social lives. Additionally, many PLHIV are simultaneously coping with grief from having lost their loved ones to AIDS (Fabianova 2011). As a result of these stressors, people diagnosed with HIV infection often suffer from a number of psychological symptoms, including anger, frustration, anxiety, depression and post-traumatic stress disorder (Saadat, Behboodi & Saadat, 2015).

Research has highlighted the impact of HIV and AIDS on the psychological health of HIV infected individuals, mainly in Europe and North America and recently in other parts of the world, showing that HIV infection is associated with the increased incidence of common psychological conditions such as anxiety and depressive disorders, (Do, Rosenberg, Sullivan, Beer, Strine, Schulden, & Skarbinski, J. (2014). According to the Global Burden of disease study in 2010, a substantial proportion of the world's disease of burden came from mental, neurological and substance use disorders (Whiteford, Ferrari, Degenhardt, Feigin, & Vos,

(2015). In 2012 on ABC news in America, Mikaela Conley reported that one in five Americans experienced some kind of mental illness in 2010 (<http://www.reportingonhealth.org/%40mikaelaconley>).

Greenberg, Fournier, Sisitsky, Pike & Kessler, (2015) also indicates that “neuropsychiatric disorders are the leading cause of disability for people aged 15-44 years old resulting in almost 400 million disability days per year in the United States alone. These studies attribute this burden, in part, to the chronicity of illness and the lack of, or limited access to psychological or mental health services around the world. This limited access has become more salient within the context of the HIV and AIDS epidemic

According to Leserman (2008), some stress-related psychological conditions such as depression, can also reduce the motivation to seek health care. They can impair compliance and adherence to treatment, decrease the quality of life, and increase mortality. The neuropsychiatric effects of the virus can lead to dementia and motor disorders that further affect the quality of life. Psychological illness can also be a risk factor for HIV infection. Certain psychological conditions, including substance abuse, increase the vulnerability to HIV infection. In North America, HIV risk among people with major psychological conditions has been associated with lack of condom use, multiple sexual partners, and injection drug use. The social exclusion that often accompanies life with a severe psychological illness may also increase vulnerability to infection, leading to the exchange of sex for money or goods and an increase in coercive sexual encounters. Cognitive deficits associated with certain psychological conditions may impair judgment and the ability to negotiate safe sexual encounters (Freeman, Patel, Collins & Bertolote, 2005).

Few research studies have been conducted on how PLHIV cope with psychological risk factors caused by the diagnosis of HIV and the treatment thereof, especially in Sub-Saharan Africa. There is little substantial systematic review of existing evidence for the link between psychological illness and HIV (Myer, Seedat, Stein, & Williams, 2009). Such research is crucial in order to inform the provision of HIV care services. While there is increasing attention to the medical needs of HIV-infected individuals in Sub-Saharan Africa, there is less attention paid to the psychological needs of these individuals, (Collins, Holman, & Freeman, 2006). In a setting of high prevalence such as South Africa, where a large portion of the population knows someone infected with or affected by HIV, the scope of this need is

substantial (Myer, Seedat, Stein, Moonal, & Williams, 2009). In South Africa the notion of psychological conditions is engulfed by stigma, where people with psychological conditions are treated differently and with isolation. It is important to note that persons living with HIV and AIDS and psychological conditions are subjected to a double stigma: being HIV positive and being psychologically ill.

According to Freeman, Nkomo, Kafaar and Kelly (2007) HIV and AIDS and psychological conditions or mental health illnesses have been the focus of many researchers since the spread of the HIV and AIDS epidemic. Understanding psychological conditions and HIV and AIDS is an enormous task, since both are illnesses that carry substantial stigma in our society (van Rooyen, et al., 2014). The very fact that such stigma exists tends to reduce the amount of social support that would be available if one were physically ill, thereby decreasing the chance that the individual will recover (Simbayi, et al. 2016). Many PLHIV have remained silent about their infection for fear of stigma and discrimination. This sometimes results in them suffering in silence, and bearing the brunt from some of the psychological conditions as discussed in this chapter.

Baingana, Thomas and Comblain (2005), in their paper on HIV and AIDS and mental health, maintain that mental and neurological disorders have an intertwined relationship with HIV, yet are often overlooked when AIDS interventions are planned and implemented. Cognitive disorders, substance abuse, and disorders of personality can influence behaviour in ways that lead to a greater risk of HIV infection. Conversely, HIV and AIDS itself can cause a number of psychological conditions due to circumstances surrounding the disease and psychiatric conditions resulting from HIV-related neurological changes. These disorders can adversely influence the progression of the disease, lead to noncompliance with prescribed medical treatment, and increase the likelihood that PLHIV will engage in high-risk behaviours. Each of these increases the chance of HIV transmission (Davids, Simbayi & Van Wyk, 2015). Furthermore, due to new treatments and increasing life expectancies, mental disorders are becoming progressively more relevant for HIV and AIDS management.

There is a clear need for services that will improve the psychological health of PLHIV (Adams, Zacharia, Masters, Coffey & Catalan, 2016). Improved psychological services not only help them but also may help the general public. High levels of depression and maladaptive coping with HIV have been associated with substance use, dangerous drinking

of alcohol and risky sexual activities which put others at risk of acquiring HIV (Garey, Bakhshaie, Sharp & Neighbors, 2015). There is a sense of vicious reciprocity where HIV AND AIDS diagnosis exacerbates mental health challenges, and compromised mental health thus, leading to risky sexual behaviour. Risky sexual behaviour increases the chances of sexually transmitted infections including HIV. This vicious cycle needs to be broken.

### **2.3. FUNDAMENTAL FACTS ABOUT HIV AND AIDS**

The Human immunodeficiency virus (HIV) and Acquired immunodeficiency syndrome (AIDS) were identified more than three decades ago but continue to devastate human beings all around the world. Many efforts have been made to prevent the spread of HIV infection. However, some countries seem to be more successful than others, therefore HIV and AIDS still remains a threat worldwide. The introduction of ART has made this disease manageable and is now treated as a chronic disease in most but not all countries.

#### **2.3.1. Human Immunodeficiency Virus**

Human Immunodeficiency Virus is a virus that can lead to AIDS, even though not everybody living with HIV progresses to AIDS. Unlike other viruses, the human body cannot get rid of HIV once it is in the body. This means that once one has it, it is there for life. However, the availability of treatment called ART (Antiretroviral therapy) can dramatically prolong the lives of many people infected with HIV and lower their chance of infecting others ([www.cdc.gov/hiv](http://www.cdc.gov/hiv), 2014).

#### **2.3.2. Acquired Immune Deficiency Syndrome (AIDS)**

AIDS is an acronym for *Acquired Immune Deficiency Syndrome*. AIDS is *acquired* because it is not a disease that is inherited. It is caused by a virus called HIV, which enters the body from outside. A *deficiency* is the weakening of the *immune system* so that it can no longer defend itself against usual infections. A *syndrome* is a medical term for a collection of illnesses that occur, in the case of AIDS, as a result of the weakened immune system. Even though AIDS is usually referred to as the disease, it does not qualify as such. It is the collection of many different conditions that manifest in the body or a specific part of the body because the HI virus has weakened body's immune system. Van Dyk (2012) declares that it is therefore more accurate to define AIDS as a syndrome of opportunistic diseases, infections

and certain cancers, where each has the ability to kill the infected individual in the final stages of the disease.

#### **2.4. THEORIES OF THE ORIGIN OF HIV AND AIDS**

According Schoub (1999) in Van Dyk (2012) there is little, if any, knowledge of the origins of any human virus, let alone the HI virus. There are two theories about the origins of the HIV and AIDS epidemic. The first one conceives of AIDS as a centuries-old disease of Africa and the second theory postulates that HIV crossed the species barrier from primates to humans.

The first theory suggests that AIDS is not a new disease but has been present for centuries in central Africa. However, argument against this theory is that modern testing of archived blood samples from Africa rarely show any signs of HIV infection before 1980s (Schoub, 1999) in Van Dyk (2012). It is said that only one early blood sample showed positive for HIV antibodies was taken in 1959 in Kinsasha in the Belgian Congo. Other than that, doctors with many years of clinical experience in Africa have never seen diseases resembling the very obvious features of AIDS, so it can be concluded, therefore, that AIDS is indeed a new disease and that HIV was introduced into the human population in the 1950s.

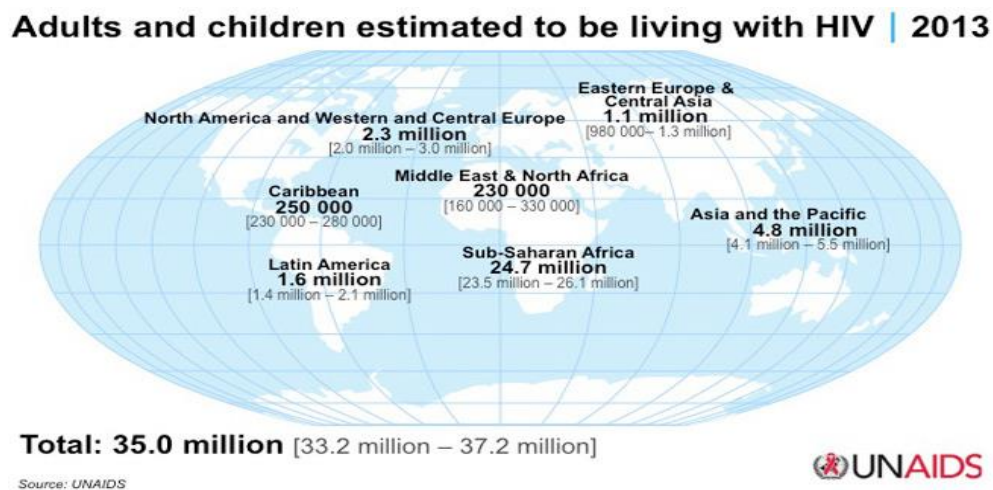
The second theory suggests that HIV crossed the species barrier from primates to humans some time during the twentieth century. According to Hemelaar, (2012) HIV is related to a virus known as Simian Immunodeficiency Virus (SIV) found in primates. It is believed that under natural conditions each strain of virus will infect only its own specific species and will not infect humans. Suspicion arises because SIV and HIV are said to show a close relationship, especially with HIV type 2, which is mostly found in West Africa where sooty mangabey monkeys are found. The link between HIV-1 and SIV is not so clear, (Hemelaar, 2012). However the question remains as to how simian viruses could have been transmitted from monkeys to humans. Heller (2015) also calls for clarity on this subject as rumours on the origin of HIV and AIDS hamper the prevention of HIV and AIDS among African American communities. It looks like the origin of HIV which causes AIDS is still unknown as the above theories leave many questions unanswered.

## 2.5. THE EPIDEMIOLOGY OF HIV AND AIDS

According to Moore, Chen, Lee, LeBlanc, Fleming & Caban-Martinez, (2016) epidemiology is the study of the distribution and the determinants of states of health in populations, with the objective of prevention and controlling ill health. HIV and AIDS epidemic data is estimated by means of three data sources, namely, national household surveys, antenatal surveys (pregnant women), and from reports of AIDS-related deaths. Each of these methods has its own advantages and disadvantages, so it is important to assess these estimates critically. Whiteside & Sunter (2006) clarify this by saying it is not known how many people are infected and of those how many will fall ill or die and when they will do so, but we can only estimate the numbers.

### 2.5.1. Global Epidemic

HIV and AIDS remains a big contemporary health challenge on many fronts and in many spheres of life, globally. UNAIDS and many organisations globally have worked tirelessly to eliminate this disease, yet it continues to hinder many efforts to prevent it from spreading and preserving human potential in poor resource settings worldwide.



**Figure 2** Adult and children estimated to be living with HIV, 2013.

A UNAIDS (2013) report estimates that there were about 35.0 million [33.2 million–37.2 million] people living with HIV at the end of 2012. This report revised the estimate of the number of people living with HIV in 2008 of 33.4 million [31.1 million–35.8 million] published in AIDS epidemic update in November 2009. This revision is based on additional data becoming available for many countries, including data from population-based surveys.

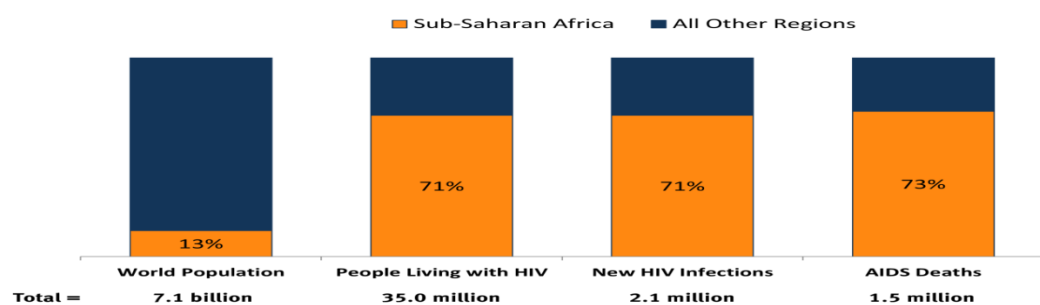


UNAIDS (2012) argues that, despite recent improved access to antiretroviral treatment and care in many regions of the world, the AIDS pandemic is still a worrying factor.

UNAIDS (2012), noted that the epidemiological data shows the continuing rise in the population of people living with HIV. It reflects the combined effects of continued high rates of new infections and the beneficial impact of antiretroviral therapy with 4 million people in low- and middle income countries receiving antiretroviral therapy, a ten-fold increase over a five year period (Slaymaker, et al., 2014). According to UNAIDS (2012) HIV and AIDS still continues to be a major global health priority due to the continuous rise in new HIV infections. There is geographic variation of the prevalence and epidemiology between and within countries and regions where the epidemic is evolving, ranging from drug-user transmission in some countries to sexual transmission in other countries. There is also increased evidence of risk among key populations such as men having sex with men (MSM) and sex workers (Department of Health, 2011; Solomon et al., 2015)).

### 2.5.2. Sub-Saharan Africa Epidemic

The Sub-Saharan Africa contains the majority of PLHIV globally. This region counts for 71% of HIV infections worldwide. With all the efforts in fighting this disease, this region still struggles to combat the scourge of HIV and AIDS due to a number of issues including poverty in this region.



SOURCE: Kaiser Family Foundation, based on UNAIDS, Gap Report; 2014 and Population Reference Bureau, 2013 World Population Data Sheet; 2013.



**Figure 3: Sub-Saharan Africa as share of Global HIV Prevalence Incidence, and Deaths Compared to Share of World Population, 2013**

UNAIDS (2009) reports that in 2008, an estimated 1.9 million [1.6 million–2.2 million] people living in sub-Saharan Africa became newly infected with HIV, bringing the total number of people living with HIV to 22.4 million [20.8 million–24.1 million]. While the rate of new HIV infections in sub-Saharan Africa has slowly declined with the number of new infections in 2008 approximately 25% lower than at the epidemic’s peak in the region in 1995, the number of people living with HIV in sub-Saharan Africa slightly increased in 2008, in part due to increased longevity stemming from improved access to HIV treatment. Adult (15–49 yrs. of age) HIV prevalence declined from 5.8% [5.5–6.0%] in 2001 to 5.2% [4.9–5.4%] in 2008. In 2008, an estimated 1.4 million [1.1 million–1.7 million] AIDS-related deaths occurred in sub-Saharan Africa. This number represents an 18% decline in annual HIV-related mortality in the region since 2004. Comparing these figures to the global epidemic it shows that sub-Saharan Africa remains the most affected region worldwide. In a recent survey by UNAIDS reported in 2013, sub-Saharan Africa accounts for 71% of HIV infections worldwide (UNAIDS, 2013).

### 2.5.3. South African Epidemic

In 2011, the sub-Saharan Africa was estimated to 23.5 million PLHIV. Of which South Africa accounted for 5.6 million PLHIV and that number has since increased in 2012 to 6,4 million. South Africa remains the only country with highest HIV prevalence in the world.

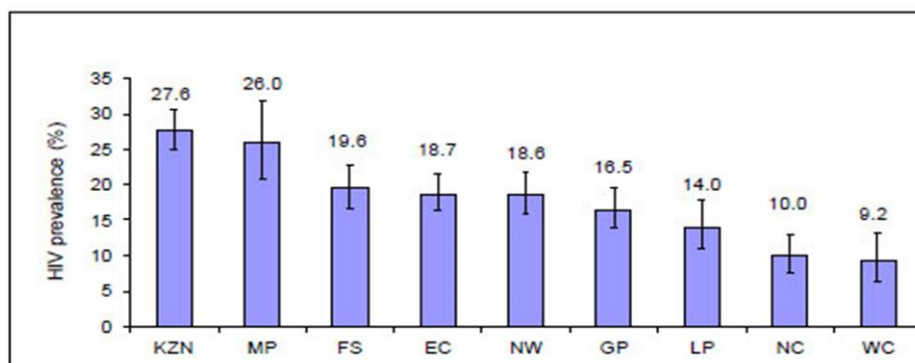


Figure 4: HIV prevalence by province (15 – 49 years) South Africa 2012. Source: HSRC Report, 2014

According to the Human Science Research Council (HSRC) in its study of the South African National HIV prevalence, incidence and behaviour survey in 2012, South Africa has an approximately estimate of 6,4 million people living with HIV and AIDS. This is 1.2

million more than in 2008 (10.6% or 5.2 million). The adults aged (15 – 49 yrs.) prevalence rate was 19.0% [18.1 – 19.9%]. Women aged 15 and up living with HIV were 3 500 000 [3 300 000 – 3 700 000], while children (aged 0 – 14 years) living with HIV were estimated at 360 000 [320 000 – 390 000]. Deaths due to AIDS were 200 000 [170 000 – 220 000] and orphans due to AIDS and aged 0 – 17 years old were estimated at 2 400 000 [2 200 000 – 2 600 000].

According to the Metropolitan Foundation conducted a study, which showed the Eastern Cape Province, where the study was conducted, as the third ranked province with the total population of 730 000 (11%) of PLHIV (PLHIV) and 1 in every 5 adults was estimated to be HIV positive in 2008. An estimated 110 000 people were in need of antiretroviral treatment in 2008 with around 44% having taken up treatment (Nicolay, 2008). In the Eastern Cape alone AIDS deaths were estimated at 44 000 per year, with new infections of 81 000 per year (Nicolay, 2008). With this in mind in the HSRC, 2012 study the Eastern Cape, which had remained stable since 2005, had increased from 9.0% in 2005 to 12.2% in 2012 (HSRC, 2012).

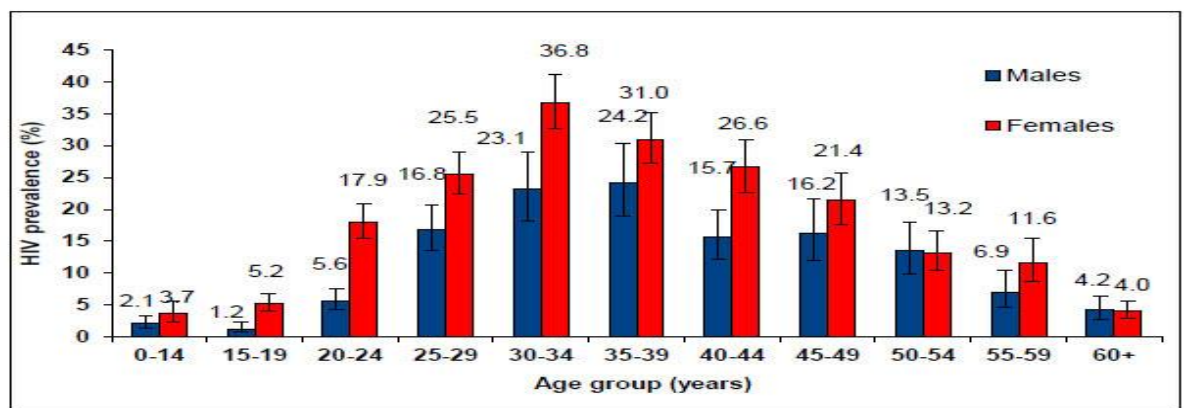


Figure 5: HIV prevalence by age and sex, South Africa, 2012

Source: HSRC Report, 2014

## 2.6. TYPES AND SUBTYPES OF HIV

According to Van Dyk (2012), HIV is divided into two types, namely HIV-1 and 2. These types are further divided into subtypes. HIV types are classified into one of three groups, based on their degree of genetic similarity namely Group M (the main group behind the global epidemic), Group N and Group O. The M Group is further divided into subtypes

using the letters from A to K. Each of these subtypes dominates in different parts of the world. Take for example the epidemic in Southern Africa, India and China. It is essentially driven by the HIV-1 subtype C viruses, while the HIV-1 subtype B viruses are predominantly found in Europe, North America, Japan and Australia. HIV-2 is classified into genetic subtypes A to G and most infections are caused by subtypes A and B. This classification of HIV multiple strains and subtypes makes it very challenging to develop a vaccine that would combine all subtypes due to the complex nature of HIV and its ability to recombine and form new subtypes.

## **2.7. HIV AND AIDS TRANSMISSION**

According to the Van Dyk, (2012) the HI virus enters one's body through three modes of transmission namely; unprotected sex with an HIV positive person (vaginal, anal and oral sexual intercourse transmission), HIV positive blood contamination, and either peri- or post-natal mother - to- child transmission. HIV has been identified in various body fluids, but it is highly concentrated in the following body fluids; blood, semen and vaginal secretions. Although HIV is present in such fluids as saliva, tears, sweat, breast milk and urine, the concentration of the virus is too low for successful transmission. For infection to occur there must be an entry point where the virus enters the blood stream and it must connect to CD4 receptors. In other words, the following must occur; presence of the virus in sufficient quantities, the virus gaining access into the blood stream and the duration of exposure should be long enough for transmission to occur (Van Dyk, 2012).

### **2.7.1. Sexual HIV transmission**

In South Africa the main mode of transmission is unprotected sexual intercourse with HIV infected people followed by the mode of perinatal transmission. Whiteside and Sunter (2006) argue that the initial cases of HIV infection in South Africa were discovered among homosexual men. It later spread to the heterosexual population. Sexual transmission occurs when one engages in unprotected sexual intercourse (vaginal, anal or oral) with someone infected by HIV. This happens due to the exchange of high-risk body fluids, namely; semen, vaginal fluids and blood.

The question of the transmission of HIV across an intact genital mucous membrane is answered by Evian (2000) in his explanation of how cells known as antigen-presenting cells

(APCs) such as Langerhans cells could transport HIV directly to the CD4 receptors of the CD4 cells. These cells are found in the skin and in the mucous membranes of the body and there are large numbers of these cells in the mucous membrane of the female and male genitalia. Langerhans cells circulate continually between the peripheral mucous membranes and the CD4 lymphocytes found in the lymph nodes and other lymphoid tissue Ribeiro, Sarrami-Forooshani & Geijtenbeek, (2015). Besides the Langerhans cell's route, HIV can also move directly into the bloodstream during sex through the delicate membrane lining of the anal-rectal and vaginal area. This membrane could get torn through friction during sexual intercourse. Another easy route for HIV transmission is sexually transmitted infections (STIs). Individuals who have STIs such as herpes, syphilis, gonorrhoea, and Chlamydia are particularly prone to HIV infection. These conditions create openings in the mucous membrane through which HIV can move freely (Camaroni, Toskin, Ndowa, & Gerbase, 2014).

The WHO (2005) reports that the risk of becoming HIV infected during unprotected vaginal intercourse is two to four times higher for women than men. The reasons put forth are; women are recipients of infected semen and exposure to semen is longer than that of men to vaginal fluid, women also have a larger surface area of mucosa (the thin lining of vagina and cervix) exposed to her partner's semen during sexual intercourse, a woman may go on without knowing that she has an STI inside the vagina or cervix, and women may also expose themselves through engaging in dry sex, or using such spermicidal preparations containing nonoxynol-9 which may cause irritation and inflammation of the vaginal walls Van Der Pol, (2014).

Apart from biological factors that expose women to HIV infection, socio-economic factors also render women vulnerable. Poor women with a very low status in their communities are put in a position where they have no say or cannot negotiate safer sex practices with their partners because they fear abuse, violence, or abandonment should they challenge their partners. Poverty also contributes in spreading HIV because women who are left behind by men who migrate to cities do not return. These women resort to selling their bodies without using condoms just to feed their children. Access to health care systems range from very difficult to none for people in poverty stricken areas. Rape of infants and girls has become a devastating phenomenon in these areas. According to Smith, Bryant-Davis, Tillman & Marks, (2010) a shocking report by Medical Research Council of South Africa (MRC-SA)

showed that the majority of women in their study who reported that they had been raped were between the ages of 10 and 14 years of age at the time of the rape, and that schoolteachers were the perpetrators in 33% of these cases. In many cases the teachers threatened to fail the girls in their examinations if they did not have sex with them. Young girls are often coerced, raped or enticed into sex by someone older, stronger or richer than themselves (Panday, Makhiwane, Ranchad & Letsoalo, 2009). HEAIDS (2010) reports that young women in universities are often offered money in return for sex by older men commonly known as 'sugar daddies', and more often than not condoms are not used during sex (Dunkle et al, 2004). Sometimes there is a high level of alcohol and drug use in night clubs and at parties to where these young women are often taken.

The notion that women are more susceptible to HIV infection than men and as backed up by statistics does not mean men do not contract HIV. It means only that the risk for women is even higher than that of men (Van Dyk, 2008).

### **2.7.2. Blood HIV transmission**

The HI virus is found in body fluids of the infected individual and even though some fluids in one's body do not carry high levels of HIV, blood is one of those high risk fluids followed by semen and vaginal secretions. All instruments with contaminated blood that are re-used without sterilising them can transmit HIV to another user. These are syringes, needles, razor blades, and other sharp instruments. According to Whiteside & Sunter (2006) the use of contaminated blood or blood products is a very effective way of transmitting the virus, since it deposits the HIV directly into the bloodstream. However, precautions to screen donated blood and blood products have since been implemented worldwide. According to the WHO, (2005) all blood transfusion services throughout the world follow guidelines to ensure a safe blood supply. These include screening of donated blood for HIV, hepatitis B & C and syphilis. According to Van Dyk (2012) blood products such as factor VIII (proteins promoting the clotting of blood and used for haemophiliacs) are heated up to 60°C and this heating process destroys the virus. Even though precautions are taken to screen blood, people who engage in high risk sexual activities should take moral and ethical responsibility not to donate blood.

Injection drug users who share syringes and needles are at a high risk of contracting HIV. In many countries outside Africa, such as Italy, Portugal and Spain over half of all AIDS cases have been attributed to the use of contaminated needles used to inject drugs, (UNAIDS, 2010). With the increasing prevalence of drug use in Africa, Van Dyk, (2012) cautions that African Governments should not wait until it is too late before educating people about how easy it is to transmit HIV by sharing blood infected needles.

Health care workers who work with HIV positive people are always cautioned about the accidental exposure to infected blood and should exercise precautionary measures all the time (Messam & Fraser, 2016). Even though the chances are minimal, nothing is 100% safe. Health care centres dealing with client participants especially PLHIV, should make available post-exposure prophylaxis (PEP) in a form of antiretroviral medication to all health care workers who have been exposed to HIV infected blood. There is no empirical evidence as to how much blood is required to transmit HIV. It depends on the volume of viral load in the blood stream. It is always important, therefore, to take proper precautions when handling blood and any other body fluids.

### **2.7.3. Mother-to-child HIV transmission**

Van Dyk (2012) believes that mother-to-child transmission (MTCT) or vertical transmission of HIV is the major perpetrator of HIV infection among children. South Africa continues to have a high rate of mother-to-child transmission of HIV. Almost 28% of pregnant women and 30% of mothers are HIV-positive and an estimated 300,000 mothers need treatment each year. The National HIV and AIDS and STI Strategic Plan for South Africa, 2011-2016 (NSP) aimed to reduce the rate of mother-to-child transmission to less than 5% by 2011. Progress with the implementation of the PMTCT programme has been mixed, with greater gains made in some health districts than others. Reaching the NSP target will require a major national effort, including social mobilisation and investments in health systems. The transmission of the virus from the mother to the child can occur inside the uterus (*in utero*) during the last weeks of pregnancy and at childbirth. In the absence of treatment, the transmission rate between a mother and her child during pregnancy, labour and delivery is 25%. However, when the mother takes antiretroviral therapy and gives birth through caesarean section, the rate of transmission is approximately 1%. The risk of infection

is influenced by the viral load of the mother at birth; the higher the viral load, the higher the risk. Breastfeeding also increases the risk of transmission by about 4% (Evian, 2003).

Current recommendations by the World Health Organisation state that when replacement feeding is acceptable, feasible, affordable, sustainable and safe, HIV-infected mothers should avoid breast-feeding their infants. However, if this is not the case, exclusive breast-feeding is recommended during the first six months of life and discontinued thereafter (Kuhn et al., 2007). Exclusive breastfeeding for up to six months was associated with a three to four-fold decreased in the risk of transmission of HIV compared to non-exclusive breastfeeding in three large cohort studies conducted in Côte d'Ivoire, South Africa and Zimbabwe (Olagunju, Khoo & Owen, 2016).

## **2.8. MYTHS ABOUT HIV AND AIDS**

HIV AND AIDS was introduced in our society by means of fear inducing tactics, such as 'AIDS KILLS' slogans together with the mysterious elements of the origin of HIV and AIDS Bayer & Fairchild, (2016). This contributed to some myths regarding the disease. These myths became extremely dangerous as they created adverse consequences and led to criminal behaviours such as rape of virgins a driver of a high HIV infection rate. These myths include people infected by HIV believing that they can remove it by having sex with fat women (as opposed to the myth coming from 'slim disease' where slim people are seen as having AIDS); or have sex with virgins which leads to the increased rape of children both girls and boys under the age of 12. Van Dyk (2012) believes that acts such as these could lead to indecent criminal behaviour and can definitely reverse strides already taken to prevent the spread of HIV and AIDS in the world, especially in South Africa.

It is very intriguing to note the similarity between the virgin syphilis cleansing myth that occurred in the 19<sup>th</sup> century and the 21<sup>st</sup> century myth on HIV and AIDS both being sexually transmitted infections (Leclerc-Madlala, 2002). In the 19<sup>th</sup> century, as Leclerc-Madlala (2002) purports, men in England believed that sexual intercourse with a child virgin would cure syphilis. In Liverpool people pretended to be medical doctors and kept special brothels to provide this cure. Girls who were used in this horrifying act were often mentally impaired. It is therefore important for people to be educated about HIV and AIDS accurately and responsibly to dispel myths around HIV and AIDS.

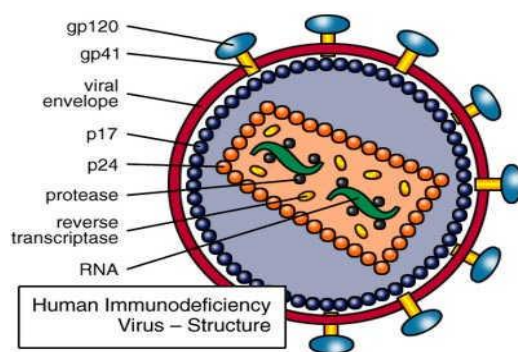


## 2.9. HIV AND AIDS AND THE IMMUNE SYSTEM

HIV attacks the white blood cells called CD4 cells or T-helper cells that help protect the body against numerous illnesses and it weakens the immune system gradually by destroying these cells and replacing them with virus-loaded cells (Nowak & McMichael, 2003). This process continues until there is a greater volume of virus in the bloodstream than CD4 cells and the body eventually gives in to opportunistic infections. At this stage the person starts developing what is called, Acquired Immune Deficiency Syndrome (AIDS). If treatment is not prescribed early enough, these opportunistic infections could resist treatment and the immune system becomes completely destroyed, eventually leading to death (Whiteside & Sunter, 2006).

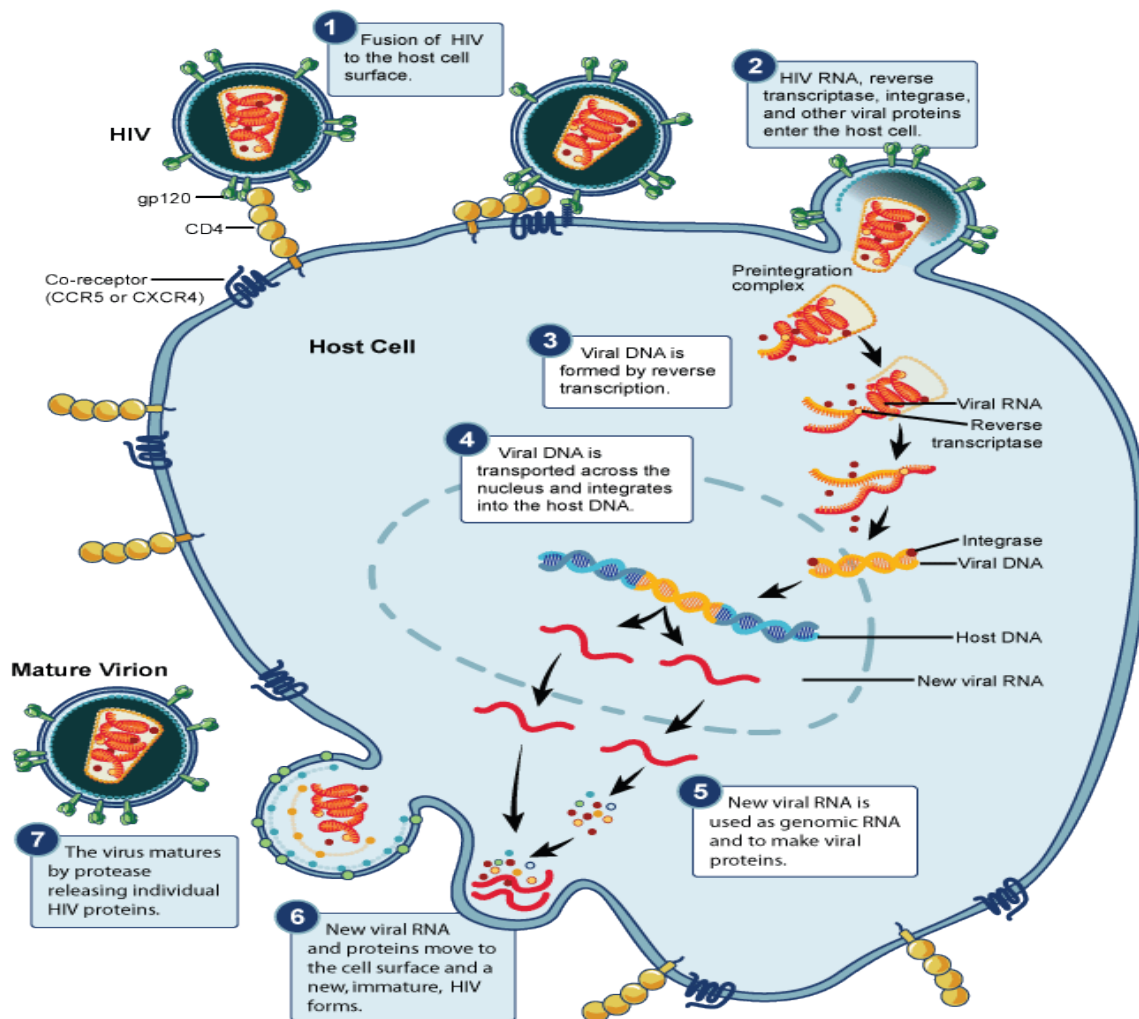
When HIV invades the body, macrophages attempt to do their job, which is to capture the invader, in this case, HIV. According to Sompayrac, (2015) the macrophages carrying HI virus go to warn the CD4 cells that there is an invader but unfortunately the invader is attached to the ‘whistle blower’ and then the problem begins. The HI virus attacks the CD4 cells directly and this is the unique strategy of HIV that makes it so dangerous to human beings. In other words CD4 cells get ‘hijacked’ by HIV to channel their activities into manufacturing more viruses. This is how HIV invades the CD4 cell, (see the diagram below).

### The HIV Structure



The HI virus is round in shape. Its RNA is covered by an envelope that has many glycoprotein projections on the surface. To enter the body, the following (simplified) process unfolds: projections attach themselves to CD4 receptors of the CD4 cells/T4 cells, the virus core enters the cell and its RNA is converted to DNA, the DNA enters the nucleus and is combined with the DNA of the host cell.

**Figure 6.** Source: <http://www.avert.org/hiv-virus.htm>



**Figure 7: HIV Life cycle diagram**

**Source:** <http://www.freehealthfacts.com/hivlifecyclediagram.htm>

The steps by which HIV infects and kills helper T cells are described below and can be viewed in Figure 7.

### 2.9.1. HIV Infection Cycle

- The first step in HIV's attack on helper T cells is attaching to the cell. Helper T cells contain proteins called CD4 proteins in their cell membrane that extend outside of the cell. Normally, these gp120 glycoproteins help the cells to bind to antigens (infectious particles) in order to stimulate activation of the helper T cells, and they are also required for normal T cell development. Unfortunately, however, CD4 proteins also function as receptors for HIV, allowing the virus to attach itself to the cell and thereby gain access to the cell's biochemical machinery.*

- *Once the virus has attached to a helper T cell, it injects its genetic information (as RNA) into the cell, along with the enzyme reverse transcriptase.*
- *Reverse transcriptase catalyses the production of DNA from the viral RNA, making a DNA copy of the virus's genetic material. This DNA copy is capable of incorporating itself into the cell's genetic material, because it is now in the same form as the cell's chromosomes. Hence, the step catalysed by reverse transcriptase is one of the most important steps in the infection cycle.*
- *The viral DNA copy then enters the nucleus of the infected helper T cell, where it is incorporated into the cell's genetic material (i.e., the chromosomes).*
- *Using the cell's own DNA-replication mechanisms, the viral DNA replicates.*
- *Using the cell's mechanisms for producing proteins from the genetic information contained in DNA, many copies of the proteins needed by the virus are made from the replicated HIV DNA. As part of this step, RNA copies of the viral DNA are made.*
- *When they are first synthesised, the proteins are too long (containing extra fragments) to be assembled into new viruses. They must be cut into their proper size. The HIV enzyme protease, which is produced by the cell's biochemical machinery from the viral DNA incorporated into the cell's chromosomes, catalyses the cutting of these proteins to their proper size.*
- *New HIV particles (viruses) are assembled inside the cell from the cut viral proteins and the viral RNA copies.*
- *Once assembled, the new viruses then burst out of the host cell (killing the host cell) and invade the new cells, continuing the HIV*  
*(<http://www.freehealthfacts.com/hivlifecyclediagram.htm>).*

As can be seen from the steps outlined above, enzymes play a vital role in HIV's attack on helper T cells. The generation of a DNA copy of the viral genome by reverse transcriptase (Step 3) and the cleavage of viral proteins (Step 7) by protease are two important processes catalysed by enzymes. Therefore, the enzymes reverse transcriptase and protease are major target sites for HIV-fighting drugs.

## **2.10. MANAGING HIV INFECTION AND ANTIRETROVIRAL THERAPY (ART)**

A person diagnosed with HIV infection has a life-long condition and goes through several stages of the disease. HIV and AIDS are manageable conditions and PLHIV with

their health care providers, have the responsibility to manage these conditions. In order for the PLHIV to manage these conditions, they need to get as much information and education about the disease and how best they can take care of themselves. They need to know, and maintain self-care, take prophylactic medication and eat well. They need to take care of their financial situation, maintain good psychological health, and know more about sexual reproductive health. PLHIV need to be educated about antiretroviral treatment benefits and their side effects as well as the importance of adherence and compliance (Masoke, 2003).

The PLHIV must visit health care providers regularly. If a person shows no symptoms and is coping well, twice a year visits are in order. More frequent visits of at least four times a year are essential for persons with symptoms and when ARVs have already been taken. For very ill people daily or weekly visits are required. It is advisable that PLHIV maintain regular visits to their health care providers for they may detect some conditions before they pose a danger. Frequent visits also allow health care providers to start preventative treatment (prophylactic medication) in good time (Quinlan, 2010).

At each visit, a thorough check-up is done by taking a number of tests to look for signs and symptoms of insidious opportunistic infections. Examples of tests taken include: full blood count to check for levels of different cells in the blood, and which can be low in the case of an HIV positive person. Other tests that are run include CD4 T-cell count to track immune deficiency levels. The viral load test is also done from time to time to check the level of HIV in the blood where higher levels indicate more virus activity and increasing damage to the immune system. For people on TB treatment and ARVs, other blood tests are done to check liver and kidney functioning (Evian, 2003; TB Control Programme, 2000; WHO, 2000).

A person living with HIV and AIDS can be well with no symptoms for many years, but eventually it becomes necessary at some point to take ARVs. The ARVs work directly on HIV to slow down its replication. This in turn slows down the loss of CD4T-cells that the virus is targeting. This slows down further damage to the immune system or even allows it to recover resulting in weight gain and a general improvement in health with fewer opportunistic infections, less need for other medication and hospitalisation (SA HIV Clinicians Society, 2005).

An ART is not a cure for HIV and AIDS but it reduces the HIV viral load. There are four goals ART sets out to achieve, namely, 1) *Virological goal* (even to undetectable levels for as long as possible), 2) *Immunological goal* (assures less damage to the immune system and delay the onset of AIDS), 3) *Therapeutic goal* (enhances quality of life and reduces opportunistic infections) and 4) *Epidemiological goal* (to reduce the impact of HIV transmission in the community). However there is also a downside and limitations to taking ART. It requires strict adherence and compliance, and has side effects that can make a person stop using them. They are very expensive and the fact that the individual takes them for the rest of his/her life are all reasons some people refuse ART.

