

“I felt that I deserved it”

**An Investigation into HIV-Related PTSD, Traumatic Life Events, and the
Personal Experiences of Living with HIV: A Mixed-Method Study**

Melissa Jane Boulind

Supervisor Professor Charles Young

PhD Thesis

Rhodes University

Submitted in February 2014

This research was supported by a MRC scholarship.

Declaration of Originality

I, the undersigned, hereby declare that the work contained in this thesis is my own original work, unless otherwise referenced. Furthermore, it has not previously been submitted at any other university for the purposes of fulfilment of a degree.

Signed: _____

Date: _____

Abstract

There appears to be a growing body of literature focusing on PTSD and HIV-related PTSD (the diagnosis of HIV being the significant traumatic event) amongst HIV-positive samples, but only a few African studies that attempt to estimate the prevalence of PTSD amongst HIV-positive people, and even fewer that attempt to estimate the prevalence of HIV-related PTSD. The systemic review presented in this study is currently fully inclusive and is the most up-to-date available. Estimates of the prevalence of PTSD and HIV-related PTSD in South Africa range from 0.7 to 54.1% and, 4.2 to 40% respectively.

The current cross-sectional study made use of a mixed-method approach to investigate traumatic life events, PTSD and HIV-related PTSD within a primary health-care centre in KwaZulu-Natal. The quantitative sample consisted of 159 adults (18-50 years) who were compliant on ARV medication. Using the CIDI-PTSD module, the adapted CIDI-PTSD module for HIV, and IES-R, findings indicated that 62% had reported some kind of traumatic event in their lifetime, with 29.6% of participants meeting the criteria for lifetime PTSD, and 40.9% meeting the criteria for lifetime HIV-related PTSD. Altogether, 57.9% of individuals met the criteria for some form of PTSD (either regular PTSD or HIV-related PTSD), and 12.6% met the criteria for both PTSD and HIV-related PTSD. Of the different categories of traumatic events, interpersonal violence has the highest rate of PTSD, followed by a diagnosis of and living with HIV, and then disaster. Furthermore, the IES-R was compared for its usefulness as a screening measure for PTSD against both the CIDI, but results suggest that it is an inferior screening measure to the PDS.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

The qualitative study consisted of six participants who were examined using IPA methodology informed by the Ehlers and Clark (2000) Model of trauma. Their experiences revealed experiences of stigma, a number of negative appraisals, negative emotions and coping behaviours. Some of the latter might serve as compensatory mechanisms to avoid negative judgements. Hypervigilance seems to be a feature of ARV-compliance that might confer added vulnerability to PTSD and other anxiety disorders.

Acknowledgements

First and foremost, to Prof Charles Young and his family: Thank you for taking me on as a student, appreciating my idea, enhancing it and enabling me to complete this project. Also thank you for taking this research to Turkey and the UK and assisting me with my poster presentations for the ICP2012. You have been an amazing mentor.

To Prof Sarah Radloff thank you for your fantastic guidance with the quantitative analysis.

To the staff of the HIV clinic and the participants who opened themselves up to me: THANK YOU for sharing your lives with me, and answering my many questions fully and candidly.

To the Medical Research Council: thank you for the (much needed) financial assistance during 2010.

To my husband Andrew, and my family – thank you for always being so encouraging and believing that I could do this. A special THANK YOU to my wonderful dad for the long hours of proofreading.

Dedication

This thesis is dedicated to my Nanny Binkie who passed away on the 5th February 2009, just after I heard that I had been accepted into the PhD program.

A further dedication is warranted to all those living with HIV. I hope that this thesis contributes to a greater understanding of the strength you display and difficulties you endure, and it is my wish that it helps to improve services available at primary health facilities.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Table of Contents

Chapter 1.....	17
1.1. Significance of Present Study	17
1.2. Aim.....	21
1.3. Context of the study.....	21
1.4. The Public Health-Care System in South Africa and Availability of treatments.....	23
1.4.1. Patients who qualify for HAART.....	24
1.4.2. Treatments available.....	25
1.4.3. Challenges of HIV treatment in South Africa.....	26
1.4.4. Barriers to adherence.....	30
1.5. The Ugu District and G J Crookes Hospital.....	33
1.5.1. HIV testing and ARV treatment at G J Crookes Hospital.....	33
1.5.2. Initiation on ARV treatment.....	35
1.6. Overview and General Orientation of the Study.....	38
Quantitative Study.....	40
Chapter 2: HIV Prevalence.....	40
2.1. HIV Worldwide Statistics.....	41
2.2. HIV in Sub-Saharan Africa.....	43
2.3. HIV in South Africa.....	44
2.4. Summary.....	46
Chapter 3: Stigma and HIV.....	47
3.1. Definitions of Stigma.....	48
3.2. The Impact of Stigma.....	48
3.2.1. Public Stigma.....	48
3.2.2. Self-Stigma.....	49
3.3. HIV-Related Stigma.....	50
3.3.1. Individual models of stigma.....	51

HIV, PTSD AND TRAUMATIC LIFE EVENTS

3.3.2. Social models of stigma.....	52
3.4. Stigma and Disclosure.....	54
3.5. Common Stigmas.....	57
3.6. Coping with HIV-Related Stigma.....	58
3.7. Stigma as a Potential Change Agent.....	59
3.8. Summary.....	61
Chapter 4: Traumatic Life Events.....	62
4.1. The Difficulty in Defining Traumatic Events.....	63
4.2. The Burden of Traumatic Events in South Africa.....	67
4.3. Traumatic Events Associated with HIV.....	71
4.4. Summary.....	76
Chapter 5: The Emergence of PTSD as a Diagnosable Disorder.....	78
5.1. PTSD in DSM-IV-TR and DSM-5.....	79
5.2. PTSD in ICD-10.....	84
5.3. Critiques of the Concept of PTSD.....	86
5.3.1. The conceptual bracket creep in the definition of trauma.....	86
5.3.2. Pathologising.....	89
5.3.3. Culturally and socially decontextualised.....	91
5.3.4. Demand characteristics.....	94
5.4. The Question of Whether the Diagnosis of a Life-Threatening Illness Should be Included as a Category A Event that can Result in PTSD.....	95
5.4.1. Should a diagnosis of HIV be seen as a qualifying event?.....	98
5.5. Summary.....	103
Chapter 6: Ehlers and Clark Model.....	105
6.1. Understanding PTSD and Trauma Using the Ehlers and Clark Model.....	106
6.1.1. Deficits in autobiographical memories.....	107
6.2. Appraising Trauma and its Consequences.....	109
6.3. Strategies to Control the Threat and Symptoms.....	113

HIV, PTSD AND TRAUMATIC LIFE EVENTS

6.4. Implications of the Ehlers and Clark Model for the Treatment of PTSD.....	115
6.5. Support for the Ehlers and Clark Model.....	118
6.6. The Usefulness of the Ehlers and Clark Model in Understanding HIV-Related PTSD.....	120
6.7. Summary.....	122
Chapter 7: A Systemic Review of HIV-Related PTSD in Africa and Specifically in South Africa	125
7.1. Results.....	126
7.1.1. Assessment measures.....	126
7.1.1.a. A note on the different diagnostic instruments used in the studies.....	127
7.1.2. Demography.....	130
7.1.3. Time-frame.....	130
7.1.4. Geography.....	131
7.1.5. Design.....	131
7.1.6. Sample Size.....	132
7.1.7. Findings.....	132
7.1.7.a. Prevalence of PTSD using symptom checklists.....	133
7.1.7.b. Prevalence of PTSD using structured clinical interviews.....	133
7.2. Discussion.....	134
7.3. Summary.....	141
Chapter 8: Quantitative Methodology.....	147
8.1. Objectives.....	147
8.2. Participants.....	148
8.3. Measures.....	148
8.3.1. Consent forms and intake questionnaire.....	148
8.3.2. The Composite International Diagnostic Interview (CIDI).....	149
8.3.3. The Adapted PTSD Module of the Composite International	

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Diagnostic Interview (CIDI-HIV-PTSD).....	152
8.3.4. The Impact of Events Scale Revised (IES-R).....	152
8.4. Procedure.....	156
8.4.1. Responsibilities of the researcher.....	156
8.4.2. Data collection.....	156
8.5. Statistical Analysis.....	158
8.5.1. Bivariate analysis.....	159
8.5.2. Multivariate analysis.....	160
8.5.3. Receiver Operating Characteristic (ROC) curve.....	161
8.6. Ethical Considerations.....	163
8.6.1. Informed consent.....	163
8.6.2. Privacy and confidentiality.....	164
8.6.3. Risks and benefits.....	165
8.6.4. Compensation.....	165
8.6.5. Conflicts of interests.....	165
8.7. Summary	165
Chapter 9: Quantitative Analysis.....	167
9.1. Demographic Characteristics	167
9.1.1. Age.....	167
9.1.2. Gender.....	167
9.1.3. Race.....	168
9.1.4. Marital status.....	168
9.1.5. Education.....	168
9.1.6. Employment.....	168
9.1.7. Reason for HIV test.....	168
9.1.8. Length of time since diagnosis.....	169
9.1.9. Disclosure.....	169
9.1.10. CD4 count.....	169

HIV, PTSD AND TRAUMATIC LIFE EVENTS

9.2. Frequency of Item Responses.....	169
9.2.1. The Impact of Events Scale Revised (IES-R).....	169
9.2.2. The Composite International Diagnostic Interview (CIDI-PTSD) PTSD module.....	172
9.2.3. The Adapted PTSD Module of the Composite International Diagnostic Interview (CIDI-HIV-PTSD).....	172
9.3. Total Prevalence of PTSD, HIV-related PTSD and the Combined Prevalence of PTSD and HIV-Related PTSD.....	174
9.3.1. Lifetime Prevalence of HIV-related PTSD according to the CIDI- HIV-PTSD module.....	174
9.3.2. Lifetime prevalence of PTSD according to the CIDI-PTSD module..	174
9.3.3. Total and combined lifetime prevalence of PTSD and HIV-related PTSD.....	175
9.4. Frequency of Traumatic Events.....	176
9.4.1. Comparison of traumatic events.....	177
9.5. Bivariate Statistical Analysis.....	178
9.5.1. Gender.....	178
9.5.2. Age.....	179
9.5.3. Length of time since diagnosis.....	179
9.5.4. CD4 count.....	179
9.5.5. Disclosed their HIV-positive status to their family.....	179
9.5.6. Disclosed their HIV-positive status to their friends.....	179
9.5.7. Reason for HIV test.....	179
9.5.8. Previous experience of traumatic events.....	180
9.6. Multiple Regression Analysis.....	180
9.7. Logistic Regression Analysis.....	180
9.8. ROC Curve.....	181
9.9. Summary	183

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Chapter 10: Discussion.....	185
10.1. Demographic Characteristics.....	185
10.1.1. Race, gender and marital status.....	185
10.1.2. Education and employment.....	189
10.1.3. Reasons for being tested.....	191
10.1.4. Length of time since diagnosis.....	192
10.1.5. Disclosure.....	193
10.2. The Life-Time Prevalence of HIV-Related PTSD.....	195
10.3. The Life-Time Prevalence of PTSD.....	199
10.4. Total and Combined Life-Time Prevalence of PTSD and HIV-Related PTSD.....	202
10.5. The Lifetime Prevalence of Traumatic Life Events.....	203
10.6. The IES-R as a Screening Measure for HIV-Related PTSD.....	204
10.7. Summary.....	205
Qualitative Study.....	207
Chapter 11: Qualitative Methodology.....	207
11.1. Using an IPA Methodology with a Theoretical Model of Interpretation.....	207
11.2. Interpretative Phenomenological Analysis.....	208
11.3. The Origins of IPA	210
11.3.1. Phenomenology.....	211
11.3.2. Hermeneutics.....	212
11.3.3. Idiography.....	213
11.4. The Aim of the Qualitative Study.....	214
11.5. Researcher as an Active Participant.....	217
11.6. Limitations of IPA.....	217
11.7. Qualitative Data Collection.....	218
11.8. The Sample.....	219
11.9. Data Collection.....	219

HIV, PTSD AND TRAUMATIC LIFE EVENTS

11.10. Data Analysis.....	222
11.10.1. Step One: Reading and re-reading.....	223
11.10.2. Step Two: Initial noting.....	223
11.10.3. Step Three: Developing emergent theme.....	223
11.10.4. Step Four: Searching for connections across emergent themes.....	223
11.10.5. Step Five: Moving on to the next case.....	224
11.10.6. Step Six: Looking for patterns across cases.....	224
11.11. Validity.....	224
11.11.1. Validity in heory.....	224
11.11.2. Sensitivity to context.....	225
11.11.3. Commitment and rigour.....	225
11.11.4. Transparency and coherence.....	226
11.11.5. Impact and importance.....	227
11.12. Ethical Considerations.....	227
11.13. Summary	228
Chapter 12: Qualitative Findings and Discussion.....	229
12.1. Participants.....	229
12.1.1. Participant A	230
12.1.2. Participant B	231
12.1.3. Participant C.....	231
12.1.4. Participant D	232
12.1.5. Participant E	232
12.1.6. Participant F	233
12.2. Themes.....	234
12.2.1. Theme 1: Stigma.....	235
12.2.2. Theme 2: Negative Appraisals of the Self, World and Future.....	238
12.2.2.a. My life is not worth living.....	239
12.2.2.b. My life is threatened.....	240

HIV, PTSD AND TRAUMATIC LIFE EVENTS

12.2.2.c. I am cursed	242
12.2.2.d. I am contaminated.....	243
12.2.3. Theme 3: Emotional Responses.....	245
12.2.3.a. Fear, helplessness and horror	246
12.2.3.b. Anger, sadness, guilt and frustration.....	248
12.2.4. Theme 4: Cognitive and Behavioural Coping Strategies.....	250
12.2.4.a. Social withdrawal.....	251
12.2.4.b. Denial.....	252
12.2.4.c. Rumination.....	253
12.2.4.d. Hypervigilance.....	255
12.2.4.e. Embracing responsibility.....	258
12.2.4.f. Having a positive outlook.....	262
12.2.4.g. Religion.....	263
12.2.4.h. Social support and disclosure.....	265
12.3. Summary.....	270
Chapter 13: Conclusions.....	271
13.1. Findings of the Systemic Review.....	271
13.2. Quantitative Findings.....	272
13.3. Qualitative Findings.....	274
13.4. The Usefulness of a Mixed-Method Approach.....	275
13.5. Implications.....	276
13.5.1. Recommendations.....	277
13.6. Limitations.....	278
13.7. A Note of the Changes Introduced by DSM-5.....	279
13.8. My Reflections	282
Reference List.....	284
Appendix.....	351

List of Tables

Table 1: Statistics for the GI Drop-in Centre (ARV Clinic) at G J Crookes Hospital, Kwa-Zulu Natal, 2009-2010.....	37
Table 2: DSM-IV-TR Criteria for PTSD	81
Table 3: New DSM-5 Criteria for PTSD.....	83
Table 4: ICD-10 Criteria for PTSD.....	85
Table 5: Ehlers and Clark's Examples of Negative Appraisals.....	112
Table 6: Selected Studies of PTSD in Africa and South Africa.....	143
Table 7: Composite International Diagnostic Interview, PTSD Module (CIDI-PTSD) Sample Items	151
Table 8: Impact of Events Scale - Revised (IES-R) Sample Items Grouped According to Domain.....	155
Table 9: Summary of Attendance	158
Table 10: Selected Variables.....	170
Table 11: The IES-R Frequency Distribution of Responses.....	171
Table 12: Frequency of Individual Responses, CIDI-PTSD and CIDI-HIV-PTSD.....	173
Table 13: Prevalence of PTSD, HIV-Related PTSD and the Combined Prevalence of PTSD and HIV-Related PTSD.....	175
Table 14: Frequency Distribution of Traumatic Events other than the Diagnosis of HIV Event.....	177
Table 15: Rate of PTSD.....	178
Table 16: IPA Schedule of Questions.....	221
Table 17: Demographic Data of Qualitative Sample.....	230
Table 18: Group Themes.....	234

List of Figures

Figure 1. The adapted Ehlers and Clark (2000) Model for HIV-related PTSD.....	124
Figure 2. Roc Curve	182
Analysis.....	

Chapter 1

In 1983 scientists isolated and named a virus which was found to be the cause of a new disease called Acquired Immunodeficiency Syndrome, more commonly coined 'Aids' (Broder & Gallo, 1984). Aids is an infectious disease of the immune system which is caused by a human immunodeficiency virus (HIV), and characterised by a decrease in the number of helper T cells which results in severe damage to the immune system, leaving the body vulnerable to a variety of infections. HIV is transmitted via bodily fluids such as semen and blood (AIDS.gov, 2012; The American Heritage Science Dictionary, 2013). This life-threatening condition has formed the basis of much research and debate, but, in contrast to many other studies that focus on the biomedical aspects of HIV infection, this research explores the psychological traumas associated with HIV infection amongst a population of HIV-positive individuals who are already compliant on anti-retroviral (ARV) medication. The significance of this study is described, followed by the context in which the data was gathered.