There are currently four groups of ART drugs available and which work against the virus in different ways at different points in the cycle of the virus. HIV uses enzymes to replicate itself inside the CD4 cells, as shown in Figure 7. so ARVs act by blocking the action of these enzymes. The first group is Nucleoside Reverse Transcriptase Inhibitors (NRTIs). The second group is Non-Nucleoside Reverse Transcriptase Inhibitors (NNRTIs), third group is Protease Inhibitors (PI) and the fourth group is Fusion Inhibitors (FIs). There is the fifth group still under research, called Integrase inhibitors (IIs).

NRTIs and NNRTIs interfere with the reverse transcriptase enzyme in the early replication of the virus, which prevents it from changing its RNA into DNA. PIs interfere with the formation of new viruses by paralysing the protease enzyme and prevent the assembly and release of newly replicated HI viruses from the infected cells. FIs prevent HIV from entering the host cell by affecting the interaction between the virus and the cell. In this way binding, fusion and entry into the CD4 cell is blocked. These drugs are said to be very expensive. The IIs, which are still under research and not yet available in South Africa will work by interfering with the integrase enzyme and by so doing prevent the process of HIV integrating into the host genome or core of the CD4 cell, and which will render the virus unable to replicate. It looks like scientists and researchers are finding ways of disempowering the virus for now and until there is a cure to destroy HIV completely.

**Table 1.: Classification of ARV drugs in South Africa**

Nucleoside reverse transcriptase inhibitors (NRTI)		Non-nucleoside reverse transcriptase inhibitors (NNRTI)		Protease inhibitors (PI)		Fusion inhibitors (FI)	
Proper name	Trade name	Proper name	Trade name	Proper name	Trade name	Proper name	Trade name
Zidovudine (AZT)	Retrovir	Nevirapine (NVP)	Viramune	Indinavir (IDV)	Crixivan	Enfuvirtide (T-20)	Not yet available in South Africa
Lamivudine (3TC)	Epivir	Efavirenz (EFV)	Stocrin	Saquinavir (SQV) hard and soft gel	Invirase and Fortovase		
Didanosine (ddI)	Videx			Ritonavir (RTV)	Norvir		
Zalcitabine (ddC)	Hivid			Lopinavir/ritonavir	Kaletra		
Stavudine (d4T)	Zerit			Amprenavir	Preclir		
Abacavir (ABC)	Ziagen			Nelfinavir (NFV)	Viracept		
Tenofovir (TDF)							

Guidelines for the use of antiretroviral therapy are available where maximum suppressive antiretroviral regimens are recommended in order to obtain the best clinical results and to prevent resistance. Individuals entering ART are counselled and informed of everything regarding the use of ARVs and they are monitored as well (SAHCS 2005).

**Source: SAHCS (2005).**

## **2.11. HIV AND AIDS PHASE AND OPPORTUNISTIC INFECTIONS (OIs).**

There are a number of OIs associated with AIDS. OIs are related to the stages of HIV infection. It is therefore important to look at the stages of HIV infection and associated opportunistic infections as the virus grows in the body. Van Dyk (2012) asserts that although these stages theoretically exist, in practice they are not distinct with easily identifiable boundaries and HIV and AIDS client participants do not move in a distinct order from stage one to four. The development of opportunistic diseases depends on the relationship between the CD4 cells and the viral load. It is also imperative to identify psychological illnesses related to the progression of the HIV and AIDS diseases (Van Dyk, 2012).

Pre-clinical stage: Acute sero-conversion illness: This is the stage at which a person's HIV status converts from being HIV negative to HIV positive. This stage is often accompanied by feelings of shock, anger, disbelief and even denial from learning about one's sero-positive diagnosis. It occurs at about six weeks after infection with the HI virus. A common illness associated with this stage is glandular fever, with symptoms of the usual flu such as sore throat, swollen lymph nodes, joint pains and so forth. alleges that the HIV viral load is usually very high during this stage due to very rapid multiplication and replication of the virus after infection. This makes the infected person highly infectious before the immune system gets a chance to counter-attack the virus (Van Dyk, 2008).

Stage 1: The Asymptomatic latent stage. At this stage infected individuals are not even aware of the HI virus in their bodies, but the virus is already active and continues to make damage undermining the person's immune system. The HIV infected person at this stage shows no symptoms. A positive HIV antibody test is often the only indication of HIV infection during this stage. At a psychosocial level the infected individual presents with difficulties related to changes in lifestyle and to living with an infectious disease. While there are no physical symptoms some clients may develop health anxiety, misinterpreting minor non-HIV health symptoms, as indicators of the disease progression. This is the stage where clients confront issues related to disclosure of status, rejection and discrimination. Some suffer multiple bereavements with friends and acquaintances dying from HIV related illnesses. Within this context of multiple loss, clients may develop anticipatory loss reactions related to their own serostatus. The most prevalent diagnoses made during this phase are

adjustment disorders, depression, substance use, panic disorder, personality problems and psychogenic sexual dysfunction (WHO, 2010).

Stage 2: The minor symptomatic stage. Mild to moderate symptoms of HIV disease begin to manifest at this stage. The person living with HIV might present with one or more of the following OIs but is not limited to these; occasional fevers, herpes zoster or shingles, skin rashes, oral ulcerations, upper respiratory tract infections, fatigue and lethargy, weight loss up to 10% of usual body weight, and so on. The CD4 cell count at this stage is usually between 350 and 500 cells/mm<sup>3</sup>. Comparative studies of HIV negative and HIV positive people reveal that individuals experience significantly higher psychological morbidity in the third phase of the disease continuum. They usually present with higher levels of anxiety and depression. Other common diagnoses include organic brain syndromes such as HIV dementia, HIV minor neurocognitive, delirium related to opportunistic infections and substance dependency and use. Some may experience HIV-related sexual dysfunction such as erectile dysfunction or retarded ejaculation. All these conditions may adversely impact on an individual's effective use of condoms, and which may result in infecting others or re-infection. These psychological conditions may continue through to the major symptomatic phase and to the AIDS stage (WHO, 2010).

Stage 3: The major symptomatic stage: At this point the CD4 cell count becomes very low and the viral load becomes very high. Major symptoms and opportunistic infections/diseases start to bother the person infected with HIV. These OIs, are, but not limited to, TB, persistent and recurrent oral and vaginal thrush, shingles, chronic diarrhoea, unexplained loss of weight, intermittent fever, night sweats, abdominal discomfort, headaches, and many opportunistic diseases of various kinds including AIDS-related cancers like Kaposi sarcoma. The CD4 cell count is now between 200 and 350 cells/mm<sup>3</sup>. Clients may now experience adjustment disorders related to disease onset, loss of autonomy, grief and loss and increased suicidal ideation (WHO, 2008)

Stage 4: The Severe Symptomatic stage (AIDS-defining conditions). PLHIV can only be said to have AIDS when they enter this stage. This stage is marked by severe HIV disease symptoms that usually do not respond to antibiotics or medications associated with them. Their immune system has now deteriorated exponentially. A CD4 cell count is now below 200 cell/mm<sup>3</sup>. However, it has been noted that even people with a CD4 cell count below 200



cell/mm<sup>3</sup> can survive when antiretroviral drugs are administered. Dominant psychological illnesses at this stage are stress-related disorders including acute stress, AIDS dementia complex and mood disorders. Psychological assessment and diagnosis demand that the practitioner is able to consider the relative contribution of metabolic disturbances, constitutional illness, pre-morbid conditions, iatrogenic effects and psychological factors in mood and behaviour disturbances (Cohen, Smith, Muessig, Hallett, Powers, & Kashuba, (2013).

## **2.12. PSYCHOSOCIAL AND EMOTIONAL EXPERIENCES AMONG PLHIV**

According to Francisco, Fernandez and Pedro Ruiz (2006) individuals living with HIV confront a number of adverse psychological and social consequences common to those suffering from chronic illnesses. These involve having a life-threatening disease and the coping process related to receiving an initial diagnosis of being HIV positive, the onset of opportunistic infections, and the abrupt changes in physical and neuro-cognitive functioning. They argue that other psychosocial challenges may develop in the adaptation to having HIV, such as social stigma, changes in social roles, decisions linked to disclosure of illness status, changes in sexual practices and uncertainty about financial and material resources. Some psychosocial challenges may develop in the adaptation to starting antiretroviral therapy such as experiencing severe side-effects, adherence and compliance issues, and even to being seen to be taking chronic medication.

Among people living with HIV, a history of traumatic stressful life experiences has been associated with negative outcomes including reduced antiretroviral medication adherence (Mugavero & Saag 2007), virologic failure (Pence, Miller, Gaynes, & Eron, 2006), mortality, and opportunistic infections (Leserman et al, 2007; Mugavero & Saag, 2007) as well as increased sexual and drug use behaviours that raise the risk for secondary HIV transmission.

The burden of current or on-going traumatic and stressful experiences has not been widely characterised among individuals with HIV and AIDS. However, studies that have investigated recent trauma among HIV-infected individuals have identified relatively high levels of these experiences. For example, the HIV and AIDS Cost and Service Utilization Study (HCSUS), a national study of HIV-infected individuals receiving medical care (1996-

1998), asked research participants about physical abuse since HIV diagnosis and documented that 20.5% of women, 11.5% of men who reported having sex with men and 7.5% of heterosexual men reported physical abuse by a partner since HIV diagnosis. The World Health Organisation Report (2008) recommended that attention to the psychosocial needs of people with HIV and AIDS should be an integral part of HIV and AIDS care. An assistance given to PLHIV early in the diagnosis would prevent development of serious psychological conditions as the disease progresses.

The impact of HIV is significant for every individual but it also impacts on their families, friends and the wider community. The psychological suffering and deaths that HIV and AIDS has caused at an individual and at a community level had had a substantial impact on South Africa's overall social and economic development (Ardington, Bärnighausen, Case, & Menendez, 2014). Antiretroviral Therapy allows PLHIV to maintain their health and often allows them to lead relatively normal lives. Although a number of PLHIV on ART has increased, there is still those who do not have access to this treatment.

When people first hear of their diagnosis the emotional experiences are similar reactions to those defined by the Kubler Ross stages of loss (Telford, Kralik & Koch, 2006). They experience, fear, loss, grief, guilt, denial, anger, anxiety, low self-esteem, depression, suicidal behaviour or thoughts, spiritual concerns, socio-economic issues, then hope and equilibrium. Support of significant others and counselling play an important role in the person's physical and psychological care and help the individual to reach the level of hope and equilibrium where she/he accepts living positively with HIV and AIDS.

### **2.13. STRESS-RELATED PSYCHOLOGICAL CONDITIONS AND HIV AND AIDS**

In the early years of the HIV epidemic it was said that when someone became infected with HIV, there was little to offer. A seropositive status then was seen as a 'death sentence'. Medical practitioners measured hope and optimism in weeks and months. People infected with HIV were obviously experiencing significant levels of psychological distress. The condition would be exacerbated by the collapse of the immune system and the attack of opportunistic infections and neoplasm. According to April, et al., (2013) the introduction of the Antiretroviral Therapy (ART) brought back hope and optimism for a restored psychological and emotional state for persons sero-positive for HIV. However, there is still

little information available on psychological health service use among PLHIV (Leserman, 2008).

Psychological health care has been integrated into HIV programmes in well-resourced countries for many years as a result of substantial evidence of the linkages between psychological health and HIV (Collins, Holman, Freeman & Patel, 2006). Studies from these countries suggest that people with HIV often suffer from depression and anxiety disorders as they adjust to the diagnosis, struggle with the meaning of a positive HIV test result, adapt to life with a chronic life-threatening illness, anticipate and receive news of the disease's advance, and witness the death of friends and family. In the United States evidence of the relationship between HIV AND AIDS and mental health illnesses has resulted in the development of HIV Clinical Guidelines for primary care practitioners (Aberg, Gallant, Ghanem, Emmanuel, Zingman & Horberg, (2013). Bing, Burman and Longshore (2001) found a 36% 1-year prevalence of depression and a 16% prevalence of anxiety among a large national sample of HIV-positive men and women in the United States, while Ciesla and Roberts (2009), in their meta-analysis of the relationship between HIV infection and risk for depressive disorders indicated that HIV positive individuals are nearly two times more likely to have had a recent episode of major depressive disorder when compared to HIV negative individuals.

This chapter will, therefore, deal with the description of some stress-related psychological conditions that affect individuals living with HIV and AIDS, their effects on them, and brief focus on the treatment of some of these disorders.

### **2.13.1. Anxiety disorders and HIV and AIDS**

Before examining the various anxiety disorders and how they affect HIV and AIDS, it would be appropriate to take a closer look at the changes individuals normally experience when they perceive a threat. Wells (2013) believes that a person's response to fear and anxiety is actually a package of responses, namely; physical, emotional, and cognitive responses. He argues that fear excites a number of physical responses such as perspiring, rapid breathing, muscle tension, accelerated heartbeat, nausea, trembling, horror and panic. These responses are generated by the action of the body's autonomic nervous system (ANS), the extensive network of nerve fibres that connects the central nervous system (CNS) to all

the other organs of the body. When the brain interprets a situation as dangerous, it excites a special group of ANS fibres that quicken heartbeat and produce other changes that are experienced as fear or anxiety. These ANS nerve fibres are referred to as the sympathetic nervous system, which is also called the *fight, flight or freeze state*. When the perceived danger passes, the functioning of the brain returns to normal and this is the responsibility of the second group of ANS nerve fibres, called the parasympathetic nervous system. Both systems work together to regulate fear and anxiety reactions, as well as other responses to stress, and enable the body to maintain both the stability and the adaptability essential to life functioning (Berceci, 2009).

### **2.13.2. Anxiety Disorder**

Anxiety is a mood state characterized by marked negative affect and somatic symptoms of tension in which a person apprehensively anticipates future danger or misfortune (APA 1994). Lader, (2015) argues that to study anxiety is very challenging, especially with humans, since it can be a number of reactions, a subjective sense of uneasiness, a set of behaviours or a physiological response originating in the brain as reflected in elevated heart rate and muscle tension. According to Lorig, Holman & Sobel (2013) people with anxiety disorders experience on-going fear and anxiety that disables them and prevents them from leading a normal life.

Piazza, Charles, Sliwinski, Mogle & Almeida, (2013) argue that anxiety and stress are experienced by most people in their day-to-day encounters. People may experience stress and anxiety at work, with financial concerns, family demands and social interactions. Mild or moderate stress is usually not harmful. However, excessive stress has proven to be detrimental to one's health. Many studies have shown that many diseases are caused or aggravated by an interaction of psychological, biological and social factors. This interaction has been shown to contribute to a more rapid progression from HIV infection to AIDS and to the rapid deterioration of the immune system in HIV-positive individuals (Cole, Kemeny, Fahey, Zack & Naliboff, 2003). Self-efficacy in handling stress is associated with a slower deterioration of the immune system in PLHIV (Brashers, Basinger, Rintamaki, Caughlin & Para, 2016). Anxiety disorders of interest in this study include acute stress, post-traumatic stress and adjustment disorders.

### **2.13.3. Acute Stress Disorder**

According to the Diagnostic and Statistical Manual of Mental Disorders Fifth Edition (DSM-5, 2013) the essential feature of acute stress disorder which falls under trauma and stressor-related disorders, is the development of characteristic anxiety and dissociative and other symptoms that occur within one month after the exposure to an extreme traumatic stressor. According to Srinivas & Malladi (2016), individuals experiencing acute stress disorder often experience severe feelings of anxiety and helplessness, find difficulty in experiencing pleasure in previously enjoyable activities, frequently feel guilty about pursuing usual life tasks, and appear detached from their bodies. They also exhibit poor concentration, sleep disturbances, angry outbursts, avoidance of interpersonal involvement and loss of sexual interest, dissociative amnesia, irritability, as well as distress on exposure to reminders of the stressor. Van Dyk (2012) purports that some people experience acute stress disorder after an HIV-positive diagnosis, or after the death of a significant other, so it is an anxiety disorder that develops in response to an extreme psychological or physical trauma, and which can seriously disrupt one's social or occupational functioning.

### **2.13.4. Posttraumatic Stress Disorder (PTSD)**

According to DSM IV (1994, p424) the post-traumatic stress disorder's diagnostic essential feature is "the development of characteristic symptoms following exposure to an extreme traumatic stressor involving direct personal experience of an event that involves actual or threatened death or serious injury". A diagnosis of post-traumatic stress is usually considered if the symptoms of acute stress disorder persist for more than a month. The symptoms of PTSD can occur at any time after the stressful event and last for longer than a month, while those of acute stress disorder occur within a month and last from a few days to one month (Van Dyk, 2012).

Sue and Chu, (2003) argue that not all people who experience a traumatic event develop PTSD. Factors such as the person's individual characteristics, his or her perception of the event, and the existence of support groups and family support also influence whether a PTSD will develop. Some social and cultural factors play a major role in the development of PTSD and this might be true in the case of HIV and AIDS. The results from a number of studies are very consistent in showing that, if you have a strong and supportive group of

people (social support), it is much less likely that you will develop PTSD after a traumatic event (Williams & Poijula, 2016). The reason for this is that as social animals, having loving and caring people around us directly affects our biological and psychological responses to stress. A number of studies in the area of HIV and AIDS agree with this notion (Berscheid & Regan, (2016).

### **2.13.5. Depressive Disorders**

Most people's moods are transient and their feelings of elation or sadness are understandable responses to daily events and change readily without affecting the overall tone of their lives. In contrast, mood disorders tend to last a long time and disrupt their normal functioning. According to Maj and Sartorius (2002) depression as a diagnostic and clinically meaningful term has a short history. They believe that no one has claimed fame for coining the term 'depression'. It is a term widely used, not only in psychopathology but also in economics, in meteorology, in life sciences and in several other areas of human endeavour. All the varieties of emotional reactions to actual or anticipated loss, and all feelings of distress and sorrow arising from the adversities of life have been associated with depression. Depression today is viewed as a part of the life experience one has to go through at least once in his or her lifetime and is considered to self-cure by will power. However, Maj and Sartorius (2002) argue that this carefree diagnosis which fails to distinguish between transient dysphoric loss-related emotional states and clinical depression, is both misleading and hazardous.

#### **2.13.5.1. Depression disorder and HIV and AIDS**

The diagnosis of depression has remained unsatisfactory and limited options force one to compromise on what is available and attempt to revise it periodically Mahendra et al., (2007) point out that psychiatrists are aware that more than 80% of depressed client participants are treated by general practitioners or traditional healers and in some studies specialists treat fewer than 5% of all client participants with depressive disorders. Several studies confirm that primary care physicians do not make the diagnosis of depressive disorders in more than half of clients who satisfy the criteria for depressive disorder (Psaros, et al. 2015). Depressive disorders are amongst the most common health problems in any community. They are usually under-recognised, under-diagnosed and therefore under-treated

(Nanni, Caruso, Mitchell, Meggiolaro & Grassi, (2015). The obstacles to recognition and diagnosis are; the stigma associated with diagnosis, presentation with somatic symptoms that mask the depression, and lack of training in diagnosing depressive disorders. The WHO (2011) has predicted that by the year 2020 depression will be the leading cause of worldwide disability.

According to the DSM 5 there are different types of depressive disorders including major depressive disorders, persistent depressive disorder (dysthymia), disruptive mood dysregulation disorder, substance/medication-induced depression disorder and specified and unspecified depressive disorders.

Like many other mental disorders, depression is characterised by the presence of a number of symptoms which are changeable over time. The most common and most severe type of depression is called 'major depressive disorder (MDD), which is classified based on the level of severity and psychotic features. The core symptoms, which if present in sufficient number and duration, provide for a reliable and valid diagnosis of MDD as a distinct psychopathological syndrome. According to Beck and Alford (2009) these symptoms include sad and/or irritable mood, loss of interest, weight loss or gain due to lack or over appetite, loss of energy, insomnia or hypersomnia, hallucinations, delusions, cognitive, motivational, vegetative and physical manifestations. Dysthymic disorder as classified by DSM 5-300.4(F34.1) is less severe but usually lasts longer than the MDD. Prevention from full functioning in this type of depressive disorder widely varies.

According to Freeman (2004) depressive disorder is not an automatic or expected reaction of being HIV positive. It may be caused by psychological stress, neuropsychiatric changes in the brain because of the HIV infection, or because of psychiatric side-effects of ARV medication which may fit the DSM 5 classification of the substance/medication-induced depressive disorder which varies according to the medication or substance given. However, the good thing is that, depression can be treated. However, if untreated, depression can result in lower quality of life, decreased productivity, high-risk behaviour (of concern to HIV prevention efforts), lower adherence to ARVs, higher mortality rate, earlier HIV disease progression, and the heightened risk of suicide.

According to Leserman (2008), depression is the most commonly observed mental health disorder among HIV-infected client participants, affecting up to 22% of client participants. The prevalence may be even greater among substance users. Depressive symptoms have been associated with risk behaviour, non-adherence to medication, and shortened survival. Although sadness and grief are normal responses to many of the consequences of HIV infection, clinical depression is not. Leserman (2008) agrees with Freeman (2004) that failure to recognise depression may endanger both the patient and others in the community. He adds that, client participants with depression are at higher risk for co-morbid psychiatric, alcohol, and substance use-related disorders, particularly alcohol, cannabis, and cocaine use.

HIV infection affects all aspects of an HIV infected individual's life and results in physical, psychological, social, and spiritual adaptation. Mental health problems among individuals with HIV infection include grief, stigmatisation, fear of the reaction from others, uncertainty about the future, and changes in identity as well as psychological conditions, especially depression. According to Jayasvasti, et al. (2011) in Thailand the stigmatisation is a major social problem among HIV infected client participants, and it contributes to the high rate of depression. It is estimated that by 2020 depressive disorders will produce more than 17% of disability associated with mental health problems worldwide (WHO, 2011). Several studies have shown that the prevalence of depression among HIV infected client participants and AIDS client participants was higher than in the normal population with a prevalence of about 15-30% (Crepaz, et al. 2008; Reungtrakul, 2005).

Freeman (2004) reports that, in Zambia, 85% of HIV positive pregnant women had major depression and suicidal thoughts, and in Kampala, Uganda 54.3% of PLHIV attending the TASO (The AIDS Support Organisation) clinic were seen as meeting the criteria of major depression. In Tyberberg Hospital, Cape Town, South Africa, 38.1% of black and coloured female HIV positive outpatient participants met the diagnostic criteria for depression. 19% of the women had a history of depression before being diagnosed with HIV and 11% were deemed at risk of suicide.



### **2.13.5.2. Barriers to diagnosing depression in PLHIV**

According to Chandra, Desai and Ranjan (2005) several barriers exist in the diagnosis of depression in HIV AND AIDS patients. Patients may be unwilling to discuss their moods and emotions with the health care provider for fear of being stigmatised. Bishop, Ramsay, Casalino, Bao, Pincus & Shortell, (2016) confirm that primary care physicians play an important role in the diagnosis and management of depression. Yet little is known about their use of care management processes for depression. Obstacles to recognition and diagnosis add to the stigma associated with mental health illness, and presentation with somatic symptoms that mask the depression and/or lack of training in diagnosing depressive disorders (Ayalon, Karkabi, Bleichman, Fleischmann & Goldfracht, 2015). The diagnosis of depression may be further complicated by the presence of comorbid neurological illness, substance abuse and use of multiple drugs including anti-retroviral drugs that are known to cause depressive symptom as a side effect. The importance of diagnosis of major depression in HIV and AIDS lies in the fact that response to therapy in HIV and AIDS client participants is as good as in the uninfected population and when not recognised it has a negative impact on adherence to medical treatments, quality of life and overall outcome (Treisman, Angelino, Hutlon, Hsu, & Lyketsos, 2005).

To overcome the diagnostic barrier, Perkins, Leserman and Stern, (2005) recommend that health care providers should encourage expression of emotions in clinics and non-specialists need training in the assessment of psychiatric syndromes in HIV client participants. Several types of clinical rating scales have been developed for diagnosis and rating of depression. Studies have shown that in otherwise asymptomatic HIV infected client participants physical symptoms of fatigue insomnia, and weight loss are related to psychological disturbances, possibly major depression (Nanni, Caruso, Mitchell, Meggiolaro & Grassi, 2015).

### **2.13.5.3. Depression treatment in PLHIV**

Yip and Lee (2002) point out that psychiatrists are aware that more than 80% of depressed client participants are treated by general practitioners or traditional healers and in some studies specialists treat fewer than 5% of all client participants with depressive disorders. According to Antoni (2003) and Komiti, et al, (2003) treating depression can help

PLHIV improve their overall health. It could enhance the quality of life, improve adherence to medication, reduce high risk behaviours and suicide as well as enhance immune system functionality (Colibazzi, Hsu & Gilmer 2006). Recovery from depression takes time but treatments are effective. At present, the most common treatments for depression include; Cognitive behavioural therapy (CBT), a type of psychotherapy, or talk therapy that helps people change negative thinking styles and behaviours that may contribute to their depression. According to some researchers (Rabkin, Wagner & Rabkin 1999; DeSilva, LeFlore, Marston & Rimland 2001), selective serotonin reuptake inhibitor (SSRI), a type of antidepressant medication that includes citalopram (Celexa), sertraline (Zoloft), and fluoxetine (Prozac), and serotonin and norepinephrine reuptake inhibitors (SNRI), a type of antidepressant medication similar to SSRI that includes venlafaxine (Effexor) and duloxetine (Cymbalta), are some of the more frequently prescribed anti-depressant medications.

While currently available prescription anti-depression treatment is generally well tolerated and safe, to avoid dangerous drug interactions, people with HIV and AIDS and depression should talk to their health care providers about side effects, possible drug interactions, and other treatment options. Medications can take several weeks to work and may need to be combined with on-going talk therapy or may need to be changed or adjusted to minimise side effects to achieve the best results. Other specific types of psychotherapy, or ‘talk’ therapy, together with body therapy, can also relieve depression.

Some individuals living with HIV and AIDS attempt to treat their depression with herbal remedies. However, recent research cautions that the use of herbal supplements of any kind should be discussed with a physician before they are tried. Van Dyk (2012) argues that recently some scientists discovered that St. John's wort, a herbal remedy sold over-the-counter and promoted as a treatment for mild depression, can have harmful interactions with other medications, including those prescribed for HIV. In particular, St. John's wort reduces blood levels of the protease inhibitor indinavir (Crixivan®) and probably the other protease inhibitor drugs as well. If taken together, the combination could allow the HI virus to rebound, perhaps in a drug-resistant form.

Further complicating the issue starting from diagnostic problems, the treatment of depression in HIV and AIDS client participants faces many limitations both from the side of the patient and health care provider. DeSilva, Le Flore, Marston and Rimland (2001) argue

that client participants already on multiple drugs for HIV and other infections may have a tendency to have poor compliance to antidepressants and health care providers may also be reluctant to add drugs to client participants who are already on multiple drugs. Furthermore, it was seen in a trial with fluoxetine that the drug was found to be effective in comparison to a placebo but the attrition rate was high. The trial also concluded that the severity of immune-suppression was not related to antidepressant response, attrition or side effects and fluoxetine treatment was not associated with changes in CD4 cell counts.

HIV and AIDS is not only responsible for individual morbidity and mortality but also is a familial and social burden in itself. Treatment of HIV infection is costly and complicated. The high incidence of depression and anxiety further aggravates the complication. Bing, Burnam and Longshore (2005) purport that, besides pharmacotherapy, supportive psychotherapy has an important part to play in the treatment of those client participants who interpret their symptoms to be a reaction to the diagnosis of HIV infection. Other forms of useful psychotherapy are interpersonal psychotherapy, cognitive behavioural psychotherapy, body-mind therapy and these are more effective when combined with pharmacotherapy for the treatment of severe depression and other stress-related conditions.

#### **2.13.6. Adjustment Disorders and HIV AND AIDS**

Van Dyk (2012) argues that some people often find it difficult to adjust to common life stressors such as divorce, loss of significant other, loss of job, chronic medical condition and so on. If a person struggles to adapt and experiences excessive distress, this then leads to adjustment disorder with anxiety and be classified as [309.24 (F43.22)] or with depressed mood and be classified as [309.0 (F43.21)]. Adjustment disorder as classified under the trauma-and stress-related disorders in the DSM 5, is a behavioural or emotional reaction to a stressful event or change. Factors contributing to the development of adjustment disorder are both intrinsic and extrinsic (Benton & Lynch, 2009). An HIV positive diagnosis can lead to the development of an adjustment disorder. According to (DSM 5, 2013), adjustment disorders usually develop within three months of the stressful experience and usually disappear within six months depending on the specified diagnostic criteria. Adjustment disorders are seldom very serious, and they decrease in severity as people adapt to the stressor or the stressor has been dealt with. However, a medical chronic condition such as HIV and AIDS may prolong the adjustment disorder beyond six months. This type of

disorder may not just affect PLHIV but also their relatives when they hear of the diagnosis and when their PLHIVs health deteriorates rapidly towards death. Especially those who feel intense guilt, resentment, or anger towards the deceased may experience adjustment disorder with either depressed mood [309.0(F43.21)] or mixed anxiety and depressed mood [309.28(F43.23)] (Fernández & Ruiz, 2006).

PLHIV face many stressors such as declining health, unpredictability of disease progression, need for constant monitoring of viral load and CD4 cell count, insomnia, opportunistic infections, chronic pain, cognitive decline, physical wasting, medication side effects, loss of significant others, disclosure of HIV positive status, financial instability, stigma and discrimination, and all these stressors impair the person's quality of life and interfere with the ability to adhere to a complicated medication regimen. Also these stressors overwhelm the PLHIVs ability to cope emotionally with HIV and AIDS. Effective coping may have a restorative effect on the immune system and slow HIV progression (Gray & Carson, 2002).

#### **2.13.7. Alcohol Use Disorder and HIV and AIDS**

Mellins, et al. (2008), point out that, in about 30 years of the HIV epidemic in the US, HIV and AIDS cases have shifted from a high prevalence in men who have sex with men and injection drug users to more socially vulnerable and disenfranchised sub-populations, including those with co-morbid mental illness and/or substance abuse. High rates of substance abuse and mental illness have been found in studies of HIV-infected adults (Pence, Miller, Whetten, Eron, & Gaynes, 2006 ; Dausey & Desai, 2003), with co-morbid substance abuse and mental illness reported in 40% of different subpopulations of adults, including injection drug users (Galvan, Burnam, & Bing, 2003; Turner, Laine, Cosler, & Hauck, 2003). The presence of either mental illness or substance abuse in HIV-infected adults has been significantly associated with non-adherence to antiretroviral (ARV) medications (Ingersoll, 2004; Mellins, Kang, Leu, Havens, & Chesney, 2003; Uldall, Palmer, Whetten, & Mellins, 2004). According to Bogart, Kelly, Catz, and Sosman, (2000) some physicians may be reluctant to initiate ARV therapy in client participants with psychiatric hospitalisation or alcohol or drug abuse.

Bryant, Nelson, Braithwaite and Roach (2010) determined that scientists are gaining a better understanding of the complex relationship between alcohol consumption and HIV infection. Abusing alcohol or other drugs can impair judgment thus leading a person to engage in risky sexual behaviours. Bryant et al. (2010) maintain that people who drink also tend to delay getting tested for HIV and, if they do test positive, tend to postpone seeking treatment. When receiving treatment, they may have difficulty following the complex medication regimen. Alcohol consumption has also been shown to significantly increase the blood serum level of abacavir (NRTI drug) by competing for alcohol dehydrogenase. However, with chronic use of alcohol, CYP3A4 can be induced and can decrease levels of PI (Protease Inhibitors) and NNRTIs (Non-nucleoside reverse transcriptase inhibitors). All of these factors increase the likelihood that an infected person will infect others or will go on to develop AIDS, (Scribner, Theall, Simonsen & Robinson, 2010; Samet & Walley, 2010).

Pandrea, et al. (2010) believe alcohol consumption is associated with missing doses of medication and HIV client participants' ART is less effective at keeping the virus in check if they do not adhere to their regimens. Also, drinking would likely interfere with people's ability to stick to the ART regimens taken for prevention just as it does in treatment. Alcohol use is one of the factors that increase the risk of HIV transmission among heterosexuals. Particularly among women, a strong association has been seen between alcohol and other drug abuse, infection with HIV, and progression to AIDS (Rosenberg et al. 2015).

ART itself can be problematic in people who drink. Barve, et al. (2010) argue that a major cause of illness and death among HIV-infected client participants that has emerged since the advent of ART is liver disease. Antiretroviral medications are not only processed in the liver, but they also have toxic effects on the organ and some drug combinations can lead to severe toxicity in up to 30% of client participants who use them. A large proportion of people with HIV also are infected with hepatitis C (HCV). Alcohol abuse and dependence significantly increase the risk of liver damage both in people with HIV alone and with HCV co-infection (Braithwaite & Bryant, 2010).

Pandrea, Happel, Amedee, Bagby, and Nelson (2010) suggest that alcohol may interfere directly with ART medications used for HIV, essentially blocking their effectiveness. According to Pandrea, et al. (2010), alcohol also works indirectly to raise the risk for contracting HIV and for the problems associated with this virus. For example, alcohol

consumption often occurs in night clubs and bars where people meet potential sexual partners. These establishments create networks of at-risk people through which HIV can spread rapidly. In addition, alcohol abusers' high-risk sexual behaviours make them more likely to be infected with other sexually transmitted diseases and those, in turn, increase the susceptibility to HIV infection.

### **2.13.8. Stigma and Discrimination (S&D)**

Throughout history many diseases have carried considerable stigma, including leprosy, tuberculosis, cancer, mental illness, and many sexually transmitted diseases. HIV and AIDS is only the latest disease that carries such a stigma. Goffman (2003) describes stigma, in general, as an undesirable attribute that a person possesses which and reduces that person's status in the eyes of society. Stigma can result from a particular characteristic, such as a physical deformity, or it can stem from negative attitudes toward the behaviour of a group, such as homosexuals or commercial sex workers. Stigma is such a powerful force that it will persist despite protective legislation or even disclosures by well-known public figures that they have AIDS or are infected with (HIV Lee, Kochman & Sikkema, 2002).

In its most extreme form, discrimination against PLHIV has led to violent murders as documented in Colombia, India, Ethiopia, South Africa and Thailand (Brown, Macintyre, & Trujillo, 2003). When conditions exist which make PLHIV afraid to acknowledge their HIV status openly due to fear of being ostracised by their families and communities or shunned and shut out of their livelihoods, they are likely to sacrifice treatment and support and may feel forced to act in ways that endanger others.

Society plays a major role in how HIV and AIDS are perceived. Where individualism is valued, much of the blame for infection will be directed at infected individuals themselves. Conversely, in societies that hold collectivism in high regard, families and communities may be considered responsible for infection within their midst. These cultural differences will impact upon how societies react to the disease and what forms S & D takes. Likewise, religious doctrine, can have a strong influence on how HIV and AIDS is viewed and some religions have fuelled S&D by portraying AIDS as a punishment for sin. According to Simbayi et al, (2007) when S & D are strong, they can easily be internalised by PLHIV, causing severe pain and suffering and leading to self-induced isolation from society and self-

stigma. Stigma has been found to lead to depression and the fear of being labelled and thus prevent people from seeking treatment. For people living in rural areas, S & D are common in both community and health care settings (Tshabalala, 2008). This can be especially difficult to cope with because of the lack of alternative care providers, social isolation, and a lack of transportation and/or resources to travel for services. Stigma, whether related to mental illness or HIV and AIDS, causes extreme stress. For people living with HIV, stress has been linked to faster progression of the disease.

#### **2.14. Health Care Workers' role in the psychological well-being of PLHIV**

According to Chen, et al., (2013) health care workers play a significant role in the psychological and physical well-being of PLHIV from HIV diagnosis to treatment and adherence to medication. Teixeira, Gordon, Camhi & Barcken (2011) reported that PLHIV believe that HCWs need to fully understand the client's current situation, including physical and psychological status, to enhance clinician-patient engagement and make HCW more supportive of their clients. Chen et al (2013) describes engagement as a process where a client has full access to HCW, able to share health information with, client is involved in her/his own health decision-making and self- care activities, HCW's respect and support of client choices and management of client concerns.

In a study conducted by Teixeira et al (2011) on the HIV patients' willingness to share personal information with their HCPs, most study participants (84%) believed that trusting their primary health care practitioners is important in the clinician-patient relationship. This trust can encourage PLHIV to share personal health information with their HCPs. In the same study Namibian participants had the highest engagement with their HCPs with better overall Quality of Life (QoL) compared to the rest of study participants. This could be attributed to the fact that Namibia has less technologically driven health system which gives patients more face to face support and they might also feel culturally supported. Contrast against Chinese participants who had less engagement due to probably, less opportunity for negotiation with HCWs and reported cases of stigma as severe in China. It is clear that in order for clients to handle own stress-related challenges, they need to engage with the very important people in their health struggle, which is health care workers. Without

this engagement clients may continue being disarmed by overwhelming stress-related illnesses in their lives.

On the other hand, as clients demand engagement from health care workers, HCWs are overwhelmed by heavy workloads with limited support from the health facility management systems. Since 2000 numerous reports have emerged from South Africa regarding widespread dissatisfaction, distress and demoralisation of nurses and physicians working in the public sector (Hall, 2004). The burden of the disease exhausted and stressed HCWs. Reasons for exhaustion were ranging from lack of acknowledgement about HIV and AIDS crisis, high volume of patients, lack of medical equipment, lack of patient support from relatives, drop in the quality of care with heavy workload cited as the most debilitating factors. Although some of the above factors have been receiving attention, there is still reminiscence of them continuing to worry this sector. Expressed concerns are still around inadequate availability of medical equipment, shortage of nurses, deteriorating hospital infrastructure in low resource settings (Makhado & Davhana-Maselesele, 2016). There has been some improvement in the government's response to HIV and AIDS, addressing some needs of health care practitioners, introduction of lay health care workers which assisted in the heavy workload not without challenges of course (Koto & Maharaj, 2016).

## **2.15. RATIONALE FOR PSYCHOLOGICAL SERVICES FOR PLHIV**

According to WHO, USAID & (FHI) Family Health International (2007), primary health care providers need to be aware of the specific and general factors that may trigger or exacerbate psychological distress or psychiatric disorders in PLHIV and their families. They list a number of crisis points as to when this support is necessary:

- a) Learning of HIV positive status
- b) Disclosure of HIV positive status to family and friends
- c) Introduction to Antiretroviral therapy (ART)
- d) Occurrence of any physical illness
- e) Recognition of new symptoms and progression of disease (major drop in CD4 cells or rise in Viral load)
- f) Necessity for hospitalisation
- g) Death of a significant other



- h) Diagnosis of HIV
- i) Changes in major aspects of lifestyle (loss of job, end of relationship, relocation)
- j) Necessity of making end-of-life and permanency planning decisions
- k) Exacerbation of pre-existing psychological conditions can interfere with the ability to cope with HIV infection, as much as HIV itself can be a risk factor for the development of a range of psychological conditions discussed above.

It is therefore necessary for primary health care providers to note the above points and give necessary support for PLHIV to avoid a major negative impact on their health.

## **2.16. CONCLUSION**

In conclusion, numerous studies have found that mental health care or psychological services in developing countries have been seriously neglected, but with the advent of the HIV pandemic, researchers, policy-makers, and planners are now considering mental health issues as a global health concern. Mental health services are scarce and there is a great need to address the gap in service provision, and such services are particularly essential for PLHIV who are at risk of developing severe mental health disorders. The most important role of mental health providers is to understand the psychosocial and sociocultural context of HIV, alleviate mental health problems, and ensure treatment adherence as well as prevention. Mental health providers should be an obligatory part of the multidisciplinary treatment team.

## **CHAPTER 3**

### **THEORETICAL FRAMEWORK**

#### **3.1. INTRODUCTION**

A number of theories and therapeutic approaches have been used to understand the psychological well-being of PLHIV (PLHIV) (Lechner, et al., 2003). Cognitive Behavioural therapy (CBT) has been widely used by many psychologists in this field (Tshabalala, 2008). The Multi-modal Transactional intervention has also received attention as has Psychodynamic Theory. However, with the complexities of HIV and AIDS, therapists and health care workers in general are forced to be more creative in their interventions. This chapter focuses on the few theories and interventions which give insight into the development of the intervention using an integrative psychotherapy approach.

#### **3.2. INTEGRATIVE PSYCHOTHERAPY APPROACH**

PLHIV are more likely to feel rejected and stigmatized by society. Due to this perception the use of a psychotherapy that affirms the inherent value of each person would be highly recommended. The integrative psychotherapy approach brings together the affective, cognitive, behavioural, and physiological systems within the individual and with an awareness of the social, cultural and spiritual dimensions surrounding the individual (Beutler, Consoli & Lane, 2005). The aim is therefore, to maximise the person's well-being and full human functioning. However, Corey (2014) cautions that in attempting to integrate, one should guard against merging concepts that are too diverse such as a classical psychoanalytic approach and radical behaviourism. Despite such divergence in theories, there are possibilities for a creative synthesis among some interventions. Exploring and developing a therapeutic intervention that integrates social, economic, spiritual and cultural factors would benefit both PLHIV and health care workers.

An integrative psychotherapy approach to psychological well-being ensures that practitioners attend not only to clients' cognitions and behaviours, but also to their diverse cultural and spiritual pathways (Wilber, 2000). In the context of South Africa, an integrative psychotherapy approach would allow a focus on other types of healing such as traditional healing practices, thus acknowledging the complex ways in which the social and cultural context, body-mind, and emotions continually interact and influence an individual's well-

being. According to WHO (2008), 90% of people of African origin still seek traditional healing practices, therefore to ignore this important aspect in dealing with PLHIV in Africa, would be to ignore an aspect of the lives of the individuals we are helping.