1.1. Significance of the Present Study

“Mental health interventions are critical to worldwide efforts to contain the spread of the Human Immunodeficiency Virus (HIV) and to treat those who are already infected or affected by it” (Cournos, Mckinnon & Wainberg, 2005, p. 135). As the prevalence¹ has grown, so has our understanding of the illness. The variety of treatments now available has transformed the perception of HIV in that it is no longer viewed as a necessarily fatal illness (Donenberg & Pao, 2005), but rather as a life-threatening, chronic medical

¹ “Prevalence” is the total number of cases in a given time frame (The American Heritage Stedmans Medical Dictionary, 2007).

HIV, PTSD AND TRAUMATIC LIFE EVENTS

condition (Withell, 2000). However, in this respect, South Africa is still behind the developed world: though the medical advances in the understanding and management of HIV infection are advanced, the significant mental health consequences of HIV infection are only now starting to be appreciated. HIV disease progression may be influenced by a number of physical and psychological stressors which impact on functioning and daily life (Scott-Sheldon, Kalichman, Carey & Fielder, 2008). Living with HIV involves managing many stressful disease-related events in addition to the normal burdens of everyday life (O’Cleirigh, Ironson & Smits, 2007). Consequently, mental health problems may occur as risk factors for HIV, co-morbidly with HIV, or as a result of HIV and the consequences thereof (Cournous et al., 2005). The Human Sciences Research Council’s (HSRC) Round Table Discussion on Mental Health and HIV/AIDS concluded that the extent of mental health problems in HIV-positive individuals in Africa is largely unknown, and studies which focus on the prevalence of mental health problems within an HIV-positive population appear to be a research deficit in need of rectification (Kelly, 2003a; Kelly 2003b). The diagnosis and treatment of such problems are of the utmost importance as psychiatric manifestations may result on serious consequences if not identified (Owe-Larsson, Säll, Salamon & Allgulander, 2009).

The prevalence of mental disorders appears to be higher among HIV-positive individuals than in the general population (Freeman, Nkomo, Kafaar & Kelly, 2008), which may be attributed to pre-morbid mental conditions (which may in turn increase vulnerability to infection), the effect of the virus on the nervous system, the psychological impact of living with HIV/AIDS, the side-effects of the medication and/or the result of stigma and

HIV, PTSD AND TRAUMATIC LIFE EVENTS

discrimination (Freeman, Patel, Collins & Bertolote, 2005). Bing et al. (2001) found that the prevalence rate of psychiatric disorders among patients suffering from HIV in the United States was approaching 50%, while a study conducted in Nigeria found co-morbid psychiatric disorders in 59% of HIV-positive participants (Adewuya, Afolabi, Ola, Ogundele, Ajibare & Oladipo, 2007). This is supported by a large South African study, which found that 44% of patients with HIV met the criteria for at least one psychiatric disorder (Freeman et al., 2008). It is evident that detecting, understanding and treating the behavioural and psychiatric problems that interfere with safe sex practices or contribute to unsafe (HIV-risk) practices should be a global priority (Cournous et al., 2005), as undiagnosed and untreated mental illness may well lead to riskier behaviour amongst HIV patients, which may in turn contribute to the further spread of the HIV virus (Hutton, Lyketsos, Zenilman, Thompson & Erbeling, 2004). Although the treatment of anxiety and depression in HIV patients was not a significant area of concern in the past, when most medical attention was focused on keeping people alive for as long as possible, the necessary mental health care is becoming increasingly apparent as more and more HIV-positive patients survive for longer (Cabaj, 1996). My study is one such contribution to this current research deficit.

Of the various psychiatric disorders associated with HIV, the focus of this study is on post-traumatic stress disorder (PTSD). The prevalence of PTSD amongst those who are infected with HIV in South Africa may be high for a variety of reasons - including the fact that they have been exposed to the trauma of being diagnosed with a life-threatening, stigma-associated illness, and have often experienced the trauma of HIV-related medical complications (Leserman, 2003), as well as the fact that those at the highest

HIV, PTSD AND TRAUMATIC LIFE EVENTS

risk of HIV infection are also at risk of stigmatisation, violent domestic abuse and crime (Young, 2011). It is essential that the prevalence of PTSD and traumatic life events is carefully measured so that appropriate public health interventions can follow.

A number of South African studies examine PTSD amongst HIV-positive people (e.g., Els, Boshoff, Scott, Strydom, Joubert & van der Ryst, 1999; Joska, Fincham, Stein, Paul & Seedat, 2010; Myer, Smit, Le Roux, Parker, Stein & Seedat, 2008; Olley et al., 2003; Olley, Seedat & Stein., 2006), but few have examined HIV-related PTSD. Such studies (Freeman et al., 2008; Martin & Kagee, 2008; Olley, Zeier, Seedat & Stein, 2005) restricted their focus to the prevalence of PTSD following the receipt of an HIV-positive diagnosis. To date there are no published South African studies that specifically report and explore the prevalence of traumatic events, PTSD, HIV-related PTSD (with living with HIV as the qualifying trauma), and the combined prevalence of PTSD amongst a sample of ARV-compliant participants making the present study unique. Furthermore, at the time of this research, this study provides the most up-to-date systemic review of the prevalence of PTSD in Africa and South Africa. Moreover, it contextualises the quantitative data with rich qualitative data by which our understanding of the prevalence rate is advanced. For example, while it is often assumed that successful ARV treatment may alleviate many of the fears that follow HIV diagnosis, my study suggests that ARV treatment inevitably involves such a level of hypervigilance that it might actually be implicated in maintaining PTSD and other anxiety disorders.

1.2. Aim

The aim of this study is to contribute to the growing literature which deals with HIV and the psychological consequences thereof. This project is original in that it uses a mixed-method approach which focuses on the prevalence of diagnosable symptoms of PTSD and the prevalence of traumatic life events in an HIV-positive sample of 159 individuals who are compliant on anti-retroviral treatment. This is followed by the rich qualitative accounts of six individual cases using an Interpretive Phenomenological Analysis (IPA) approach which are contextualised using the Ehlers and Clark (2000) Model of PTSD.

1.3. Context of the Study

This study took place at a primary health-care centre in the province of KwaZulu-Natal in South Africa. To contextualise the parameters, the public health-care system, qualifying criteria for anti-retroviral medication, treatments available and barriers to adherence are discussed below. This is followed by an overview of the locality of the hospital, and in particular the staff and patients attending the HIV clinic. Before this, however, I briefly describe my own growing involvement and interest in the mental health care of those who are HIV-positive.

My relationship with trauma and PTSD has been longstanding. Prior to receiving my Masters Degree in Clinical Psychology at Rhodes University in 2004-2005, I was working for a non-government organisation called SafeCare, in KwaZulu-Natal. This body was involved in the providing of support to survivors of accidents, rape, assault and other trauma. In addition to this, I was already serving as a volunteer Life-Line call centre counsellor working with similar cases.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

In 2006 I was allocated to G J Crookes Hospital in Kwa-Zulu Natal for my community service year in clinical psychology, following which I was offered a post as a junior level clinical psychologist at the same hospital. The only available office space at this time happened to be adjacent to the ARV Clinic, and it quickly became apparent that the clinic was extremely busy. I was frequently asked to assist with those who were non-compliant with their medication, as well as with other cases where the ARV Counsellors felt that the patients would benefit from psychotherapy. With so many sick people attending the ARV clinic, it was evident that this was an area which would benefit from further research and intervention. Being familiar with the hospital setting, HIV protocols and procedures gave me the confidence to undertake the research, and further enabled me to communicate with participants comfortably and in a knowledgeable manner (Wengraf, 2001).

In my role of psychologist I worked closely with the medical officers and the dietician, and frequently heard their frustrations that there were so many patients and such limited resources. After four years of watching and learning, I approached the research with caution, anticipating that it would lead me to motivate for more HIV counsellors and with the expectation that there is a need for psychologists allocated specifically to HIV departments. This would assist not just the patients, but also the staff members who deal with life-threatening illnesses like HIV on a daily basis. While undertaking the research, it became apparent that this topic fulfilled two of my personal goals: firstly, to create a change within the government psychology department; and secondly, to help with and make meaning of something which apparently makes no sense other than a legacy of sadness and despair. Elliot, Fischer and Rennie (1999) highlight that taking responsibility for

HIV, PTSD AND TRAUMATIC LIFE EVENTS

one's own emerging perspectives during research is as important as identifying one's own initial perspective. During the research I was astounded by the resilience of the participants and sometimes shocked by the stories of trauma and hardship. It made my efforts to motivate for further support in HIV departments even more strenuous.