According to Norcross and Goldfried (2005) Integrative psychology includes the often marginalised study of spirituality, intentional consciousness, body therapy, meditation, biofeedback, imagery, somatic practices, creativity and expressive arts, human ecology, postmodern gender and cultural psychologies and their application in clinical settings. At the same time the field values mainstream psychological interventions and emphasises research based on systems theory, human sciences and integrated methods (Erskine & Moursund, 2010).

According to Norcross and Goldfried (2005), an integrative approach recognises four routes to integration, namely; Common Factors, Technical Eclecticism, Theoretical Integration and Assimilative Integration.

- Common Factors is an integration approach which seeks to determine the core ingredients that different therapies share in common. According to Norcross and Goldfried (2005), the advantage of this route is the emphasis on therapeutic actions that have been seen to be effective. However, its shortfall is that common factors may overlook specific techniques that are inherent within particular theories.
- The second approach is Technical Eclecticism which was developed to improve the practitioner's ability to select the best treatment for the person and the problem, guided primarily by data on what has worked best for others in the past. The advantage of this approach is that it encourages the use of diverse strategies without being hindered by theoretical differences. A disadvantage is that there may not be a clear conceptual framework describing how techniques drawn from divergent theories might fit together. The most well-known intervention of technical eclectic psychotherapy is Arnold Lazarus' (2005) Multimodal Therapy. Another example of this approach is Larry Beutler's intervention of Systematic Treatment Selection (Beutler, Consoli & Lane, 2005).
- Theoretical Integration is the third approach recognised by Norcross and Goldfried (2005), where two or more therapies are integrated to strengthen the results. The criticism of this approach is that each approach or contribution may unintentionally lose its meaning (Evans & Gilbert, 2005).

- Assimilative Integration is the fourth approach in integration therapy. It is characterised by a gradual assimilation of techniques and concepts into the psychologist's original theoretical orientation. The meaning of new concepts interacts with the original orientation and, as a result transforms both. The goal is to maintain one's original theoretical orientation while using empirically validated techniques to fill in the gaps that the original orientation is unable to fill-in an unaltered state. The main critique of this approach is that the power of the original orientation may become too diluted (Boswell, Nelson, Nordberg, McAleavey & Castonguay , 2010). Increasingly, integrationists are acknowledging that most counsellors will prefer the security of one foundational theory as they begin the process of integrative exploration. Formal interventions of assimilative integration based on psychodynamic foundation have been described as well as those based on cognitive-behavioural therapy (Striker & Gold, 2005; Castonguay, Newman, Borkovec, Holtforth, & Maramba, 2005).
- Other emerging interventions are: the Hill's Three Stage intervention of helping skills which encourages counsellors to emphasize skills from different theories during different stages of helping. Multi-theoretical psychotherapy is another new integrative intervention that combines elements of technical eclecticism and theoretical integration (Brooks-Harris, 2008). Therapists are encouraged to make intentional choices about combining theories and intervention strategies.

### **3.2.1. Technical Eclecticism Approach**

This study will be based on the Technical Eclecticism intervention, which is designed to improve the therapist's ability to select the best treatment for the person and the problem. Sexton, Weeks and Robbin (2008) describe Technical Eclecticism as the pragmatic case-based approach in which the ingredients of different approaches are employed without trying to build a unifying conceptual theory. According to Kraft and Kraft, (2007), the rationale for employing this approach is that it allows greater flexibility in the treatment of any given individual or group and therefore offers the opportunity for increased efficacy and acceptability of the care (Safran & Segal, 1996, Weeks & Robbin, 2008).

Orr, (2014) argues that Technical Eclecticism is beneficial in that it can be applied more efficiently to a broader client population. Techniques and goals can be adapted to the

type of client presenting, the treatment setting and the time available for therapy. An example of this integrative psychotherapy is the Lazarus Multimodal Therapy (MT) intervention, which is based on the concept that humans are biological beings that think, feel, act, sense, imagine and interact and that each of these should be addressed in psychological treatment (Lazarus, 2005). This study, therefore, embraces the use of different techniques from different approaches including techniques used in Body-mind Therapy, Cognitive-Behavioural and Multicultural Therapy.

### **3.3. BODY-MIND THERAPY**

According to Davidsen, Guassora & Reventlow, (2016) the present day understanding of body-mind therapy, both in a psychological and in a medical sense, is that, the body, mind, emotions and spirit are dynamically interrelated. They also add that each time a change is introduced at one level, it has a ripple effect throughout the entire system. Psychology deals with the content of the mind, and neurology deals with the way the brain processes this content (Santrock, 2007). For successful trauma or stress recovery it is necessary to deal with the content of the brain, the manner in which the brain processes the content and the physical, and spiritual changes the person experiences in the recovery process (Aposhyan 2007). In other words, recovery from psychosocial disorders requires attention to the body, mind and spirit at different stages of the recovery process. Body techniques help the brain to shift into a state of empowerment where it is no longer ruled by past cues but functions in the present moment (Gallager, 2005).

The modern world has not changed our physiological nature. We still have the same emergency system that served our primitive ancestors. For example the disruptive effect of fear and anger upon the digestive system or upon sexual behaviour is common knowledge (Drossman, 2016). Digestive functions and many aspects of sexual activity are largely controlled by the parasympathetic system and are thus inhibited by intense sympathetic arousal (Irwin & Vedhara, 2005; Leserman et al, 2006). The after effects of this arousal can sometimes be more permanent, causing profound and long lasting bodily harm (Loubser, 2016).

Berceli (2008) observes that our culture presents us with considerable psycho-emotional trauma, the kind of trauma caused by social conditioning. He argues that situations

that threaten our social self, such as rejection, shame, fear of failure and negative judgment by others, cause us to react in the same manner as if we were being physically threatened. The body takes up a position of submission and withdrawal, slumping forward with the head down, the precise posture it assumes when threatened by physical trauma. Bercei (2008) believes that no matter what our culture, language, religion or psycho-social backgrounds are, as traumatised individuals we all have access to a natural process genetically encoded within the body that enables us to recover from trauma/stress and other psycho-physiological-social illnesses. According to Aposhyan (2007) the human body is capable of healing itself from even the most debilitating experiences, in most cases without the cost of expensive prescription medicines and often without having to unwillingly get professional help. The emotional pain we carry within us is not just in our head, it is also engraved into our muscles (Van de Kolk, 2014; Rothschild, 2000).

Body-Mind Therapy is simply the inclusion of the body in the therapy. It combines the strengths of talk therapy with bodywork such as postural alignment or movement education and exercise. This brings increased awareness of one's bodily sensations, (also known as somatic therapy) allowing the connection of these sensations to one's feelings and historical events. It helps one release a wide range of feelings that have been withheld as a means of coping and surviving (Kammer, 2010). This process allows one to be more grounded in ones body and become conscious of what it really feels to live in one's body, allowing awareness of how one feels when anxious, hopeless, needy, desperate, and frightened, (Röhricht, 2009).

The body holds all experiences including physical stress and emotional injury. Happy experiences are stored in the body cells which inform and direct the here and now responses to life events, through the stored pattern of expectations acquired thus far. Unacknowledged feelings from past experiences are stored in the body and then unconsciously have a powerful effect on who one is, how one behaves, and how one feels about one's self. Using the body as the gateway to awareness, buried feelings and memories can surface, freeing individual from old patterns and energy blocks that keep one feeling stuck and unable to live life to its fullest. The mind may avoid certain emotions and memories, but the body remembers it all Rothschild (2000).

According to research on the brain, as well as the ancient wisdom of traditional healing approaches, recognise that what hurts us in life primarily affects non-verbal areas of our brain, which means that talk alone cannot help us to feel better (Corrigall, Payne & Wilkinson, 2014). In order to truly heal, we need to access and integrate all levels of the human experience such as sensory-motor, emotional, cognitive, behavioural, and spiritual experiences. By facilitating a dialogue between the mind and body, we develop greater control over our internal processes. Old, dysfunctional patterns are actually re-patterned in our nervous systems. A healthy nervous system means greater resilience, fewer symptoms, and greater opportunities for a new way of being in one's life.

Body-mind therapy has been widely used to develop alternative ways to therapy. In a report, published by Shapiro, et al., (2007), researchers assigned 37 depressive participants to 20 yoga sessions. Among the 17 participants who completed the study the researchers observed a significant decrease in depression, anger, anxiety and neurotic symptoms. Wang, Wang, Cui, Zhu, Rong and Chen (2008) in a meta-analysis of eight trials with a total of 477 participants where acupuncture (needle-based ancient Chinese therapy) was used, showed a significant reduction of the severity of disease in client participants with depression. In a pilot study of 28 people with depression, researchers determined that mindfulness-based cognitive therapy (a healing approach that pairs mindfulness meditation with CBT) helped reduce depression symptoms (Barnhofer, Crane, Hargus, Amarasinghe, Winder & Williams, 2009).

One recent example which this study will focus on is the Trauma Release Process (TRE) also called Trauma/Tension/Stress Releasing Exercise developed by Berceli, (2008). This technique was developed through 20 years of observation of people going through traumatic experiences in different countries from different cultures and with different experiences of trauma/stress and included victims of war, tsunamis, earthquakes, political upheavals, soldiers of war, abused individuals and survivors of other traumatic experiences (Berceli, 2008). He has used this technique to heal many people around the world.

According to Berceli (2008) people store many traumas in their bodies with no outlet to release this pent-up negative energy. They keep on adding stress and trauma and the body keeps on storing this history from childhood to adulthood until such time that these experiences manifest themselves through psycho-physiological illnesses (Corey, 2014).

Berceli (2008) argues that, unlike animals, human beings have locked away their natural way of releasing trauma/stress by blocking neurological tremors that occur in the body as a way of releasing that particular trauma. This blockage is caused by our ego defense mechanisms that prevent us from being authentic to our experiences (Berceli, 2008). By trembling (voluntary shaking of one's body) we are able to release the toxic build-up of stored chemicals which make us stressed and eventually ill. Berceli (2008) devised simple-to-learn exercises that quickly release trauma or stress in one's body. These exercises induce trembling, which restores the body to its natural state of balance and deep relaxation. This exercise works very well even when combined with other psychological interventions such as Cognitive Behaviour Therapy (CBT), Gestalt Therapy and others.

When animals in the wild experience a traumatic event, they pass through their freeze state by trembling (Levine, 2011). This alleviates any PTSD reactions and allows the animal to become fully mobile and functioning again (Levine, 2011). Scaer, (2014) and Muggenthaler, (2001) in their research into mammalian tremors recognised that these tremors involved an expenditure of energy at a particularly vulnerable time of physical stress. Muggenthaler, (2001) realised that there is a brief window of recovery in which the body only uses recuperative mechanisms after a traumatic event. It is within this small window of recovery that mammals tremor (Berceli, 2008). This innate neurogenic trembling mechanism discharges high biochemical and neuromuscular charge from the body thereby facilitating a spontaneous recovery from the recent traumatic event experienced by the animal (Levine 2011). This trembling according to animal researchers, provides animals in the wild with a built-in immunity to PTSD that enables them to return to normal life after a highly charged life-threatening experience without developing PTSD symptoms (Levine, 2011).

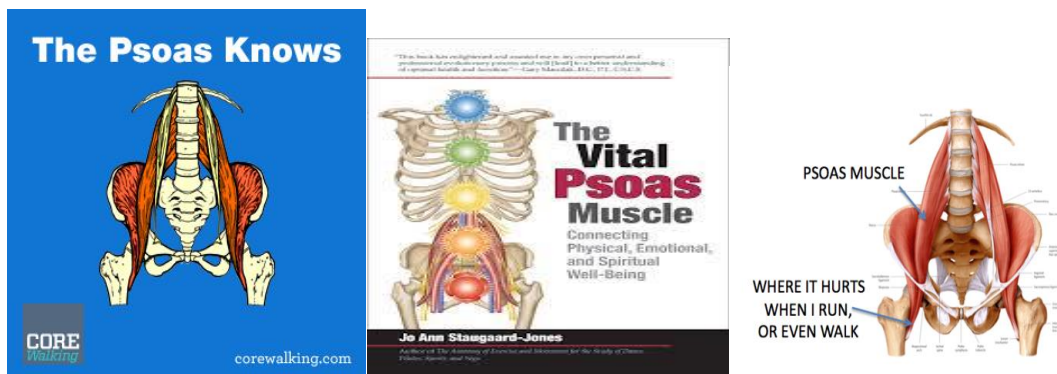
Levine, (2011) believes that for these tremors to have survived the evolution of species, there must be a survival advantage to this behaviour. Neurogenic tremors are commonly reported as disturbing symptoms among humans and are recognised as diagnostic features of Panic Attacks 300.01(F41.10), Social Phobias 300.23 (F40.10), Generalized Anxiety Disorder 300.02 (F41.1), and Post Traumatic Stress Disorder 309.81(F43.10) in the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2013). The onset of these tremors can often be attributed to traumatic or stressful events (Smaga, 2003). Until recently, this trembling was considered a pathological expression of the



nervous system. However, new theories of neurogenic tremors suggest that it is the body's natural mechanism to extinguish the hyper-startle response and restore the homeostasis of the body after the traumatic event has ended (Scaer, 2014; Levine, 2011).

Trauma/Tension releasing exercises (TRE™) were designed to engage the primitive mammalian survival mechanisms used to recover from a traumatic event. The same tremors found in other mammalian species can also be easily evoked in the human species through a series of five simple exercises. The exercises produce a slight fatigue in the major muscle groups of the legs and pelvis. This is done by isolating the muscle groups and exercising them individually. The induced muscle discharge in the form of tremors is used to extinguish somatic procedural memory, thereby mitigating on-going symptoms of trauma (Scaer, 2014). Usually, when one experiences a traumatic event, attention is moved out of conscious awareness because the situation is overwhelming and the conscious mind does not know how to process this experience. However, the reactions from the event are stored in the body through primitive and instinctual postures of defence (Van de Kolk, 2014; Levine, 2011; Berceles 2008; Rothschild, 2000). This instinctual posture not only causes the nervous system to react but it also produces changes in muscle tone and reflexive reactions (Scaer, 2014). The muscles may become more powerful or more flaccid, they may rigidify if the freeze response is activated or begin to tremor after the danger has subsided.

The primary muscles involved in this process are known as the flexor muscles. Collectively these muscles contract to roll the body forward into a ball. This forward bending movement helps to protect the core or underbelly of the body (Van de Kolk, 2012). The core flexor muscles of the startle response known as the 'psoas muscles' are particularly vulnerable to later motor dysfunction and chronic contraction. The psoas muscles, connecting the spine, pelvis, and legs, are one of the most primitive core muscles used intrinsically in flexor responses of the startle reflex (Loubser, 2016). Procedural memory for repetitive psoas activation causes chronic tension and increases baseline levels of arousal, postural dysfunction, and back pain (Scaer, 2005).



(Source: [www.emotionaltuning.com](http://www.emotionaltuning.com) & [www.neverstoprunning.wordpress.co](http://www.neverstoprunning.wordpress.co))

**Figure 8: Structure of the Psoas muscle**

Body therapy such as TRE offers an opportunity for health care workers and therapists working with PLHIV in treatment settings where resources are limited and where there is limited time available for psychotherapy, to help their client participants in a holistic manner. The advantage of this technique is that it allows the individual to practise the technique in the comfort of her/his home and within groups and the counsellor/therapist can monitor progress through the personal journal of the client.

In this study TRE will be used to allow clients to work out the past traumatic and stressful experiences they might be carrying in their bodies by taking them through a simple exercise routine that induces shaking and trembling of the body (Berceli, 2008). The client is also given a chance to reflect on how she/he experiences the process during and after the exercises. The client is encouraged to keep a journal so as to track changes in the trembling patterns. The reflection on the process assists the therapist to establish a relationship between the body and mind and to see where she/he can introduce other approaches such as cognitive behavioural techniques and other therapeutic methods.

Even though this technique has not been specifically used on PLHIV, individuals who have been exposed to this therapeutic technique have reported relief from noticeable body and emotional pains caused by stress in their lives. They also reported positive changes in the way they now handle their problems and they feel more grounded. For example, some people noted being less irritable and less short-tempered than before starting this treatment. Individuals who used this technique and were on anti-depressants stopped using their medication after three months of applying this technique in their lifestyle

([www.traumaprevention.com/2011](http://www.traumaprevention.com/2011)). These are testimonies from people who have utilised this method, even though it has not yet been empirically tested.

### **3.4. COGNITIVE BEHAVIOUR THERAPY (CBT)**

The history of CBT can be traced back to the development of behaviour therapy in the early 20<sup>th</sup> century, the development of cognitive therapy in the 1960s and the subsequent merging of the two. It was during the period of 1950 to 1970 that cognitive-behavioural therapy became widely used by researchers in the United States (US), United Kingdom (UK) and South Africa (SA) who were inspired by the behaviourist learning theory of Ivan Pavlov, John B. Watson and Clark L. Hill (Rachman 1997).

Farmer and Chapman, (2016) purport that, although the early behavioural approaches were successful in treating many of the neurotic disorders, they had little success in treating depression and also failed to make their mark due to the emerging Cognitive Therapy. The therapeutic approaches of Albert Ellis's Rational Emotive Therapy and Aaron T. Beck's Cognitive Therapy were now gaining popularity among behavioural therapists. Cognitive therapy rapidly became a favourite intervention technique to study and use in psychotherapy research in academic settings. During the 1980s and 1990s cognitive and behavioural techniques were merged to form Cognitive Behavioural Therapy.

Fundamental to this merger was the successful development of treatment for panic disorders by David M. Clark in the UK and David H. Barlow in the US (Rachman, 1997). Concomitantly with the contributions of Ellis and Beck in the late 1950s and continuing through to the 1970s, Arnold A. Lazarus developed the first form of broad-spectrum cognitive behavioural therapy with broadened focus on behavioural treatment to include cognitive aspects. He went on to include physical sensations, visual images and biological factors (Lazarus, 1971).

Cognitive-behavioural therapy is an approach that aims to solve problems concerning dysfunctional emotions, behaviour and cognitions through a goal-directed, systematic procedure. According to Butler, Chapman, Forman and Beck (2006), there is empirical evidence that CBT is effective for the treatment of a number of conditions, including mood, anxiety, personality, eating, stress, substance abuse and psychotic disorders. The CBT

treatment varies according to the client's needs, where most clients are able to complete their treatment in a few weeks or months (Bea & Tesar, 2002). It can be used in individuals as well as in group therapy and techniques are often adapted for self-help application. According to Foa, Rothbaum and Furr (2003), some therapists are more behavioural-oriented using in vivo exposure therapy, while some are more cognitive-oriented employing such techniques as cognitive restructuring, while others combine the two using techniques in imaginal exposure therapy. CBT includes a variety of approaches and therapeutic systems such as Cognitive Therapy, Rational Emotive Behaviour Therapy, and Multimodal Therapy (Corey 2014).

The scope of what constitutes CBT is very challenging due to varying approaches to treatment (Corey 2014). However, commonly used therapeutic techniques include: keeping a diary of significant events and associated feelings, thoughts and behaviours, questioning and testing cognitions, assumptions, evaluations and beliefs that might be unhelpful and unrealistic; gradually facing activities previously avoided and trying out new ways of behaving and reacting. Relaxation, mindfulness and distraction techniques are also included. A CBT client takes on valuable homework projects to speed up progress in therapy (Petrik & Kazantzis, (2014).

From a cognitive behavioural perspective, feelings and thoughts are two sides of the same coin (Meichenbaum, 2012). Each reflects a highly interdependent bi-directional process, a two-way street of feelings influencing thought processes and thoughts influencing feelings. For example, a depressed individual views the world and the self in negative terms and selectively pays attention to negative events from the past, the present and the future. The depressed individual also tends to have negative expectations that can become self-fulfilling prophecies (Beck, Rush, Shaw, & Emery 1979). Moreover, depressed people often are unaware of how they inadvertently and even unknowingly elicit reactions such as rejection, criticism, and withdrawal from others (Luyten & Fonagy, (2016). This depression is not something that just arises in the mind or emotions of individuals. It is a reflection of the cumulative stressors to which individuals are exposed.

Clients come to psychotherapy to find solutions to their problems. They need to change something in their lives, whether it is the way they act, feel or how others treat them, such as being discriminated against because they live with HIV and AIDS (Tshabalala, 2008). They often describe presenting problems in vague, global, metaphoric terms. A central

feature of cognitive-behavioural interventions is to help clients re-conceptualise their predicaments in problem-oriented terms that will lend themselves to solutions, and to break up problems into smaller, discrete units that can lead to solutions (Meichenbaum & Cameron, 1982 in Vanryckeghem, & Brutton, (2012). The constructivist approach adds to this problem-solving task by helping clients to retell their stories in a more 'hopeful voice' or what has been characterised as 'patient re-moralisation' (Meichenbaum 2012). They observed that participants in cognitive-behavioural treatment demonstrated a 60% to 80% symptomatic alleviation of depression, within the first four sessions, well before the usual introduction of techniques specific to the treatment of depression such as cognitive restructuring. They attributed this improvement (positive treatment expectations, ability to combat feelings of hopelessness, and greater sense of self-efficacy) to the therapeutic impact of initial treatment features, including; the opportunity given to clients to talk about their 'problems' and 'strengths', establishment of a 'therapeutic alliance', the therapist's credible explanation of the treatment, the client's self-monitoring and the discussion of such monitoring with the therapist.

According to Meichenbaum (2012), assessment and treatment in CBT are highly interdependent processes. The type of questions the therapist asks, the specific tests that are administered, the self-monitoring exercises clients are asked to do, and the feedback provided to clients and significant others are all means of assessment as well as ways to treat clients through education and the instillation of hope. The assessment tools engage clients in a productive, collaborative re-conceptualisation of their presenting problems. Assessment devices are also useful in treatment planning, goal-setting, monitoring progress and outcome evaluation.

According to Plotnik (2002) applications and principles of CBT are educational. The therapist focuses on the client's problem, identifies specific thoughts and behaviours that need to be changed, and provides techniques that are based on learning principles to make desired changes. For example, the therapist may turn toward uncovering the belief system of an HIV-positive person that makes her or him angry or hurt, i.e. a belief that rejection means he/she is worthless. The goal of CBT would be to challenge this underlying belief in order to alleviate anger or hurt. Through the use of CBT methods, the client discovers more adaptive ways of thinking and behaving. The client learns how to correct faulty cognitive processing and eventually becomes independent (Corey, 2014).

Beck (1987) as cited by Corey (2014) writes about the cognitive triad (three components) as a pattern that triggers depression. The first component of the triad is that clients hold negative views of themselves. They usually blame their setbacks on personal inadequacies without considering circumstantial explanations and are convinced that they lack qualities important to bring happiness in their lives. The second component is the interpretation of these experiences in a negative manner. It always seems that depressed people select certain facts that conform to their negative conclusions. The third component involves the continuous projection of this negative vision into the future. Depressed clients expect their present difficulties to go on and on and they always anticipate failure. These observations by Beck then resulted in the designing of a standardised device to assess the depth of depression (Beck, 1987).

CBT is usually brief and most clients are able to complete their treatment in a few weeks or months, as opposed to traditional therapies, which often take years to resolve or perhaps not resolve the problem at all. CBT also offers long-term treatment for clients with complex problems or clients forced to live in adverse conditions beyond their control. In other words, the length of therapy depends on the client's needs and the way the CBT therapist prefers to work. As a rule, however, most clients, particularly those in crisis may begin with two or more sessions a week until their condition is stabilised that they can safely attend therapy once a week (Bush, 2003)

Researchers have noted that those who are depressed and living with HIV and AIDS also have common distortions in their thoughts and view certain situations from a negative perspective. For example:

- Loss as related to depression means to them:
  - 'So many of my friends have died'*
  - 'I've lost my health'*
  - 'I have nothing to look forward to'*
  - 'My life is out of control'*
- Future developments: Uncertainty associated with fear and anxiety
  - 'I'm next to die'*
  - 'I'll be unattractive and won't be able to go out'*
  - 'I'll never find a partner now'*

*'No one will look after me when I'm dying'*

- Being 'caught out' and the inability to overcome the illness, are associated with frustration.

*'Why me?'*

*'The virus has taken over my life'*

*'I shouldn't have led such a double life'*

- Cognitions regarding self-judgment of sexuality and sexual behaviour which is associated with guilt

*'Sex is off', 'I never want to have sex again'*

*'I shouldn't have been so careless (promiscuous)'*

*'If only I had used a condom'*

- Anger: Either directed onto those who infected them or inward onto themselves

*'I shouldn't have trusted my partner'*

*'How could I have been so stupid'*

*'If only I had been more careful'*

### **3.4.1. The use and limitations of CBT**

A criticism of CBT is that it is less concerned with unconscious factors and ego-defenses. Neenan & Dryden, (2014) argue that emotions are a crucial part of an individual and an important focus of change where some problems can be resolved by exploring unconscious material. Corey (2014) believes that there is value in paying attention to the client's past. He finds it hard to believe that clients can make lasting and significant changes until they first recognise and accept their history and then come to terms with past, unfinished conflicts so that these feelings do not interfere with their present functioning.

Another criticism of CBT is that the limited ability for abstract thinking may interfere with the client's ability to grasp and apply CBT, techniques whose effectiveness relies on accurate recognition of cues to trigger their application (Patterson, 1986). Another limitation of CBT especially in a multicultural setting would stem from a negative interpretation of dependency. Some cultures view dependency as necessary for good mental health. Haaga and Davison (1986) point out that Asian culture and certain non-western cultures promote interdependence as opposed to individualism, through stressing the importance of the

individual's tailoring his or her behaviour to the needs of the family and the larger community.

### **3.5. MULTICULTURAL APPROACH**

The multicultural approach challenges the notion that problems are found exclusively within an individual. It recognises that some problems reside outside the person, more especially in the subject of HIV and AIDS in South Africa. For example, stigma and discrimination of PLHIV are more external issues than coming from within the person (Ivey, Pederson & Ivey 2008). Corey (2014) argues that multicultural work involves strategies that cultivate understanding and appreciation of diversity in such areas as culture, ethnicity, race, gender, class, religion, disability, and sexual identity. For example, WHO, (2005) indicates that 90% of people of African origin consult traditional healing practitioners. Bodibe (1988) argues that traditional healing or the African world view, can contribute to a positive paradigm shift in the delivery of therapy services in South Africa. He continues to argue that the African world view is not resistant to change and is, indeed, also informing the process of change. Therefore, the western therapists, in collaboration with traditional healers can zero-in on therapeutic methods that operate within a holistic paradigm (Moodley & West 2005).

Heine, (2015) defines culture as the set of attitudes, values, beliefs and behaviours shared by a group of people, but different for each individual, communicated from one generation to the next. He argues that culture is not rooted in biology, race and nationality. He describes the dualism in culture with the dimensions of individualism and collectivism, which refer to the degree to which a culture encourages, fosters, and facilitates the needs, wishes, desires and values of an autonomous and unique self over those of a group (Van Dyk, 2012). The grading of communalistic and individualistic cultures may range from very weak and passive to very strong and active. For example, in Africa the communalistic culture has gradually changed because of the dynamic nature of culture. Changes such as poverty, wars, famine, migrations, and diseases have brought about significant inner conflicts among Africans.

Therefore Idemudia, (2015) believes that we should ask ourselves this question, what is the role of culture in psychological conditions among PLHIV? He cautions that in order to understand culture in this context we need to first know and understand clearly what mental



health is about and how it is conceptualised from the African world view. Unfortunately most research originates from within Western cultures, and produces an ethnocentric view of psychopathology that can limit the African psychologist's understanding of disorders in general and can also limit and restrict the way they approach diagnosis and treatment (Flint, 2015; Lifschitz, 1989). The result is that they may be distracted and diverted from questions of the moment in their native communities and this has explained several omissions in the quest for African psychology (Idemudia, 2015).

### **3.5.1. African worldview on mental illness**

Africa is a continent that is culturally diversified. Harkness and Keefer (2000) note that although there are cross-cultural and ethnic differences, there is nonetheless, a general belief that both physical and mental diseases originate from various external causes such as a breach of taboo or customs, disturbances in social relations, hostile ancestral spirits, spirit possession, demonical possession, evil machination and the intrusion of objects, evil eye, sorcery, natural causes and affliction by God or gods. It is not that the above influences do not exist in other continents but in Africa they tend to define the African belief system (Madu, 2015). According to Idemudia, (2015) disease causation can be due to things both seen and not seen. As a result, many things not seen by the naked eye are embedded in the African belief systems, cultural and social values, philosophies, and expressions. According to Flint (2015) in the African attitude toward illness behaviour, every disease is systematically acknowledged as having a supernatural origin, either a grief or ancestors or witchcraft. According to Tsala-Tsala (1997) and Flint (2015) biology alone does not explain disease causation, because it is seen as a social phenomenon and as such has significance for the whole ethnic group and immediate community members. Collective rituals are performed in many African communities and families sometimes to stop transmission of some diseases believed to be passed from one generation to another because of the stains of a fault that have not been cleared (Lambo, 2004).

According to Tsala-Tsala (1997) the African way of viewing health and disease as a matter of harmony and disharmony between an individual and a larger context is similar to the holistic perspective advanced by Western researchers (Carlson & Sheild, 1989). Some societies in Africa also believe that illness can even befall one relative for another relative's

wrongdoing. Hammond-Tooke (1989) notes that the motives behind external causation of conflict lie deep in the human psyche and are not confined to traditional Africa. For example, witchcraft in Western Europe can also be explained in terms of social tension and antagonism. Pearce (1989) agrees that this idea appears to be similar to the Western view that defective interactions within a family could result in psychosocial disturbances in one member (i.e. scapegoat, stereotyping, prejudice and discrimination). While the modern Western social perspective links outcomes to natural and mechanical causes, African social interventions use spiritual/religious idioms. However, both interventions view illness as a sign of distress in social relationships, in contrast to the traditional biomedical intervention (Gordon, 1990).

Idemudia, (2014) and Flint (2015) argue that in most African societies psychophysiological complaints are often formulated as subjective bodily sensations, including heat in the head and body, a sensation of worms crawling all over the body, a sensation of heaviness in the brain, the sense that the heart is melting and wants to fly away and a lump in the throat. Several mental health researchers in Africa have described these complaints as the somatisation of emotional distress. According to Morakinyo, (1985) these somatic complaints are usually presented by clients to obscure some psychic distress or ‘cloaked phobic states’.

### **3.5.1.1. God and the ancestors as causal agents of illness**

According to Van Dyk (2012), some traditional religious systems in Africa see God (uQamata in Xhosa or Modimo in Sotho) as too important to bother with everyday problems. The living spirits of the deceased ancestors are the ‘mediators’ between the people and God. Ancestors are seen as benevolent spirits who preserve the honour and traditions of the tribe, and they usually protect their people against evil and destructive forces. Even though they can punish those who do not follow the ways of tradition, their anger or displeasure is only expressed through the withdrawal of protection so that their descendants are left exposed to attacks by witches and sorcerers. It is believed that the illness they can cause is seldom serious or fatal and the relationship can be restored with them through offerings and sacrifices (Flint, 2015; Beuster, 1997; McCall, 1995; Bodibe, 1992; Hammond-Tooke, 1989; Sow, 1980; Mbiti, 1969). However, Van Dyk, (2012) maintains that there is no indication in the literature that traditional Africans attribute HIV and AIDS to the anger of ancestors or to

God's punishment. It is often African Christians who believe that HIV and AIDS is God's punishment for immorality and sins. This is where Mpopu et al., (2014) argues for the partnership of faith-based organisation with HIV and AIDS public health care systems, as these organisations command power and influence among people of the world.

It has been argued that Africans prefer to use treatments that recognise their ways of thinking and their value systems (Idemudia, 2015; Smith 2015; Madu & Idemudia 1997). Given this perspective, it may be questioned how then can a 'transitional African' (one who has received Western education and as such has acquired both African and western values and is most likely to seek help of a psychotherapist) suffering from a mental problem, be helped.

Moodley and West (2005) claim that in the context of HIV and AIDS in South Africa where counselling is emphasised as part of a treatment modality, most clients are transitional Africans and health care workers/therapists need to be sensitive to both value systems. For example a western doctor/therapist might encounter clients who, even though they are seeking help from a western-oriented therapist, are at home being told that they need to perform a certain ritual in order to be healed from the disease.

Many families in South Africa, faced with understanding the scourge of HIV AND AIDS have gone to traditional healers for help, because physical symptoms of HIV AND AIDS are interpreted as being caused by ancestral anguish or evil forces. The transitional Africans will also seek western help from doctors to treat symptoms of the same condition. These clients might not report to the western doctor/therapist that they are also taking medication from traditional health practitioners, for fear of being judged as backward. It is therefore paramount for the therapist to explore this aspect with the client and understand where the client comes from so as to incorporate the client's belief system in therapy (Van Dyk, 2008; Bodibe, 1988)

### **3.5.1.2. Implications of the external causation of illness for HIV and AIDS Education**

Van Dyk (2008) argues that ignoring and ridiculing traditional witchcraft beliefs and ancestral beliefs has adverse effects on HIV and AIDS prevention programmes. She believes

that these beliefs of witchcraft and ancestral causation of illness should be recognised and integrated into HIV and AIDS programmes in a manner that respects individuals who believe in them. However, emphasis must also be placed on the immediate cause of the illness, which in this case, is the sexually transmitted ‘virus’ that also affects people of the Western cultures. It should be stressed that even though they may know where the HIV infection originates, it is as important to know what it does inside the body, so as to prevent getting or, transmitting it as well as treating its impact (Van Dyk, 2012).

### **3.5.2. Multicultural Competencies and Standards**

According to Sue and Sue (2007) in Erickson, Schreier and Nadkarni (2010), the Professional Standards Committee of the Association for Multicultural Counselling and Development, generated a basic set of multicultural competencies and standards that outline some challenging goals that may be useful to the therapist as she/he conceptualises her/his personal goals as a helper. These are:

- The Counsellor/therapist must be aware of personal cultural values and beliefs.
- The Counselor/therapist must be aware of the client’s culture and worldview.
- The Counsellor/therapist should utilize culturally appropriate intervention strategies.

Sollod (1993) believes that it is unfortunate that western psychology has tended to de-spiritualise psychotherapeutic endeavour by overlooking the spiritual dimensions of life and experiences. He believes that contemporary psychotherapy has much to gain from a world view that reconnects human beings with one another and with universal and spiritual purposes (Stockton, Nitza, Ntinda & Ncube 2015).

Nicholas and Damianova (2015) agree that it is now time to merge the western approach with cultural dimensions to assist people to overcome emotional and mental disorders. This is especially important for understanding the fears and aspirations of clients and which often become the causes of health problems. This, therefore, should be the major concern of psychologists, especially those working closely with African clients. Idemudia (2015) calls for the revision of the current practice of western psychotherapy in Africa and he believes that psychotherapy without cultural justice can be better termed as placebo psychotherapy (Sue, Zane, Hall & Berger, 2009; Bodibe, 1988; Manganyi, 1974).

The combination of these three approaches in developing the intervention of this study created an integrative intervention that allowed for the treatment of stress-related psychological conditions among PLHIV. The health care workers in the study were trained on this integrative intervention and in turn used it on their client participants in their respective health care facilities. The use of CBT psycho-educational techniques and cognitive restructuring combined with trauma releasing exercises allowed for the synergy of the two approaches with a focus on a complex traditional African culture.

### **3.6. CONCLUSION**

This chapter has focused on choosing the best theoretical foundation of the study. The use of the technical eclecticism approach of the integration psychotherapy has allowed for the incorporation and integration of three psychotherapies to form one treatment plan. CBT uses such techniques as relaxation exercise which body-mind therapy specialises in and this makes it easy to justify the use of TRE in developing the intervention used in this study. The multicultural perspective with special emphasis on African traditional healing viewpoint has also been incorporated without complicating the foundation of the study. The next chapter deals with research methodology of this study.

## **CHAPTER 4**

### **RESEARCH METHODOLOGY**

#### **4.1. INTRODUCTION**

This study was conducted in order to develop an intervention that would assist health care workers assist people living with HIV and AIDS (PLHIV) experiencing stress-related psychological conditions cope better. This chapter, therefore, discusses the methodology used to collect and analyse data. The chapter describes the design and research methods implemented to illustrate the procedure followed in developing the intervention to assist PLHIV cope better with stress. This chapter also includes a description of the setting, sample and sampling procedure, ethical considerations and instruments used to collect data.

#### **4.2. RESEARCH AIM AND OBJECTIVES**

The main aim of this study was to develop a counselling intervention using an integrative approach that would be used by health care workers to help PLHIV experiencing stress-related psychological conditions. In so doing health care workers will understand different behaviours PLHIV tend to exhibit and why they do so. The objectives of the study as influenced by the aim are as follows:

1. To determine the psychological conditions experienced by PLHIV.
2. To develop a counselling intervention to be applied by health care workers managing PLHIV.
3. To implement the counselling intervention
4. To conduct a preliminary evaluation of the efficacy of the counselling intervention.

#### **4.3. RESEARCH DESIGN – INTERVENTION RESEARCH DESIGN**

In the intervention research, the design and development of the intervention is a vital aspect of evidence-based practice. The intervention research design was employed in this study as a design that would enable for the development of the counselling intervention for PLHIV experiencing stress-related psychological conditions. As discussed and illustrated in

chapter one by means of a diagram (figure 1), intervention research involves six phases. However, dissemination of the intervention as the last phase of the intervention research has not been effected in this study due to the limitations imposed by the nature of this thesis. The recommendation on applying this phase has been positioned in chapter seven.

The design of this study made use of both qualitative research methods where questionnaires and focus groups as data collection strategies were utilised at different stages of the research. The use of these research methods compensates for weaknesses of each data collection strategy utilised individually.

#### **4.3.1. Qualitative method**

The qualitative approach is said to be particularly useful in the health care setting as it offers health care practitioners an opportunity to understand the complexity of human interaction and how people interpret this interaction, before attempting to quantify such behaviours and events (Jack, 2016). Qualitative research methods which are subjective, flexible, theory-based and interpretive in nature, have also been used in this study. Qualitative techniques are aimed at answering the ‘how’ and ‘why’ of behaviours and experiences by understanding, describing, discovering and exploring. According to Mason (2002), qualitative research primarily assumes that behaviours and experiences are not context free and therefore one should try to understand people’s personal meanings and values in their real world. He suggested that qualitative research adopts a constructivist view on events with sensitivity to social contexts. This implies that the researcher in a qualitative study is located in the context of the participants which enhances his exposure to details of social, cultural processes and dynamism (Denzin & Lincoln 2008).

This study used qualitative research methods to establish the meanings participants attached to their experiences of the social world and how they made sense of it. According to Lewis (2015) the qualitative research method is particularly useful in the health-care setting as it offers health-care practitioners an opportunity to understand the complexity of human interaction and how people interpret this interaction, before attempting to quantify such behaviours and events (Lewis, 2015).

While both methods (quantitative and qualitative) can study the same phenomenon, they do so through different lenses and answer different, yet somewhat complementary, questions that can yield both comparable and parallel findings. While quantitative research methods are objective and can be generalised to a larger population, qualitative research methods yield much detailed and rich subjective data.

Trustworthiness of qualitative research has generally been questioned by positivists, perhaps because their concept of validity and reliability cannot be addressed in the same way as in quantitative research. Nonetheless several writers have demonstrated different ways in which trustworthiness can be incorporated into qualitative research (Rossman & Rallis, 2016). One example is that of Krefting (1991) who suggests four criteria to ensure valid interpretation of data namely: trust value, applicability, consistency and neutrality. In the present study qualitative method was used on two focus groups sharing similar characteristics but interviewed separately in different settings. Data collected yielded similar responses which showed credibility, applicability, consistency and trust value of the data.

#### **4.3.2. Quantitative research method**

Quantitative research methods have been used to collect data that assisted in developing the intervention. Quantitative methods are primarily rooted in the tradition of positivism and deductive logic that sees behaviours, feelings and attitudes quantified, counted, measured and analysed with appropriate inferential statistical tests to test hypotheses (Robson & McCartan, 2016). It may be described in general terms as that approach that is highly formalised, and which uses standardised measures that fit diverse opinions and experiences into predetermined response categories. The techniques employed in quantitative methods are meant to help generalise the findings from a sample to the population thereby making this approach more applicable to large scale samples as well as involving macro-level analyses (Scandura & Williams 2000).

Some of the advantages of the quantitative methods are that numbers can be subjected to mathematical procedures and worked out on a computer in order to deal with large bodies of data. In this study quantitative methods were used to draw statistical conclusions from the results obtained from the data collected from PLHIV on their physical and mental functioning using the Medical Outcome Study HIV MOS-HIV, from assessing their psychological state



regarding depression using the Beck Depression Inventory BDI-II and from gathering their biographical information and the effects of living with HIV. Data collected were used in developing an intervention.