1.4. The Public Health-Care System in South Africa and Availability of HIV Treatments

In developing countries, the advance of Highly Active Anti-Retroviral Therapy (HAART) has transformed the lives of HIV-positive people (Coté, Delmas, Delpierre, Sylvain, Delon & Rouleau, 2009) and has resulted in decreased mortality, which in turn has led to HIV infection being downgraded from a terminal illness to a chronic manageable disease. However, it is necessary for the patient to remain on HAART indefinitely as the medication does not eliminate the infection. In 2005 alone, the number of people receiving ARV medication in Africa doubled (World Health Organisation, 2006), illustrating both the need and the demand for access to treatment. By the end of March 2005, all 53 health districts in South Africa had at least one service-point available for AIDS-related care and treatment (Knight, 2006). Despite this, in 2007, an estimated 537 803 of South Africans in need of anti-retroviral medication were not receiving it, even though they had access to health clinics, and a further 4 589 436 were HIV-positive but not yet requiring treatment (Kelly, Freeman, Nkomo & Ntlabati, 2008). South Africa has the largest anti-retroviral therapy treatment programme in the world (HIV and AIDS in South Africa, n. d.), yet access to treatment remains low. Statistics indicate that coverage for HIV treatment in South Africa in 2010 is at approximately 50% of diagnosed sufferers (Department of Health, 2010).

HIV, PTSD AND TRAUMATIC LIFE EVENTS

In August 2011, the South African government announced the raising of the ARV minimum qualifying CD4 count from 200 to 350 (HIV and AIDS in South Africa, n.d), in line with the World Health Organisation guidelines, which increased even further the number of people qualifying for ARV medication but not currently receiving medication (Granich et al., 2012).

1.4.1. Patients who qualify for HAART. In KwaZulu-Natal the ARV treatment programme in the public sector began in March 2004 (Vella et al., 2008) in accordance with the South African Department of Health's (2004) suggested guidelines for the initiation of HAART treatment. These guidelines have been updated and improved since the data collection phase of this study when patients who qualified for ARV medication were required to have a CD4 count of less than 200 (Department of Health, 2004). The only exceptions were HIV encephalopathy (as diagnosed by a psychiatrist) and HIV-positive expectant mothers, who were started on ARV treatment regardless of their CD4 status. In addition, it was recommended that the following psycho-social factors be considered:

- a demonstration of “reliability” in that patients have attended three or more scheduled visits to an HIV clinic,
- no current alcohol or substance abuse,
- no untreated active depression,
- disclosure of status to a family member or a member of a support group,
- acceptance of HIV status and insight displayed into the consequences of HIV infection and the role of HAART,
- ability to attend future appointments at the ARV clinic regularly,
- willingness, motivation and readiness to undergo and adhere to the

HIV, PTSD AND TRAUMATIC LIFE EVENTS

HAART medication regime (Department of Health, 2004).

During the course of this research, in 2010, the South African government's ARV guidelines did not correspond with the World Health Organisation (WHO) recommendations that HIV-positive individuals should start ARV treatment when their CD4 counts drop below 350 (Mayosi, Lawn, van Niekerk, Bradshaw, Abdool Karim, & Coovadia, 2012), whereas South Africa maintained the status quo – that most of the HIV-positive population would only become eligible to begin treatment when their CD4 counts dropped to 200, except for pregnant women, those with tuberculosis (TB) with a CD4 count below 350, and individuals with multi-drug resistant TB or those who present with stage 4 opportunistic infections (Alcorn, 2010). However, a year later the government amended the treatment guidelines in line with the WHO recommendations. So, since 2011, treatment was initiated at a CD4 count of less than 350 (HIV and AIDS in South Africa, n.d; Irin/Plus News, 2009; Irin, 2011). The challenge for HIV clinicians, however, is that many people present for testing and treatment only when they are sick, regardless of the ARV qualifying criteria (Lawn & Wood, 2006).

1.4.2. Treatments available. Anti-retroviral (ARV) treatments delay the progression from HIV to AIDS and allow HIV-positive individuals to live relatively normal, healthy lives. Such treatments have been available in the wealthier developed world since 1996 (Thom, 2008). In 2004 there were twenty ARV treatments available to private medical practitioners in South Africa (Abah et al., 2004). However, within the public sector of the health system there are only two regimes available, and these utilise only a handful of different medicines (Department of Health, 2004; Department of Health, 2010): all patients begin treatment on the first-line regimen and, should this

HIV, PTSD AND TRAUMATIC LIFE EVENTS

fail, they are then prescribed the second-line regimen (Vella et al., 2008). If this also fails, the patient has exhausted the options within the public sector, unless a specialist salvage treatment programme can be identified, which, in an overburdened and under-resourced public health-care system, is quite unlikely.

Durante et al. (2003) found that knowledge regarding the effects of anti-retroviral medication on the viral load is a better predictor of compliance than education level, thus stressing the significance of providing information to patients. It is of the utmost importance that details be provided by health professionals using terminology that patients can understand. Gray (2006) found that the quality of the patient and service-provider relationship combined with the support from friends and family encourages high adherence to treatment programmes, which is essential for medication to be effective in minimising the viral load and preventing drug resistance. Due to the very limited treatment alternatives within the public health system, adherence is even more important than it is elsewhere. It is stressed to patients that they cannot skip their medication and that doses should be taken at the same time every day, indefinitely. Highly-active anti-retroviral therapy (HAART) requires an adherence rate of 95% to achieve a beneficial long-lasting effect (Paterson et al., 2000). Thus it is essential that researchers examine the risk factors, including mental health issues like PTSD that may interfere with adherence, as this study does.

1.4.3. Challenges of HIV treatment in South Africa. The ARV roll-out in South Africa follows years of government denial that resulted in thousands of needless deaths. A conservative estimate is that 330 000 individuals died between 2000 and 2005 as a result of being HIV-positive and

HIV, PTSD AND TRAUMATIC LIFE EVENTS

not having access to an ARV treatment programme (Chigwedere, Seage, Gruskin, Lee & Essex, 2008). A qualitative study conducted in KwaZulu-Natal, South Africa, found that participants felt powerless and accepted HIV-related deaths as being part of their everyday lives (Demmer, 2007). The delayed start to the national roll-out resulted in even greater pressure on the health service, as health-care practitioners, already attempting to treat thousands of HIV-positive patients without the necessary medicines, then had the additional burden of enrolling them on to newly-established ARV clinic programmes in a massive effort to catch up with much of the rest of the continent.

The South African government initiated ARV treatment in 2004. The regimes are predominantly hospital-based and are monitored by the medical officer (Palitza, 2009). The sheer size of the HIV-positive population places a huge strain on the public health system, which already carries a significant workload (UNAIDS, 2006) and which is characterised by major human resources deficiencies and other weaknesses (Coovadia, Jewkes, Barron, Sanders & McIntyre, 2009). South Africa's National Strategic Plan 2007-2011 expanded the role of health-care workers by including nurses in the management of ARV treatment and care, in order to alleviate some of the responsibility from medical officers and to allow ARV medication to be more accessible to far-flung communities. Yet hospitals with centralised treatment centres are frequently overburdened, and as a result patients sometimes wait months to gain access to treatment (Palitza, 2009). In 2007, only 34% of those needing access to treatment were able to obtain anti-retroviral medications (Palitza, 2009) compared to an estimated 94% accessibility rate in western countries (Coté et al., 2009).

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Some patients already enrolled on ARV programmes have not consistently received their medication for a variety of reasons. In some cases drugs are not getting to the clinics timeously, and in others strike action by hospital and clinic employees has affected access to treatment. In 2010, a three-week public service strike disrupted health services across the country (Smith, 2010) with nurses and doctors refusing to come to work. Many hospitals were forced to close their doors because it was felt that intimidation by strikers rendered it too unsafe for patients and those members of staff who wished to work to attend. As a result, many patients who were involved in ARV treatment programmes were unable to access their local health centres when they attempted to do so. Others may have stayed away voluntarily due to safety concerns.

In 2008-2009 the health budget in the Free State Province was exhausted, resulting in a four-month ARV moratorium (El-Khatib & Richter, 2009; Hodes & Grimsrud, 2011). Such inconsistencies within the health department lead to a lack of faith in the public health system, which only exacerbates the feelings of anxiety surrounding an HIV-positive diagnosis (Young, 2011).