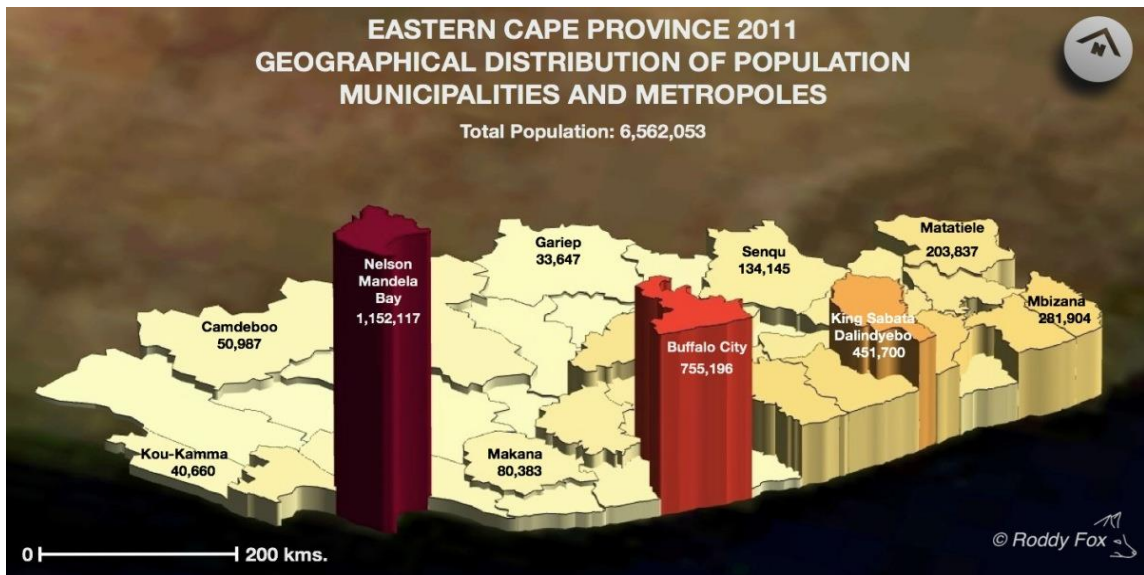
In the present study quantitative and qualitative research methods focused on generating data that assisted the researcher in developing the intervention and gaining a sense of the mental health status of people PLHIV. Data was collected from multiple sources including (PLHIV, health-care workers, home-based carers and centre coordinators) through standardised and non-standardised questionnaires and focus group interviews.

#### **4.4. RESEARCH SETTING**

The study was conducted in the BCM, which falls under the Amathole District of the Eastern Cape. Buffalo City is mainly peri-urban with a few rural villages and with East London as the main city. The population in BCM has shown a steady growth over the years. It has grown from 704 885 in 2001 to 755 200 in 2011 (Census, 2011) with the following racial breakdown: Black African = 642 753 (85,11%); Coloured = 45 442 (6,02%); Indian/Asian = 6 241 (0,83%); White = 58 258 (7,71%); other = 2 506 (0,33%). The total population of Buffalo City is 755 200, with Mdantsane being the most highly populated area, followed by the East London area, (Statistics SA. 2011). PLHIV in this municipality were estimated at 9.0% in 2005, but had recently increased to 12.2% in 2012 (HSRC, 2012).

The Buffalo City Municipality consists of a corridor of urban areas stretching from the port city of East London to the east through to Mdantsane and reaching Dimbaza in the west. East London is the primary node whilst the King Williams Town area is the secondary node. There is also a wide band of rural areas on either side of this corridor.

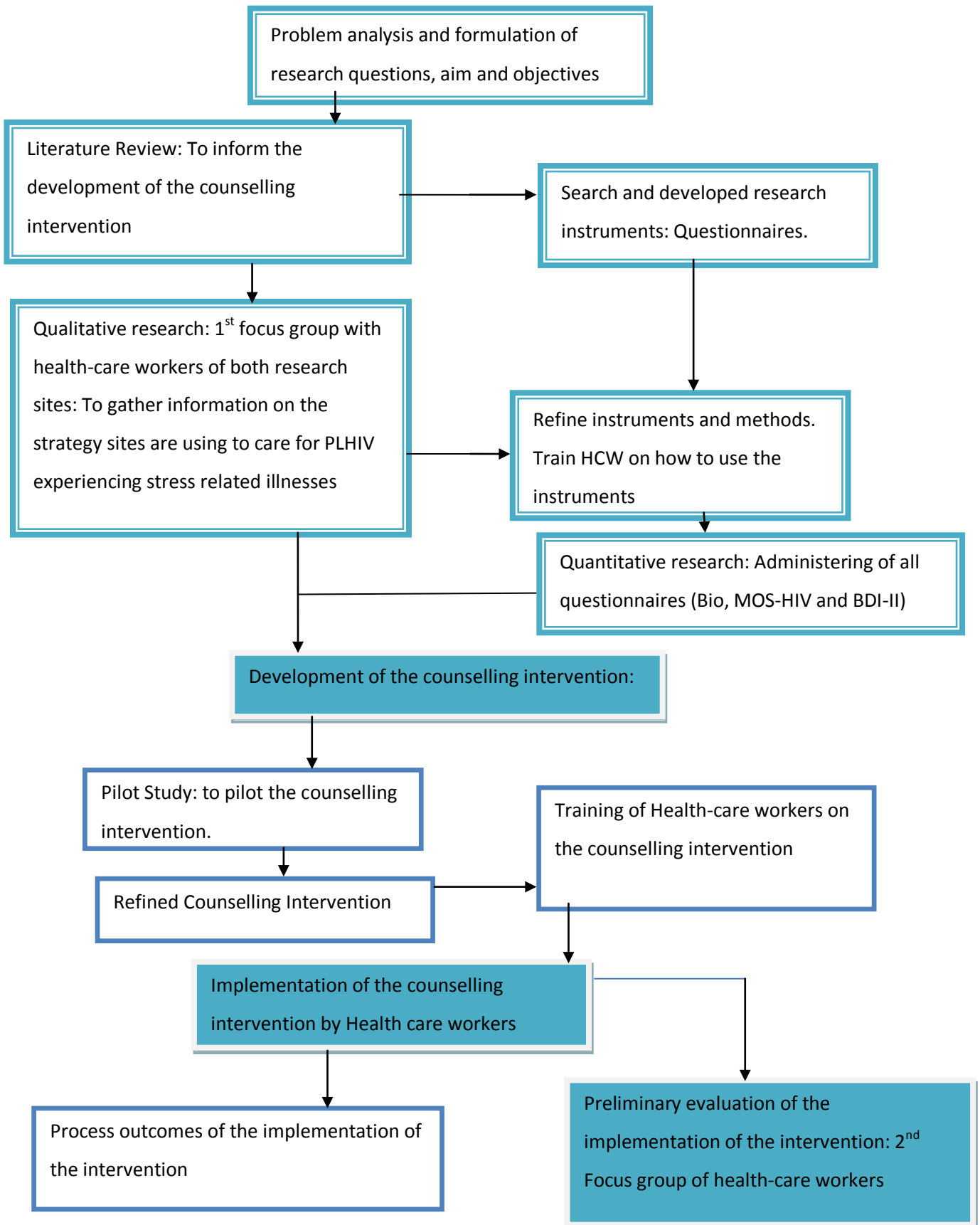
The BCM has five public hospitals, 9 private hospitals including specialised hospitals, 28 municipality primary health care facilities and more than 50 poorly resourced government clinics. These clinics are located in almost every village and ward of the BCM.



**Figure 9:** (Source: <http://rodnyfox.wordpress.com/2012/11/29>)

The focal point of this research was on two clinics, namely, one public/governmental clinic called Nontyatyambo clinic, situated in Mdantsane township, the second largest township in South Africa and one non-governmental health facility called Sophumelela Centre, in the City business development area (CBD) in East London. These two centres were chosen because they accommodate a vast number of PLHIV from major wards of the BCM. They offer HIV and AIDS services including HIV Counselling and Testing (HCT), positive living talks, CD4 count tests, viral load tests, antiretroviral therapy (ART), opportunistic infections (OIs) treatment and Antiretroviral (ARV) compliance and adherence meetings with monthly medical consultations by medical practitioners. Clients who require home-based care are referred to an attached home-based care facility and those in need of disability grants are referred to the Social Development Department (SDD). However, Sophumelela centre, instead of referring clients for home-based care, handles it through the use of home-based care-givers.

At both sites the study sampled health care workers who work directly with people living with HIV and AIDS. Unlike at Sophumelela, where staff involved in the study, were mostly home-based carers, at Nontyatyambo most health care workers were professional nurses.



**Figure 10: Summary of the research process.**

#### **4.5. POPULATION AND SAMPLE**

The population of the study were health care workers and PLHIV (client participants) drawn from Sophumelela Centre and Nontyatyambo Clinic health facilities of the Buffalo City Municipality in the Eastern Cape Province. Health care workers were further selected to be only those who directly work with PLHIV. Client participants were those clients or patients who are living with HIV receiving health care support from these health facilities. All participants were both males and females of 18 years and above old. All participants therefore were sampled using purposive sampling. Purposive sampling implies that the sample is purposely selected to include people of interest in the research process. This involves searching for cases or individuals who meet a certain criterion such as having a certain disease or having had a particular life experience (Palinkas, Horwitz, Green, Wisdom, Duan & Hoagwood, 2015).

Purposive sampling techniques have also been referred to as non-probability sampling or purposeful or qualitative sampling. As noted, these involve selecting certain units or cases based on a specific purpose rather than randomly. The advantage of purposive sampling is that it permits the researcher to study a small subset of a larger population where members of the subset are easily identified (Etikan, Musa & Alkassim, 2016). It also allows the researcher to select participants based on internal knowledge of said characteristics. The disadvantage of purposive sampling is that not all persons are given an equal chance of being sampled.

The inclusion criteria for participants in this study were that they should be health-care workers, e.g. nurses, care-givers and counsellors/lay counsellors, working at the selected HIV and AIDS centres where PLHIV are receiving counselling, treatment and other health needs, working directly with PLHIV. The exclusion criteria for health care workers were to work indirectly with clients or patients living with HIV. The inclusion criteria for client participants was to be 18 years and older, living with HIV, being the client of Sophumelela centre and Nontyatyambo clinic receiving counselling, testing and treatment at these health facilities. Client participants could also be on the home-based programmes or out-patient or support group of these two study facilities. The exclusion criteria were PLHIV who do not receive counselling, testing and treatment at the selected health care facilities in this study.

Sample size of the health care workers was determined by the number of health care workers who directly work with PLHIV in the two selected study health facilities to twenty (20) HCW in total. For example, all ten health care workers at Sophumelela centre were included with the exception of the Director of the centre. This number also was determined by the number of patients that can be used for focus group interviews. The same applied at Nontyatyambo clinic. The sample size for client participants (PLHIV) was determined by the number the health care workers can handle when implementing the intervention. Each health care worker was to work with five client participants. Although the researcher sampled 100 client participants, unforeseen variables (such as transport problems, domestic emergencies, and so on) interfered with this number, reducing it to 78. Twenty-two client participants who were present in the introductory session could not make it in subsequent sessions and were therefore excluded from the study.

#### **4.5.1. The sample of PLHIV participants for the development of the counselling intervention**

This phase comprised of 100 client participants who were also people living with HIV and AIDS during the introduction stage of the study; 54 from Sophumelela centre and 46 from Nontyatyambo clinic. However, this number decreased to 78 as the study proceeded to other stages of data collection. Client participants were purposively sampled to establish their level of vulnerability to stress-related disorders using three different instruments. All participants were older than 18 years. The demographic features of the sample are illustrated on the table below.

**Table 2: Biographical information of participants (PLHIV) who were sampled (n = 100)**

<b>Gender</b>	<b>Frequency</b>
Male	33
Female	67
<b>Total</b>	<b>100</b>
<b>Educational Background</b>	
Primary	35
High School	49
College/University	10
Not given	6
<b>Total</b>	<b>100</b>
<b>Marital Status</b>	
Single	55
Married	31
Divorced	1
Separated	4
Cohabiting	6
Widowed	3
<b>Total</b>	<b>100</b>

As the study went on PLHIV participants dropped out of the study due to different reasons including, no money for transport to come to the clinic, had to take care of children and other domestic emergencies.

#### 4.5.2. The sample of health care workers for the development of the counselling intervention

Twenty (20) health care workers who provided services to PLHIV at Sophumelela Centre and Nontyatyambo Clinic at the BCM were sampled. The number of participants was determined by the number of health care workers at the facilities and the required number for focus group creation. They were interviewed in two separate focus groups. The demographic features of the health care workers are provided on the table below.

**Table 3: Distribution of the sample of health care workers from both facilities by designation (n= 20 )**

Designation	Frequency
Home-based carers	8
Lay Counsellors	2
Professional Nurse	8
Social Worker	1
Programme Coordinator	1
<b>Total</b>	<b>20</b>

#### 4.5.3. The sample for the implementation of the counselling intervention

The sample comprised 18 health care worker participants eight of which were home-based carers, 2 lay counsellors and 8 professional nurses. The two health care workers who were present in the first stage, one social worker and one programme coordinator were excluded from the implementation of the counselling intervention as they were not part of the staff directly involved with the clients in the field. During this stage all health care worker participants were trained on the counselling intervention. After training they implemented the intervention

From the 78 client participants 16 home-based clients from Sophumelela centre and 10 client participants from Nontyatyambo clinic totalling up to 26 were purposively sampled for the implementation of the intervention. However during the feedback and reflection phase sessions only 13 of the 18 HCWs participated. Five members could not be available for the most part of the sessions due to the structure of their work at the clinic.

#### **4.5.3. The sample of health care workers for the preliminary evaluation of the efficacy of the counselling intervention**

This stage comprised the same health care workers who implemented the counselling intervention to give a preliminary evaluation of the efficacy of the intervention. The evaluation sessions were two groups (eight health care workers from Sophumelela centre and five from Nontyatyambo clinic).

### **4.6. RESEARCH INSTRUMENTS**

#### **4.6.1. Biographical Questionnaire**

This questionnaire was administered to all PLHIV clients/client participants at both health facilities. Data obtained via the biographical questionnaire gathered information on gender, location, educational levels, marital status, how and when they knew about their seropositive status and how they reacted to HIV positive diagnosis, whether they were attending counselling sessions or not, as well as their ART status. (See Appendix: I).

#### **4.6.2. Medical Outcomes Study – HIV Health Survey (MOS-HIV)**

The MOS-HIV has been widely used and the issues of validity and reliability as a quality of life (QoL) measure for client participants with HIV illness have been cleared. Krentz and Gill (2003); Rosen, Ketlapile, Sanne and DeSilva (2008) have used this instrument to measure the early impact of antiretroviral therapy on functional impairment, symptom prevalence and employment at three clinics in South Africa as well as in other Sub-Saharan countries. Folk (2009) also used this instrument in his study on HIV and AIDS secondary infections and immune modulation. Rosen, Ketlapile, Sanne and DeSilva (2008) using MOS-HIV also conducted the study in Cape Town, to see differences between client



participants not yet taking ART and those initiating ART in normal activities, job performance and symptom prevalence.

Data from numerous studies support the internal consistency and reliability of the multi-item scale in the MOS-HIV (Skevington, & O'Connell, 2003). In most cases, Cronbach's alpha coefficients exceed 0.70, suggesting adequate reliability for group comparisons. In preliminary analysis Cronbach's alpha coefficients for the physical health summary score ranged from 0.90 to 0.92 and the coefficients for the mental health summary scores ranged from 0.91 to 0.94 across different samples (Wu, et al.1991). The studies provide evidence that the MOS-HIV instrument is a valid and reliable measure of health-related quality of life (HRQoL) and can be used in a wide variety of study populations (Babikako, Neuhauser, Katamba, & Mupere 2010).

Like the BDI-II and the biographical questionnaire, PLHIV clients/client participants were given the MOS-HIV questionnaire to answer at both health facilities in the same way. MOS-HIV was administered to check the overall health status of the participants.

#### **4.6.3. Beck Depression Inventory (BDI)**

In addition to the biographical questionnaire and focus group interviews, psychological assessments such as the Beck Depression Inventory second edition (BDI-II,) and a Medical Outcomes-HIV questionnaire (MOS-HIV) were used. The BDI-II is a 21-item self-reported instrument intended to assess the existence and severity of symptoms of depression as listed in the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders fourth edition (DSM-IV; 1994). There are three versions of BDI, namely: the BDI original, first published in 1961 (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961), and revised in 1978 as BDI-1A, and subsequently the BDI-II published in 1996. This test was first designed by Aaron T. Beck, a pioneer in cognitive therapy (Beck, Rush, Shaw, & Emery, 1979).

The BDI-II has been used for more than 40 years and has been reported to be highly reliable regardless of the population (Sharp & Lipsky, 2002). It has a high Cronbach's coefficient alpha (80). Its construct validity has been established and it is able to differentiate between depressed and non-depressed client participants (Beck , Steer, Ball & Ranieri, 1996).

The BDI-II has been shown to be valid and reliable with results corresponding to clinician ratings of depression in more than 90% of all cases (Beck, Guthy, Steer & Ball, 1984).

A study conducted by Kasese-Hara, Mayekiso, Modipa, Mzobe and Mango (2008) on the depression, mother's concerns and life events experienced by HIV-positive, HIV-negative and mothers with unknown HIV status in Soweto, used the BDI-II to assess depression symptoms in the sample. Mfusi and Mahabeer (2000) also used BDI-II in their study on Psychological adjustment of pregnant women infected with HIV and AIDS in South Africa. In a study on factors related to postpartum depression in South Africa BDI-II was used (Steele & Edwards, 2008).

In this study the BDI-II was administered to 100 PLHIV clients/client participants to assess the existence and severity of symptoms of depression among participants. As with the biographical questionnaire, BDI-II was administered by both the researcher and home-based carers who were trained to administer and collect these questionnaires

#### **4.6.4. Focus group interviews**

Data was gathered by means of the focus group session using semi-structured questions, attached as (Appendix L). This session was tape-recorded to allow the researcher to analyse it at a later stage. This was basically information about how clients/client participants are received and assisted with HIV counselling and testing, diagnosis and treatment as well as identifying clients with stress-related illnesses and identifying the types of interventions they have. The second focus group session with the same participants was conducted after the implementation of the intervention as a feedback mechanism

### **4.7. RESEARCH PROCEDURE**

The research procedure followed the intervention research phases. The first phase was the development of an integrative intervention and involved a number of steps to gather information. These steps were:

- Focus groups discussions, quantitative measures (biographical questionnaire and psychometrics measures), piloting of the instruments, relevant literature review and the integration of the chosen theoretical framework and intervention research design to guide the research.

- Drafting of the counselling intervention.
- Pilot testing of the intervention
- Produce a final draft of the counselling Intervention.
- HCW participants were trained on the counselling intervention
- Trained HCWs participants implemented the intervention.
- The focus group discussion for the evaluation of the intervention was conducted to determine the efficacy of the intervention.

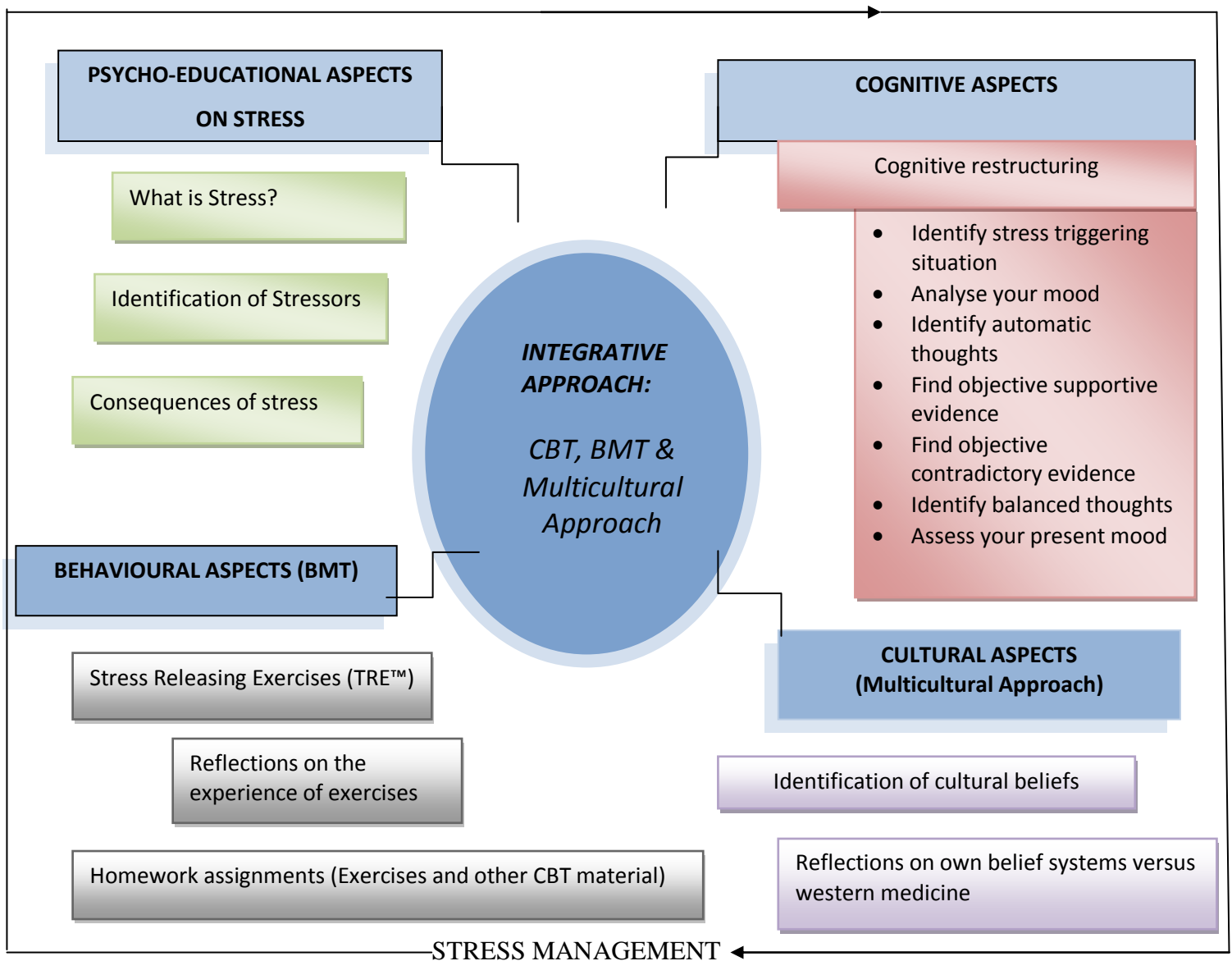
On receiving permission from the Director of the Centre to use the centre for this research, an interview meeting was secured to establish how the centre operates. The second meeting was conducted with the focus group of eight (8) home-based carers, one (1) social worker and one (1) programme coordinator to collect data for Phase one. After explaining the aims and procedure of the study, caution was taken to ensure that all participants were made aware of their ethical rights and informed consent forms were signed and collected.

The focus group interview was conducted using an audiotape to find out more about the process of assisting client participants. Since home-based carers were the ones in contact with the clients in their homes, the researcher requested them to administer questionnaires during their rounds with clients. They were then trained on how to obtain informed consent and to administer questionnaires to clients. Questionnaires were written in English. In order to make sure that HCW would be able to administer questionnaires satisfactory, the researcher went through all questionnaires with them and also requested them to respond to all the questionnaires as if they were clients and ask questions where they needed clarity. This facilitated their understanding of each question asked and the procedure to administer each questionnaire.

Each HCW had six clients. Each week the researcher met carers to collect questionnaires from HCWs and to check for any challenges they might have encountered during the administering of questionnaires. At the end of three weeks all questionnaires were collected. Out of 300 questionnaires printed and distributed, a total number of 200 questionnaires (78 of the Biographical questionnaire, 56 of the MOS-HIV and 66 of the BDI-II) were collected. Reasons for attrition differed ranging from HCW finding their client participants not at home on the day of collecting data or client participants being unable to go to the health care facility on the day of administering questionnaires.

## **Development of the Intervention**

After receiving all questionnaires the researcher started working on the intervention. All data from four sources thus, focus group interviews of the two groups of health care workers, biographical information, MOS-HIV and BDI-II were analysed using SPSS system. The results as shown in chapter 5 showed that client participants do not show clinical symptoms of depression as assumed, but rather stress-related challenges of every-day life. This led to the development of a stress management intervention using the integrative approach outlined in chapter three. Data collected from the first focus groups gave information on stress-related problems experienced by PLHIV from the health care workers' perspective. The BDI-II also indicated very low percentage of client participants who could be clinically depressed, most of them were between normal and mild levels of depression. The MOS-HIV also did not show a big range in terms of physical and emotional ill-health interference with daily functioning.



CBT: Cognitive Behaviour Therapy, BMT: Body Mind Therapy and Multicultural Therapy

**Figure 11: Diagrammatic presentation of the counselling intervention**

The counselling intervention was then developed with the notion that very few client participants showed severe stress-related psychological conditions such as severe depression but they required psycho-educational skills to deal with daily stressors and stress in their lives. An agreement with HCWs was reached to develop a stress-management intervention comprising of three intensive sessions using the selected theoretical framework. A combination of CBT psycho-educational techniques and stress releasing exercises (Appendix A.) was designed such that the client would be able to reflect on thoughts, feelings and

behaviour before, during and after the session. The third session also included thoughts and feelings around cultural values and beliefs regarding HIV and AIDS.

After the intervention was developed the researcher gathered four members of staff who were also working with clients living with HIV at the researcher's organisation health facility for content validation of the intervention. Inclusion and exclusion criteria similar to the main study sample were used.

- **Sophumelela Centre**

An arrangement for the training of home-based carers was made and training was conducted for three days over a period of three weeks. Due to the tight schedule in this facility, the researcher was given only Fridays to conduct training for the carers. Even though this was time-consuming it made it easier for the researcher to give homework assignments to practise over a longer period. After the intensive training each carer had to choose two clients with whom to implement the intervention.

They were given a programme covering three intensive sessions with their clients that involved exercising and reflection on thoughts, feelings and behaviour before, during and after exercises. The second session concentrated specifically on cognitive restructuring with a number of homework assignments that they were given and asked to bring back in the next clinic visit. The last session also included thoughts and reflection. It took three weeks before the researcher could call HCWs for Phase three.

- **Nontyatyambo Clinic**

At Nontyatyambo Clinic an appointment was secured to meet with the manager after the researcher received the letter of permission from the Eastern Cape Department of Health: Epidemiological and Surveillance Research, to explain the process and purpose of the study. The same research procedure as at Sophumelela centre was followed at Nontyatyambo Clinic. However, as a governmental clinic some procedures were far different from the NGO. After having met with the manager who referred the researcher to the relevant department, a meeting was then sought with health care workers. The first meeting with the HCWs was to explain the study and its process. Unlike in the case of Sophumelela Centre, this clinic had more than ten HCWs, which then implied that some kind of criteria had to be established.

Only HCWs directly working with PLHIV from client intake interview to treatment adherence and those working with the support group were selected. About 17 HCWs came to the introductory meeting but only 10 were required as per guidance for focus group interviews.

The study was conducted at the time when governmental health services were integrating services. There were no HCWs for client participants living with HIV per se and all client participants, whether HIV positive or not, were seen by all HCWs in the same way. Then eight (8) nurses, and two (2) lay counsellors were selected. A focus group interview session was then conducted after obtaining informed consent. The client participants were met before the training of HCWs to administer questionnaires. This facility had a support group of both HIV infected and affected people and the researcher met the support group and explained the study and its aims and informed consent was obtained from participants. Questionnaires could not all be completed on one day. HCWs participating in the study were then requested to collect the remaining questionnaires from the client participants the following day. Having client participants in one sitting assisted the researcher in terms of time-saving and in clearly explaining the procedure of the study and how to fill in the questionnaires. At Nontyatyambo clients were asked to go to the clinic and a number of factors affected their attendance such as cold weather, transport and other domestic reasons. There was also some kind of intransigence among senior staff at Nontyatyambo Clinic due to the perceived bad publicity on the government health facilities.

As at the Sophumelela Centre, a three-day training session was arranged and HCWs were trained on the intervention by the researcher. Unlike Sophumelela Centre, the three-day training was conducted over one weekend, due to a different scheduling at this facility. This saved time for the researcher though it meant some sacrifice on the part of the participants, as weekends were the only time they could attend to their personal obligations.

The last focus group discussion with HCWs was to reflect and give feedback on what they had experienced with their client participants using this intervention.

## **4.8. DATA COLLECTION**

### **4.8.1. The development of the counselling intervention**

The development of intervention involved the analysis of the problem in chapter one, information gathering in the literature review chapter, theoretical framework, collection of data through qualitative (through focus groups) and quantitative methods, and content validation session. This study has not focussed on dissemination as the last phase of intervention research design. Recommendations were made on how the intervention could be disseminated.

#### **4.8.1.1. A review of literature**

There are a number of studies that assisted in providing valuable information towards the development of the intervention. The major areas of focus for the study entailed stress-related psychological conditions such as depression, anxiety, acute stress disorder, PTSD, and adjustment disorders including psychosocial and emotional aspects such as stigma and discrimination that PLHIV may experience, and as described in Chapter Two.

The selection of research instruments was influenced by the focus of this study, which was the development of an intervention that would help alleviate stress-related psychological illnesses among PLHIV. While BDI-II focused only on testing depression, the MOS –HIV covered a number of health aspects including; mental, physical, cognitive, pain, energy, social, role, health distress, general health and quality of life aspects of a person living with HIV and AIDS. The biographical questionnaire also captured anxiety issues as related to diagnosis, treatment, care and support.

#### **4.8.1.2. An integration of the theoretical framework to guide the research**

The development of the intervention was informed by various theories and interventions. These include; an integrative perspective focusing on Cognitive Behaviour Therapy, Body-Mind Therapy and Multicultural Counselling.



#### **4.8.1.3. Biographical questionnaire and psychometric assessment**

A biographical questionnaire was developed to gather information on the participants. The questions included; gender, level of education, marital status, ethnic background, knowing own HIV status, availability of support groups, availability of counselling, about treatment (ARVs). The biographical questionnaire also included open ended questions on how client participants felt during the time of HIV diagnosis, time of starting ARVs and their fears and coping skills they used. Additional information was sourced through administering BDI-II and MOS-HIV assessments. This helped to establish the level of stress-related illnesses (in this case depression through BDI-II), and checked for an overall health picture of the participants through using the MOS-HIV Survey. A mix of quantitative and qualitative data was collected from all questionnaires that were administered to client participants/PLHIV. Data was analysed using SPSS.

#### **4.8.1.4. Focus group discussions with health care workers**

A focus group of between 6 – 10 people is a form of qualitative research in which a group of people are asked about their perceptions, opinions, beliefs and attitudes towards a particular subject (Gillham, 2005). Focus groups in this study consisted of two groups of ten health care workers per group. They were requested to participate in the study after the researcher had been granted permission by the Centre Manager to conduct her study.

The process took the form of pre-and-post-intervention interviews, in that health care workers were interviewed before the development of the intervention. They were then interviewed after implementing the intervention. This design was employed with health care workers for reasons of continuity and to avoid attrition. Health care workers were more likely to remain where they were at least for an approximate period of three years or for the duration of this research. Qualitative data was captured on an audiotape using semi-structured questions (as Appendix L). Data was then transcribed verbatim using themes.

#### **4.8.1.5. Pilot Testing**

The pilot testing sample was a purposive sample where staff members from the researcher's workplace health facility dealing with HIV and AIDS education and counselling

were chosen. The inclusion and exclusion criteria also applied in the same manner as with the main study sample. An added advantage of the pilot study sample, even though not a requirement for the study was that these members were openly living with HIV. This aspect made this session stronger due to experiences they had encountered as PLHIV working with clients who also live with HIV. They were able to note elements that could hinder their clients and themselves as PLHIV from responding to certain issues during these sessions because they themselves have experienced such issues. Another omission on multicultural approach which was not filtered through in the first focus group interviews and on all questionnaires was also identified by this group. This was resolved by including it in the training of health care workers and the implementation of the counselling intervention.

**Table 4: Distribution of the pilot study sample by designation and gender**

Designation	Frequency (n)	Gender	
		Female	Male
Health care worker and PLHIV	4	3	1
Psychologist and Life style management lecturer	2	2	0
Total	6	5	1

According to Burns and Grove (2010) a feasibility study is crucial to check whether questionnaires are reliable and would yield valid responses. Part one of the content validation session was undertaken prior to the development of the intervention to examine the appropriateness of the questionnaires, particularly the one that is not standardised. The questionnaire was tested for its comprehensibility and to identify any weaknesses to be addressed. A convenient sample of four respondents was asked to complete the questionnaires; biographical, BDI and MOS-HIV. The respondents were further asked to make a mark next to questions or items they felt were confusing and to make general comments on items that did not apply to them. Since the study used two standardised instruments and biographical questionnaire with just 23 items, respondents found the questionnaires suitable and easy to understand. Despite the sensitive nature of the research items, there was an overwhelming willingness on the part of the respondents to take part in the study.

The second part of the pilot study was based on the intervention itself. Two colleagues of the researcher, a counselling psychologist and a lecturer in the lifestyle management field were approached by the researcher to assist with the pilot study. Together with the health care workers looked at the intervention and made comments on whether it would be suitable for use. They made some comments and advised on reducing homework assignments and number of sessions. They advised that it would be beneficial for participants to have one and not three homework assignments for each day they were away from the sessions so as to give them more practice but not to overwhelm them. A note was also made on the exercises. They suggested that exercises should be allocated more time in the last part of the session to allow for more relaxation and reflection. Their input was valuable considering the time constraints of the study. These inputs were incorporated in the final draft of the intervention.

#### **4.8.2. Implementation of the counselling intervention**

The implementation of the counselling intervention is set to introduce change into the behaviour of the individuals affected. In this study this activity is represented by the training of HCWs on the intervention and the implementation of the intervention on their clients/client participants as shown in figure 11.

##### **4.8.2.1. Training of HCWs**

The implementation of the intervention started with the training of HCWs of the two facilities. A three-day training session of HCWs at the two facilities was done on separate occasions due to delays in obtaining permission to enter one of facilities. HCWs were trained by the researcher. The researcher trained the health care workers on the intervention manual on stress management developed by the researcher, in the same way as they would interact with their clients. Each session was introduced, defined, and illustrated by examples with exercises involving working in dyads, group work and/or individual assignments. Modifications made to the intervention based on the feedback received from the previous focus group session were included.

The first day of training covered introduction, expectations, objectives of the training, stress definition, how stress affects our bodies and the introduction of stress releasing exercises. The second day covered the reflection on the homework assignments that were given the previous training session, the introduction of CBT's cognitive restructuring with role-plays and group discussions. The day closed with stress releasing exercises and how to teach clients these exercises. The third day started by sharing homework assignments, practising CBT in dyads, incorporating multicultural aspects on the cognitive restructuring process and closing the day with practising stress releasing exercises. This training equipped health care workers with skills to share the knowledge gained in exactly the same way it was presented to them. The intervention also allows HCWs to benefit by avoiding their own burn-out and many stressful situations in their lives.

#### **4.8.2.2. The implementation of the counselling intervention by HCW participants**

After the training, the researcher monitored the implementation of the intervention by health care workers. All HCWs of both facilities were to choose two clients from those who had participated in the development of the intervention stage for the implementation of the intervention as shown in figure 11. They were given three weeks to complete the exercise. They conducted three counselling sessions each over a period of three weeks. With clients at Sophumelela Centre it was easy to control the stress releasing exercise part of the implementation one-on-one. However, at Nontyatyambo HCWs brought their clients together for exercises during support group sessions but continued with counselling sessions one-on-one.

It was decided that exercises would take a longer time during individual sessions, therefore they could be covered during support group sessions since all client participants participating also belonged to the support group. This made it easier for HCWs to only deal with the cognitive restructuring sessions and aspects of the multicultural perspective during counselling and deal with the stress releasing exercises during support group sessions. The duration of the support group sessions was one hour and thirty minutes, whereas individual counselling took 30 minutes. Individual counselling focused on reflecting on the homework assignments and what changes the client noticed with body therapy (exercises).

#### **4.8.3. Preliminary evaluation of the implementation of the counselling intervention**

After three weeks of implementing the counselling intervention, the researcher conducted the preliminary evaluation of the intervention through focus group discussion to evaluate how the HCWs experienced this intervention and whether it benefited their client participants/clients or not.

#### **4.9. ETHICAL CONSIDERATIONS**

Ethical clearance was sought from the Human Research Ethics Committee at the Nelson Mandela Metropolitan University (NMMU). Permission to conduct the study at the non-governmental Centre, thus, Sophumelela Centre, was obtained from the Programme Director of the centre, whereas permission to conduct the study at the government clinic; Nontyatyambo Clinic, was obtained from two offices, the Provincial Department of Health Epidemiological Research Deputy Director and Sub-district Manager. Informed consent from all participants was obtained (refer to Appendix: F) and participants were assured of their anonymity, confidentiality, privacy, and that their participation was voluntary. They were made aware that they were free to withdraw from the study at any point if they wished to do so. In addition, they were informed that they were not obliged to answer any of the questions and that if they felt that some of the questions were too personal or if they were uncomfortable answering them, they had the right to refuse to answer them (refer to subject information sheets—Appendices: G and H ).

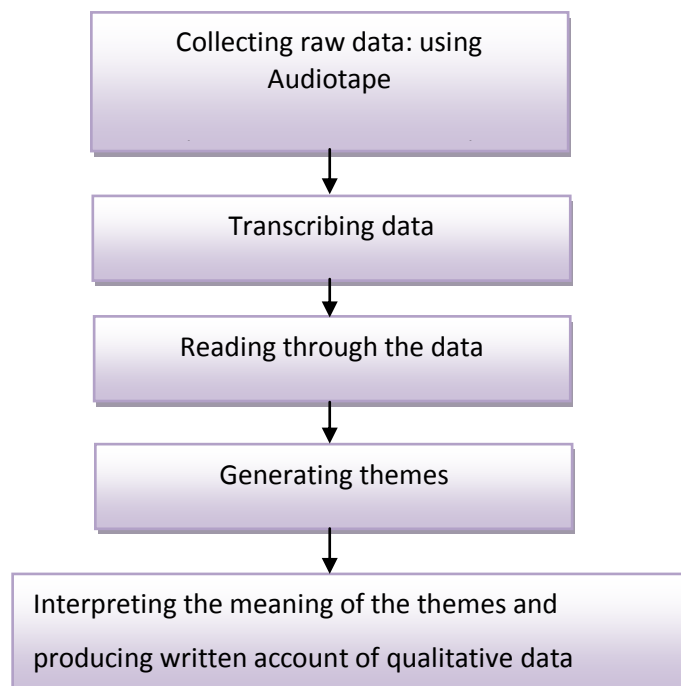
In addition, health-care professionals were urged throughout the course of data collection to maintain confidentiality and not disclose information gathered during these sessions to anyone other than the researcher and her supervisor. Data collected were to be stored under lock and key for a period of five years from the date of collection.

A meeting was arranged between the researcher and the Programme Director. The researcher submitted a written request for ethical clearance from Nelson Mandela Metropolitan University (NMMU) Research ethics Committee –Human (REC-H) (Appendix: B), but also verbally explained how the study would be conducted in the facility. Permission

was granted after the Programme Director had discussed the matter with the Superintendent of the facility (Appendix: C).

#### 4.10. DATA ANALYSIS

Quantitative data were analysed using SPSS and illustrated through cross-tabulations, frequency distribution and simple statistical techniques such as pie charts and histograms or bar charts. This data were collected from the all questionnaires used in this study namely, biographical information questionnaire, MOS-HIV and BDI-II. While qualitative data were collected from focus group unstructured interviews and were analysed by themes from descriptions by participants in their language. Qualitative data by nature is descriptive and is useful in finding out in depth, the ways in which people think or feel. It is concerned with understanding human behaviour from the participant's perspective. It assumes a dynamic and negotiated reality (Mincheiello et al., 1990). The following figure illustrates the process of analysing qualitative data used in this study.



**Figure12: Data Analysis process of Qualitative Research**

#### 4.10. CONCLUSION

This chapter has clearly defined and discussed the research methodology followed to collect and analyse data. The following has been described in this chapter, research setting,

research design, sample and sampling, instruments used and research procedure as well as description of ethical considerations. The next chapter involves the tabulation of the finding of this study.

## **CHAPTER 5**

### **FINDINGS OF THE STUDY**

#### **5.1. INTRODUCTION**

This chapter presents findings in accordance with the aim and objectives of this study. The aim of this study was to develop a counselling intervention that could assist health care workers in identifying stress-related psychological conditions among PLHIV and help them manage stress in their lives. A detailed description of the development and implementation of the intervention was presented in Chapter 4.

This chapter presents findings of the ninety-eight (98) research participants (78 PLHIV and 20 health care workers) who took part in the study. The participants' responses to the questionnaires are illustrated by means of tables and figures, and qualitative responses are classified according to themes that give an account of participants' experiences with their verbatim responses illustrated by means of tables and charts. The study findings followed three steps, namely: the development of the counselling intervention; implementation of the counselling intervention and the preliminary evaluation or feedback session. All participants both health care workers and PLWH clients, participated in all steps except in the last step where only HCWs in the evaluation of the counselling intervention.

#### **5.2. THE DEVELOPMENT OF THE INTERVENTION**

The development of the intervention entailed a number of steps. It started with problem analysis and a literature review exploring and discussing types and effects of stress-related disorders among PLHIV. Furthermore, the literature review studied some efforts made by HCWs to assist PLHIV experiencing stress-related disorders. The theoretical framework that guided the research in Chapter 3 was also used to structure this intervention. This was followed by data collection stage which involved administering questionnaires to 78 PLHIV participants and focus group interviews with 20 health care workers from the two health facilities namely: the non-governmental organisation, Sophumelela Centre and the governmental facility, Nontyatyambo Clinic to inform the development of the intervention.



Before the focus group interviews were conducted the aims and procedures of the study were thoroughly explained to participants and their cooperation was sought. The participants were given consent forms after the explanation and were asked to give an informed consent for this study. They were made aware of their ethical rights and responsibilities. A separate meeting with PLHIV at Nontyatyambo clinic was conducted where the same procedure was followed for the administration of questionnaires. At Sophumelela centre, health care workers (home-based carers) were the ones to administer questionnaires to PLHIV participants during their home visits and they followed the same research procedure in informing PLHIV participants.

Health care worker participants were trained on how to obtain informed consent, administer questionnaires and to return completed questionnaires to the researcher on the agreed upon dates. Based on the quantitative and qualitative information gathered from biographical questionnaire open –ended questions and other questionnaires administered to PLHIV participants as well as qualitative data from the focus group discussions with HCWs the counselling intervention was developed. The next step conducted was a pilot study where the intervention was piloted among four PLHIV health care workers who work at the researcher’s workplace health care facility with the assistance of the researcher’s two colleagues with psychological background for comments. The intervention was then refined based on the remarks made by participants and professionals and was implemented (as Appendix A.). All this is clearly described in Chapter 4.

### **5.2.1. QUANTITATIVE DATA FINDINGS**

The following tables (5 - 23) and figures (13 - 23) come from the quantitative data collected which is fully explained in Chapter 4 and attached as Appendix: I. The quantitative data for the development of the intervention was distributed to and collected from 78 client participants instead of 100 who attended the first meeting. From this seventy-eight some of the participants dropped out along the way due to a number of challenges facing PLHIV. The attrition was also due to the fact that data collection was not all done on the same day, some client participants could not turn up on all data collection days.

The following were townships covered by the home-based care programme at Sophumelela Centre, namely; Amalinda, Buffalo City, Duncan Village, East London, Mdantsane, Mzamomhle, Nompumelelo, Pefferville, Reeston and Scenery Park where the study was conducted and client participants who were part of the support group as offered by Nontyatyambo Clinic in Mdantsane Township. Fifty-nine (59) of the participants were females (75.6%) and 19, were males (24.0%). Seventy-one (71) were of Xhosa background (91.0%) and seven, 7 (8.9%) were of so called ‘coloured’ background. All participants were above 18 years of age. The sample took a different shape with reduced number of participants as shown by Table 5 and Figure 13.

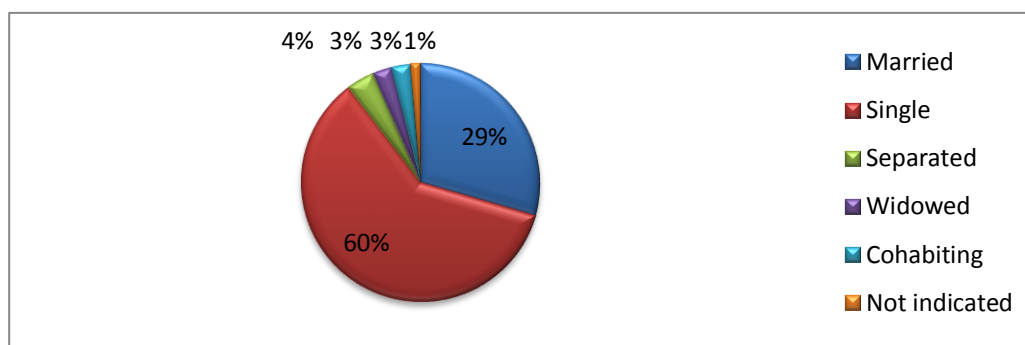
- **Findings from the Biographical questionnaire**

The following Tables (5 -12) and Figures (13 -16) illustrate data from the Biographical questionnaire

**Table 5: PLHIV participants' level of education**

<b>Level of education</b>	<b>Number (n)</b>	<b>Percentage (%)</b>
<b>Primary school</b>	26	33.3
<b>Secondary/high school</b>	41	52.6
<b>College/University</b>	6	7.7
<b>Not indicated</b>	5	6.4
<b>TOTAL</b>	<b>78</b>	<b>100</b>

The majority of 52.6% had high school and only 6.4% had college or university education. With 33.3% of participants obtained primary education, the researcher had to train research assistants on how to administer questionnaires. A flexible arrangement of self-administration for those who can clearly understand English language was made and for those who could not research assistants had to administer questionnaire by going through with them, as explained in Chapter 1.



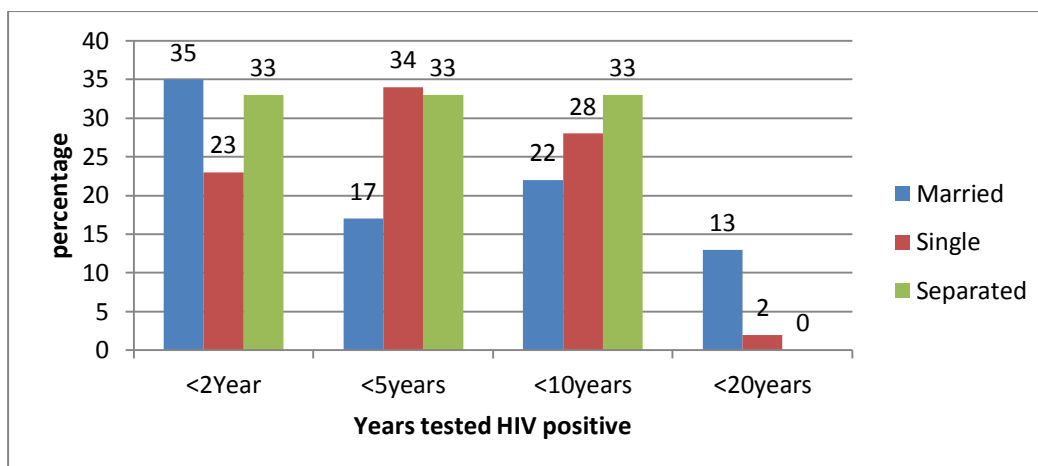
**Figure 13: Participants' marital status**

Forty-seven (47) of the participants were single (60.3%), twenty-three (23) were married (29.5%), while less than 4% were either: separated, widowed or cohabiting, respectively (Fig. 13).

**Table 6: Periods when participants tested HIV positive**

Period tested HIV positive	Number	Percentage
Less than 2 years ago	21	26.8
3 to 5 years ago	23	29.5
6 to 10 years ago	19	24.4
11 to 20 years ago	5	6.4
More than 20 years ago	2	2.6
Not indicated	1	1.3
Not applicable	7	9.0
<b>TOTAL</b>	<b>78</b>	<b>100</b>

The participants were asked when they tested HIV positive and n= 68 (97.1%) of the n= 70 participants who answered the question tested HIV positive less than 20 years ago while only two participants tested HIV positive more than 20 years ago. Table 6, shows the breakdown of the periods in which the participants tested HIV positive.



**Figure 14: Marital Status against years living with HIV**

Figure 14 shows that more married participants (35) have tested HIV positive in the past two years while single participants (34) came to know their HIV status in the past three to five years and thirty-three separated participants have shown consistency in all the years except >20 years. When considering the number of married participants and that of single participants, married participants who contracted HIV in the past two years constitute a higher number than single participants. This may indicate that being married does not always give one the security against contracting HIV but may actually expose the person due to a number of factors including culture and relationships.

**Table 7: Person counselling participants for HIV**

	Number (n)	Percentage (%)
<b>Person helping me (Nurse)</b>	19	24,4
<b>Lay Counsellor</b>	47	60,3
<b>Not indicated</b>	12	15,3
<b>TOTAL</b>	78	100

Lay counsellors are critical in the provision of HIV counselling. Table 7 indicates that 47 (60.3%) participants said they received counselling from a lay counsellor while 19 (24.4%) were counselled by the person testing them, most probably a nurse and 12(15.3%) did not indicate. This generally indicates that lay counsellors are being utilised extensively in the clinics and are the essential component in providing counselling for PLHIV.

**Table 8: Fearful of testing HIV positive**

	<b>Number</b>	<b>Percentage (%)</b>
<b>Yes</b>	43	55,1
<b>No</b>	25	32,0
<b>Not indicated</b>	10	12,9
<b>TOTAL</b>	78	100

Despite being provided with counselling, 43 (55.1%) participants said that they were fearful of testing HIV positive, 25 (32.1%) said they were not, while 10 (12.9%) participants did not respond. Participants who were fearful before testing expressed that they were afraid of dying and those who were scared after testing positive were afraid of getting sick, dying and stigma. Half of the sample (50%) said that they were not sick before testing and 40% said that they were sick. Most of those who were not sick just wanted to know their HIV status out of curiosity because a friend/wife/girlfriend had tested positive and some were pregnant. Those who were sick had suffered a number of illnesses, such as shingles, headaches, loss of weight and appetite, coughing and feeling very weak.

**Table 9: Support group membership**

<b>Support group member</b>	<b>Number</b>	<b>Percentage (%)</b>
<b>Yes</b>	41	52.6
<b>No</b>	23	29.5
<b>Not indicated</b>	14	17.9
<b>TOTAL</b>	78	100

Support groups are an integral part of the well-being of people infected with and affected by HIV. Table 9 shows that more than half of the participants 41(52.6%) were members of a support group offered by a clinic or hospital twenty-three (29.5%) were not members of a support group and 14(17.9%) participants did not indicate. When asked why

they did not participate in the support group, those who were not members, or were members but not active in the support group, recited challenges such as fear of being stigmatised, not being interested, scared of disclosing and that the venue for the meetings was far from where they stayed and they had no money for transport. Those who were participating in the support groups said that their support groups provided them with some form of assistance such as giving them more information about HIV and AIDS, being helped to disclose, were more empowered to deal with the disease, gained confidence, did not fear stigma and were able to support each other.

**Table 10: Period when participants started taking ARVs**

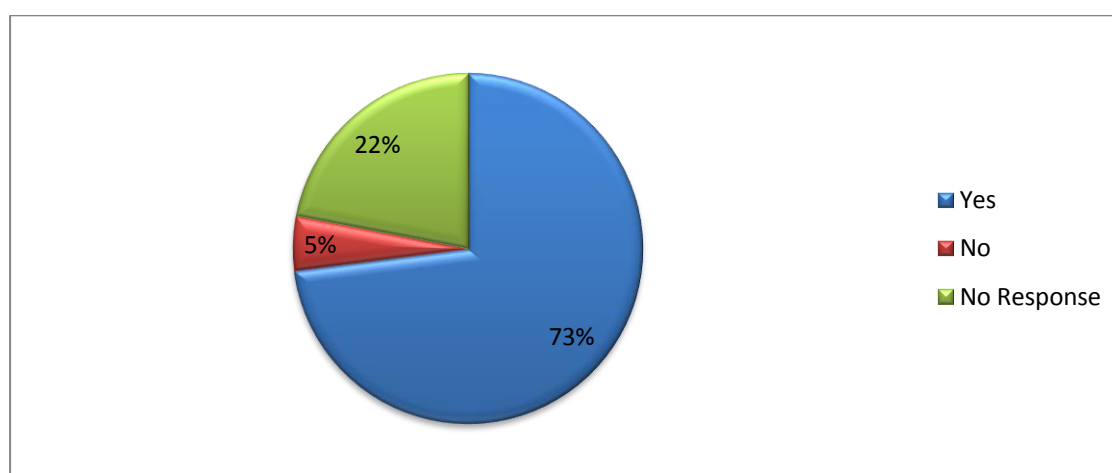
<b>Period on ART</b>	<b>Number</b>	<b>Percentage (%)</b>
<b>Less than a year ago</b>	12	19.4
<b>1 to 2 years ago</b>	11	17.7
<b>3 to 5 years ago</b>	23	37.1
<b>6 to 10 years ago</b>	12	19.4
<b>More than 10 years ago</b>	3	4.8
<b>Not indicated</b>	1	1.6
<b>TOTAL</b>	<b>62</b>	<b>100</b>

When the client participants who are on ART were asked how long have they been on ART. The majority of 62 (88.5%) of the 70 HIV positive participants said that they were currently on ART. Of the 62 participants on ART, 58 (93.5%) had started taking ARVs less than 10 years ago, while only three (4.8%) had been on ART for more than 10 years.

**Table 11: Profile of client participants on ART by gender**

Gender	Number (n)	Percentage %
Male	15	24.2
Female	47	75.8
Total	62	100

When the participants on ARVs were profiled by gender, more females 47 (75.8%) were on ART compared to males 15 (24.2%) as shown in Table 11.



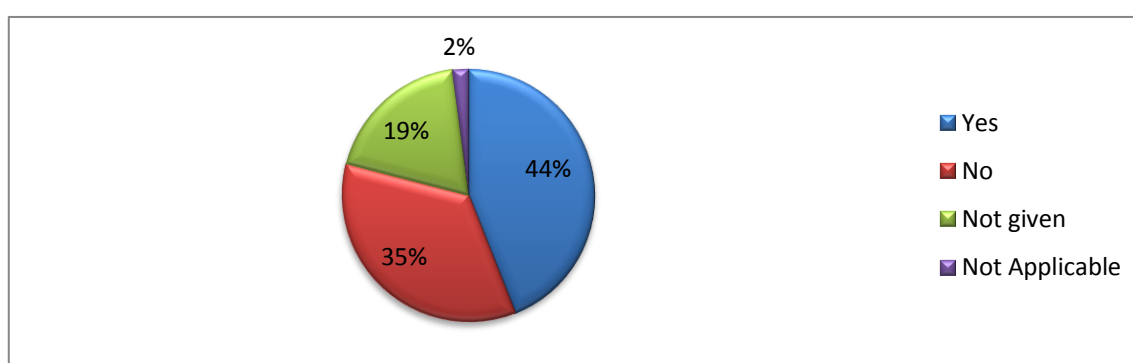
**Figure 15: PLHIV participants who received ART Counselling**

Since intensive and thorough counselling is recommended before one can be put on ART, (73%) of the 61 HIV positive participants who responded to the question on whether they received counselling on ARVs before starting on them said that they did, while (5%) said that they did not receive any counselling. Responding to the qualitative question on whether they were afraid to start ARVs, more than half of the 61 participants said that they were afraid or anxious when they started taking ARVs 34(55.7%) compared to 27 (44.3%) who said that they were not afraid.

**Table 12: Measures that helped participants cope with fear of starting on ARVs**

Helped cope with fear	Number	Percentage
Counselling at clinic or hospital	17	27.6
Family member	13	20.9
Friend	13	20.9
Self-counselling	1	1.6
Not indicated	18	29.0
<b>TOTAL</b>	<b>62</b>	<b>100</b>

HIV Counselling, be it given at health facilities or talking to a family member or a friend, helped the participants to cope with their fear of starting ART as shown in Table 12. Counselling received at the clinic or hospital was regarded as more helpful (27.6%) following the family and friends with both (20.9%).



**Figure 16: Anxiety over taking ARVs**

Figure 16 shows that 44% of participants indicated that they were anxious over starting ARVs. When asked why they feared starting the treatment, they claimed that they had been told that ARVs would make them see things (hallucinate), change their physical make-up. Some said they that were just scared to be dependent on pills for the rest of their lives while those who were sick did not care. They just wanted to be better and were looking forward to starting the treatment.



- **Findings from the Medical Outcomes Survey – HIV (MOS-HIV)**

The following Tables (13 -22 ) and figures 17 and 18 come from the Medical Outcomes Survey-HIV (MOS-HIV) which was fully explained in Chapter 4 and attached as Appendix: K. The client participants who turned up for this questionnaire were only 56 out of the 78 that initially took the first questionnaire. The reasons for the attrition were tabled in the previous chapter which included transport and domestic problems.

**Table 13: PLHIV participants' description of their health status**

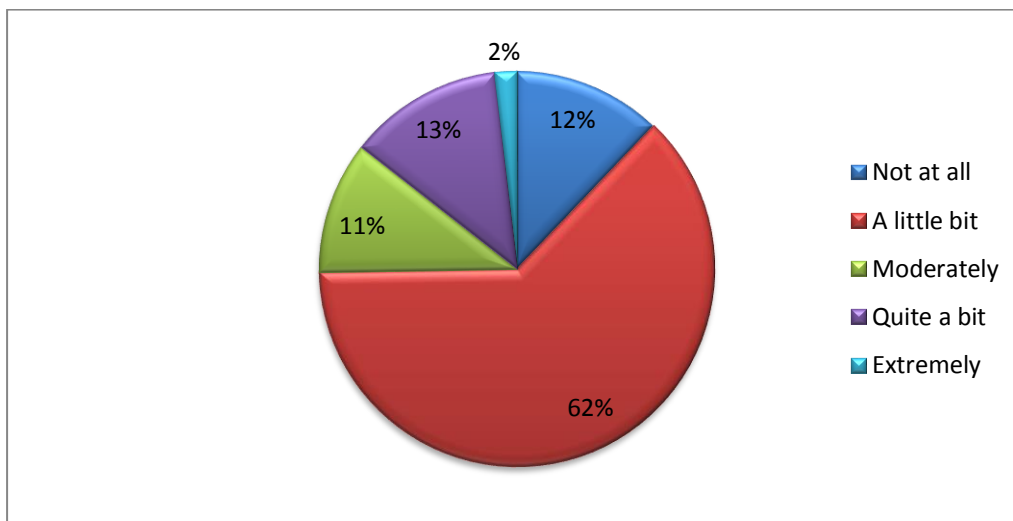
<b>Health status</b>	<b>No. of participants (n)</b>	<b>Percentage (%)</b>
Excellent	6	10.7
Very good	25	44.6
Good	21	37.5
Fair	322	5.4
Poor	1	1.8
<b>TOTAL</b>	<b>56</b>	<b>100</b>

Data was collected from 56 PLWH participants from the two research sites through the MOS-HIV self-administered questionnaire. The participants were asked to describe in general how they experienced their health status, the majority 31 (55.3%) said it was excellent and very good, and 24(42.9%) said it was good and fair, while only 1 (1.8%) said that they had poor health as shown in Table 13.

**Table 14: Severity of bodily pains in the past 4 weeks**

Severity of bodily pain in the past 4 weeks	N	%
None	2	3.6
Very mild	25	44.6
Mild	18	32.2
Moderate	6	10.7
Severe	4	7.1
Very severe	1	1.8
<b>TOTAL</b>	<b>56</b>	<b>100</b>

Very few participants, 5 (8.9%), reported that they had had severe to very severe bodily pain during the previous four weeks as shown in Table 14, while the majority of participants 45 (80.4%) reported very mild, mild to no pain at all. Bodily pain among PLHIV is one of the significant symptoms that make them tired and feel very sick. It is interesting and encouraging to note that this particular group did not experience very severe bodily pain.



**Figure 17: Interference of bodily pain with participants' normal work in the past 4 weeks**

When asked if the pain interfered with their work, 62% reported that bodily pain interfered slightly with their normal work, while only 2% indicated that the pain extremely interfered with their normal work as shown in Figure 17. Sometimes PLHIV ended up being

boarded at work due to low productivity which is cause by being sickly and experiencing pain all the time.

**Table 15: Limitations of participants to do certain activities**

Limited by pain	Vigorous activities N (%)	Moderate activities N (%)	Walking uphill N (%)	Bending or lifting N (%)
Yes, limited a lot	16 (29.1)	19 (34.5)	22 (40.7)	15 (27.8)
Yes, limited a little	30 (54.5)	27 (49.1)	21 (38.9)	23 (42.6)
No, not limited	9 (16.4)	9 (16.4)	11 (20.4)	16 (29.6)
<b>TOTAL</b>	<b>55 (100)</b>	<b>55 (100)</b>	<b>54 (100)</b>	<b>54 (100)</b>

When the participants were further probed on whether the health status limited them in a variety of activities, such as vigorous or moderate activities as well as walking uphill or climbing a flight of stairs, more than 70% of those who responded to the question reported that the pain limited them to some extent as shown in Table 15.

**Table 16: Participants' limitations by pain to do daily activities**

Limited by pain	Walking N (%)	Eating or dressing N (%)
Yes, limited a lot	11 (20.8)	7 (13.0)
Yes, limited a little	21 (39.6)	9 (16.7)
No, not limited	21 (39.6)	38 (70.3)
<b>TOTAL</b>	<b>53 (100)</b>	<b>54 (100)</b>

On the other hand, walking did not seem to be limited much by bodily pain as 21(39.6%) of participants said that they were not limited and the same number indicated they were limited a little, (Table 16). Regarding everyday activities like eating or dressing, a high percentage of the participants 67.9% reported that they were not limited by pain in performing these activities.

**Table 17: Participants' inability to work due to ill-health**

<b>Health keeping them from doing work</b>	<b>Does your health keep you from working N (%)</b>	<b>Have you been unable to do certain kinds of work? N (%)</b>
Yes	16 (28.6)	12 (22.3)
No	40 (71.4)	42 (77.7)
<b>TOTAL</b>	<b>56 (100)</b>	<b>54 (100)</b>

Health did not seem to affect the participants' ability to go to work, do household chores as more than 70% of the participants reported and that their health did not inhibit them. It is clear that participants in this study are not physically affected yet by ill-health.

**Table 18: Participants' general feelings in the past 4 weeks**

<b>How often do you feel?</b>	<b>Limited social activities N (%)</b>	<b>Been very nervous N (%)</b>	<b>Felt calm and peaceful N (%)</b>	<b>Felt downhearted and blue N (%)</b>	<b>Been a happy person N (%)</b>	<b>Felt down in the dumps N (%)</b>
<b>All of the time</b>	4 (7.1)	2 (3.6)	11 (20.4)	1 (1.9)	8 (14.5)	4 (7.1)
<b>Most of the time</b>	10 (17.9)	9 (16.1)	7 (13.0)	9 (17.3)	16 (29.0)	6 (10.7)
<b>A good bit of the time</b>	14 (25.0)	7 (12.5)	11 (20.3)	4 (7.7)	15 (27.3)	6 (10.7)
<b>Some of the time</b>	11 (19.6)	16 (28.6)	16 (29.6)	21 (40.4)	10 (18.2)	12 (21.4)
<b>A little of the time</b>	8 (14.3)	13 (23.2)	4 (7.4)	8 (15.4)	3 (5.5)	10 (17.9)
<b>None of the time</b>	9 (16.1)	9 (16.0)	5 (9.3)	9 (17.3)	3 (5.5)	18 (32.2)
<b>TOTAL</b>	<b>56 (100)</b>	<b>56 (100)</b>	<b>54 (100)</b>	<b>52 (100)</b>	<b>55 (100)</b>	<b>56 (100)</b>

The participants were then asked how much of their feelings in the past 4 weeks had limited their social activities. As indicated in Table 18, that very few participants felt very nervous in general, only 2(3.6%) or downhearted 1(1.9%) all of the time, while 21 (40.4%) felt downhearted some of the time. It looks like when it comes to feelings the majority could become uninterested or limited to be involved in social activities. HIV and AIDS affect a number of people mostly emotionally especially at the beginning of the diagnosis and when the person starts getting sick.

**Table 19: Participants’ feelings about their health in the past four weeks**

<b>How often do you feel?</b>	<b>Felt full of zest N (%)</b>	<b>Felt worn out N (%)</b>	<b>Felt tired N (%)</b>	<b>Had enough energy to do what they wanted N (%)</b>	<b>Felt weighed down by health problems N (%)</b>	<b>Discouraged by health problems N (%)</b>
<b>All of the time</b>	9 (17.6)	7 (13.0)	4 (7.4)	4 (7.4)	2 (3.6)	-
<b>Most of the time</b>	11 (21.6)	12 (22.2)	11 (20.4)	10 (18.5)	9 (16.4)	10 (18.2)
<b>A good bit of the time</b>	5 (9.8)	5 (9.3)	11 (20.4)	16 (29.6)	9 (16.4)	4 (7.3)
<b>Some of the time</b>	15 (29.4)	15 (27.8)	15 (27.8)	11 (20.4)	17 (30.8)	16 (29.1)
<b>A little of the time</b>	4 (7.8)	6 (11.1)	12 (22.2)	13 (24.1)	15 (27.3)	12 (21.8)
<b>None of the time</b>	7 (13.8)	9 (16.6)	1 (1.8)	-	3 (5.5)	13 (23.6)
<b>TOTAL</b>	<b>51 (100)</b>	<b>54 (100)</b>	<b>54 (100)</b>	<b>54 (100)</b>	<b>55 (100)</b>	<b>55 (100)</b>

Furthermore, the participants were asked how often during the previous 4 weeks they had felt; full of zest, or felt worn out, felt tired, had enough energy to do the things they wanted to do, felt weighed down by their health problems, were discouraged by their health problems, felt despair over their health problems, or were afraid because of their health problems.

A comparison between participants who felt a certain negative feelings all of the time or most of the time versus those who felt the same way some of the time, a little of the time or none at all, showed that the higher percentages of the participants were those of people who felt tired, weighed down or discouraged by their health problems some of the time as shown in Table 19.

**Table 20: Times participants felt despair and difficulties in reasoning and keeping attention because of their health**

	<b>Felt despair over their health N (%)</b>	<b>Afraid because of their health N (%)</b>	<b>Difficulty reasoning or solving problems N (%)</b>	<b>Forgot things that happened recently N (%)</b>	<b>Trouble keeping attention on activities N (%)</b>	<b>Difficulty doing activities involving concentration N (%)</b>
<b>All of the time</b>	2 (3.6)	3 (5.5)	2 (3.6)	1 (1.8)	3 (5.5)	4 (7.3)
<b>Most of the time</b>	7 (12.7)	5 (9.1)	4 (7.3)	6 (10.9)	5 (9.1)	6 (10.9)
<b>A good bit of the time</b>	6 (10.9)	5 (9.1)	5 (9.1)	5 (9.1)	2 (3.6)	5 (9.1)
<b>Some of the time</b>	18 (32.7)	12 (21.8)	16 (29.1)	17 (30.9)	14 (25.5)	8 (14.5)
<b>A little of the time</b>	12 (21.8)	16 (29.1)	7 (12.7)	6 (10.9)	10 (18.2)	14 (25.5)
<b>None of the time</b>	10 (18.3)	14 (25.4)	21 (38.2)	20 (36.4)	21 (38.1)	18 (32.7)
<b>TOTAL</b>	<b>55 (100)</b>	<b>55 (100)</b>	<b>55 (100)</b>	<b>55 (100)</b>	<b>55 (100)</b>	<b>55 (100)</b>

Questions were further asked on how often during the past 4 weeks the participants had felt despair over their health, were afraid because of their health problems, had difficulty reasoning and solving problems, forgot things that had happened recently, had trouble keeping attention on any activity for long or had difficulty doing activities involving concentration and thinking. Comparisons on how often the participants had negative feelings about their health showed that very low percentages (less than 15%) of the participants experienced such feelings all of the time, most of the time or a good bit of the time as shown in Table 20.

**Table 21: Ratings of the participants' health status**

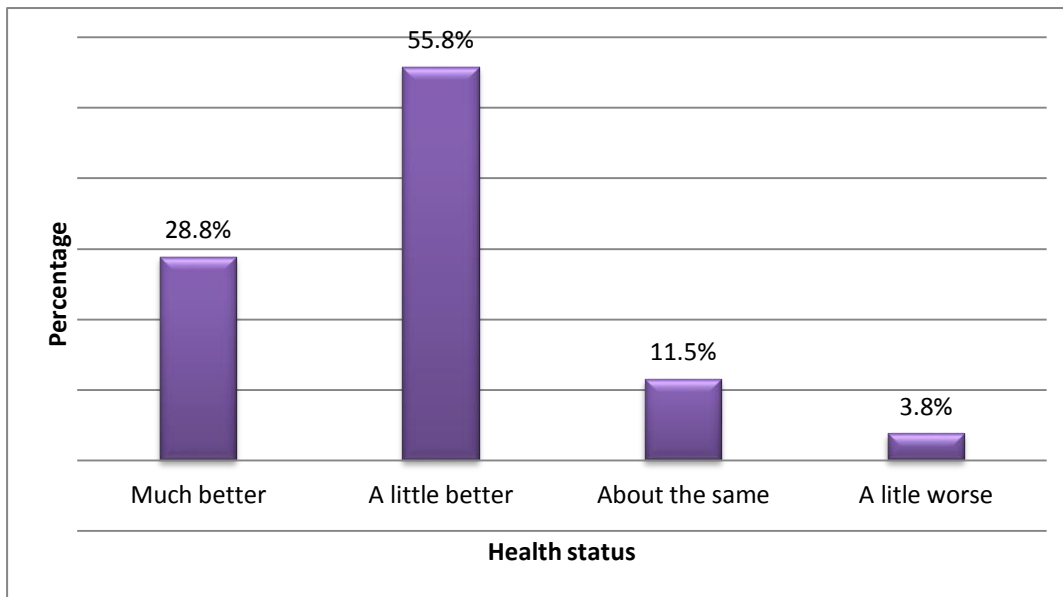
	<b>'I am somewhat ill'</b> N (%)	<b>'I am as healthy as anybody I know'</b> N (%)	<b>'My health is excellent'</b> N (%)	<b>'I have been feeling bad lately'</b> N (%)
<b>Definitely true</b>	11 (20.8)	4 (7.4)	5 (9.4)	4 (7.5)
<b>Mostly true</b>	9 (17.3)	25 (46.3)	20 (37.7)	8 (15.1)
<b>Not sure</b>	14 (26.4)	12 (22.2)	13 (24.5)	22 (41.5)
<b>Mostly false</b>	13 (23.8)	7 (13.0)	9 (17.0)	12 (22.6)
<b>Definitely false</b>	6 (11.7)	6 (11.1)	6 (11.4)	7 (13.3)
<b>TOTAL</b>	<b>53 (100)</b>	<b>54 (100)</b>	<b>53 (100)</b>	<b>53 (100)</b>

In Table 21, participants were then asked to subjectively rate their health status and the highest percentages were observed among the participants who reported as mostly true that they were as healthy as 'Anybody I know' (46.3%) and (47.1%) of participants who reported as mostly and definitely true on their excellent health, whereas only (28.4%) reported their health as not excellent at all.

**Table 22: Quality of participants' life in the past 4 weeks**

<b>Quality of Life</b>	<b>N</b>	<b>%</b>
<b>Very well, could hardly be better</b>	9	17.0
<b>Pretty good</b>	30	56.6
<b>Good and bad parts about equal</b>	11	20.7
<b>Pretty bad</b>	3	5.7
<b>TOTAL</b>	<b>53</b>	<b>100</b>

When the participants were asked about the quality of life in the past 4 weeks, the majority 39(73.6%) of the participants reported that they felt very well or pretty good about their quality of life, while 11 (20.8%) said that it was balanced. It is interesting to note that only 3(5.7%) of participants recorded that they felt pretty bad about their quality as illustrated in Table 22.



**Figure 18: Participants' current physical health and emotional status compared to 4 weeks ago.**

The participants were then asked to compare their current physical and emotional health status with how they had felt four weeks previously. Forty-four (84.6%) of the participants said that they felt better than they had done four weeks previously, fifteen felt much better (28.8%) and 29 (55.8%) a little better (Fig.18).

- **Findings from the Beck Depression Inventory-II (BDI-II)**

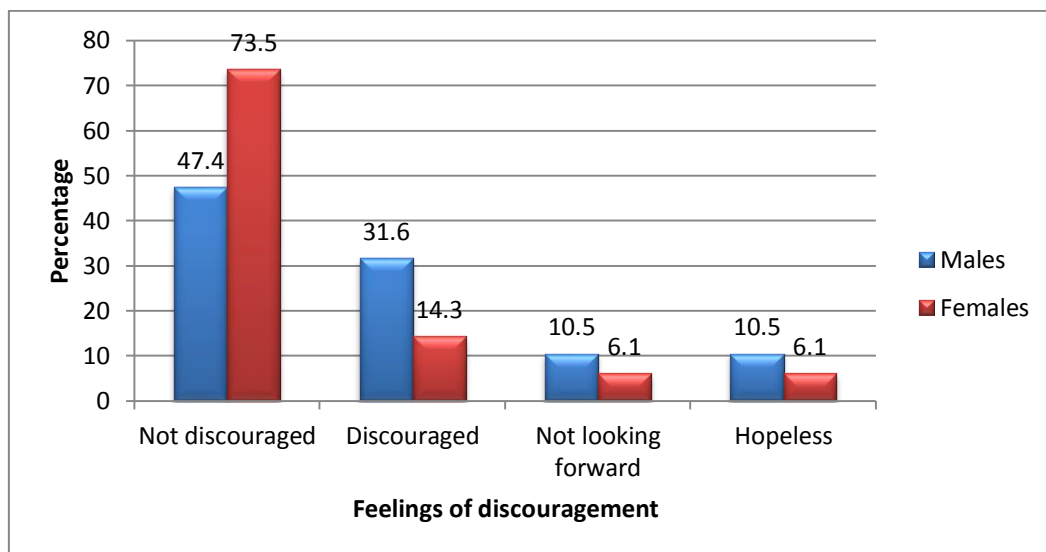
The following Table 23 and Figures (19 – 23) come from the Beck Depression Inventory II (BDI-II) which is fully explained in Chapter 4 and attached as Appendix: J. Out of the 78 client participants 66 responded to this questionnaire.

**Table 23: Levels of depression of the participants (n = 66) as measured by the BDI –II**

Level of depression	Frequency	Percentage %
Normal (0-9)	38	58
Mild depression (10 – 16)	11	16
Borderline depression	3	5
Moderate depression	8	12
Severe depression	6	9
<b>Total</b>	<b>66</b>	<b>100%</b>

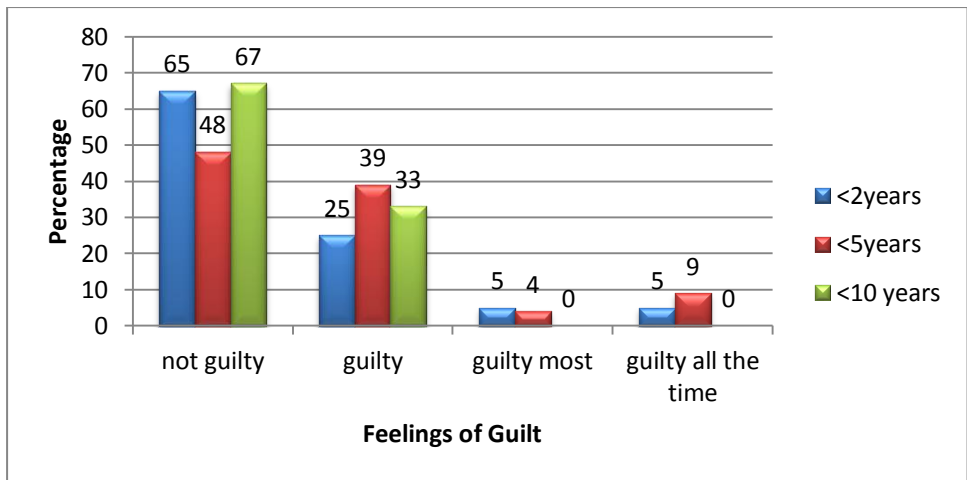


Table 23 indicates the levels of depression reported by the participants. Forty-nine participants (58%) indicated No depression or mild depression and 14 (21%) participants indicated moderate to severe depression. It is noted with interest that only six (9%) recorded with episodes of severe depression. These findings are slightly different from the previously documented studies on HIV and AIDS and depression. The majority of studies have confirmed that most PLHIV are predisposed to depressive disorders.



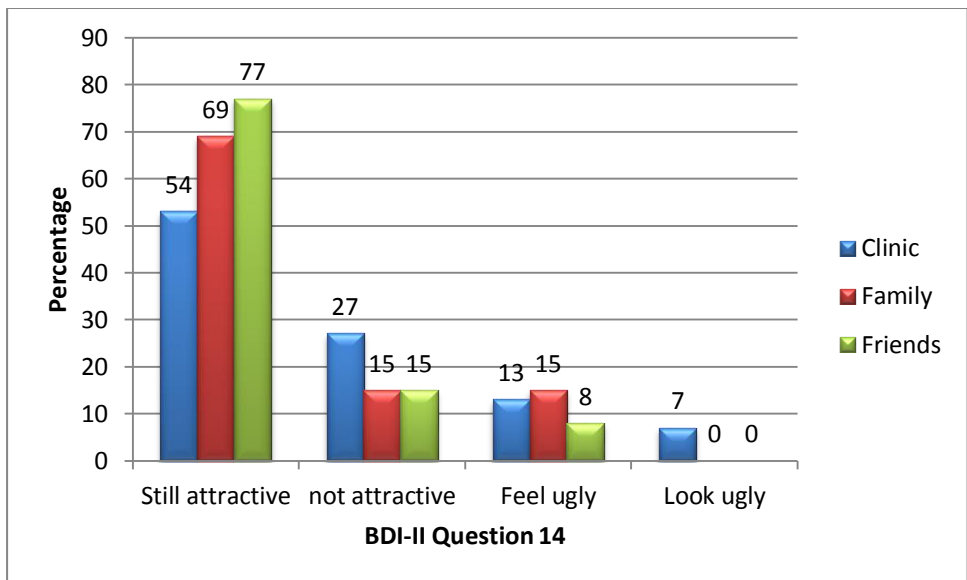
**Figure 19: A comparison of males and females on feelings of discouragement**

Figure 19, shows a majority of 73.5% of females and 47% of males who show no signs of discouragement, whereas 31% of males and 14% of females felt discouraged by their own health status. Although females are considered to be more affected and infected by HIV and AIDS they seemed to be the most resilient population when it comes to health issues and even in enduring pain than males. This has been proven by many studies. This study also shows the resilience of females.



**Figure 20: Comparison of participants' feelings of guilt with years living with HIV**

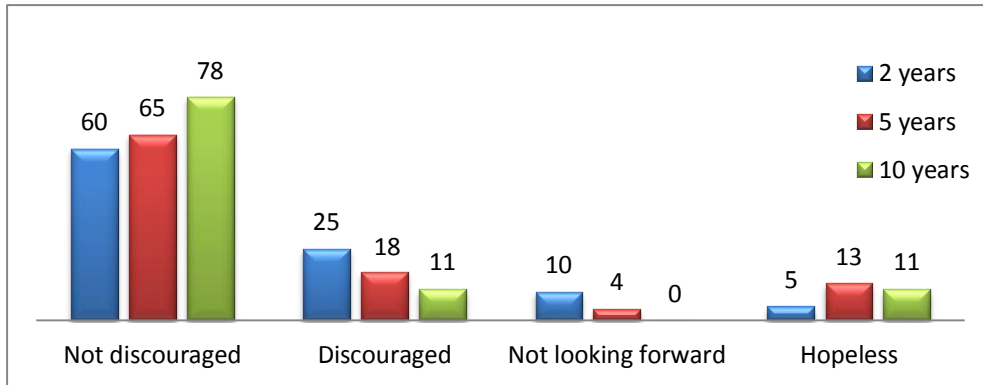
Figure 20, compares responses of those who felt guilty with the length of time they had known their HIV status. The statistics show that regardless of length of time the majority of the participants felt little to no guilt and very few, regardless of length of time felt guilty most or all the time. It is interesting to see 65% of the sample who are less than two years reporting that they feel not guilty about their HIV status.



**Figure 21: Comparison of participants' self-perception with support given**

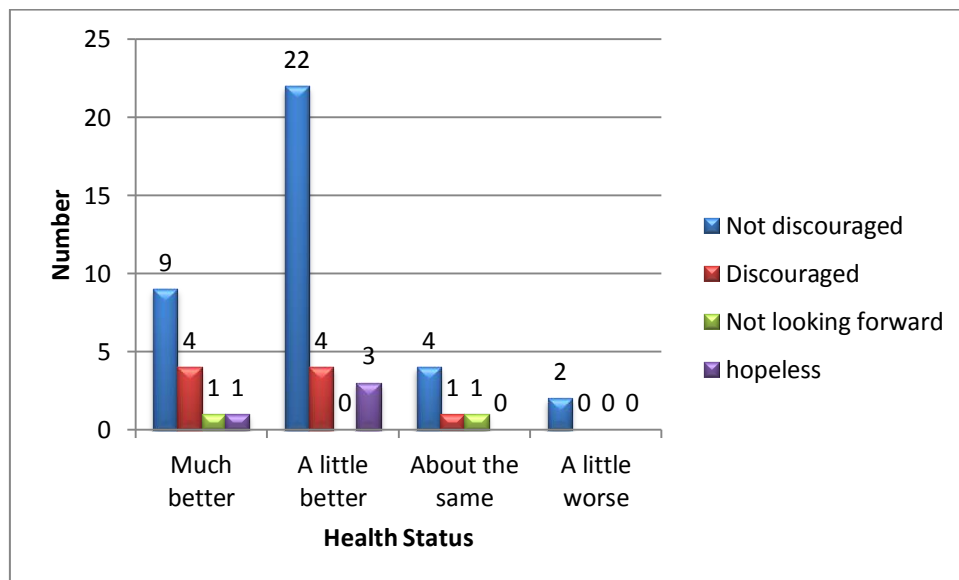
When comparing self-perception of participants with support given by family, friends or at the clinic, the majority of participants felt attractive. However, those with no or very

little support from the clinic, family and friend felt the least attractive. 7% of the sample felt very ugly and unattractive. This perception of self-image impacts on one's health.



**Figure 22: Comparison of participants' feelings of discouragement with years of living with HIV**

Figure 22, indicates that the majority of participants did not feel discouraged regardless of length of time they have lived while HIV with very few participants who felt discouraged regardless of length of time had known their HIV status.



**Figure 23: Participants who rated their health status versus feelings of discouragement**

Figure 23 indicates a comparison of participants' feeling of discouragement with their health status as people living with HIV. Twenty-two participants (75.2%) who were feeling a

little better did not feel discouraged, while none of the respondents felt hopeless even though their health status was a little worse.

### 5.2.1. QUALITATIVE DATA FINDINGS

- **Findings from the First focus group discussions**

The focus group discussions with ten (10) health care workers from Sophumelela was conducted and another focus group discussion took place at Nontatyambo Clinic where a further ten (10 HCW) participated. A biographical summary of the groups appear below in table 24 and 25 respectively.