Moreover, poor infrastructure, especially in rural areas, may mean that some patients do not have access to reliable transportation to enable them to reach clinics. In recognition of this, in the Ugu District of KwaZulu-Natal, an organisation named Nakimpilo-Care for Life, is based at G J Crookes Hospital, and is associated with the Department of Health to assist in providing transport funds to 100 HIV-positive mothers so that they can attend the ARV centre (Impumelelo, 2008). An additional challenge occurs when patients are reluctant to apply for assistance because they are afraid either of

HIV, PTSD AND TRAUMATIC LIFE EVENTS

what the treatment entails, or of the stigma they may experience if they are publicly perceived to be HIV-positive.

Efficient HAART distribution requires a well-run, efficient health system, sufficient staff and adequate funding. A study conducted in South Africa, Lesotho, Swaziland and Botswana found that 90% of participants do not have health insurance, which would indicate that the vast majority of people living with HIV/AIDS have no option but to rely upon government-funded health services for HIV care and treatment (Makoea et al., 2005). Fox and Rosen (2010) found that, after a review of patient-retention studies, the two-year retention rate for patients on ARV treatment is 70%. Some of this may be attributed to current difficulties within the South African health system, like poor infrastructure, an inconsistent supply of ARV medication, and a shortage of dedicated health-care professionals who remain in government service. Thus, Cournous et al. (2005) make the point that HIV treatment will only be both sustainable and affordable if the number of new infections is reduced.

The HSRC's Round Table Discussion held in 2003 mentioned the role of traditional healers as an important resource in the management of HIV and the impacts thereof (Kelly, 2003b). But a South African study found that, although their understanding of HIV was deemed adequate, 21% of traditional healers continued to believe that there was a "cure" for AIDS and engaged in several HIV risk procedures (Peltzer, Mngqundaniso & Petros, 2006). In particular, 73% of the traditional healers studied had performed incisions or scarifications whilst 43% had carried out enemas in the three months prior to the research. In addition, 4% had re-used a razor blade and 9% had re-used enema equipment without sterilisation. Twenty percent of the traditional

HIV, PTSD AND TRAUMATIC LIFE EVENTS

healers were found to be attempting to treat HIV, and 26% did not know where to refer patients for HAART. As HAART does not eliminate the HIV virus, and because there is a high risk of developing resistance, ongoing compliance with ARV medications is essential, and everyone needs to work together to promote adherence to the treatment regime, including traditional healers who are often the first port of call for many South Africans, so these findings were somewhat disconcerting.

Despite some of the practices described above, in South Africa the role of traditional medicine is important and forms a respected and integral part of many communities. Traditional healers often act as herbalists, prophets and psychologists (Bouzaglou, 2006) and, as such, are in a position to encourage ARV adherence. The Ugu Health District recognises the role that traditional healers have in creating HIV awareness and reducing stigma associated with being HIV-positive (Cele, 2008).

1.4.4. Barriers to adherence. It is essential for health-care practitioners to be aware of any factors negatively impacting on their patients' adherence to treatment regimes. Such barriers may include factors such as level of education, employment, transportation difficulties or cost associated with travel, lower socio-economic status, side-effects of ARV medications (Chesney, Morin & Sherr, 2000; Heyer & Ogunbanjo, 2006), the stigma of HIV and its treatment (Cao, Sullivan, Xu & Wu, 2006; Chesney & Smith, 1999; Chesney et al., 2000; Kalichman & Simbayi, 2003), domestic violence, drug and alcohol use (Chesney et al., 2000; Nordqvist, Sodergard, Tully, Sonerborg & Kettis Lindblad., 2006), mental illness (Kagee, 2004a; Nordqvist et al., 2006) individual or cultural beliefs (Groh et al., 2011; Heyer & Ogunbanjo, 2006; Lindegger & Quayle, 2009; Van Dyk, 2001). It is

HIV, PTSD AND TRAUMATIC LIFE EVENTS

worrying to note that a study investigating the physical symptoms and beliefs about treatment compliance illustrated that participants who continued to display physical symptoms whilst on HAART misconstrued these symptoms to indicate that either that the treatment was not working, or that HAART itself was causing the symptoms (Gonzalez et al., 2007).

It is likely that most of the patients who are not retained by ARV treatments may have died of HIV-related illnesses, creating the impression that the medicines are not effective. Furthermore, shortages of medications (possibly due to lack of funding or an unforeseen increase in the numbers of patients) are likely to contribute to a loss of faith in the government health system, which may well exacerbate patients' lack of compliance and their failure to keep follow-up appointments. The stigma of being HIV-positive (which is discussed further in Chapter 3), affects every HIV-positive patient without exclusion, and may hinder access and/or medication compliance primarily because people are reluctant to risk disclosure (Whetten, Reif, Whetten & Murphy-McMillan, 2008). Furthermore, a study of Xhosa women living with HIV in the Western Cape Province in South Africa has associated HIV-related stigma with poorer mental health (Wingwood et al., 2008).

Whetten et al. (2008) mentioned the lack of trust in both government and health-care providers as hindering HIV prevention and the use of medical services available. Prior to the introduction of ARV medication in 2004, many HIV-positive people received disability grants because they were unable to work on the grounds of ill-health (Paoli, Mills & Gronningsaeter, 2012). An unintended consequence of ARV medication is that it may lead to an improvement in health which precludes the entitlement to a disability grant, thereby removing the only source of income for purchasing food and

HIV, PTSD AND TRAUMATIC LIFE EVENTS

other essentials. As a result, HIV-positive individuals may elect to not take their ARV medications properly in order to restrict their CD4 counts to a level where they are considered disabled (HIV and AIDS in South Africa, n.d; Leclerc-Madlala, 2006; Nattrass, 2006; Paoli et al., 2012),

A study by Vella et al. (2008) on the ARV therapy programmes in KwaZulu-Natal found that staff working at such facilities felt that poor social-economic conditions, low levels of adherence, the presence of side-effects, failure to keep appointments and the advanced stage of the HIV infection when patients began ARV treatment all affected the delivery of care to HIV-positive patients.

Psychological, psychosocial and psychiatric factors play an important role in compliance with ARV treatment regimes and should be taken into consideration to prevent drug-resistance (Baingana, Thomas & Comblain, 2005). Indeed, Kelly et al. (2008) highlight that mental stability, sobriety and emotional robustness are all necessary to cope with the first few months of ARV treatment, which is when the greatest number of side-effects is likely to be experienced.

It seems that the poor mental health of many HIV-positive people in South Africa is a barrier to ARV compliance that is yet to be comprehensively addressed (Kelly et al., 2008). Exploring in detail every hindrance to adherence is beyond the scope of this thesis, but it is evident that the mental health of individuals is a significant area requiring further study and intervention. The present study, which examines not only PTSD and HIV-related PTSD, but also the total and combined prevalence of PTSD and HIV-related PTSD, is an important step forward.

1.5. The Ugu District and G J Crookes Hospital

The study was based in the Ugu Health District in KwaZulu-Natal. The total population of the Ugu district is estimated to be 722 484, people, 53% of whom are female (Frith, 2011; Statistics South Africa, 2011). This district is classified as mostly (76%) rural, with 8% of the population living in informal settlements (Department of Health, 2012b). The unemployment rate is high and the majority live below the economic breadline.

The Ugu District consists of six local municipalities, and is serviced by three district hospitals, one regional hospital, one specialised hospital, 38 fixed clinics and 15 mobile clinics with 215 visiting points (Department of Health, 2012a). Within the Ugu District there is an integrated TB/HIV and AIDS nutrition programme in place, which is offered by all facilities. Furthermore, these same treatments are available in all hospitals (Department of Health, 2012b).

This study took place at G J Crookes Hospital, a 300-bed primary health-care centre situated in Scottburgh, a small town 50 kilometres south of Durban. The hospital serves three municipalities covering 2 470 square km (Department of Health, 2012c), assisting with the health-care needs of a quarter of a million people in the surrounding rural areas (Vella et al., 2008). It operates as a referral centre for 15 clinics and has four mobile clinics (Department of Health, 2012c).

1.5.1. HIV testing and ARV treatment at G J Crookes Hospital. G J Crookes Hospital is a designated site for the roll-out of anti-retroviral medication with an estimated cross-cultural, multi-racial HIV-positive patient base approaching 3000, many of whom are children.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

From personal observation, on a patient's first visit to the hospital he/she is directed to the file admission department where a hospital file is opened. The waiting period to obtain a hospital file varies according to the time of each patient's arrival. Non-urgent files are issued between 7am and 1pm daily, Monday to Friday. Outside these hours, only emergency files are issued. In the clinicians' experience, some people arrive at the hospital before 6am especially to be near the front of the queue, in the hope of reducing their waiting time. Once a hospital file has been opened the person is given a blue out-patient ("OP") card showing the appropriate unique file number. On subsequent visits, each patient is required to show the OP card to enable the appropriate hospital file to be drawn before being seen by the medical officer. No staff member is permitted to see a patient who has not collected his/her file.

At G J Crookes Hospital the waiting times are displayed on the notice-board in the Admissions Department. At the time of this study, the approximate waiting time to collect a hospital OP file, was 1 hour, whilst the average waiting time to see a medical officer was 5 hours, but this could vary either way, depending on the availability of staff. Such estimates are based on patient waiting time surveys which take place on specific days each year.

HIV testing at G J Crookes Hospital at the time of the research was conducted in a prefabricated structure named the Gateway Clinic. This clinic tests for HIV and/or TB. Patients may be tested either of their own volition, or on referral from a doctor. Counselling is given by trained HIV counsellors both before and after the HIV test. In KwaZulu-Natal the training for HIV Counsellors is a 10-day course given by the Hope Centre (which specialises in HIV) in Overport, Durban. Should a patient test positive for HIV, a blood

HIV, PTSD AND TRAUMATIC LIFE EVENTS

sample is taken and sent to the laboratory to obtain his or her CD4 count. The date of the HIV test and the patient's relevant status is recorded in the OP file.

At the time of the study, requirements for the qualification of ARV medication for HIV positive patients were: South African citizenship with an identity number, and a CD4 count of less than 200. The exceptions to the CD4 count of 200 were patients diagnosed by a psychiatrist as suffering from an HIV encephalopathy, and HIV-positive expectant mothers, who were (and still are) started on ARV treatment regardless of CD4 status. In all cases, patients are required to complete the readiness phase, demonstrate that they are ready and willing to take ARV medication, and be able to attend (and commit to attending) monthly follow-up appointments. As previously discussed, since the time of the study, the treatment guidelines have been revised in accordance with the World Health Organisation's recommendations, currently treatment is initiated at a CD4 count of less than 350 (HIV and AIDS in South Africa, n.d).

At the time of the study, the staff of the ARV Clinic, which is called the G1 Drop-in Centre, consisted of medical officers, social workers, professional nurses, staff nurses, data capturers, ward clerks, HIV counsellors and cleaners. Additional staff within the hospital to whom patients from the ARV clinic could be referred included the dietician, clinical psychologist, psychiatrist and medical officers working in various other departments (e.g. obstetrics and gynaecology).

1.5.2. Initiation on ARV treatment. Each patient is seen for a number of sessions individually by a counsellor before beginning ARV medication. During session 1, *The Readiness Phase*, the counsellors discuss living with

HIV, PTSD AND TRAUMATIC LIFE EVENTS

and managing HIV and AIDS. Patients are also educated about the medication, side effects, compliance, diet, healthy lifestyle and safe sex practices (Department of Health, 2004). In the second session, *The Initiation Phase*, treatment is started and it is the job of the counsellors to ensure that patients understand exactly how their medication is to be administered (Department of Health, 2004). A third session ascertains whether or not the patient is coping with the ARV medication. During follow-up visits, the counsellors assist the doctors and nurses in monitoring patients' compliance and coping skills. If difficulties are detected, patients are referred to the appropriate medical professionals.

Once the patients have been started on ARV they are required to attend the clinic once a month. At this visit, they are seen by an HIV counsellor and a medical officer who both monitor progress. In my experience, once compliant on ARV medication with no significant side-effects, patients are transferred to their closest community clinic for further management.

Waiting time for patients at the ARV clinic varies and no individual statistics are kept by the department in this regard. However, based on the observation of queues of patients and the limited number of staff, it is estimated that patients will spend 2-3 hours at the clinic. This was corroborated by patients who stated that it usually takes an entire morning to collect their monthly treatment.

Every patient is seen by the medical officer and HIV counsellors once every four weeks. Treatment literacy is good and patients are made aware of their treatment regime, medication, CD4 count and presenting symptoms at each visit. According to the faculty information officer, the most recent statistics indicate that the total number of HIV-positive patients on treatment

HIV, PTSD AND TRAUMATIC LIFE EVENTS

at the end of January 2010 was 5715, with an additional 44 patients waiting to begin treatment having completed the readiness phase (See Table 1).

Because the fear (and risk) of inadvertent disclosure is a major barrier to people accessing testing and care (Clark, Linder, Armistead & Austin, 2003; Nyabblade, 2006), separate hospital files are kept for the ARV treatment of patients. However, the G1 Drop-in Centre is situated in the same building as the male medical ward and, based on personal observation, there seems to be little privacy for people walking in and out. The centre is designated for ARV treatment, so staff and patients alike automatically assume that all patients at the clinic are HIV-positive. The doctor and counsellors have private cubicles, but patients sit in queues outside the office awaiting their turn. Confidentiality insofar as concerns their diagnosis and their HIV-positive status is therefore poor. A study evaluating ARV treatment across multiple centres (including the site of the current study) found that ARV clinics were in good condition but were overcrowded. As a result patients often sit outside (Vella et al., 2008).

Table 1

Statistics for the G1 Drop-in Centre (ARV Clinic) at G J Crookes Hospital, KwaZulu-Natal, 2009-2010

Patient Category	Male	Female	Total
Tested for HIV	1592	1762	3354
Testing HIV-positive	709	743	1452
Receiving ongoing counselling provided by ARV counsellors	6611	13110	19721
HIV patients screened for CD4 count	1079	1737	2816
HIV patients with CD4 counts less than 200	417	506	923

1.6. Overview and General Orientation of the Study

In the discussion above I introduced the research to the reader and plot the journey that this study has taken. I began by discussing the aims of the study, which was then contextualised with descriptions of the public health-care system of South Africa, the Ugu District and the primary health-care facility where this study took place. This is followed by a review of the relevant literature, which begins with an exploration of the prevalence of HIV in Africa and particularly in South Africa, followed by a discussion of HIV-related stigma. I then look at trauma, and the significance of examining Post-Traumatic Stress Disorder (PTSD) in relation to the Human Immunodeficiency Virus (HIV), and follow this with a systemic review, which is currently the most up-to-date available. The aim of the systemic review is to assess the prevalence, firstly, of diagnosable PTSD; and secondly, of HIV-related PTSD in a population of HIV-positive individuals, including HIV-positive people compliant on ARV medication in Africa and South Africa.

The systemic review is followed by the quantitative methodology and results, a study that investigates the prevalence of HIV-related and non-HIV-related PTSD and traumatic life events amongst a sample of ARV compliant patients at G J Crookes Hospital. The relationships between gender, race, length of time since diagnosis, age, education, HIV-related physical symptoms, traumatic life events and the presence of PTSD are also explored. The results highlight the need for appropriate mental health interventions among individuals suffering from HIV.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Finally, given that there exists a need for a PTSD screening measure, the performance of the self report revised Impact of Events Scale (IES-R) is rated against the structured Composite International Diagnostic Interview (CIDI).

The quantitative study is followed by a qualitative study, wherein the individual experiences of six participants from my sample group are explored. This is executed using an Interpretative Phenomenological Analysis (IPA), a relatively new qualitative research method which explores how participants make sense of their major life experiences (Smith, Flowers & Larkin, 2009). Smith et al. (2009) comment that the utilisation of an IPA approach to explore the individual experience of health and illness, is becoming more common. IPA studies are idiographic (Reid, Flowers & Larkin, 2005), favouring a small number of participants, and this facilitates focus on the similarities and differences of the experiences of individuals (Smith et al., 2009) as opposed to larger quantitative sample groups. It involves the detailed examination of each person's perception or account of an event (Smith & Osborn, 2003). The Ehlers and Clark (2000) Model of PTSD, considered to be one of the most comprehensive models of trauma, is used to frame the participants' responses. Finally, the different components are drawn together and I discuss the limitations of the current study and explore implications for future research.

Quantitative Study

In the following chapters I discuss the prevalence of HIV in Africa and South Africa. This is followed by an examination of PTSD as a diagnosable disorder and a discussion on the relevance of such a diagnosis in non-western countries. The prevalence of PTSD and anxiety, as well as the prevalence of PTSD and HIV-related PTSD is ascertained by means of a systemic review, the findings of which emphasise the importance of addressing mental health issues among HIV-positive individuals. This is followed by the presentation of the quantitative methodology, analysis and results, and then a discussion of the findings and their relevance.

Chapter 2: HIV Prevalence

The purpose of this chapter is to discuss the prevalence of human immunodeficiency virus (HIV) infections, taking into account (a) worldwide statistics, (b) Sub-Saharan Africa figures, and (c) data from South Africa. This will highlight the importance of addressing mental health issues in individuals who are HIV-positive, who are already living with a life-threatening illness.