**Table 24: Biographical information of participants at Sophumelela Centre**

Designation	Frequency	Gender	
		Female	Male
Programme Coordinator	1	Female	None
Spiritual Counsellor/Social worker	1	Female	None
Home-based Carer	8	Female	None
<b>Total</b>	<b>10</b>		

Table 24 shows the number of health care workers at the Sophumelela Centre. All participants were females. Out of 10 participants, eight were home-based carers who visited PLHIV in their homes and 2 participants were health care workers who were administrators and did not directly visit clients in their homes.

**Table: 25 Biographical Information of participants at Nontyatambo Clinic**

Designation	Number	Gender	
		Female	Male
Professional Nurse	8	6	2
Lay Counsellor	2	1	1
<b>Total</b>	<b>10</b>	<b>7</b>	<b>3</b>

As indicated in Table 25, there were eight (8) professional nurses, two (2) of whom were males, and two (2) lay counsellors with one (1) being male, voluntarily participated in the study. In this group there were at least three (3) male participants.

### **5.2.1.1. Findings from the HCW focus group discussions (1<sup>st</sup> FGD)**

#### **a) Services offered**

During this exploration phase of the development of the intervention, the researcher explored how health care workers in both research facilities deal with PLHIV presenting with stress-related psychological conditions. The questions asked during the interview were semi-structured open ended questions. From HCWs responses the researcher listed themes as follows:

- **Availability of HIV Counselling and Testing (HCT)**

Both facilities have the HCT service package. Sophumelela Centre offers HCT to both walk-in and referred clients. There are nurses on site who receive clients and take them through the whole process from HCT to admission at the dignity house/hospice if critically ill. The HCT is a comprehensive check-up which includes, HIV testing, CD4 count and Viral load testing, prophylactic package if tested HIV positive or referred to ARV section for further examination.

The Programme Coordinator said, *“This facility started as an ARV clinic but expanded into including comprehensive HIV Counselling and Testing (HCT) with what we called a “Dignity House” (where sick people were cared for until they could be discharged). We received referrals from hospitals, community workers and most were walk-ins for Voluntary Counselling and Testing (VCT). We offered the following services: HIV counselling and testing, CD4 count test, Viral load test and antiretroviral therapy (ART) and home-based care through weekly visits that are done by the home-based carers here.”*

Nontyamtyambo clinic HIV section receives clients (patients in the case of a clinic and hospital) from other sections in the clinic. These are people who come to the clinic for other illnesses other than HIV, but they get referred to HIV section, for example pregnant women, those who present with STIs, TB and other related illnesses which may be regarded as opportunistic infections.

The professional nurse in HIV section accounted, *“First of all our patients come to the HIV and AIDS section via other illnesses they present with. They do not come straight for HIV testing, either from PMCTC, being sick, presenting with STIs, etc. Such screening is followed by counselling and testing. The nurse explains everything according to the protocol of HIV Testing where pre- and post- testing is offered to the patient. If the patient is found HIV negative ( –) he or she is encouraged to use condoms when having sexual intercourse and asked to come back after three month for another test. This waiting period we call it window period. But, if the patient tests HIV positive (+) he or she is educated on the steps to follow towards treatment.”*

- **Availability of hospice facility**

Sophumelela centre had a hospice facility which was known as the ‘Dignity House’. However, due to financial constraints this facility was closed a few months before the researcher conducted the study. Nontyatyambo clinic as a government clinic did not offer this facility. Very sick clients are referred to the nearest hospitals namely: Frere and Cecilia Makhiwane Hospitals.

- **Availability of home-based care facility**

Sophumelela centre runs a home-based care programme that services four townships in the BCM with eight home-based carers to look after more than 200 clients. This is the flagship programme of Sophumelela centre that has survived even after other programmes were discontinued.

- **Offer of CD4 Count and Viral load tests**

Both facilities were offering the viral load and CD4 count tests for those who test HIV positive. The client had to come every three or six months for check-up and prophylactic treatment depending on the stage at which illness has progressed. As indicated previously Sophumelela centre started as an ARV site but grew up to offer a comprehensive HIV AND AIDS package service.

A nurse from Nontyatyambo clinic accounted, *“We educate the patient on CD4 count test, Viral load test, when to take ARVs, open a file and offer prophylactic treatment (Bactrim and Vitamin B complex).”*

- **Availability of Antiretroviral therapy (ART) programme**

Both facilities were registered as ARV sites. All clients eligible to start ARVs went through extensive counselling sessions together with their family members as a support structure to support the HIV positive member of the family.

- **Screening for Mental health illnesses**

Neither facility had any mental health illness screening structure. Sophumelela centre had not yet strategized around offering psychological services to their clients except appointing a social worker to occasionally offer spiritual counselling. However this service ended up focussing on social issues like social grants advice and application, and other financial matters, rather than psychological/emotional challenges.

*“Even though we have been recently trained on the importance of detecting mental health problems, we have not yet seriously considered employing experts in that area due to financial constraints”. We refer our client participants to the spiritual counsellor when we see that a client participant has defaulted on her/his treatment and when they express emotional distress,”* defended Sophumelela centre programme coordinator.

The counsellor at Sophumelela centre said, *“I would rarely receive people asking for general counselling. People would bring to me social problems, such as fighting at home over family issues, not having money to come to the centre or feeding children, etc. I would then refer these to the social worker at the patient’s ward area to handle.”*

At Nontyatyambo clinic clients with psychological problems are referred to one psychologist who comes in once a week. Though this is not enough, it is better than nothing. Clients who exhibit serious psychological problems are referred to Cecilia Makhiwane psychiatric ward.

*“Here at the clinic we do not screen for stress-related illnesses, but we refer clients to the psychologist who comes in once a week and some cases regarding social problems we send them to the in-house social worker. If the case is serious they refer to Cecelia Makhiwane Psychiatric ward. What we do during post-test counselling, we educate the client participants and encourage them to join the in-house support group. This is what the clinic can offer. We*

have two lay counsellors among us who can talk on what they do,” accounted another professional nurse.

A Lay Counsellor said, *“The present group is enthusiastic about activities. Recently they have participated in the Madiba 67 minutes project. These are things that keep them busy and involved in the activities of the support group. So we don’t only talk but do stuff with them. In a way we assist them to stop stressing out about their illness, because if they have too much time alone, they might get depressed.”*

#### **b) Challenges encountered**

All participants from both facilities mentioned challenges they noticed and sometimes tried to deal with, such as stigma, non-disclosure issues, such as clients being unable to disclose their HIV positive status to their husbands or boyfriends for fear of abuse, rejection and so on.

- **Stigma and Non-disclosure**

*“Disclosure and stigma are still a big problem in our communities. I had a client who died having not disclosed to her family for fear of stigma. The sister who knew about her sister’s status kept quiet because she promised not to tell, so at the funeral the cause of death was TB,”* said one home-based carer.

Health care workers meet problems such as non-disclosure among their clients. One home-based carer explained:

*“As I visit my clients in their homes, I sometimes find them with neighbours and friends, I would note that the client will be uncomfortable to talk in front of the neighbour or friend. This discomfort is caused by fear of stigma and that maybe the client has not totally accepted her condition to be able to talk about it to other people.”*

- **Ignorance about HIV and AIDS**

*“Another case of mine is with a woman who had not disclosed to her husband and fell pregnant. So the husband doesn’t know that his wife is HIV positive. So I also feel there is lack of knowledge, like ignorance about issues of HIV and AIDS. In another case this man*



*did not even want to see condoms in his house. He was just a walking high risk” another home-based carer accounted.*

The programme coordinator at Sophumelela centre interjected at this point registering the fact that men are needed in programmes like these to attract other men so that they can be helped too.

*“I think we need more men participating in our programmes in order to convince men to change behaviour, otherwise we are not progressing at all. I sometimes get frustrated when I hear such ignorance which leads to people getting sick and dying unnecessarily. I sometimes notice that women tolerate some of the treatment they receive from men because they are economically dependent,” a programme coordinator interjected.*

- **Stress caused by fear to disclose**

Another Lay Counsellor said, *“One guy, a client of mine expressed feelings of distress and I think he was depressed with this situation. He told me that he would like to get married. He is now 40 years old, but this problem with HIV is really depressing him because when he thinks of approaching a lady he likes, even in church, he is afraid that when he tells her about his HIV status, she will run away. He has a problem disclosing his status even to his mother. He says his mother is not discreet. She will shout at him in the street about his HIV status.”*

Sometimes health care workers had to deal with their clients’ denial, where a client could not accept that she/he now lives with HIV. This most of the time hampers all efforts to help them, one home-based carer explained.

- **Denial**

*“I have noted that some of my clients are in denial. For example, one male client of mine is a church person. He told me that God has healed him, he does not need visits anymore. I had to explain to him that, it is well and good that he has a relationship with God to make him spiritually strong but the virus is still in his blood and there is no cure for it yet. I felt that even some churches are misleading our people and we have a big challenge in this field to educate our people about consequences of not adhering to ART.”*

At Nontyatyambo clinic nurses have to deal with emotional cases as the first line of service delivery. Sometimes these cases are as serious as attempted suicide. They can also be the target of assault by patients who are shocked by receiving HIV positive diagnosis.

- **Inability to deal with HIV positive diagnosis**

*“As nurses we deal with physical illnesses, but from time to time we will encounter an odd case. Even though we will eventually refer the patient to the psychologist, the reality is that the psychologist is not in-house so we have to deal with the case in the way we know how. For example I was involved in a case of suicide attempt. A 24 year old HIV positive woman with a baby who overdosed her ARVs, told me that she is tired of living, she just wants to die. I was so shocked and did not know what to do. I learnt that trauma unit is aware about this case and they said she was doing it for the fourth time, and I rest my case,”* one professional nurse narrated.

*“I remember this case now, where a man came in the clinic with his wife drunk and the nurse took them through for HIV counselling and testing not aware that the man was drunk. After he sobered down the following day, the wife told him that he tested positive for HIV. He came in the clinic with a big knife wanting answers from the nurse who tested him. I would like to caution nurses that we do not test drunken persons, otherwise we will be in trouble.”* another professional nurse narrated the story.

- c) **Skills available to deal with encountered challenges**

Participants from Sophumelela centre expressed their lack of basic counselling skills. They felt that they were unable to help their clients to the fullest since they were not trained on basic counselling skills. They received home-based care training and felt it was not enough because they encounter deep emotional issues in the field they are not trained to handle such cases of rape by family members, child physical and sexual abuse and so on.

- **Not equipped to assist clients with emotional problems**

One home-based carer explained, *“We are not skilled to handle these issues at all. Sometimes we even find ourselves sick with terrible headaches and pains caused by these stressful situations we encounter. I myself had to deal with midnight calls where my client had a quarrel with her boyfriend. She had just found out that this boyfriend is sexually abusing her*

*child and now is beating her for confronting him. I could not sleep after that and I felt like I am unable to assist her in this matter, even though I made means for her to go and see someone at Masimanyane women's centre (a that centre dealing with women and children abuse in East London) for help."*

*Another home-based carer interjected, "It would be really beneficial for us and our clients if we could be trained on counselling. Sometimes we get stuck and do not know how to answer or respond in certain situations. We sometimes in these cases where we see real poverty give from our pockets. You can imagine now with our wages because we do not get much either. We only receive stipend here, but what can we do? Because, jobs are scarce in our country, really it's difficult."*

*A Programme coordinator explained, "It is true that we are failing to assist our carers because they are dealing with a lot out there. We do see the need for them to be trained and even to get debriefing. Some of our carers are also living openly with HIV. It must also be very painful for them to see people dying from what they are living with. Obviously one would ask herself of what will happen to me at that stage. But now our hands are tied to even suggest that because of funding organisations that are pulling out supporting South Africa in some programmes. We are now going to be integrated to the government stream in various governmental clinics. However carers will still continue their home-based care for the coming couple of years."*

At Nontyantyambo clinic, participants had all gone through a ten days basic counselling skills training. They are better equipped to handle emotional cases because additionally to the basic counselling training they are professional nurses, of which some have done psychiatric nursing modules. One professional nurse confirmed as follows:

- **Need training to manage stress in the workplace**

*"Most of us attended that 10-days basic counselling skills course. We only apply that knowledge. We have never gone to courses like a stress management course you are talking about, and we ourselves experience a lot of stress here, at work. On top of that it's our patients' problems which we sometimes are unable to comprehend let alone help them, then we end up referring even things we could have handled. The department used to offer us such*

*opportunities for staff development programme, ha! ha! But now nothing my dear! Uyazibonela ngoku (you see for yourself now).”*

From this statement and the cry of home-based carers previously, it became clear that participants are in need of stress management training or at least debriefing sessions, which are not available in their place of work.

### **5.2.1.2. Pilot Study**

On completion of the draft intervention, the researcher requested her two colleagues, a psychologist and a social worker all of whom are lecturers and trainers, to comment and make suggestions on the intervention before piloting it with the staff working in the researcher's university department. After the incorporation of colleagues' suggestions a pilot study was conducted. Four people living with HIV in the researcher's place of work were approached to participate in the session. Areas of concern on the intervention were addressed. These included concern on the number of CBT homework assignments given which were subsequently cut out from four to two assignments, number of counselling sessions were cut down from six to three, reason being long intervals from one session to another and the other suggestion was to open space of six weeks for HCWs to conduct these sessions. This was done to accommodate HCW participants to work on this exercise during their normal working hours. The intervention was then refined incorporating colleagues' suggestions and changes made as a result of the content validation. Considering the themes identified during the focus groups with health care worker participants and information gathered from PLHIV through questionnaires, the intervention was then designed to incorporate a stress management strategy to help PLHIV cope with stressors in their lives including psycho-social problems. The intervention is attached as (Appendix A)

Based on the qualitative information collected during focus groups from health care worker participants and quantitative information collected from PLHIV participants and presented in this chapter, and with the incorporation of a literature review from Chapter 2 and the chosen theoretical framework in Chapter 3, the intervention was developed.

## **5.3. THE IMPLEMENTATION OF THE COUNSELLING INTERVENTION**

The implementation of the counselling intervention fulfilled two objectives, namely: 1) the training of health care workers participating in this study and 2) the implementation of the intervention with PLHIV participants by health care worker participants from the two research sites; Sophumelela Centre and Nontyatyambo Clinic.

Two training sessions for the eighteen health care workers from both health facilities (purposively sampled as indicated in Chapter 4) on the counselling intervention (Appendix 1) were conducted. The first training session was conducted at Sophumelela Centre where eight home-based health care worker participants were trained over three days spread over three

weeks, thus, training took place once a week. Likewise, ten Nontyatyambo clinic health care workers were also trained on the counselling intervention. The training sessions took place on three consecutive days over a weekend.

The counselling intervention training of health care workers entailed three sections namely; stress management, stress releasing exercises, cognitive behavioural therapy and participants' views on alternative medicine especially focused on the intervention by African traditional healers. After the training, health care worker participants were requested to select two of their clients in the workplace using the purposive sampling method as indicated in Chapter 4. Likewise PLHIV participants were made aware of their ethical rights and informed consent was obtained.

Thirteen health care worker participants implemented the intervention with eighteen PLHIV participants of the two health facilities over a period of three months. They all had three sessions to cover the process of the intervention implementation (as illustrated in chapter 4, Figure 11). All health care worker participants completed their sessions intermittently. The researcher had one-hour, monthly process evaluation sessions with health care worker participants to check for any challenges that might hinder the process.

### **5.3.1. Process of outcomes of the implementation of the intervention**

Both Sophumelela centre and Nontyatyambo clinic HCW participants implemented the intervention following the same arrangement of three sessions of the implementation of the intervention. Out of eighteen, only thirteen HCWs were able to participate in this phase. All Sophumelela centre HCW participated, the challenge was with five of Nontyatyambo clinic HCW who were unable to get reliable clients for this exercise. Data was collected using an unstructured interview with HCW participants. The audiotape recorder was used and the researcher analysed the transcription verbatim.

#### **Session 1: Application of CBT psycho-education on stress and TRE**

During this session both HCW participants and the client participants exchanged greetings and the HCW explained clearly what the session would entail. Since they knew each other there was no need to make formal introductions. This session encompassed doing some activity on stress first, like filling-in the stress quiz, (attached as Appendix N). Time taken to complete the quiz and reflect on it was twenty minutes. After the quiz, the HCW

participants went through the brief lecture on what stress managements entails, this leads to dealing with stress physically by introducing stress releasing exercise and handing out homework assignment.

This activity involved asking the clients about what stressed them the most and how they usually dealt with such stress. The following quotes testify to the activity given by HCW participants.

*“I engaged my clients in an activity where they had to identify their own stressors, causes and the effects of these stressors on their bodies.”*

*“I explained that we are going to do an activity which involves telling us about your present stressor, its cause and the effect of it in your body. I gave them stress cards you gave us.”*

*“One of my clients struggled to do this exercise. His situation of not been able to find a job was depressing him. But I explained to him that in as much as this exercise might not help to find a job but he will be able to cope in a manner that will not be detrimental to his health.”*

*“We mostly used their examples as they chose to tell their own stories and we identified the effects of such stressors from their stories.”*

After giving information on stress, its causes and effects, an introduction of a new technique called Trauma/Stress releasing exercise (TRE) was made. HCW participants had to explain what TRE is all about, how it came about and how it helps people with a number of illnesses including stress, relieving symptoms of depression, different types of traumas, even being able to regulate certain chronic illnesses. This includes demonstrating a set of exercises. The time spent on demonstrating exercises takes about 15 minutes and engaging participants is 30 minutes. All participants explained this process as follows:

*“After demonstrating how to do the exercises, everyone had to do these exercises and this took approx. 45 min. I also explained that from today for three weeks one is required to practise at home every day and share the experience when we meet again.”*

TRE exercises are attached together with the intervention as Appendix A. At the end of this session HCW participants were asked to give their client participants homework assignments

## **Session 2: Reflection on homework and application of CBT cognitive restructuring continuing with TRE**

Participants were to begin this session with greetings and reflection on the homework assignment that was given at the last session. After this they were to introduce cognitive behavioural therapy as one of many kinds of treatments for stress-related psychological conditions. The sequence of these sessions followed exactly their training and how counselling sessions are usually conducted. However, these had an exception because an infusion of techniques can be noted where exercises were not only relaxation exercises but are multipurpose exercises, both relaxing and healing the physical and spiritual dimensions of the body.

They accounted for the session as follows:

*“After exchange of greetings I did a recap on what we did in the last session and some reflections on the TRE home practice. I was now ready to introduce CBT by asking them more about stressful issues in their lives here and now. These are stressful issues they will deal with during this and the last session intensively. I took the role of an educator illustrating my lesson using (worksheets). Time taken was 60 minutes. When we were all finished we did TRE (30mins), and I gave them CBT homework.”* explained one participant.

*“We recapped and shared some reflections on the TRE. The CBT was a big challenge for me to introduce, I had to seek the researcher’s assistance to tackle the subject. However letting them use their stress experiences from the previous session helped me a lot and referring to my own stress experience hand-out I did during training refreshed me, and we gave them CBT homework,”* explained another participant.

*“My clients shared similar positive reactions to TRE as they continued doing TRE together. CBT was a little challenging for clients to understand as it dealt a lot about feelings, which thing they do not express much,”* said one participant.

*“Feedback on TRE was not so good because of space. My clients live in very small shacks so space is a big issue. So they did not have much to say about TRE. CBT was introduced very well and I was also confident about it from my training”. After the lesson on CBT we tried to*



*do TRE again together for 30 minutes, and I gave them CBT homework assignment,”* another participant explained.

*“I wasn’t sure whether I followed the instructions on CBT well, but with TRE my clients seemed to have enjoyed moving their muscles a bit. They say even though they are encouraged to exercise but they never do it. Now they can see the benefit of it. They thought exercising is for getting slimmer and they definitely did not want to be thin. But now they can see the benefit emotionally, we then gave them CBT homework.”* explained one participant.

### **Session 3: Continuing with CBT and introduction of traditional healing perspective as well as reflection on all approaches.**

This was the last session for all participants, where all aspects of the previous sessions were summarised and evaluated with some reflections on the way forward. Even though CBT proved to be challenging for both HCW and their client participants but it helped to assist them to be aware of negative cognitions they hold, and to be able to challenge such thoughts. An open discussion on traditional healing aspects was conducted by HCW participants. They reported that in their sessions this part of the session became a heated topic among all participants.

One HCW participant narrated, *“My clients reported that TRE had helped them relax and one said her children were mimicking her thinking she was just doing ordinary exercises. With CBT, client had to deal with an issue of uncertainty about future. The client was also worried about the issue of children if anything happens to her.”*

Most client participants commented about their TRE experience. Those who were able to do the exercises seemed to have enjoyed the relaxation effect of the exercises, some confessing having been able to sleep after many years of insomnia. Some have even stated that tremors can induce deep seated emotional pains, such as the rape experience.

*“My client cried during TRE when during trembling, I asked her about it, she said there is something when she tremors that comes between her breasts and try to squeeze her and this is emotionally painful. When I asked her further I found out that she was once raped as a teenager which is how she got HIV. The emotions she was releasing were those emotions of her ordeal of rape,”* narrated one HCW participants.

TRE has shown that it can start process of healing or make one aware of such injuries as fractured limbs or any other injury on one's body.

*"We reflected on the second session and homework assignments. Clients reported that they experienced tremors only on the lower body and one client reported that on her right leg tremors were very strong. When asked if she remembered any incident on that leg she said she fell on that leg 15 years ago,"* one HCW participant explained.

In some cases HCW participants were able to report on client participants who expressed fear of their situation, thus, living with HIV. Since they see people living with HIV fall sick and some die they fear for themselves and for their children.

One HCW participants explained, *"My clients enjoyed this session because it gave them time to release some emotional burdens they carry in this struggle of living with HIV. Their issues ranged from fear of their HIV+ status getting known by certain people in the community, fear of falling sick to fear of dying while their children are still young."*

One HCW participant reported that her client participants that experienced difficulty engaging with the TRE due to lack of space to practise in their small shacks. However, there are TRE exercises that can be done without requiring much space because they can be done while standing or lying down on the bed or on the floor space of sleep.

Another HCW participant reported, *"With my clients TRE in their shacks was a big challenge and they are not doing TRE. CBT homework assignments were done and discussed. The big issue here was of course place to live and unemployment."*

*"Uncertainty was a big issue with my clients. However, we managed to work through all the presented issues through CBT activities especially the cognitive restructuring,"* one HCW participant reported.

HCW participants were asked to incorporate in their sessions a question that would steer a conversation about traditional healing as an important component of the study. They were requested to ask client participants to express how they felt about mixing traditional medicine with ARVs and whether they themselves had consulted traditional healers. The following quotes are responding to the traditional healing discussions:

*“I introduced another topic for discussion, Traditional or alternative ways of dealing with HIV, stress and even mental health illnesses. My clients did not deny that they would sometimes seek the direction of the traditional healer in their village,”* one HCW participant noted.

Another HCW participant explained, *“My clients agreed that they do perform such rituals like ‘imbeleko’ (introducing the child to the ancestors), traditional male circumcision and ceremonies to acknowledge and thank their ancestors. When there is a condition that western medicine is not tackling well they seek spiritual guidance from their ancestors through consulting a traditional healer.”*

*“My clients did not come out clear about this issue. They said some of their family members believe in traditional healers but themselves they have not solicited any help from them,”* said one HCW participant.

*“My clients also have not denied having consulted traditional healers. One client admitted that at first when she got sick she went to ‘isangoma’ but luckily this was a modern one, the one who referred her to the clinic when she noted that she needed medical attention. So she referred her and advised her to take HIV test and then come back if she still felt it necessary,”* accounted another HCW participant.

*“My clients were excited to discuss this topic because they felt like some of the traditional healers are abusing people and destroying the integrity of traditional healing. They explained the categories of traditional healers. I asked them if there is someone among them who is a traditional healer and it happened that they both have ‘sangomas’ in their families and one of them is supposed to go for training but was still collecting some money to go for training,”* explained one HCW participant.

- **Nontyatyambo Clinic comments on all sessions**

From ten HCW participants at Nontyatyambo Clinic only three nurses and two lay counsellors participated in the implementation phase of the study. They were requested to select two clients each following purposive sampling as indicated in Chapter 4. They requested them to sign informed consent forms first after explaining the process of implementation. They were able to have ten (10) PLHIV clients/client participants to

participate in this phase. They agreed to meet once a week at the clinic's support group venue, but only five (5) completed the three sessions.

Findings on the implementation phase of the intervention were similar to those of Sophumelela centre except in few areas as the settings were not the same. HCW participants also went through three sessions with their client participants following the same pattern as indicated above. In terms of areas where they differed will be illustrated in the following quotes:

*“All clients responded well to TRE, except that they complained about not having enough time so as to get used to it and reflected both in a group and individually with the counsellor (HCW participant). However, we promised to continue with them during our support group meetings and teach others to join the exercises. Some reported getting dizzy after shaking and were advised to stay longer on the floor until they feel fine. Most of them said they felt relaxed and slept well. The one who had headaches does not close her mouth on how TRE has helped stop headaches. After doing these exercises for three weeks one client claimed to have released a lot of toxins or poison in her body. We asked how does she know it was toxins. She said every time after trembling she would throw up a bitter taste liquid. Even though she had eaten before but the body would not release the food but this liquid would come out.”*

CBT seemed to be challenging for both HCW and client participants. Some HCW participants encountered difficulty explaining the concept and they requested for clarity from the researcher prior meeting with their client participants. This helped them articulate the strategy to introduce the session on CBT. Some client participants as reported by HCW participants had difficulty going deeper into their feelings regarding anger over their HIV status and relationship with their partners and family.

*“With CBT clients noted how they talk themselves to failure. They also noted that they sometimes use anger to express these feelings of failure. The couple was able to connect after talking about how they treat each other. Getting insight on why they react the way they were reacting to each other assisted them to connect in a positive and encouraging way. Lay counsellors will be able to continue with this intervention in the support group as a way of alleviating stress among its members,”* reported one HCW participant.

*“Even though they were excited about exercises, they were struggling to look inward during CBT session. One client said “This is challenging because I have never had anybody asking me about how I feel. I am the one always focussing and making sure everyone is happy. Now that I have to focus on me I do not feel comfortable at all”. “As a counsellor I thought this is the case to explore even beyond this study”* said another HCW participant.

The general comment on traditional healing was of the opinion that it is widely used by Africans in South Africa for different reasons. Some consult only when the western medicine has failed, some consult to connect with their ancestors, some consult to request protection and seek direction on family issues.

*“It looks like traditional healing is still held in high esteem by some clients. They believe that tradition has its place in their lives and seeking ancestral guidance and protection is very important. They still perform such traditional rituals as required by their own family tradition. Even though some consulted traditional healers before they got to know about their HIV+ status, they do follow up on western medicine to heal them physically. Some would seek help from traditional healers when western medicine has failed to yield relief. They will go to ‘isangoma’ so as to communicate with the ancestors and seek direction on the condition presented at that moment,”* commented one HCW participant.

### **5.3.2. Summary of the benefits of the three sessions**

All HCW participants were asked to summarise how their client participants benefited from the three sessions and in their own words they said the following:

*“My clients reported feeling alert and very light. One client said, “It feels like a heavy load has been lifted off my back.”*

*“They said that learning about how stress affects their bodies and eventually causing many illnesses have been an eye-opener to them,”* noted one HCW participant.

*“I did not know that the chest pain I have been complaining about for years might be caused by stress,”* confessed one client participant confess.

*“Living with this disease of HIV is not easy because you always attribute each and every pain to it, only to find that this could be avoided just by releasing stress”*

*“One client claimed. “kaloku thina maXhosa yonke into eyi ntlungu emzimbeni siyifunela iyeza side siye nasemagqirheni xa ingeva yeza, asiyazi uba kukho iintlungu ezingasuswa nje kuku jima qha” (All we know as Xhosas about pain is that pain needs medicine we even seek traditional healers if it persists, I was not aware that some pains can be eliminated just by doing exercises) said one client.”*

All clients agreed that TRE made them relax especially the first day they did it.

*“I have not been sleeping well ever since I started taking ARVs and my children are still small (young) so they also bother me a lot, but the way I slept that night it was like I had taken strong sleeping pills, this is just amazing, said one client very excited.”*

*“My client who cried during trembling reported feeling light shoulders now and more relaxed. She said she even finds it easier to speak about rape.”*

*“One client said “I also think I will use the CBT worksheet on organising my week because I have a tendency to forget and I procrastinate a lot.”*

*“Another client told us her story about how she has been looking at herself in a negative way. “Ever since I was diagnosed HIV positive, I lost self-confidence and I have not been able to see me as a person who can be attractive to men because I feel ashamed that I have this disease. It’s like everybody looks at me like I’m dirty and it stresses me a lot. I sometimes feel safe when I’m alone”. She said that being able to talk freely about how she feels has given her a new look in life and she will continue with positive self-talk.”*

*“It looks like traditional healing is still held in high esteem by some clients. They believe that tradition has its place in their lives and seeking ancestral guidance and protection is very important. They still perform such traditional rituals as required by their own family tradition. Even though some consulted traditional healers before they got to know about their HIV+ status, they do follow up on western medicine to heal them physically. Some would seek help from traditional healers when western medicine has failed to yield relief. They will go to ‘isangoma’ so as to communicate with the ancestors and seek direction on the condition presented at that moment,” said one HCW participant.*

*“I had two cases that made me think deeply about my capability to help people. Even though I am a nurse I have not explored my client participants’ feelings and thoughts before. I have been a more physical person focusing on the illness. Now I was challenged to get to know my patient deeply. I must say it is difficult but not impossible.”*

Looking at their comments on benefits of the sessions, engaging clients introducing stress management education would go a long way in preventing unnecessary stress-related illnesses experienced by PLHIV. Some aspects in their stress are due to negative thoughts caused by influences of the environment they live in and stigma they carry around. They also seemed to have enjoyed the practical part of releasing stress (TRE™) more than talking about stress. Regarding the traditional healing versus western medicine, this particular group seemed to have received more information on the two treatment modalities. This could be due to the Hawthorne effect as they are already people on the programme of these two health facilities. Knowledge about the effects of mixing traditional and ARVs has been stressed to them.

### **5.3.3. Summary of challenges of the three sessions**

*“My two clients were not cooperative at first when presented with the study. They expressed being used as guinea pigs because they live with this disease (HIV and AIDS) Hey! It was all political talk I know nothing about. I had to stop their raving, which I believe stems from not being able to get jobs”. “But we also told them that we are also living with the virus and we believe that research will come with the cure one day. They eventually warmed up because they trust us, otherwise I could see that they are ready to fight whoever because they seem frustrated over the scarcity of jobs,” explained HCW.*

HCW participant also mentioned a challenge of space especially for demonstrating and practising TRE. *“Even though TRE did not require much space but in the shacks with one room where everything is done in one place it becomes a big challenge to move around, let alone doing physical exercise.”*

According to one HCW, one of her clients did not follow-through with CBT homework assignments even though there was a whole week in between their meetings. When asked why, she listed reasons involving tiresome unending fights with her boyfriend and ended up forgetting.

One HCW participant mentioned spending more time listening to the clients' socio-economic problems than exploring emotional and psychological problems. *“So as a person helping I had to deduce how she feels from what she is telling me because she is unable to pin down the exact feeling about her situation. The most painful thing about us visiting clients in their homes, we get to see the struggles they go through especially poverty and end up giving them money from our own pockets and this sometimes is our last money for transport we have”*. One HCW participant interjected, *“Sometimes in these cases I see that my situation is better even though I struggle financially too.”*

On the question of traditional healers another HCW participant said, *“Some believed that like in churches you get fake pastors/ ministers so as in traditional healing there are fake traditional healers who claim to cure HIV and AIDS. So, some of us will fall prey of the fake ones because of ignorance and desperation.”*

Nontyatyambo clinic HCW participants reported a number of challenges with the support group. Since the research was conducted among those who attended support group meetings, it proved challenging to receive a different reception from the usual. Reasons for not honouring these appointments were the same as the reasons lay counsellors receive during their normal support group meetings.

*“Low turn-up was our biggest issue in this facility. Different reasons for no show varied from no taxi-fare to domestic challenges,”* explained one HCW participant (Counsellor).

*“Some of our clients will only show up for support group when they know that there will be tangible benefits like money or food, They need to be motivated to do things themselves. That is why we have started some gardening here at the clinic and few projects that will help them feel motivated,”* added another Counsellor.

The challenges stated were more on structural arrangement than with internal locus of control. With those staying in formal settlement the problem was with space and poverty. Another big challenge was low-turn-up for support group sessions. Some expressed that when support group is not creative enough to produce incentives for them they see no use of attending.



#### **5.3.4. Summary of identified themes from both first focus group discussions and during the implementation of the counselling intervention.**

##### **Introduction:**

The following are identified themes cutting across the first focus group interviews of both research facilities and the process outcomes of the implementation of the intervention.

##### **Theme 1: Counselling services and screening tools available for clients.**

Both research facilities; Sophumelela Centre and Nontyatyambo Clinic, in this study reported that there were no screening tools available for identifying stress-related problems as experienced by PLHIV and very limited psychological services. Sophumelela Centre had the spiritual counsellor to cater for PLHIV in need of this service. The majority of PLHIVs present more consistently with social problems rather than emotional and psychological problems. This does not imply that the stress-related psychological problems are not present, rather that the social problems are more easily identified and provision is more readily made for social workers to be part of the team than for psychologists. The social challenges clients encountered were best handled by social workers on referral. At Nontyatyambo Clinic there was one psychologist who visited only once a week and one social worker on site. However, cases that were often referred to the psychologist were extreme cases of suicide and clear psychotic cases rather than daily stress-related problems.

##### **Theme 2: HIV-related Stigma**

HIV perceived stigma was identified by all health care worker participants during their first focus group interview as the main deterrent for PLHIV to come forward with problems related to HIV and AIDS. They listed a number of examples in their own work settings where they used to be stigmatised by the general public for doing the work they are doing as home-based carers. Some people, as one participant reported, would comment, *“I would rather die of hunger than do the job you are doing, this thing of taking care of people with AIDS”*. HCW participants noted that people do not hold such strong stigmatising attitudes anymore, but some people living with HIV, especially those recently diagnosed, struggle with self-stigma due to non-acceptance of their sero-positivity status (Pyle et al, 2015).

During the implementation of the intervention some of the PLHIV clients verbalised some of these negative comments of stigmatising attitudes and their own self-stigmatization or internalisation of stigma. One example of perceived stigma effects is that of a 40 year-old man wishing to get married but harbouring fears of rejection if he discloses his HIV positive status. This is the typical effect of societal stigma which prevents PLHIV from leading a normal life and in turn they will internalise stigma, as this man did.

### **Theme 3: Disclosure**

Non-disclosure of HIV positive status is closely associated with HIV-related stigma and discrimination, (Simbayi & Kalichman, 2006). Health care worker participants in this study reported that the other problem they encountered with PLHIV is non-disclosure of their HIV status for fear of being rejected by those they disclose to. The example of a 40 year-old above illustrates fear of rejection and therefore reluctance to disclose. Disclosure is a big problem when it comes to relationships, especially sexual relationships, where one is faced with the life of another in her/his own hands. Not disclosing one's status may lead to infecting another person with HIV because he/she might refuse to use a condom. Women, especially pregnant women, also become conflicted when it comes to disclosing their HIV+ status to their husbands or boyfriends. A pregnant woman has to take a decision to protect her unborn child. On the other hand she needs to solicit support from the father of this unborn child who does not know his wife is HIV+. Some women who are dependent on their male partners financially may decide not to disclose for fear of losing financial security or even his love. An example is that of a case of one participant whose client had not disclosed her HIV+ status to her husband for fear of rejection with his child. Most of the participants in this study have related to this problem of non-disclosure among the communities they serve and they believe if it could be dealt with successfully it would immensely reduce new HIV infections.

#### **Theme 4: Denial**

One of the participants reported that one of her clients had told her to stop coming for visits because he is healed by God. She had noticed that her client, in spite of three years of living with HIV and ARVs, is still in denial. He had recently attended a charismatic church and his dedication to this church was making the participant uneasy as the participant was told not to come because the pastor of that church confirmed he was healed of the disease through holy water and prayers. Some of the participants confirmed that these kinds of cases are common as they have encountered such beliefs, even with people who are not their clients in their communities. They claimed that some PLHIV who have not accepted their HIV+ status would overly indulge in alcohol and drugs or would start having multiple sexual relationships (engaging in unprotected sexual intercourse) to avoid thinking about and dealing with their condition.

#### **Theme 5: Depression**

Even though this study set out to explore the presence of depression and other stress-related psychological conditions among PLHIV, findings did not conclusively show that PLHIV in this sample suffer severe depression. Only 4% of respondents showed symptoms of severe depression. What seemed prevalent was stress they experience in daily life.

#### **Theme 6: Training of health care workers on stress management and debriefings**

In both health facilities, Sophumelela Centre and Nontyatyambo Clinic, health care worker participants indicated the need for stress-releasing trainings to help them with burnout at work. Home-based carers deal with emotionally burdened cases which require professional counsellors to handle, such as the one where the client disclosed about being raped. Another participant also mentioned that her client called her in the middle of the night after discovering that her boyfriend was sexually abusing her 5 year old child (crying and asking her for help). They argued that these cases drain them and as people living with HIV themselves they need professional and debriefing sessions. They said they would appreciate something like the TRE to be done every week with them as well as supportive de-briefing individual counselling.

## **Theme 7: Stress Levels**

The study did not measure stress among people living with HIV. Clients were asked to identify their stress levels using a stress- level check quiz during the implementation of the intervention. From the stress quiz responses during the development and implementation of the intervention sessions it became clear that almost all PLHIV clients, as well as health care worker participants, suffer from stress one way or another. Their stressors were a variety of social challenges ranging from poverty caused by not finding jobs, to feeding their families, worry about children when they become sick and conflict in relationships.

## **Theme 8: Traditional healer (TH) consultation**

To explore the multicultural approach, a question was posed to health worker participants who ran the sessions on whether their client participants ever consulted traditional healers. Most clients responded that they consulted traditional healers for different reasons. They sometimes consulted TH when western medicine had failed to diagnose the illness (this is when, for example, the person is seriously sick but doctors cannot see what the person suffers from). Sometimes they consulted to seek spiritual direction from the ancestors and for protection from evil spirits. A few of the clients were indifferent about consulting traditional healers. This concurs with the report that about 80% of African people still believe in traditional healing, (WHO, 2005). When asked during the last session with health care worker participants if they thought that their HIV+ status resulted from not attending to ancestral needs, no one confirmed such notion as having happened in their case, but one client explained that sometimes when one did not heed the call of ancestors, some illnesses might befall the person. He further said ancestors turned away from you and left you unprotected, so you became exposed to all sorts of illnesses, including HIV and sicknesses caused by evil spirits. A person might be healed of the ancestor-related illnesses after taking care of the business with ancestors but cannot be cured of HIV because there is no cure.

## **5.4. Preliminary evaluation of the implementation of the intervention**

### **5.4.1. The HCW participants' responses to implementation of the counselling intervention**

#### **Introduction**

A ten-question evaluation criterion was used to evaluate the process of the implementation of the intervention among health care workers who participated in the second focus group discussions of the study.

The following is the presentation of HCW participants' responses on their experiencing of the counselling intervention.

#### ***Q1. Did you implement the whole intervention as instructed?***

All participants involved in the implementation of the intervention agreed that they were able to complete all three sessions of the intervention without any major obstacles.

#### ***Q2. Did you depart from the instructions as given in the intervention and why?***

Some participants admitted that they departed from the instructions due to a number of reasons: One participant said, "*My clients had difficulty comprehending these three sessions with what we usually engage in when we visit them.*" One HCW participant said, "*My clients were taking time to understand and I spent more time on information giving.*" One participant said, "*I had to depart a bit from the instructions because my clients had so much to say about their social problems and these issues, as they say, affect them daily, so I could not complete the work I intended to complete in one session.*"

#### ***Q3. What would you do differently?***

All participants agreed with one voice that they would allocate more time for these sessions and continue doing this for at least one year to be able to cover all the work. They also suggested that they would request to be trained further on counselling skills in order to handle some of the situations they felt needed such skills such as how to handle victims of rape, child sexual abuse because they feel helpless and ineffective.

***Q4. What surprised you during the implementation of this intervention?***

*“It was the enthusiasm of the clients in doing those TRE exercises, especially after the first day they claimed to have slept well. I was also surprised because those exercises are just simply exercises but shaking of the body in itself is really amazing,”* said one participant.

*“The other thing that surprised me was the frankness of my clients. They were not shy to talk about their intimate problems in front of us and the other client. The sessions were free and relaxed. Even though I am the one who is supposed to make my clients relaxed but it was the opposite, I guess it was because I was in their territory as a guest,”* one participant claimed.

***Q5. Did your client understand the instructional materials you used?***

One participant responded, *“When it came to CBT my clients gave me a tough time because that cognitive restructuring activity is a bit challenging. I had to call the researcher a day before to remind me how to tackle it, so my clients also struggled like I did. But since I knew it was challenging I was very patient with them. However, due to time constraints, I gave them a different homework exercise on CBT as we were given a number of different assignments during our training.”*

Another participant said, *“With the TRE I altered it a bit on the second day because of time constraints, I skipped some of the warm up exercises and did the last three because I wanted to concentrate on their shaking/tremors.”*

***Q6. How did any special accommodation of your clients affect the process?***

One participant said they were delayed by unavailability of space especially to do exercises and ended up starting very late on the first day. *“This affected the process because I had to rush the first session. I only recovered that time on the second session,”* she said.

***Q7. Who dominated the sessions was it you or your clients?***

*“This was a little awkward in my session as one of my clients was very talkative and taking too much of the quiet one. I constantly had to interrupt her even though I felt bad doing it,”* said one participant.

Two other HCW participants also related to this problem but three others noted that they were the ones doing a lot of talking because their clients were on the quiet side. *“When I noticed that I was doing more of the talking I called the researcher about it and she advised me to ask clients more open-ended questions and this helped me because they started talking more explaining things to me,”* said one participant.

***Q8. Would you use this intervention going forward?***

All participants agreed with one voice saying that they would not only use this intervention with their clients but with themselves as it had already opened their eyes to solving their own internal conflicts and stress-loaded lives.

***Q9. What would stop you from utilising this tool to help your clients?***

*“Processes at work are much different. As public clinics we do not have the luxury of paying much time on one client. We only focus on the presenting problem, address it, and move on to another one, that’s it. It is unlike at the NGOs, especially those that do home visits. I think it’s very nice. A person can tell you more about her/himself in a natural environment,”* claimed one participant. What this participant says was true because participants who were visiting clients in their homes agreed that it is easier to see someone in his/her environment than at the clinic. However, they also pointed out that since they were dealing with poor people who lived in very small spaces, exercising would be an issue in their homes.

***Q10. How was it like for you to incorporate discussion on traditional healing?***

One participant said, *“I did not have any problem at all with it because I believe I am an African person with my culture and tradition first before I am a professional. I think this is very*

*important in our field to look at. We often take this for granted and in that way we do not focus on an individual in a holistic way.”*

Most participants agreed with the participant but cautioned that they still needed to hear from the client first to avoid imposing their values in case a client, although looking African may not live like an African in terms of tradition and culture. *“Some people are taken up by these charismatic churches who preach that ancestors are demons and they believe this, so we also need to be careful and not offend them,”* said one participant.

Some of them agreed that they do consult traditional healers but also perform such traditional rituals at home from time to time and still go to church. *“There is no contradiction here and look I am wearing ‘makoti clothes’. They slaughtered a sheep for me to introduce me to my husband’s ancestors as a new member of the family, what is demonic about that?”* said one participant.

## **5.5. SUMMARY OF THE STUDY FINDINGS**

The study findings as illustrated in three steps where step one focussed on developing the counselling intervention to help PLHIV experiencing stress-related psychological conditions, step two focussed on the implementation of the counselling intervention and step three evaluated the process of implementation of the counselling intervention.

The findings of the development of the counselling intervention came from two research methods namely, qualitative through health care workers focus group discussions and quantitative through collecting data by administering questionnaires among PLHIV. Findings from offered an insight into how the two research sites work with regards to offering services to PLHIV. Both research sites offered a comprehensive HIV care package for PLHIV. However, there was lack of mental health services. As both sites indicated that they had no mental health screening facility, they only refer clients to hospitals offering mental health facility such as psychiatric clinic at Cecilia Makhiwane Hospital or refer to local psychologists. These findings concur with studies done by many researchers. Anderson and Seedat (2009) have conducted similar studies in South Africa, and Guimarães, et al (2014) have similar findings from studies in Brazil and Rowe (2015) in the rural settings.



Another important finding revealed by this study during health care workers' focus group interviews, is the inadequate training of HCW on handling common mental health issues. HCW admitted that they were not trained in basic counselling skills and they felt inadequate to assist their clients who present with numerous psychosocial challenges (Amoateng, Kalule-Sabiti & Oladipo, 2015; Morton, Mayekiso & Cunningham, 2015). Studies supporting this notion have indicated that people who look after PLHIV are often care-givers or home-based carers and sometimes lay counsellors, who are not professionally trained to deal with emotional issues. Sometimes these care-givers are people who live with HIV and they find it emotionally draining to assist their sick clients. This calls for more attention into caregivers' need for training and debriefing.

The findings of this study also revealed that HCWs encounter many psychosocial problems that their clients deal with daily. These are issues of fear to disclose due to stigma or/and financial dependency issues, where a woman is scared to disclose her HIV positive status to her husband or boyfriend for fear of losing financial support given by this man. Other problems include self-stigma and denial. This shows that even though efforts from all directions have been made to educate people about HIV and AIDS to alleviate fear of the disease, there still exist stigma and lack of disclosure in relationships which, in turn exposes the PLHIV to rapid progression of the disease.

The quantitative research findings showed that people living with HIV were able to handle their health matters when offered guidance and education on how to take care of themselves. Being a member of a functioning support group and on the home-based care programme somehow assisted PLHIV to accept their HIV positive status thereby decreasing the level of depression that could have been experienced. This is observed by the low percentage of severe depression shown by the findings in this study. Even though participants' level of depression was mild to moderate, during the implementation of the intervention, they expressed being stressed out by unemployment, and were concerned about the bleak future facing their children due to poverty and many social issues.

The implementation of the intervention where HCW participants implemented the intervention on PLHIV participants, a number of issues which HCW participants revealed during

the first focus group discussions in step one were repeated by PLHIV participants. The findings were that PLHIV although they were not personally stigmatised, knew of cases where some people experienced stigma. Some had expressed perceived stigma and self-stigma. According to findings more concern was on social issues including lack of jobs, worrying about the future of their children when they eventually die and worried about their future in general. Findings also revealed that PLHIV need stress releasing programmes because they deal with many emotional challenges which could impact on their health.

Step three findings on how the counselling intervention was implemented revealed that their clients were eager to know more especially about how to improve their health and quality of life. Their enthusiasm in expressing positive outcomes about trauma releasing exercises, awareness of how their negative thoughts and stress impact on their health, gave direction in what PLHIV really need.

Another interesting aspect of the findings is the participants' perspective on traditional or alternative healing. It was observed that the majority of participants consulted traditional healers mostly to connect with their ancestors. They need this connection for protection and for keeping their families in harmony. Such rituals like 'imbeleko'(introduction of the child to his/her ancestors), 'utsiki' (introduction of the bride (umakoti) to the living and the ancestors of her new home), 'ulwaluko'(circumcision), ' ukukhatswa nokubuyiswa kwabaphantsi' (sending away and welcoming of the ancestors ' ceremonies) and so on are still held in high esteem and some of these need consultation with traditional healers. The heated arguments that occurred during these sessions on this aspect showed that not including cultural aspects when counselling people of the African origin would be detrimental to the field of psychology in Africa. These findings also concur with what WHO (2008) on admitting that 90% of African people still consult traditional healers.

## **5.6. CONCLUSION**

Chapter 5 has presented the results of this study following three steps, namely the development of the counselling intervention which comprises both qualitative and quantitative research methods; the implementation of the intervention, which consisted of the training of HCW participants and the actual implementation of the intervention with PLHIV participants

and lastly the preliminary evaluation of the intervention which involved only HCW participants giving a process evaluation on the implantation of the intervention and their views on its future use. The next chapter will focus on the discussion of the results as presented in this chapter.

## **CHAPTER 6**

### **DISCUSSION OF THE FINDINGS**

#### **6.1. INTRODUCTION**

This chapter focuses on the discussion of what transpired before, during and after the development and implementation of the counselling intervention. It therefore encompasses discussion of the results during the development of the intervention, discussion of the results generated during the implementation phase of the intervention including identified themes, and discussion of health care workers' experiences and evaluation of the intervention after its implementation.

#### **6.2. DISCUSSION OF THE DEVELOPMENT OF THE INTERVENTION**

The development of the counselling intervention was prepared using an intervention research design. Health care worker participants were involved throughout the study and PLHIV participants were involved during data collection, with pilot testing and during the implementation of the intervention. HCW participants participated in the focus group discussions before the development of the intervention influencing the development process of the intervention. They were trained on the intervention; implemented the intervention and gave feedback on how they experienced the process of implementing the intervention. Several studies support the utilization of the experience and opinion of health care workers who work directly with PLHIV, they identified them as people who are able to provide information relevant to the health challenges of PLHIV (Famoroti, Fernandes & Chima, 2013; Odendaal & Lewin, 2014; Wringe, Cataldo, Stevenson & Fakoya, 2013). This study has also explored the experience and expertise of health care workers, both lay-professionals and professionals to assist in developing the counselling intervention. The following discussion stems from data collected using qualitative and quantitative research methods.

##### **6.2.2. Discussion of the quantitative research results**

Data from PLHIV was collected by means of a biographical questionnaire, the Beck Depression Inventory – II (BDI-II) and medical Outcomes Study –HIV health survey (MOS-HIV). The biographical questionnaire provided information related to gender, location, age and

marital status. It also asked about when and how the PLHIV participant became aware of her/his HIV positive status, when and how she/he dealt or is dealing with Antiretroviral therapy (ART) and also asked about the availability of the support system in the community. The BDI-II, which is the screening tool for depressive symptoms, was used to identify levels of depression among PLHIV participants. The MOS-HIV was administered to check participants' general health status, which may hinder them from doing things on their own and therefore bring stress into their lives.

#### **6.2.2.1. Biographical questionnaire data findings**

Many studies have indicated that females are the ones who bear the burden of HIV infection more than males, Ramjee and Daniels, (2013); Rehle et al., (2013) support this notion. This trend has also been noted in this study as there are more females living with HIV than their male counterparts. Consequently, there are many factors increasing women's vulnerability to HIV. These include women's biological make-up, behavioural, socio-economic, cultural and structural risks, (Ackermann & Klerk, 2002; Chersich & Rees, 2008).

The other element that is suggested in this study is that of marital status where there are more single persons infected by HIV than married individuals. Risk factor analysis from various HIV prevention trials suggest that being young (i.e. less than 25 years old), having had one sexually transmitted infection in the past and being unmarried were significantly associated with a high risk of HIV sero-positivity status, (Ackermann & Klerk, 2012; Wand & Ramjee, 2012; Ramjee & Daniels, 2013; Rehle et al. 2013). It can be argued that HIV has brought its negative consequences to many relationships where married people separated as a result of being accused by their partners of being unfaithful. This may have increased the number of single people more than expected. Another argument could be that people who get infected are still young and of marriageable age (Dellar, Dlamini & Karim, 2015).

When it came to testing and starting ARVs, PLHIV participants expressed that they feared testing HIV positive and as well with starting life-long treatment. Exploring this fear further, PLHIV participants indicated that they feared being stigmatised by others (perceived stigma) and they also did not want to accept that they live with HIV in their bodies. They also expressed that they feared dying, as some of them were infected before ARVs were introduced

and when HIV was still considered a death sentence. Many people fear testing for HIV because they fear that they would be stigmatised if tested HIV+, (Martin & Kagee, 2011). The issue of stigma came up again among PLHIV as was indicated before by health care workers. When it came to taking ARVs, PLHIV participants also expressed fear of the unknown and the anxiety that was caused by knowing that they would take this treatment for the rest of their lives and if they stopped taking it there was a risk of dying sooner. They also stated the side effects of the treatment such as causing hallucinations and the threat of disfigurement of their bodies. Some did not adhere to antiretroviral treatment due to various socio-economic and psycho-social reasons. These are some of the things that add to stigma because there is lack of information and some myths become stated as facts, (French et al, 2014; Miller et al,2010; Nachega et al, 2006).

With regard to the role and participation in support groups, PLHIV participants indicated that what encouraged them to accept their sero-positivity status was to join a support group, where they learned a number of coping strategies. Research has shown that a positive attitude towards the illness sets a proactive approach for an individual to cope with HIV infection or any other kind of acute and chronic illness. Therefore, healthy coping mechanisms, including the support groups, are essential to combating the HIV-related stigma, as supported by (Kumar et al, 2014). They also believed that the counselling they received from lay counsellors and nurses at the clinics contributed more to their resilience against many psycho-social stressors. It is argued that when people living with HIV and AIDS receive support from their surroundings, levels of stigma decline and disclosure increases leading to the reduction of HIV infection, (Knight et al, 2015). Even though this particular study did not look into this correlation, there was an indication that depression among people living with HIV who received support through home visits and counselling is very low, and this notion is supported by (Nakimuli-Mpungu et al, 2015).

#### **6.2.2.2. Medical Outcome Survey-HIV (MOS-HIV)**

When participants were asked to describe their general health, a percentage of 45% indicated that their health was very good as against 2% who said their health was poor. When asked about bodily pains and pain interfering with their daily activities, 62% indicated that the interference was minimal. This indicates that even though they live with HIV, the virus does not

cause them physical pains and they are able to do their daily activities, (Peltzer & Phaswana-Mafuya, 2013). The fact that a high number of PLHIV participants are on ARVs may also contribute to them experiencing no bodily pains. The ARVs have been proved to normalise PLHIV's health and lives, a notion echoed by (Chen et al., 2013; Cohen et al, 2004) in their studies.

When the feelings of discouragement as a result of their health problems were explored 29% were discouraged just some of the time as opposed to 18% of those who were discouraged most of the time while no participants were discouraged all of the time. A study conducted by Miners et al, (2014) supports the findings of this study as they reported that even though PLHIV participants are living with the disease their health-related Quality of Life is the same as the general population and they do not feel less discouraged by their health status.

Twenty-nine (29%) of client participants felt happy most of the time as opposed to 11% of those who felt down in the dumps most of the time. This could be argued in line with the way PLHIV participants are organised in terms of receiving support from the clinic through the support group and from the home-based care visits. In psychology it is argued that when human beings are handled with care and receiving more attention on their wellbeing they tend to do better or be happier. This is called the 'Hawthorne Effect' which has been defined as "an increase in worker productivity produced by the psychological stimulus of being singled out and made to feel important" (Franke & Kaul 1978 p 625). According to McCarney, et al. (2007) this definition has since been broadened to refer to treatment response rather than productivity as it was in the 1920s and 1930s.

When asked to rate their health status, 46% of client participants claimed to be as healthy as anybody they knew and more than half of all client participants said that their quality of life was pretty good. Again when asked how they felt compared to a week ago, more than 80% of them said they felt a little better as opposed to the 3,8% who felt a little worse. Also when health status was compared to the level of discouragement, 75% were undiscouraged by their health status. Nine out of 15 client participants who were much better did not feel discouraged as opposed to none of the client participants who felt a little worse. The study also noted that PLHIV participants reported fewer feelings of discouragement regarding their health status. Even

the low percentage that felt discouraged attributed such feelings to external variables such as social issues. This notion is also supported by Chidrawi, Greeff and Temane, (2014).

### **6.2.2.3. Beck Depression Inventory-II (BDI-II results)**

The Beck Depression Inventory-II, as explained in Chapter 4 measures the level of depression. Fifty-eight (58%) of PLHIV participants showed no depression, and 29% showed mild to moderate depressive symptoms. Having more than half of the client participants suffering no depressive symptoms is an indication that people living with HIV and AIDS in this study are coping very well with their HIV positive status. This is in contrast with a number of studies conducted on depression and anxiety such as, Do, et al., (2014); Breet, Kagee and Seedat (2014). However, when feelings of discouragement were compared among males and females, 32% of males felt discouraged by their health in general when compared to 73% females who did not feel discouraged by their health. Many studies indicate that when it comes to health issues men are more reluctant and discouraged to seek medical help than their female counterparts, (Banks, 2001).

In exploring feelings of guilt for having contracted HIV, 67% of those tested more than 10 years ago did not feel guilty against 33% who tested less than 10 years ago and who still felt a little guilty. This might be triggered by the fact that they were still grappling with feelings of accepting their condition and were engulfed by stigma, self-stigma or had not disclosed their status to relevant people, especially to their significant others, (Arrey et al, 2015; Mark & Cheung, 2010; Simbayi et al, 2007;).

When support and self-image questions were explored, 77% of PLHIV participants supported by friends, saw themselves as still attractive and this was followed by those supported by family. This shows that peer influence, no matter at what age, still matters. Those who indicated that they were supported by clinics/hospitals were lower in percentage and some saw themselves as ugly. This might be due to lower assurances of their worth in hospital and clinic environments, (Palmer et al, 2011).



### **6.2.2. Discussion of the qualitative research findings**

The HCW participants in their focus group interviews indicated that the intake process was not different from one health facility to another even though they operate differently as non-government and governmental facilities. The process of receiving the client or patient is similar. However, with governmental clinics like Nontyatyambo follow-ups are difficult to maintain because they do not have a home-based care system. It is, therefore, impossible to understand fully what the patient goes through at home. They rely on what they are told by the client participants and can only act on that information to attend to the health needs of the patient, (Peltzer, Pengpid & Skaal, 2012).

It has also been noted that both health facilities do not have a clear process in screening PLHIV participants for stress-related psychological conditions, although they realise the need. The government clinic indicated that they have only one psychologist who comes in once a week. They refer their client participants who show symptoms of psychotic disorders or other psychiatric symptoms to this psychologist or send client participants to Cecilia Makhiwane Hospital. Client participants with socio-economic problems get referred to the on-site social worker. The non-governmental facility, even though aware of this problem, had not expanded resources to cater for such cases due to financial constraints. This is supported by a study conducted by Petersen and Lund, (2011) on mental health service delivery in South Africa.

It is very important for health care facilities to have a mental health care unit so as to cater for PLHIV who demonstrate early symptomology of psychiatric disorders such as neurosis, before they degenerate into more severe pathology and psychotic disorders, (Petersen & Lund, 2011). This will also assist in preventing such disorders as depression, anxiety or illnesses that might be as the result of non-attended stress and stressful situations in people's lives. Many studies have reported on low detection and screening of mental illness in primary health care clinics, (Kahn et al., 2004; Stein et al. 2008). Several factors have been identified as contributing to the non-screening and later lack of identification and subsequent non-treatment of common mental disorders, (Petersen & Lund, 2011). These factors include inadequate training of primary health care (PHC) personnel, limited time available to PHC personnel and an underdeveloped referral system, (Sorsdahl, et al., 2010). Addressing these factors through integrated primary

mental healthcare for common mental disorders (CMDs) would ensure identification and referral of CMDs, either for medical or psychological treatment, (Seedat et al., 2010). Suliman et al., (2010) have also identified the need to include not only mood and anxiety disorders but also substance abuse which has been identified as problematic, particularly for men.

Health care worker participants, when asked about the variety of factors affecting the PLHIV that they encounter, listed a number of issues such as stigma, poverty, fear of disclosure, uncertainty about the future and even substance abuse, especially among male PLHIV. They noted that these matters cause high levels of stress which may result in CMDs such as anxiety, depression and suicide among their PLHIV participants as Peltzer, Pengpid & Skaal, (2012) noted in their study. However, as some clinics do not have screening tools to detect CMDs they only rely on what patients present to them and cannot go any further in terms of assisting them (Freeman et al., 2008; Kahn et al., 2004; Martin et al., 2011; Myer et al., 2008).

### **6.3. DISCUSSION OF THE IMPLEMENTATION OF THE INTERVENTION**

#### **6.3.1. Training of health care workers participants**

The implementation of the intervention began with the training of all health care workers of both research sites respectively, as presented in Chapter 4. Subsequently, the first group of the non-governmental centre training was conducted. In this training it was established that health care workers (home-based carers) were never trained in basic counselling skills, but were trained on home-based care, which covers such skills as caring, empathy, listening etc. According to Davis (1990) empathy is the essential skill in counselling and plays an important role when one can effectively apply it in a helping relationship. Many scholars from diverse disciplines have long argued over the nature of empathy which is often understood as the phenomenon of experiencing another person's feelings. Some saw empathy as a fundamental building block for positive growth and development, (Zahn-Waxler & Radke-Yarrow, 1990). Halpern in Weiner and Auster (2007) argues that empathy has both cognitive and affective elements, i.e. imagining how it feels to be in another's person's situation. Whichever way this essential element in relationships may be defined, it is what drives helping relationships to be successful in healing emotionally disturbed individuals. It was from this perspective that health care workers were asked about their counselling skills before the development of the intervention.

Health care workers expressed that they sometimes experienced what is known as ‘compassion fatigue’, popularly called ‘burnout’ in their line of work, (Svenaeus, 2014). The impact of compassion fatigue or burnout among caregivers is detrimental as it usually leads to stress-related symptoms and can be very costly both personally and professionally. It is very important, therefore, that caregivers are taken through the debriefing sessions and introduced to other stress-releasing strategies to achieve a healthy work-life equilibrium and to avoid falling ill, (Lambardo & Eyre 2011).

During the training of health care workers of both facilities, emphasis was placed on how they handled their PLHIV participants throughout the sessions, especially when it came to TRE. Health care workers were taken through training by allowing them to experience how their clients feel and they would then be expected to conduct sessions in a similar manner. Experiencing their bodies responding to exercises and understanding why such reactions were happening was vital to their TRE training. Some of them experienced both physical and emotional reactions, for example, they experienced shaking of some body parts or the whole body and emotional reactions such as crying or laughing.

#### **6.3.1.1. Trauma/Stress Releasing Exercise (TRE)**

Life is stressful, anxiety provoking and frequently traumatic. The result is that many people who are hurting are often unaware of how deep their pain runs. The hurtful and traumatic experiences that people go through leave a deep mark on both the psyche and the body. Berceli (2008) explains that our inability to switch off the muscular response of flight, flight or freeze to stressful events results in many stress-related illnesses.

According to Berceli (2008), TRE works on the psoas muscles, located in front of the spine, which protect the centre of gravity of the human body. He argues that during any traumatic experience, be it sudden or prolonged stress, the psoas muscles contract to protect the underbelly of the human animal. These muscles, that connect the back with the pelvis and the legs, remain contracted until the danger is over. The problem starts when these muscles remain contracted for a long time. To heal from trauma contractions, this set of muscles must shake out their protective tension to relax. When the shaking response of the psoas muscles is evoked by

these exercises, it reverberates throughout the entire body looking for deep chronic tension/stress in its path and naturally dissolving it (Berceli 2008).

When Berceli (2008) explains this remarkable experience of involuntary shaking of the body through these exercises, he gives an account of how animal species deal with traumatic experiences.

*The animal species that are still in their natural habitats encounter trauma/tension/stress all the time, but unlike humans they still have access to their natural ability to discharge the excess energy generated during flight/fight traumatic experience and completely recover and go on with their lives. Once the trauma is over, the body's nervous system is designed to literally shake out this deep muscular tension and help the body return to its normal state. Similarly, the mysterious key that activates the release mechanism of human species' natural recovery process can be activated within the natural physiology of the human bodies as well (Berceli 2008, p45).*

Berceli (2008) argues that the human species abandoned this natural mechanism to shake away deep muscular tension and labelled such reaction as pathological. He states that the three disciplines that recognised tremors were psychology, neurology and physiology. Psychology calls these tremors 'psychogenic tremors', neurology identified them as 'neurogenic tremors' and physiology calls them 'physiological tremors'. Psychology and neurology classified these tremors as the pathological body reaction while physiology recognised the importance of these tremors and shifted from labelling them as pathological to potentially something very useful. In the DSM V, (2011) psychogenic tremors are associated with panic anxiety, post-traumatic stress disorder, generalised acute anxiety and social phobia.

The combination of psycho-bio-neurological research has come to recognise that trauma and stress-related problems can be successfully engaged through body modalities in connection with psychological interventions. This has even led to the invention of exercise machines found in the gymnasias of many health clubs because of the usefulness of the whole body vibration, (Levine 2012).

Berceli (2008) argues that TRE induces what he calls ‘self-induced unclassified therapeutic tremors’ which when deliberately activated in a safe and controlled environment begin to happen automatically. This is the body shaking that restores the body homeostasis. Berceli (2008) also found out that this process calms down the human organism and with continuous exercise it also keeps them grounded. Some people using this technique have reported decreases in irritability, rigidity, temper, regulated blood sugar levels and blood pressure, headaches and the way they see things becomes better than before (they are more accepting and adapting when faced with stressors).

In this study, participants testified that they slept better after one day of TRE. Some confessed that they slept through until the morning, uninterrupted for the first time since they started ARVs. Even though this technique will not be experienced in the same way by each individual because people are unique and have unique needs and experiences, as Berceli, (2008) has noted, results have been consistent across cultures in that TRE down-regulates the autonomous nervous system and restores the body’s equilibrium.

#### **6.3.1.2. Cognitive Behavioural Therapy (CBT)**

The participants were also trained in CBT – cognitive restructuring as a technique to dispel negative thoughts. In this study CBT was chosen for its wide use and researched therapeutic intervention with people living with HIV and AIDS, depression and psycho-social stress related to stigma and discrimination, like in many studies such as (Jayasvati et al, 2011; Brown & Venable, 2008; Tshabalala, 2008). According to Brown and Venable (2008) a meta-analysis of 21 cognitive behavioural interventions designed to teach stress management for PLHIV, showed significant improvements in depression, anxiety, perceived stress, overall level of psychological functioning and quality of life. Therefore, Brown and Venable (2008) concluded that “overall, there appears to be promising evidence to indicate that stress management programmes are effective in reducing perceived stress levels and improving overall psychological adjustment and psychological functioning” (p35). It is therefore in this regard that the researcher chose CBT as one of the approaches to be combined with TRE and a Multicultural approach in this study.

The participants' experiences of the CBT approach varied, some were able to grasp it immediately and some required additional time as the facilitator explained it through role-playing examples. Role-play helped the participants visualise and recognise a number of cases where they were still carrying negative thoughts about many problems in their lives. Going through the cognitive restructuring technique with them and working through their cognitive distortions proved to be very helpful for them in their line of work.

Cognitive restructuring taught people to identify negative automatic thoughts, which contributed to negative emotions/feelings and eventually lead to maladaptive behaviours, (LaSala, 2004; Overholser, 1993). The use of this technique was more convincing because health care workers, during the development of the counselling intervention, mentioned that stigma and fear of rejection were high among people living with HIV and AIDS. As stigma was listed as one of the deterrents for people to freely disclose their HIV status, it was clear that they could be experiencing high levels of stress, (Simbayi et al, 2007).

The overall benefit of CBT is that it is an approach which emphasises non-judgemental, collaborative problem-solving and empowerment of the client through skill-building and strengthening of natural support systems, (Sayers & Heyman, 2003). The disadvantage is its emphasis on rational thinking which can be interpreted in ways that devalue the client's emotional expressiveness. Its individualistic focus may inhibit the therapist from addressing factors affecting the larger community relevant to the client, (Kelly, 2006). Given the above critique about CBT, it is therefore important for therapists to explore their own cultural identity to avoid offending their PLHIV participants.

### **6.3.1.3. Exploration of the African traditional healing process**

During the training of health care workers/participants some questions on cultural factors affecting their health seeking habits was explored. Many participants agreed that they consulted traditional healers for spiritual guidance, but additionally they consulted western doctors for physical and medical ailments. This relates to the point stated by Hills et al, (2013) that biomedical approaches concentrate on the body and they ignore the spiritual explanation imperative to the cultural background of some service users from African communities. Western

medicine can treat common mental illness but often it will just be about managing or suppressing or repressing the actual cause of illness, (Hill et al, 2013).

According to Lindell, Barrett and Bydowell (2005) it was estimated that 350 000 traditional health practitioners were active in South Africa and this number has surely grown by now. This was at that stage approximately 15 times higher than the number of medical practitioners Richter (2003) maintains that there has been an increased interest in the knowledge, approach and roles played by traditional health practitioners in the management of health and illness in the previous decade in South Africa. There has also been, explorations of cooperation between western medical practitioner and traditional health practitioners in the area of HIV, TB and chronic illnesses in South Africa, (Sorsdahl et al, 2009).

The participants in this study freely expressed their relationship with traditional norms and values for communication with their ancestors. Although they also expressed dissatisfaction with some traditional health practitioners who mislead poor people because of money, on average, they agreed that they consulted traditional health practitioners sometimes as a family or as individually.

The debate on combining western medicine with traditional medicine was explored further. Health care worker participants advised against combining ARVs and traditional medicines for fear of dosage interference and, in their line of work, they indicated that they were educating their clients about the dangers of this combination. One participant claimed that they had one case (not during this study) where a PLHIV was taken to a traditional healer who gave him strong herbs that made his condition worse and was hospitalised.

### **6.3.2. Discussion of the implementation of the intervention with PLHIV participants**

The trained HCW participants selected two PLHIV participants each in order to implement the intervention and conducted three sessions following a structure similar to their training (as presented in Chapter 4). These sessions were more focused towards a psycho-educational approach to equip PLHIV participants with strategies to cope with stress in their daily lives, hence working in dyads was recommended. The initial stage of the first session consisted of the intake, introductions and making PLHIV participants feel comfortable. The

second part of the session was the introduction of the topic; Stress Management, explanations on what stress is, what causes stress and the effects of stress in the body and general health of a person. This started by allowing PLHIV participants to answer quiz questions and then spending time reflecting on their answers. This commenced an indication on the level of stress they experienced daily and, therefore, served as justification for taking them through these sessions. Their realisation on how much stress they were dealing with on a daily basis made them more curious to learn ways of coping with stress. The participants took them through the effects of stress in their bodies and in their relationships with others.

The last part of the session concentrated on releasing the stress in their bodies by introducing TRE. The PLHIV participants' experience of TRE was consistent with how HCW participants experienced this technique during training. As discussed in the implementation of the participants' training, TRE has a down-regulating effect which, used over time, keeps the human organism grounded. PLHIV participants in this study experienced the calming effect of TRE even though the duration of the study was not long enough to allow for the observation of other holistic changes in their bodies. The participants agreed to continue with TRE beyond this study because they could already experience the benefits.

The next session dealt with the introduction of CBT with a special focus on cognitive restructuring. CBT was chosen because it empowers individuals and in turn it had helped PLHIV participants to build strength, support and skills to meet their goals more effectively (Sayers & Heyman, 2003). During this session PLHIV participants were able to go deeper into the causes of stressors in their lives and which had originated from the experience of being HIV positive. Themes that were identified seemed to feature openly during this session as participants felt more comfortable in expressing their feelings. Participants were able to talk about their fears of disclosure, stigma, denial and relationships with their intimate partners.

#### **6.3.2.1. Discussion of some identified themes**

Stigma, as a problem linked to disclosure of their HIV status by PLHIV, was mentioned by HCW participants and was therefore identified as one of the themes observed in their line of work with PLHIV and the communities they serve. However, the study did not identify stigma as the major contributor to their stress levels and a problem to health in general among PLHIV



participants who participated in this study, other than the perceived stigma that exists in other areas. PLHIV participants did not give any account of themselves being stigmatised. This may be due to the fact that PLHIV participants selected for this study had been in the programme for quite some time already and they may have worked through emotional issues regarding stigma.

Although there were no incidents of stigma in this group, other studies found stigma, even underlying stigma, as a destructive factor for psychological health of PLHIV in the fight against HIV and AIDS, (McCauley 2013; Meyer, 2003). HIV and AIDS fall under a perceived category of infectious diseases in which the mode of transmission is perceived as self-inflicted as a result of socially unacceptable behaviour. Therefore affected individuals are stigmatised, (Halevy 2000; Heckman et al, 2004)

On receiving and reacting to a positive HIV diagnosis there are two factors strongly identified as very important; it is how the news is delivered and how supportive or judgemental the health practitioners are in the whole process, (Hult, Wrubel, Branstrom, Acree & Moskowitz, 2012). However, much less research has been conducted in an attempt to explore and overcome the impact of stigma and discriminative acts towards PLHIV (Colbert et al 2010).

Fear of stigma, discrimination and a breakdown of social networks are the main barriers to disclosure. On the other hand, disclosure may open the opportunity for more social support, stigma reduction, improved medical treatment access and sexual behaviour change (Parsons et al, 2004; Ssali et al, 2010).

In dealing with stigma and related issues in this study, cognitive restructuring was used to dispel negative automatic thoughts about stigma. Teaching participants how to identify and dispute irrational or maladaptive thoughts and replace them with positive and rational thoughts was demonstrated to help participants cope with many psycho-social problems encountered in their lives. Cognitive restructuring helped the individual to develop a meaning in life and substituted distorted beliefs with realistic beliefs about him/herself and the future despite living with HIV, (Varni et al, 2012).

HCW participants noted feelings of guilt or self-stigma, especially among male PLHIV participants during sessions with PLHIV participants. On exploring this guilt and self-stigma

with cognitive restructuring, PLHIV participants were able to recognise their irrational thinking as continuously negatively impacting on their functioning and stopping them from progressing with their day-to-day life and activities. Some studies have found self-stigma to be associated with lower quality of life, low self-esteem, guilt, blame, poor health assessment, less likely to disclose and fear of enacted stigma (Poindexter & Linsk, 1999; Steward et al, 2008). Heckman (2003) shows the importance of the recognition of the interrelatedness of factors influencing quality of life of PLHIV. Heckman (2003) supports this notion by adding that a harmonious balance between internal and external factors influencing the quality of life of PLHIV is essential for the individual's identity as HIV positive.

Another identified theme was disclosure. Disclosure is a difficult aspect with PLHIV because it can lead to stigma and discrimination which in turn leads to silence and reluctance to seek help, (Pakenham & Rinaldis, 2002). Many societies, including the South African society, have suffered because people do not come forward for help and HIV infections are continuously increasing. According to Parsons (2004) there are both negative and positive consequences in disclosing ones HIV positive status. Negative consequences include stigma, rejection, loss of intimacy and sometimes a threat to personal integrity. One client in this study narrated that his HIV+ status prevented him from getting married for fear of rejection. He thought that his fellow church women would reject him once they knew about his HIV status and that he would never get married.

Denial was also identified as another theme which seems to have caused stress among people living with HIV and AIDS. Denial is a psychological defence mechanism that helps one avoid a potentially distressing truth. (Kúbler Ross in Van Dyk ,2008). People who find out that they are HIV positive often find it difficult to deal with the truth. They may believe that the test was inaccurate, even after a confirmatory test showing the same results is done. More often than not this is a normal reaction. However, when the person continues being in denial for too long it becomes detrimental to her/his health. This may lead to a refusal to accept necessary help and medical support, (Van Dyk, 2008).

### **6.3.2.2. Discussion of Depressive disorder among PLHIV participants**

As indicated in Chapter 4, and in the section on the discussion of the quantitative results, this study did not conclusively find severe levels of depression as could have been expected from the literature. Only 4% of PLHIV participants showed some symptoms of severe depression. These mild levels of reported depression could be as a result of a ‘Hawthorne effect’, in that PLHIV participants in this study had been attending support group meetings and had been receiving weekly visits from home-based carers.

The ‘Hawthorne effect’ is a concept associated with an increase in worker productivity produced by the psychological stimulus of being singled out and made to feel important. Subsequently, the ‘Hawthorne effect’ has been broadened to refer to treatment response rather than productivity, (McCarney, et al, 2007). In this study it refers to a number of factors including the treatment, care and support response among PLHIV participants of both research facilities. As PLHIV participants receiving attention during home-based visits and support group, they may have dealt with issues of stigma, depression, guilt and self-blame and hence these aspects are less prominent in this study. However some studies have shown that PLHIV are likely to present with severe depression accompanied by non-disclosure, fear of rejection, stigma, etc. (Freeman et al 2008).

### **6.3.2.3. Discussion of stress as experienced by both HCW and PLHIV participants**

During the training of HCW participants high levels of stress were also noted in their stress quiz results. Health care workers deal with a number of health-related cases and stressors in the workplace. Excessive stress at work has been noted with concern by many studies and the resulting burnout (Bhui et al, 2012; CDC, 2010; Marchand et al, 2014) which create negative consequences for the health care workers. Burnout is a result of constant stress, frequently aggravated by overwork and the devaluation of the service offered. Other factors such as personality traits, a person’s lifestyle and how one perceives the world, all contribute to how stress continues to be of great concern in the workplace.

Care givers who visit PLHIV participants in their homes experience high levels of emotional, psychological and physical demand and some caregivers themselves become targets

of HIV-related stigma and discrimination (Singh et al, 2010). The HCW participants in this study have narrated that they occasionally encountered unresolvable psycho-social problems such as child sexual abuse, domestic violence and relationship conflicts in the families they visited and this rendered them highly stressed to the point of burnout. However, their workplace does not have or has not been able to offer them, debriefing sessions, except that they are given Fridays off to report on their work and the challenges they met in the field. Other than that they had no other emotional outlet or formal support.

After collecting data for the development of the intervention and during the implementation of the intervention by HCW participants, it became clear that PLHIV experienced some levels of stress caused by different psycho-social stressors. According to Bernstein et al. (2008) stress is viewed as a negative emotional, cognitive, behavioural and physiological process that occurs as one tries to adjust to, or deal with, stressors. While stressors are seen as internal and external circumstances that disrupt or threaten to disrupt one's daily functioning and cause one to make adjustments, some stress is seen as good or 'eustress' as was initially suggested by Hans Selyes who coined the word 'stress' in 1936, (Auerbach & Grambling, 1998). The concept of good stress or eustress, however, has been rejected by arguments that it leads to stress being inappropriately managed, especially in the workplace where employees, such as health care workers, work under physical and psychological strain which results in 'burnout' (Le Fevre, Matheny & Kolt, 2003).

According to Passer and Smith (2007), stress does not affect people equally, but excessive stress can lead to illness and negative consequences. Stress increases the risk of depression and if one is living with HIV the chances are that those who are HIV+ face stressors every day. Even though there is no direct correlation between stress and HIV, research has shown that stress can weaken the immune system making it less able to fight off infections. The activation of the nervous system due to stress makes one more sensitive to pain and to emotional stimuli which then leads to distress. This chain reaction could result in depression and adversely depression in turn could result in the risk of ignoring ones medication. Non-adherence becomes a big risk factor among PLHIV as they develop resistance to ARVs (Treisman in Rodrigues, 2015). In other words ignoring the treatment of stress at its early stages may result in unintended consequences for PLHIV.

#### **6.3.2.4. Discussion of African traditional healing perspective**

Culture is an organising and stabilising influence in a given society. It encourages particular behaviours and thoughts and it allows people to understand and know what to expect from others in that particular culture. It is passed along by tradition and example rather than through the genes from one generation to the next (Castro & Toro, 2004). Culture is seen as the accumulation of values, rules of behaviour, forms of expression, religious beliefs, occupational choices and the like for a group of people who share a common language and environment (Fiske et al, 1998). African culture has always been associated with traditional custodians such as traditional healing practitioners or traditional healers who would perform traditional rituals and communicate with ancestors and higher power whether it is God or an Oracle.

The HCW participants in this study were taken through this discussion to air their views on the subject of traditional health practitioners and other traditional matters with implications to HIV and AIDS. Likewise PLHIV participants were also asked to share their views on how they saw traditional health practitioners helping them. Most of the PLHIV participants who were not 'born-again Christians', i.e. people who practise the new or charismatic Christianity, agreed that they consulted traditional healers. In fact some admitted that before consulting the western medical practitioners or going to the clinic they consulted their traditional healers. It was then that the traditional healer would suggest that they start at the clinic and bring with their medical results.

Nevertheless they argued that they never blamed witchcraft or ancestors for their HIV infection. Consulting with the traditional healers in this case does not necessarily mean one will believe that he/she has been bewitched or that the sickness has been caused by ancestors. PLHIV participants admitted that their consulting with the traditional healers was purely for traditional spiritual guidance and communication with their ancestors. Some PLHIV participants who believed that it is wrong to follow or worship ancestors because it is against what the bible says, believed that God can and will cleanse them of HIV and there are spiritual guides or prophets who are already curing HIV and AIDS. This discussion seemed to evoke emotions among all participants in this study. As a result it consumed most of the reflection time among PLHIV participants with no consensus reached.

#### **6.4. PRELIMINARY EVALUATION OF THE IMPLEMENTATION OF THE INTERVENTION**

Process evaluation documents the process of implementation focusing on the types and quantities of service delivery, the beneficiaries of such services, the resources used to deliver the services and ways in which problems were resolved (Moore et al, 2013). The information collected from preliminary evaluation is very useful for understanding how the intervention impact and outcome are achieved and for the intervention replication. It can also provide information about treatment services and systems by pin-pointing areas for improvement. The evaluation can assess whether the intervention could be repeated or not, and improved or implemented to who and when, (WHO, 2000).

With regards to the quantitative results in the BDI-II of this study it was shown that severe depression in this study was very low, PLHIV participants experienced mild levels of depression and the majority fell below normal level scores. What was evident and acknowledged were the high levels of stress among both participants and PLHIV participants due to external factors such as lack of financial ability to do what they need to do, relationship conflicts and socio-cultural issues. Stress factors were tackled through stress management training of participants who were assisting PLHIV participants cope with stressors in their lives so as to avoid experiencing too much stress which would in turn exacerbate their condition as noted by (Peltzer, Pengpid & Skaal, 2012).

The participants reported on how they experienced participating in the study and on being involved in implementing the intervention. Although this was a very exciting project for them, it posed some challenges with the implementation. They listed a number of barriers they had gone through such as finding suitable space to conduct sessions, especially TRE sessions, a lack of punctuality on the part of PLHIV participants due to domestic problems and some PLHIV participants expecting to be given some money for participating in this study even though everything was clearly explained at the beginning of the research. This anticipation of 'something' stems from receiving money, food and other incentives from organisations that usually work with these communities. The participants had to remind the PLHIV participants about their agreement at the beginning of the study and the consent they signed. The

precautionary measure of informed consent helped participants in dispelling these expectations. It is evident that due to exploitation, coercive measures and sometimes unethical methods some organisations use to gain entry in resource-constrained areas, participants took these measures as the norm and demanded some form of payment from the researcher even when they had clearly explained ethical foundations of the study. The subject of incentives, compensation and reimbursement to study participants as Mduluzi et al. (2013) note, remains controversial and needs serious discussion by regulatory authorities.

The benefits cited by both HCW participants and PLHIV participants were: to know more about the dangers of stress if unattended; how stress contributes to their illness; aspects of their lives that might be contributing to their stress levels; the relaxation and treatment they found with TRE and knowing that negative thoughts can distort reality and can cause stress and attract other negative behaviour into one's life. With TRE, participants felt that its use in the clinics would be beneficial, not only to PLHIV participants but to all health care workers including nurses, doctors, social workers and home-based caregivers.