HIV infections in developed countries continue to be a burden, affecting the more marginalised groups of society, such as homosexual men, migrants from developing countries, refugees, the homeless, and those who are mentally ill and/or poor (Green & Smith, 2004), whereas, in developing countries like South Africa, the HIV epidemic consists of many mini-pandemics, each having its own characteristics and trends as regards to HIV prevalence and its consequences (Grant & De Cock, 1998). AIDS continues to be a major global health priority and the number of people living with HIV continues to rise. This increase may be at least partially attributed to the

HIV, PTSD AND TRAUMATIC LIFE EVENTS

growing availability of ARV medications, which keep alive those who may otherwise have died (UNAIDS, 2011). According to the World Health Organisation (WHO), AIDS-related illnesses remain among the leading causes of death globally and are projected to continue as a significant cause of premature mortality in the coming decades (WHO, 2009).

2.1. HIV Worldwide Statistics

According to the WHO (2009), approximately 60 million people have been infected with HIV and 25 million have died of HIV-related causes since the onset of the HIV epidemic. Further data indicates that over 60% of people living with HIV have no basic knowledge of their illness, and less than 40% of people living with HIV actually know their HIV-status (UNAIDS, 2009). The WHO (2009) stressed that the number of HIV-positive individuals is still increasing, despite the progress achieved in preventing new HIV infections and in lowering the annual number of AIDS-related deaths. The WHO (2009) also expressed concern that the number of new HIV infections continues to outnumber those being treated, stating that “for every two people starting treatment, a further five become infected with the virus”.

Most recent statistics released by UNAIDS (2011) indicate that 34 million people were living with HIV at the end of 2010. This is an increase on figures from previous statistics which showed that HIV-positive numbers in 2008 had reached an estimated 33.4 million documented cases (WHO, 2009; UNAIDS, 2009). The number of new reported infections appears to have stabilised at the end of 2010 at 2.7 million annually, while the number of deaths is estimated to have dropped from 2 million in 2008 (WHO, 2009; UNAIDS, 2009) to 1.8 million in 2010 (UNAIDS, 2011), which is most likely

HIV, PTSD AND TRAUMATIC LIFE EVENTS

to be due to the increasing availability of anti-retroviral therapy (UNAIDS, 2011).

An estimated 430 thousand children were born HIV-positive in 2008, thus bringing the total number of HIV-positive children under the age of 15 to an estimated 2.1 million (UNAIDS, 2009; WHO, 2009). It has been found that, worldwide, 40% of all those newly-infected with HIV are aged 15 years and older (WHO, 2009). The continuing rise in the population of people living with HIV could possibly reflect the joint factors of an ongoing high rate of new HIV infections together with the beneficial effect of anti-retroviral therapy, as demonstrated by the fact that the total number of people living with the virus in 2008 was 20% higher than the number in 2000. This prevalence was roughly three times higher than the 1990 figure. By the end of December 2008, approximately 4 million people in low- and middle-income countries were receiving anti-retroviral therapy - a ten-fold increase over five years (UNAIDS, 2009).

In 2007 and 2008, national household surveys anonymously tested for HIV in 11 countries, including nine in Sub-Saharan Africa (UNAIDS, 2009). The epidemic appears to have stabilised in most regions, although prevalence continues to increase in Eastern Europe and Central Asia and in other parts of Asia due to a high rate of new HIV infections. Despite this, Sub-Saharan Africa remains the most heavily-affected region (UNAIDS, 2009; WHO, 2009), and accounts for 71% of all new HIV infections in 2008 (UNAIDS, 2009). As stated by Clark (2002a), Africa, particularly Sub-Saharan Africa, is regarded as the HIV pandemic's epicentre.

2.2. HIV in Sub-Saharan Africa

UNAIDS data indicates that HIV/AIDS has impacted severely on Africa, with an infection rate which has risen rapidly and a scale of prevalence which is largely unabated (UNAIDS, 2009; UNAIDS, 2010; WHO, 2009). Sub-Saharan Africa has been hardest hit by the HIV virus (HSRC, 2006; UNAIDS, 2006; UNAIDS, 2009; UNAIDS, 2011; WHO, 2009), and carries a disproportionate share of the HIV epidemic with 22.5 million HIV-positive people (68% of the global HIV statistics) living in these countries (UNAIDS, 2010). However, it appears that the rate of HIV infection in Sub-Saharan Africa may be stabilising or declining (UNAIDS, 2009; UNAIDS, 2010).

Nevertheless, Sub-Saharan Africa still accounts for approximately two-thirds of all people living with HIV worldwide, with an estimated 91% of all new infections among children, and an estimated 72% of AIDS-related deaths in 2008 (UNAIDS, 2009; WHO, 2009). Moreover, in Sub-Saharan Africa the epidemic has claimed so many lives that 14 million children have been orphaned (UNAIDS, 2009). According to the WHO (2009), the HIV epidemic varies from country to country, with Swaziland and Lesotho having the highest prevalence at 26% and 23% respectively (UNAIDS, 2008; WHO, 2009).

The HSRC highlights that the HIV epidemic exacerbates problems that children and families in Africa already face following decades of exploitation, poverty, civil and regional conflict, and natural disasters (HSRC, 2005). South Africa is home to the greatest population of people living with HIV, with approximately 5.7 million as at 2007 (UNAIDS, 2008; WHO, 2009).

2.3. HIV in South Africa

Data on the incidence² of HIV can only be obtained via large-scale cohort research, such as the South African national census conducted in 2005, which formed the basis for research by Rehle, Shisana, Pillay, Zuma, Puren and Parker (2007). Findings of this household study reflected an HIV incidence amongst ages 15 to 49 years, averaging at 2.4% per year, the highest being found in females of the 20 to 29 years age category, at 5.6%. This is significantly higher than the HIV incidence among males of the same age group (0.9%).

During the last decade a number of prevalence studies have been undertaken using different methods, the results of which vary accordingly. In 2002, 2005 and 2008 South Africa conducted cross-sectional National HIV Surveys, visiting 15 thousand households and obtaining a response rate of almost 13.5 thousand. The South African National HIV survey conducted in 2008 found that 10.9% of all South Africans over the age of two years were living with HIV, with the highest prevalence in the 15-49 years age-group (Shisana et al., 2009; South Africa HIV and AIDS Statistics, n.d.). In females, those most likely to be infected were aged 25-29 years, whilst in males the peak was reached in the 30-34 years category. Results of this study suggested that the provinces of KwaZulu-Natal, Mpumalunga and Free State have the highest HIV prevalence at 15.8%, 15.4% and 12.6% respectively (Shisana et al., 2009; South Africa HIV and AIDS Statistics, n.d.). In 2008, in the same study, the figures categorised by population group showed the highest prevalence amongst black South Africans (13.6%), followed by

² "Incidence" is the extent or rate of new infections over a specific amount of time (The American Heritage Stedmans Medical Dictionary, 2007).

HIV, PTSD AND TRAUMATIC LIFE EVENTS

coloured (1.7%), white (0.7%) and Indian (0.7%) South Africans (Shisana et al., 2009; South Africa HIV and AIDS Statistics, n.d.). The HIV-prevalence was estimated at 17.8% (roughly 5.6 million) among adults (15-49 years) at the end of 2009 (UNAIDS, 2010; South Africa HIV and AIDS Statistics, n.d.).

Recently the South African Department of Health Study examined a sample of 32 225 women who attended 1424 antenatal clinics, across all nine provinces (Department of Health, 2011; South Africa HIV and AIDS Statistics, n. d.). Findings indicated that 30.2% of pregnant women between the ages of 15 and 49 were living with HIV in 2010. In the same sample of pregnant women, the highest prevalence was seen in KwaZulu-Natal (39.5%), Mpumalanga (35.1%), and the Free State (30.6%) (Department of Health, 2011; South Africa HIV and AIDS Statistics, n. d.), mirroring the findings of the South African National HIV Survey. However, as this study targeted a specific sample group, viz. pregnant women, the results should not be generalised to other population groups.

According to UNAIDS an estimated 5.6 million individuals were living with HIV in 2011, with those in the 15-49 years age-group showing the highest prevalence rate (17.3%). There were 5.1 million HIV-positive people above the age of 15, with over half (2.9 million) of these being women (UNAIDS, 2011). Statistics South Africa (2011) estimated that 10.6% of the total population was HIV positive in 2011. Even though exact figures vary slightly according to the study, population and measures used, it is apparent that the impact of HIV on South Africa's social and economic standing has been significant. In particular, the country's average life expectancy has fallen to 54 years (Dorrington, Johnson, Bradshaw, & Daniel, 2006).