TRE is not a new technique to be employed in stress and trauma healing. There have been a number of other methods that have been used and are still used. The use of body-mind therapy is widely used in the release of prolonged stress for the benefit of the organism (Netterstrom, Friebel & Ladegaard, 2012). However, the difference in TRE is that it gives the body an opportunity to rectify and heal such traumas and injuries that have happened earlier in one's life (Berceci, 2008).

In 1995 Robert Scaer came across the works of Peter Levine who was treating his PTSD client participants with body-oriented therapy called SE (somatic experiencing). Levine, (2007) postulated that PTSD was caused by an uncompleted freeze response by the victim to a serious threat to life. During the course of his body-mind work with PLHIV participants, Levine (2012) noticed that when they trembled or discharged energy, they got better.

## **6.5. CONCLUSION**

This chapter has presented the discussion of the results of the study. The discussion of the development of the intervention included; the discussion of qualitative and quantitative results

that led to the development of the intervention, the development of the intervention, the implementation of the intervention which involved the training of the HCW participants on the intervention and the implementation of the intervention by HCW participants. A discussion of the African traditional perspective in the healing process was also presented as was the discussion of the process evaluation by HCW participants after the implementation of the intervention. Throughout the process, which was explained in Chapter 4, all participants involved were continuously made aware of the importance of maintaining ethical standards.



## CHAPTER 7

### SUMMARY, CONCLUSION, LIMITATIONS AND RECOMMENDATIONS

#### 7.1. SUMMARY

The main aim of the study was to develop a counselling intervention for PLHIV in the BCM in the Eastern Cape Province of South Africa. The study was designed to develop, implement and evaluate an intervention that could be used to assist PLHIV cope better with stress-related psychological conditions in their everyday living. Several studies have shown that PLHIV deal with a number of psycho-social and adjustment stressors which could result to stress-related psychological conditions such as depression (Chidrawi, Greef, Temane, & Ellis, 2015). Consequently, health care practitioners deal with a heavy workload in hospitals and clinics to such an extent that there is little opportunity to address and treat stress-related psychological conditions (Seedat et., 2009)

The study employed an intervention research design comprising six phases of research process in order to meet the aims and the objectives of each stage/step and the study. Data was collected by a combination of both quantitative research method using questionnaires, and qualitative research method using focus group interviews.

The study consisted of four objectives, namely:

1. To determine the psychological conditions experienced by PLHIV.
2. To develop a counselling intervention to be applied by health care workers managing PLHIV.
3. To implement the counselling intervention
4. To conduct a preliminary evaluation of the efficacy of the counselling intervention.

A sample of twenty HCW participants comprising of eight professional nurses and two lay counsellors from Nontyatyambo Clinic, eight home-based caregivers, one programme coordinator and one social worker from Sophumelela Centre made up two focus groups of ten. A

sample of 78 PLHIV participants, comprising of 56 from Sophumelela Centre and 22 members of the support group from Nontyatyambo Clinic.

During the development of the counselling intervention all data collected from the first focus group interviews with HCWs, quantitative data collected from PLHIV, theoretical foundation of the study and available literature on the subjects were combined, analysed and informed the development of the intervention. The draft intervention was validated by colleague members of the researcher where the intervention was then modified for use by HCW participants during the implementation phase of the study.

The implementation of the counselling intervention was conducted over a period of six months including preparation for the training and visits. Two groups of 10 and 8 members of health care worker participants were trained over three days. Subsequently, sessions with client participants were conducted over a period of three weeks. Some participants were unable to start their sessions at the stipulated time resulting in the implementation period stretching over three months. Of the 18 health care worker participants trained only 13 participated in the implementation of the intervention with client participants.

Preliminary evaluation on the implementation of the intervention with all health care worker participants was conducted. Two feedback group sessions were organised with the two groups respectively, where participants shared their experiences regarding the implementation of the counselling intervention.

The overall findings of the study revealed that most client participants (PLHIV) experienced high levels of stress rather than severe depression as per the supposition and several studies that support this notion. The BDI-II findings showed only 4% of PLHIV in this study who suffered from severe depression with the majority of PLHIV ranging from normal to mild depression. The information gathered from health care workers in the two focus groups was supported by the information collected during the implementation of the intervention sessions with client participants regarding causes of stress among PLHIV and these are indicated in the study as themes.

The study also revealed that health care workers need as much assistance as their PLHIV participants when it comes to stress. In fact there is a great need for all health care facilities to offer stress management courses and debriefing sessions to their health care practitioners all year round. The burnout syndrome that health care workers complained about during training and focus group sessions has adverse effects on their handling of PLHIV participants. A happy and relaxed health care practitioner makes a happy and healthy client.

## **7.2. CONCLUSION**

This study has developed, implemented and evaluated the implementation of the counselling intervention that encompasses three different psychological approaches to assist PLHIV in dealing with stress effectively in their daily lives. This integrated counselling intervention could be used by many health care centres to assist not only PLHIV but a wide spectrum of individuals and groups experiencing, or going through, traumatic and stressful situations.

On the basis of the findings and interaction with participants of this study, it can be concluded that not only can PLHIV benefit from this intervention but their caregivers and professional health practitioners can utilise this intervention to cope with work stress better. The intervention focused on both physical and emotional healing from stress and equips individuals with useful strategies, extracted from the cognitive behaviour therapy (CBT), trauma releasing exercises (TRE) and knowledge of self in a multicultural perspective. The study also offers an opportunity for health care facilities to start taking stress at work seriously among their health care practitioners.

This counselling intervention has been designed such that it requires short-term consultation with the health care or mental health practitioner. Three to six sessions would be enough depending on the individual and problem presented. Once the client grasped the process, this intervention becomes a life-time self-help therapy. Another beneficial element is that of releasing stress physically through the TRE exercises. As Berceli (2008) agrees that with people who find talking about their problems difficult, TRE gives an opportunity for them to release all emotions associated with those problems through discharging negative energy causing stress. Findings of this study also revealed that depressive disorders are less likely to be the cause for

concern when PLHIV are fully supported and engaged with their health care workers as supported by (Teixeira et al., 2011).

There was no observed link between PLHIV's high stress levels and their sero-positivity status. However, high levels of stress were attributed to psycho-social, socio-economic and cultural problems in their day-to-day life. Nevertheless, this study offers valuable data with regards to understanding and dealing with the psycho-socio-economic and cultural needs of the people living with HIV.

Regarding the use of traditional healers versus western medicine participants clearly understood the concept of drug interference as they had expressed that they do not mix ARVs with traditional medicines they get from traditional healers. Reasons for seeking the help of traditional healers includes; ancestral protection, strategies to appease their ancestors as well as to take care of evil spirits when necessary. Although multicultural perspective was not explored in the questionnaires, the content validation session noted this omission where a decision to include it in the second phase was made. It is also noted that people in South Africa still hold their African traditional healing in high esteem and they continue to use both western and African healing methods comfortable. This is supported by the WHO (2005) report that indicate 90% of people of African origin still consult traditional healers for one reason or the other and this notion is supported by studies conducted nationally by (Edwards, 2015; Sordahl et al., 2009).

### **7.3. LIMITATIONS OF THE STUDY**

In analysing the results of this study a number of limitations must be taken into consideration. These include the following:

- Sample size was too small for this study to be generalised.
- Purposive sampling by its nature offers an opportunity for selection bias. Thus, according to Tongco (2007), using home based care PLHIV participants and members in the support group who were already exposed to the programmes as related to their HIV condition may have opened room for bias.
- Another factor is the 'Hawthorne effect' as stated by McCarney et al. (2007) where individuals observed may alter their behaviour due to the attention afforded to them or

incentives given to them. In this study both HCW and client participants were equipped with education and skills to manage stress, which they desperately needed. This need to deal with their everyday stress may have created a 'Hawthorne effect'. It is possible that their motivation to participate in the study was driven by their eagerness to understand and deal with stress in their daily lives.

- Inability to evaluate the effectiveness of the intervention over a longer period of time is another limitation to be considered when analysing this study.
- A further limitation was that some variables were assessed by self-report and desirable responses may have been given.
- The last phase of the intervention research design namely, dissemination of the intervention has not been done due to the nature of the study, which is a requirement for an academic qualification and not a field study. Dissemination of the intervention would require more funding to cover costs of branding, marketing and advertising of the intervention. The study was thus limited in that manner.

## **7.4. RECOMMENDATIONS**

### **7.4.1. Recommendation on the application of the intervention**

The integration of trauma releasing exercises (TRE) into cognitive behavioural therapy (CBT) has offered more meaning to the relaxation techniques usually used in CBT as part of a comprehensive depression or/and anxiety reduction treatment. However, TRE goes beyond relaxation of the body, it goes further to heal the body of past traumas and current stress-related illnesses. Although TRE was originally aimed at releasing trauma among people in war-torn zones, soldiers and earthquake survivors, contemporary psychology researchers have adapted this technique to treat all stress-related disorders and psychosocial problems. TRE used alone has the potential to make individuals who would rather not talk about their feared situations avoid talking therapies. Thus, the combination of TRE and CBT allows for holistic healing of the body by talking about negative situations in one's life while physically healing the body. It is therefore recommended that this intervention be applied with caution to avoid cases where people would prefer to go with the exercise part of the intervention.

The merging of CBT, TRE which is body-mind therapy and multicultural approach to form an integrative intervention proved to be a welcomed intervention by health care workers who participated in this study. Their feedback and enthusiasm as people who are always overwhelmed by heavy workload has given the researcher room to modify the intervention for future use by this population. The study recommends that this intervention be incorporated into the management of common mental disorders as part of the comprehensive integrated programme and be applied to stress management programme of vicarious trauma workers such as paramedics, fire fighters, policemen, nurses, community caregivers, survivors of abuse and crime and even perpetrators of such crimes. It can also be applied to chronic disease programmes such as diabetes and hypertension in the health care system. However, it is strongly suggested that the validity of the intervention be tried before its application to a particular target group.

From the public health perspective, the current move is to integrate HIV and AIDS management into primary health care services. This move does not guarantee that common mental disorders will also be integrated into primary health care services. It is therefore recommended that this intervention be modified and incorporated into the primary health care system to detect and prevent the onset of psychological problems among people living with HIV and AIDS and other illnesses that induce stress.

To prevent the onset of severe psychological conditions, this intervention can be introduced as soon as possible after the diagnosis has been made in order to assist clients with the speedy acceptance of their condition and in order for them to be able to manage the disease's progression.

This counselling intervention may be implemented by those health care practitioners trained on it and they should continue to monitor progress among their clients until they see some improvements. Trained health care practitioners need to pay attention to the physically impaired clients before they embark on TRE. There are alternative exercises that are catered for physically impaired clients. It is also important to gather medical history of the client before starting them on TRE as these exercises may elicit both physical and emotional pains which may have existed for a long period.

It is recommended that health care practitioners using this counselling intervention need to keep an open mind about the cultural issues relating to their clients. Any effective treatment of mental health illnesses in the African communities necessitates the recognition and identification of cultural differences. According to Sorsdahl et al., (2009) alternative health practitioners, including traditional healers and religious advisors, appear to play an important role in the delivery of mental health care in South Africa.

It is also recommended that when applying this intervention more time should be allocated in order to assess its effectiveness on the client. It is important to afford one's clients an opportunity for reflection on this intervention in order for the health care worker to gain insight into how it works and can incorporate feedback received for future modification of the intervention. It is also important to note that when applying this intervention, caution be exercised, especially with raped victims when they are doing the lying-on-the-back exercise as trembling in this position may induce negative emotions and find your client experiencing dissociation. TRE is a conscious mind type of technique, so caution should be exercised to avoid dissociation.

It can be branded as a stress management programme that can be used across a wide spectrum of populations since almost all people go under stressful and traumatic situations from time to time.

#### **7.4.2. Recommendations for future research**

Public interest on new and innovative stress management techniques is growing, which suggests a great need for researchers to urgently provide the scientific evidence to improve theory and practice of TRE as well as to isolate the efficacy of this intervention and clarify its potential therapeutic value.

This study recommends that this intervention be validated by implementing it on vulnerable groups such as PLHIV, people experiencing trauma and stress related disorders who receive limited health care delivery in the rural areas. As generalisation is restricted in this study due to the type of sampling used, it is therefore recommended that the future studies be designed for generalisation.

The study also recommends further investigation of the burnout in the workplace on health care practitioners including doctors, using this intervention. Another study that can emanate from this study would be to investigate the effectiveness of this intervention among people with disability.

The study also recommends in-depth research on common mental health disorders using a modified version of this intervention. A modified version would include conducting the study for a longer period, for example, a one to two-year study and using a bigger sample size to establish the impact of the intervention.

It is also recommended that the intervention be used to study youth and adolescents in schools as a measure to gain confidence and self-resilience against many forms of abuse and stress related experiences both at home and school.

It is also recommended that research be conducted on potential gender differences in clients preferring body-based intervention versus talk therapy. Furthermore gender studies especially those focussing on gender based violence require further exploration with the application of this intervention. It could also be important to incorporate elements of multicultural therapy in a more in-depth method than this study has done to avoid misdiagnosing and mistreating clients from different cultures as ours. Being open-minded and willing to educate oneself about cultural different groups are key to successfully assisting people living with HIV and AIDS.



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**Integrative Intervention**

**Intake Form**

**Date:** .....

**Session 1:**

**Biographical Information**

<b>Name of Client:</b>		<b>Reference Code:</b>	
<b>Gender:</b>		<b>No. of Children</b>	
<b>Male</b>		<b>No. of years diagnosed</b>	
<b>Female</b>		<b>No. of years on Treatment</b>	
<b>Other : Specify</b> <b>(e.g. Transgender male)</b>			
<b>Date of Birth:</b>			
<b>Marital Status:</b>			
<b>Address and Contact Details:</b>			
<b>Type of work you do:</b>			
<b>Name of Counsellor:</b>		..... <b>Counsellor Signature</b>	

1. The counsellor should make sure that the client is comfortable and check whether the client is aware that she/he gave consent to participate in the study. The counsellor should not forget to introduce her/himself properly to the client. The client needs to be reminded that she/he is participating in the implementation of an intervention developed by a student at NMMU. Then the counsellor should proceed and let the client know how long the sessions will be for how many weeks. The counsellor should make the client understand the importance of attending these sessions as discussed.

2. When all is clarified, the counsellor introduces the topic by asking whether client has ever experienced stress. Give explanation of how stress manifest in ones life and body. At this stage, hand out a quiz form on stress for the client to fill-in. Ask the client to score and see her/his stress level. (Appendix ...)

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3. Reflect on the results of the quiz and assist the client to identify causes of her/his stress and how it affects her/his functioning. Explore how they have handled issues of stigma, disclosure and relationship conflicts due to their HIV positive status.

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4. Now that we have identified stress and its consequences, I would like to introduce you to a form of stress releasing exercise programme to alleviate your everyday stress. Let me explain how this works and how the founder came up with this technique.

5. Hand out the TRE medical history forms and ask your client to fill-in the form and hand it back to you. Explain to the client why this information is important for this type of exercise programme.

If the client has had an injury (ies) before, request her/him to be cautious and listen to your direction.

6. Give the client a hand-out of seven (7) step exercise programme and ask the client to follow your lead as you demonstrate this set of exercise moves.

7.





Source: Bercei D. (2009) Trauma releasing exercises, [www.traumaprevention.com](http://www.traumaprevention.com)

8. After exercising and trembling, counsellor should ask the client to reflect on how she/he feels and her/his physical and emotional experiencing of the TRE. Then ask the client to practice these exercises at home every day and write down any changes she/he might notice both physically and emotionally as homework. Give client the TRE sheet to record the experience.

9. Check if the client has anything to say then ask her/him to summarise this session.

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10. Agree on the date of the next session

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**Session 2:**

**Name of Client:** ..... **Ref. Code:**.....

**Date:** .....

**Name of Counsellor:** .....**Signature:** .....

1. Exchange greetings and check how the client is feeling today.

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2. Ask client what you discussed in the previous session to check if she/he remembers and close gaps if any. Ask client if she/he would like to share anything about the past week , any thoughts, feelings and behaviour regarding stress.

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3. Last week you had a homework task which I asked you to keep a record of your TRE experience by filling-in the TRE worksheet. Tell me about your experience with TRE.

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4. Reflect on the client's experience and respond to client's concerns if any.

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5. I would like to introduce another form of dealing and coping with stressors you have identified as problematic in your life. This technique is called Cognitive Behavioural Therapy (CBT). This is one of many therapies that are used widely in the field of psychology to help people deal effectively with their problems. It has a number of techniques. We are going to use this therapy in conjunction with TRE. Let me explain how CBT works.

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6. I would like you to think of a problem among the problems you are presently challenged with that you want to resolve as soon as possible. Tell me what the situation was, what your thoughts were about this problem and how you feel right now.

7. Now let us do what is called 'cognitive restructuring' one of the CBT techniques. Give an example to explain further. Cognitive restructuring refers to the process of replacing cognitive distortions with thoughts that are more accurate and useful. Cognitive restructuring has two basic steps: (1) Identifying the thoughts or beliefs that are influencing the disturbing emotion; (2) Evaluating them for their accuracy and usefulness using logic and evidence, and if warranted, modifying or replacing the thoughts with ones that are more accurate and useful. Now hand out the cognitive restructuring worksheet to the client with clear instructions.

8. Ask the client to reflect on her/his situation that evoked an emotion-causing thought, rate the automatic thought, evaluate it and modify this thought.

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9. Assist the client to challenge these thoughts by asking her/him questions that evaluate the accuracy of the thought (s).

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10. After the client has confirmed her/his understanding of the exercise, tell the client that she/he is required to continue this exercise with other problems she/he had mentioned before as a homework assignment. Give the client more cognitive restructuring worksheets to work on.

11. Now, we are going to close this session by doing our TRE exercises like we did in our last session.

12. Reflect on the exercise and check how the client feels.

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13. Ask the client to summarise the session.

**Session 3**

**Name of Client:** ..... **Ref. Code:**.....

**Date:** .....

**Name of Counsellor:** .....**Signature:** .....

1. Greet the client and check how she/he is feeling today.

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2. Is there anything you would like to share with me? Allow the client to reflect on the previous session and things related to the session that happened thereafter.

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3. Let us look at the homework assignment I gave you in the last session. Can you talk about some of the negative emotion-causing thoughts you identified in your homework assignment or some of the negative emotion-causing thoughts you can remember having over the past week.

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4. Now, let us evaluate the usefulness of these negative thoughts by listing advantages and disadvantages. Assist the client to modify these self-defeating thoughts and produce rational thoughts.

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5. Take more examples from the client's stressors and ask the client to work on modifying negative emotion-causing thoughts on each stressor until the client is able to do it on her/his own.

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6. Today I also would like us to explore the multicultural approach through African traditional healing with you as another option many people use to deal with illnesses including stress, HIV and AIDS. How do you feel about it? Have you or your family members ever consulted a traditional healer?

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7. Explain that for many South Africans, tradition is very important and they might seek both western and traditional healing, but it is important to follow doctor's instructions very well when it comes to HIV and AIDS as well as ART because some traditional healers' medicines may interfere with ARVs. So what is important here is to talk about your beliefs with your doctor and also your traditional healer. How have you incorporated the western medicine with traditional medicine?

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8. Now, we are going to focus on the TRE homework. From your TRE worksheet, what thoughts, feelings and tremors have you experienced in the past week?

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9. Which of the exercises were eliciting more tremors and which parts of the body were more vibrating than others?

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10. Explain why some parts of the body tremor or vibrate more and why some people would experience intense emotions when trembling. Encourage client to continue with TRE at least for six months to see the difference and pay more attention to physical and emotional changes. Some people report becoming grounded with continuous use of this technique.

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11. I would like us to practice TRE again and see how your muscles are responding to TRE and how you feel.

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12. As you know this is our last session of the implementation of the intervention, I would like you to continue practicing and using the techniques you have learned here. I would like you to continue identifying negative thoughts and immediately applying the cognitive reconstruction to dispel them. Mastering this technique would help you even with future problems. Feel free to come to the centre/clinic for any assistance you need.

Thank you very much for your cooperation and participation.



**Appendix: B**

**Chairperson of the Research Ethics Committee (Human)**

**NMMU**  
Tel . +27 (0)41 504-2235 Fax. +27 (0)41 504-2831

**Ref: [H11-HEA-PSY-004/Approval]**

**Contact person: Mrs U Spies**

28 May 2012

Prof T Mayekiso  
NMMU  
DVC: Research and Engagements  
01-17  
South Campus

Dear Prof Mayekiso

**INTEGRATIVE THERAPY FOR PEOPLE LIVING WITH HIV AND AIDS  
EXPERIENCING STRESS RELATED PSYCHOLOGICAL CONDITIONS**

Your above-entitled application for ethics approval served at the Research Ethics Committee (Human).

We take pleasure in informing you that the application was approved by the Committee.

The ethics clearance reference number is **H11-HEA-PSY-004**, and is valid for three years. Please inform the REC-H, via your faculty representative, if any changes (particularly in the methodology) occur during this time. An annual affirmation to the effect that the protocols in use are still those for which approval was granted, will be required from you. You will be reminded timeously of this responsibility, and will receive the necessary documentation well in advance of any deadline.

We wish you well with the project. Please inform your co-investigators of the outcome, and convey our best wishes.

Yours sincerely

**Prof CB Cilliers**  
**Chairperson: Research Ethics Committee (Human)**

cc: Department of Research Capacity Development  
Faculty Officer: Faculty of Health Sciences  
Ms. Nomvula Twise (D.Phil Student)

**Nomvula Twaise - Integrative therapy research at SCI**

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**From:** Melissa Knox <Melissa.Knox@scinc.co.za>  
**To:** "ntwaise@wsu.ac.za" <ntwaise@wsu.ac.za>  
**Date:** 2013/02/05 01:32 PM  
**Subject:** Integrative therapy research at SCI  
**CC:** Phila Gaga <Phila.Gaga@scinc.co.za>, Ethne Schaefer <Ethne.Schaefer@scin...>

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Dear Nomvula

We are excited to assist you with your research in our Home Based Care Department.

I copied Ms. Phila Gaga in this email. She is our M&E Officer as well as HBC Coordinator. Please liaise with her around the finer details of commencing your research.

You can also reach her on 043 722 2261.

Just a reminder to please bring your approval letter from the Research Ethics Committee with to your next visit.

I trust your Mtatha trip will go well and we look forward to hearing back from you next week.

Kind Regards

**Melissa Knox**

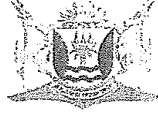
Operations Manager

Tel: +2743 722 2261

Fax: 086 766 0467

[www.sophumelela.org](http://www.sophumelela.org)





**Eastern Cape Department of Health**

Enquiries: Zonwabele Merile

Tel No: 040 608 0830

Date: 06<sup>th</sup> June 2013  
e-mail address: zonwabele.merile@impilo.ecprov.gov.za

Fax No: 043 642 1409

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Dear Mrs Twaise

**Re: Integrative therapy for people living with HIV/AIDS experiencing stress related psychological disorders**

The Department of Health would like to inform you that your application for conducting a research on the abovementioned topic has been approved based on the following conditions:

1. During your study, you will follow the submitted protocol with ethical approval and can only deviate from it after having a written approval from the Department of Health in writing.
2. You are advised to ensure, observe and respect the rights and culture of your research participants and maintain confidentiality of their identities and shall remove or not collect any information which can be used to link the participants.
3. The Department of Health expects you to provide a progress on your study every 3 months (from date you received this letter) in writing.
4. At the end of your study, you will be expected to send a full written report with your findings and implementable recommendations to the Epidemiological Research & Surveillance Management. You may be invited to the department to come and present your research findings with your implementable recommendations.
5. Your results on the Eastern Cape will not be presented anywhere unless you have shared them with the Department of Health as indicated above.

Your compliance in this regard will be highly appreciated.

**DEPUTY DIRECTOR: EPIDEMIOLOGICAL RESEARCH & SURVEILLANCE MANAGEMENT**



*Isithixo Sisonke*



Province of the  
**EASTERN CAPE**  
HEALTH



## Amathole District

Buffalo City Sub-district:

Enquiries: Mrs N.V.Nelani

9 Vincent Road, Vincent, East London, 5200, Eastern Cape  
Private Bag x 9015, Main Post Office, East London, 5200, Eastern Cape  
Tel No. +27 (0)43 711 1100 Fax No. +27 (0)43 721 1972  
Website [www.ecdoh.gov.za](http://www.ecdoh.gov.za)

To:	Clinic Supervisor Operational Managers: Buffalo City Sub District facilities
From:	Buffalo City Sub-District Manager
Subject:	Permission to conduct a research study in Buffalo City Sub District on: <b>Intergrative therapy for people living with HIV/AIDS experiencing psychosocial distress</b>
Date:	08/07/2013

This communiqué serves to inform the operational managers of Buffalo City Sub District that Ms. Nomvula Twaise has been given permission to conduct research at Nontyatyambo CHC and Gateway Clinic in Buffalo City Sub District.

The sub district office requests that the researchers be assisted with the information they need without compromising confidentiality of both the consumers of the service and the image of the department.

Your co-operation is always appreciated.

*pp. W. Uet*

DM LUSASA

SUB-DISTRICT MANAGER

BUFFALO CITY SUB-DISTRICT

*08/07/2013*

DATE

*Appendix: F*

**INFORMATION AND INFORMED CONSENT FORM**

I ..... am being asked to participate in a research  
*Participant Name & Surname*

***Project Title: Integrative therapy for people living with HIV and AIDS, experiencing stress-related psychological conditions.***

The researcher, ***Nomvula Twaise*** has explained the nature of the study to me. I understand that the anticipated benefits of my participation are to enable health care professionals to effectively help people living with HIV and AIDS to cope with their daily lives in dealing with psychosocial distress.

The researcher will make every effort to safeguard the confidentiality of the information that I provide. Any information obtained from this study that can be identified with me will remain confidential and will not be given to anyone without my permission.

If at any time I would like additional information about this project, I can contact the researcher at **043 709 4757/2**.

I understand that I have the right to refuse to participate in this study. I also understand that if I do agree to participate, my signature below indicates that I have given my informed consent to participate in the above-described project. My signature also indicates the following:

- ✓ I have been given the opportunity to ask questions about the described project and my participation in it.
- ✓ My questions have been answered to my satisfaction.
- ✓ I have been permitted to read this document and have been given a signed copy of it.
- ✓ I am at least above 18 years old and legally able to provide consent.

**I therefore voluntarily give my consent to participate in this study.**

Signed at.....on.....2013

.....  
Signature: Participant

.....  
Signature: Researcher

July 2013

Appendix: G

Dear Health Care Worker participant,

I am currently studying towards Doctoral Degree in Psychology at the Nelson Mandela Metropolitan University. The study aims to develop an integrative therapy/intervention that will assist people living with HIV and AIDS cope with stress-related psychological disorder that they might suffer from. Stress affects many lives and people living with HIV and AIDS are no exception. Living with such stress can lead to anxiety, depression, substance abuse and many illnesses. This study seeks to explore and describe ways and means of helping people living with HIV and AIDS overcome psychosocial challenges. As health care workers you are faced with challenges of taking care of people living with HIV and AIDS and many other complicated illnesses. We will be gathering information from you using focus groups. You are therefore requested to participate in this study by joining the focus group of health care workers in your facility.

The Eastern Cape Department of Health: Epidemiological Research & Surveillance Management and Sub-District Office have given permission for this research project to be conducted. You have the right to withdraw at any time, however your participation is appreciated. Confidentiality will be maintained at all times.

The findings of this study will be made available to you and this facility as well as at the Nelson Mandela Metropolitan University's Library. No reference to individual names will be made and no individual will be identified in the reported findings. If you have any questions prior to your participation or at any time during the study, please do not hesitate to contact me at this number: 043 709 4757/2. Please note that I will collect the consent forms as soon as you finish completing them. However, if you feel you need to take it home and read it through, please feel free to do so and you can bring it back the following day.

Your participation in this study is highly appreciated.

Yours sincerely

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Nomvula Twise (Researcher)

Supervisor: Prof Thoko Mayekiso

Co- Supervisor: Pr 

**Nelson Mandela  
Metropolitan  
University**  
*for tomorrow*

March 2013

Appendix: H

*Dear Research PLHIV Participant,*

I am currently studying towards Doctoral Degree in Psychology at the Nelson Mandela Metropolitan University. The study aims to develop an integrative therapyintervention that will assist people living with HIV and AIDS cope with stress-related psychological conditions they might suffer from. Stress affects many lives and people living with HIV and AIDS are no exception. Living with such stress can lead to anxiety and depression. This study seeks to explore and describe ways and means of helping people living with HIV and AIDS overcome psychological challenges. You are therefore requested to participate in this study voluntarily. If you choose to participate, you will be required to complete three measures as follows:

1. A Biographical Questionnaire: where we require you to answer questions related to yourself except your name.
2. Medical Outcomes Study – HIV (MOS-HIV): This test consists of 35 items where you are required to talk about your general health to evaluate your quality of life (QoL).
3. Beck Depression Inventory – A 21 item inventory to assess the level of stress and depression

The maximum time you will spend responding to all the above-mentioned tests is 1hr with 5 minute breaks in-between.

The Eastern Cape Department of Health: Epidemiological Research & Surveillance Management has given permission for this research project to be conducted, however your participation is voluntary, and you have the right to withdraw at any time. Confidentiality will be maintained at all times.

The findings of this study will be made available at the Nelson Mandela Metropolitan University's Library and a copy will also be available to you through Nontyatyambo Clinice. No reference to individual names will be made and no individual will be identified in the reported findings.

If you have any questions prior to your participation or at any time during the study, please do not hesitate to contact me at this number: 043 709 4757/2. Please note that I will collect the consent form as soon as you finish completing it. Your participation in this study is highly appreciated.

Yours sincerely,

---

Nomvula Twise

(Researcher)

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Supervisor: Prof. Thoko Mayekiso

Co-Supervisor: Prof. D. Elkonin



**BIOGRAPHIC QUESTIONNAIRE**

**Instructions:** This questionnaire consists of 23 questions asking about your background and HIV- health related matters. Kindly indicate your answer by ticking the appropriate box where necessary and give explanation where required.

**Note:** Your identity is anonymous and your answers are strictly confidential. No one will be able to trace this information back to you.

Thank you for participating in this study.

**Code:**----- for office use only

**Today's Date:**-----

**Township/Village:**-----

**Age:**-----

**1. Nationality:**

**South African**

**Other: Specify: .....**

**2. Gender:**

Male

Female

**3. Ethnic Background:**

a. Xhosa

b. Coloured

c. White

d. Other: Specify:


.....

**4. The highest year of education completed:**

Primary:

High School:

College/University:

Postgraduate:


**5. Are you currently**

Married

Single  
Separated  
Divorced  
Widowed  
Cohabiting


**History of HIV Positive Status**

**6. When did you test HIV positive. [Tick your answer]**

- a. Less than two years ago
- b. Less than Five years ago
- c. Less than Ten years ago
- d. Less than Twenty years ago
- e. More than Twenty years ago

**7. Did you receive pre and post -test counselling?**

Yes

No

Somewhat

**Explain:**

**8. Who gave you pre and post-test counselling? [Tick your answer]**

- a. Person testing me
- b. Lay Counsellor
- c. Other: Specify .....

**9. Where did you receive pre and post-test counselling?**

- a. Clinic
- b. Hospital
- c. Campaign/Mobile
- d. Other: Specify. ....

Appendix: J

*This questionnaire consists of 21 groups of statements. After reading each group of statements carefully, circle the number (0,1,2,3) next to the one statement in each group which best describes the way you have been feeling the past week, including today. If several statements within a group seem to apply equally well, circle each one. Be sure to read all the statements in each group before making your choice.*

<b>1</b>	0	I do not feel sad.	<b>2</b>	0	I am not particularly discouraged about the future.
	1	I feel sad.		1	I feel discouraged about the future.
	2	I am sad all the time and I can't snap out of it.		2	I feel I have nothing to look forward to.
	3	I am so sad or unhappy that I can't stand it.		3	I feel that the future is hopeless and that things cannot improve.
<b>3</b>	0	I do not feel like a failure.	<b>4</b>	0	I get as much satisfaction out of things as I used to.
	1	I feel I have failed more than the average person.		1	I don't enjoy things the way I used to.
	2	As I look back on my life, all I can see is a lot of failure.		2	I don't get any real satisfaction out of anything anymore.
	3	I feel I am a complete failure as a person.		3	I am dissatisfied or bored with everything.
<b>5</b>	0	I don't feel particularly guilty.	<b>6</b>	0	I don't feel I am being punished.
	1	I feel guilty a good part of the time.		1	I feel I may be punished.
	2	I feel quite guilty most of the time.		2	I expect to be punished.
	3	I feel guilty all of the time.		3	I feel I am being punished.
<b>7</b>	0	I don't feel disappointed in myself.	<b>8</b>	0	I don't feel I am any worse than anybody else.
	1	I am disappointed in myself.		1	I am critical of myself for my weaknesses or mistakes.
	2	I am disgusted with myself.		2	I blame myself all the time for my faults.
	3	I hate myself.		3	I blame myself for everything bad that happens.
<b>9</b>	0	I don't have any thoughts of killing myself.	<b>10</b>	0	I don't cry any more than usual.
	1	I have thoughts of killing myself, but I would not carry them out		1	I cry more now than I used to.
	2	I would like to kill myself.		2	I cry all the time now.
	3	I would kill myself if I had the chance.		3	I used to be able to cry, but now I can't cry even though I want to.
<b>11</b>	0	I am no more irritated by things than I ever am.	<b>12</b>	0	I have not lost interest in other people.
	1	I am slightly more irritated now than usual.		1	I am less interested in other people than I used to be.
	2	I am quite annoyed or irritated a good deal of the time.		2	I have lost most of my interest in other people.
	3	I feel irritated all the time now.		3	I have lost all of my interest in other people.

<b>13</b>	0	I make decisions about as well as I ever could.	<b>14</b>	0	I don't feel that I look any worse than I used to.
	1	I put off making decisions more than I used to.		1	I am worried that I am looking old or unattractive.
	2	I have greater difficulty in making decisions than before.		2	I feel that there are permanent changes in my appearance that make me look unattractive
	3	I can't make decisions at all anymore.		3	I believe that I look ugly.
<b>15</b>	0	I can work about as well as before.	<b>16</b>	0	I can sleep as well as usual.
	1	It takes an extra effort to get started at doing something.		1	I don't sleep as well as I used to.
	2	I have to push myself very hard to do anything.		2	I wake up 1-2 hours earlier than usual and find it hard to get back to sleep
	3	I can't do any work at all.		3	I wake up several hours earlier than I used to and cannot get back to sleep
<b>17</b>	0	I don't get more tired than usual.	<b>18</b>	0	My appetite is no worse than usual.
	1	I get tired more easily than I used to.		1	My appetite is not as good as it used to be.
	2	I get tired from doing almost anything.		2	My appetite is much worse now.
	3	I am too tired to do anything.		3	I have no appetite at all anymore.
<b>19</b>	0	I haven't lost much weight, if any, lately.	<b>20</b>	0	I am no more worried about my health than usual.
	1	I have lost more than five pounds.		1	I am worried about physical problems such as aches and pains, or upset stomach, or constipation.
	2	I have lost more than ten pounds.		2	I am very worried about physical problems, and it's hard to think of much else
	3	I have lost more than fifteen pounds. (Score 0 if you have been purposely trying to loose weight.)		3	I am so worried about my physical problems that I cannot think about anything else.
<b>21</b>	0	I have not noticed any recent change in my interest in sex			
	1	I am less interested in sex than I used to be.			
	2	I am much less interested in sex now.			
	3	I have lost interest in sex completely.			

# MOS-HIV HEALTH SURVEY

## INSTRUCTIONS TO THE STUDY COORDINATOR:

The following questionnaire asks the patient about many aspects of his/her health and health care. It should be given to the patient prior to the clinical exam and preferably in a quiet secluded area (e.g., exam room or other office).

It is important to be familiar with the content and format of the questionnaire before giving it to study participants. At the first visit, please begin by telling the participant:

"We would like you to answer some questions about how you are feeling and the kinds of things you are able to do. Your answers will help us understand the effects of the medication you are taking. We appreciate your filling out this questionnaire."

You should then briefly go over the format of the questions and how to complete them. Have the participant complete the questionnaire before vital signs, history and physical are completed.

The questionnaire is very brief and should take no more than 10 minutes to complete. Before giving the patient the questionnaire, please fill out the header(s) and **DETACH THIS PAGE**.

Each question is in the same general format. Note that the patient is always asked to check one box for each question. All questions refer to the **PAST 4 WEEKS**.

Collect the completed questionnaire before the clinical exam. Before going on, review the questionnaire for omissions. If the participant missed any of the questions, point this out and have him/her complete the omissions.

## **PLEASE COMPLETE THE FOLLOWING ITEMS AFTER PATIENT COMPLETES THE QUESTIONNAIRE OR AFTER YOU ASCERTAIN THAT THIS IS NOT POSSIBLE:**

1. How was the questionnaire completed? ..... 1  Self administered by the study participant  
2  Face-to-face interview that you conducted  
3  Phone interview  
4  Not completed  
5  Other

If Other, specify: \_\_\_\_\_

2. If you answered 2 or 4, please indicate the reason(s) why:

Patient refused initially: ..... 1  Yes 2  No

Patient's reading level not adequate: ..... 1  Yes 2  No

There was not enough time: ..... 1  Yes 2  No

Patient forgot reading glasses: ..... 1  Yes 2  No

Other reason: ..... 1  Yes 2  No

If Other, specify: \_\_\_\_\_

**First Focus groups discussion (interview) questions:**

- Do you test people for HIV, CD4 count and Viral load?
- If a person tests positive for HIV, what do you do?
- If a person tests negative for HIV, what do you do?
- Do you sometimes get HIV and AIDS client participants who show symptoms associated with the following disorders: Acute anxiety, depression, post-traumatic stress disorder, stress, adjustment disorder, and suicide?
- What procedure do you use in diagnosing PLHIV complaining of psychological conditions/stress mentioned above?
- Do you have systems in place that deal with the above-mentioned conditions?
- If yes, how are these systems helping PLHIV showing symptoms of psychological conditions and stress?
- If there are no systems in place, what do you usually do to deal with these client participants as health care workers?
- Have you ever attended HIV and AIDS Counselling training?
- If yes, are you presently applying the knowledge you got from this training?
- If no, how are you helping people needing counselling intervention in your clinic/centre?

<b>Cognitive Restructuring Worksheet Example</b>	
<p><b>RATINGS:</b> Both before and after you complete column 4: (A) In column 2, rate the intensity of the emotions (0-100); and (B) In column 3, rate your degree of belief (0-100%) in the automatic thoughts</p> <p><b>COGNITIVE DISTORTIONS:</b> In column 3, identify any cognitive distortions in the ATs.</p>	
<p><b>1. Situation:</b> Thinking about not having a girlfriend.</p>	<p><b>2. Emotions / ratings:</b> Sad / Depressed; Discouraged; Ashamed. Rating before = 70-90; Rating after = 40. New emotion: Encouraged (rating = 50)</p>
<p><b>3. Automatic thoughts / ratings:</b></p> <p>I'm a loser because I've never had a girlfriend. I am undesirable. (Before: 95%; after = 45%) [name calling, magnifying negative-minimizing positive, overgeneralizing, unfair judgments]</p> <p>I will never have a girlfriend. (Before: 75%; after = 25%) [fortune telling, overgeneralizing]</p>	<p><b>4. Evaluate &amp; modify thoughts</b></p> <p>Does never having a girlfriend equal being a loser? No, it is a cruel distortion to call myself a loser. I have many positive qualities that contradict the label of loser.</p> <p>Does never having a girlfriend mean I am undesirable? Although it is possible that women find me undesirable, there are other plausible explanations for my never having a girlfriend- most notably the fact that I have never asked a woman out on a date. Why not? Because I've been perhaps too pessimistic and this has discouraged me and made me nervous.</p> <p>Is there any evidence that I may not be undesirable? Yes, I have been told by several people I am good looking, smart, and hard-working.</p> <p>It may be true that I will never have a girlfriend if I never make any attempts to get one. What can I do about this? I can work to correct my overly negative thinking. I can learn to gradually increase my confidence and comfort in interacting with women by learning new skills and by trying out new behaviors. The fact that I have never had a girlfriend in the past does not have to generalize to the future.</p>

## How stressed are you? Take this quiz to find out

<b>In the last month, how often have you:</b>	Never	Almost Never (1)	Some- times (2)	Fairly Often (3)	Very Often (4)
1. Been upset because of something that happened unexpectedly?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Felt that you were unable to control the important things in your life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Felt nervous and "stressed"?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Felt unsure about your ability to handle your personal problems?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. Felt that things weren't going your way?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. Found that you could not cope with all the things that you had to do?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. Been unable to control irritations in your life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. Felt that you weren't on top of things?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. Been angered because of things that were outside of your control?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. Felt difficulties were piling up so high that you could not overcome them?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<a href="#">Show Score</a>					



Score:

Interpreting the score:

Score	Your stress level
0 to 10	<b>Below average.</b> Congratulations, you seem to be handling life’s stressors well at the moment.
11 to 14	<b>Average.</b> Your life is far from stress-free so now is the time to learn how to reduce your stress to healthier levels.
15 to 18	<b>Medium-High.</b> You may not realize how much stress is already affecting your mood, productivity, and relationships.
19 +	<b>High.</b> You’re experiencing high levels of stress. The higher your score, the more damage stress is doing to your mind, body, and behavior.
Next Step	<b>Read <a href="#">Stress Management</a>.</b>

**This questionnaire is not intended to replace professional diagnosis.**  
*Adapted from: Perceived Stress Scale - Sheldon Cohen*



Pictures taken during TRE by: Dr David Berceli the founder of TRE and South African TRE practitioners including the researcher of this study.