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Despite the high prevalence of HIV, a sample group studied by Olley et al. (2004) found that 78% of participants had not disclosed their HIV status to their partners and, in the same sample, 46% had no knowledge of their partners' HIV status, perhaps this has to do with the stigma attached to a diagnosis of HIV and AIDS. This situation seems to have improved with ARV rollout as seen in a study by Thom (2008) which revealed that 75% had disclosed their HIV-positive status to their partners.

2.4. Summary

In the above chapter the prevalence of HIV worldwide, in Sub-Saharan Africa and in South Africa has been discussed. It is clear that the overall number of people suffering from HIV is high and, as a result, the average life expectancy in South Africa has dropped. With the introduction of more HIV treatments and anti-retroviral medications being made available at a growing number of primary health-care centres, it is to be hoped that HIV becomes a more manageable disease in the years to come.

With the high numbers of HIV-positive cases, the mental health issues of this life-threatening illness are correspondingly prevalent (Freeman et al., 2008), which leads directly to the focus of my research. In the following chapter, the stigma associated with HIV is discussed, followed by an exploration of traumatic life events within both a general and an HIV-positive population.

Chapter 3: Stigma and HIV

It has been suggested that HIV/AIDS is possibly the most stigmatised medical condition in the world (Simbayi, Kalichman, Strebel, Cloete, Henda & Mqeketo, 2007). Indeed, being the recipient of an HIV-positive diagnosis in such a context may be viewed as a particularly traumatic event (Aidsmeds, 2010; Kagee, 2008; Tull, 2012). In addition, the stigma that is experienced following such a diagnosis may be similarly traumatic, particularly when it involves violence or discrimination (International Centre for Research on Women, 2010; Mahajan et al., 2008;). Stigma is also a barrier for HIV-positive individuals to the access of preventative treatment and care services (Chesney & Smith, 1999; Kalichman & Simbayi, 2003), with negative implications for both mental and physical health.

In fact, stigma is an important contextual factor when it comes to the mental health implications of HIV infection in general and HIV-related post-traumatic stress in particular. As will be discussed in a later chapter, dominant models of post-traumatic stress disorder give emphasis to the meaning that people make of the trauma they experience. In the case of HIV infection, these meanings are inevitably shaped by the stigmatising beliefs they and others hold (Young, 2011). Because stigma is so implicated in the mental health consequences of HIV infection, it is defined and discussed in this chapter, with a particular focus on the implications that such stigma has for both the individual and the community.

3.1. Definitions of Stigma

Stigma can be dated as far back as the ancient Greeks who cut or burned marks into the skin of slaves and criminals as an indication to all that these people were tainted or immoral and should be avoided (Goffman, 1963). Defining stigma has been the source of some debate (Link & Phelan, 2001), but has been described as the reduction of a person's status in the eyes of society as a result of having any desirable or discrediting attributes (Brown, Trujillo & McIntyre, 2001; Bos, Kok & Dijker, 2001; Goffman, 1963;). It is further seen as a powerful and discrediting social label which changes the way in which people view themselves and are seen (Siyam'kela, 2004). Others have defined it as a mark of social disgrace which prevents social acceptance, and is used to set the affected person or group apart from society, leading to devaluation and discrimination (Brown et al., 2001; Goffman, 1963).

Social disqualification also occurs in certain diseases, like leprosy and tuberculosis, where the actual diagnosis and or behaviours of the individual become the brunt of such stigma (Weiss, Ramakrishna & Somma, 2006). However, no disease is stigmatised quite like HIV, and in particular AIDS.

3.2. The Impact of Stigma

The impact of stigma has been widely researched, but broadly falls into two categories:

3.2.1. Public Stigma. Public stigma is the term given to the social and psychological reaction of the general population to someone who is perceived to have a stigmatising condition (Corrigan & Watson, 2002; Pryor and Reader, 2011). It comprises cognitive (stereotypes), affective (prejudices) and behavioural (discriminatory actions) components. Stigmas surrounding a

HIV, PTSD AND TRAUMATIC LIFE EVENTS

diagnosis of HIV appear to be commonplace (Kalichman & Simbayi, 2003; Shisana & Simbayi, 2002; Visser, Makin & Lehobye, 2006) and may result in behavioural discrimination such as withholding help, avoidance, or coercive treatment (Corrigan & Watson, 2002).

Experiences of stigma are varied and may include social inequalities as well as being oppressed, rejected, punished, blamed, excluded or harassed, and categorised (International Centre for Research on Women, 2010; Policy Project, Centre for the Study of AIDS, USAID and the Department of Health, 2003; Srivastav, 2006), and may result in a number of feelings or behaviours, such as silence, ignorance, anger, a sense of inferiority, resentment or confusion (Srivastav, 2006). Deacon (2005) makes the distinction between stigmas, which are the derogatory attitudes that people hold, and discrimination, which is the behavioural enactment of this stigma.

3.2.2. Self-Stigma. Self-stigma refers to the perceived (felt) or anticipated stigma and is similar to Goffman's (1963) internalised stigma. It may include the fear of stigmatisation and internalisation of the negative beliefs associated with the stigmatised condition (Brouard & Wills, 2006; Corrigan & Watson, 2002; Herek, 2002; Pryor & Reader, 2011) and it is probable that a person in a society which endorses such stigmatising ideas will internalise these perceptions belittling themselves and believing that they do not deserve to be treated equally, while expecting to be stigmatised further (Deacon, 2005; Visser, Kershaw, Makin & Forsyth, 2008) and suffer lower self-esteem as a result. As a result, individuals may be unwilling to seek help or may be deterred from accessing resources, highlighting the importance of addressing such stigma (International Centre for Research on Women, 2010; Siyam'kela, 2004;). In contrast, some individuals become

HIV, PTSD AND TRAUMATIC LIFE EVENTS

angered at their mistreatment, leading to empowerment and, in the case of illness, encourage patients to be active participants in their treatment plans (Corrigan & Watson, 2002).

3.3. HIV-Related Stigma

As with stigma generally, there are many competing definitions and theories, and sub-types of HIV-related stigma. According to UNAIDS (2007), HIV-related stigma and discrimination may be defined as processes by which people, who are either living with or associated with HIV and AIDS, are devalued. HIV-related stigma can refer to either real or imagined negative responses to the news that a person or a community is HIV-positive (Seale, 2004).

Discrimination follows stigma and can be seen as the unfair and unjust treatment of an individual, based on his or her actual or perceived HIV status. This is clearly demonstrated in the publicised South African case of Mlangeni, who experienced his first stigmatising response after he was tested for HIV, when the nursing sister shook her head and stated that he was HIV-positive so he must have been ‘messing around’ (Timberg, 2005). In the same article Mlangeni recounted how he had his own plate and cup at home which served as a constant reminder that he was different from the rest of the family (Timberg, 2005). One of the worst cases of stigma and discrimination that has been documented is that of Gugu Dlamini, a 36-year-old South African woman who, in 1998, disclosed her HIV-positive status on a radio talk show. She was murdered three weeks later, after being accused of bringing shame to her local community (Deacon, Uys & Mohlanhle, 2009).

HIV, PTSD AND TRAUMATIC LIFE EVENTS

The stigma associated with HIV has consistently been linked to poorer compliance with treatment regimes (Chesney & Smith, 1999; Cao et al., 2006; Demi, Bakerman, Moneyham, Sowell & Seals, 1997; Nyblade, Pande, Mathur, MacQuarrie & Kidd, 2003;) and is seen to be a significant barrier to HIV prevention and treatment (Kalichman et al., 2005; Kalichman & Simbayi, 2003; Lawn & Wood, 2006). According to Santana and Dancy (2000), AIDS/HIV-related stigma impacts on the lives of HIV-positive individuals and may lead to a number of problematic behaviours such as withdrawal from society, self-doubt (Cao et al., 2006; Lee & Craft, 2002), lower self-esteem, depression, anxiety (Cao et al., 2006; Stutterheim, Pryor, Bos, Hoogendijk, Muris & Schaalma, 2009), the lowering of the immune system, interference with romantic relationships (International Centre for Research on Women, 2010), and potentially even premature death, as stigma may deter sufferers from being tested for HIV (International Centre for Research on Women, 2010; Kalichman et al., 2005; Mahajan et al., 2008; Meiberg, Bos, Onya & Schaalma, 2008; Vermeer, Bos, Mbwambo, Kaaya & Schaalma, 2009), or seeking treatment (Chesney & Smith, 1999; Kalichman et al., 2005; Mahajan et al., 2008; UNAIDS, 2008). Furthermore, stigma undermines public support for social programmes developed to help people (Kalichman et al., 2005) and may negatively impact on social interactions between HIV-positive individuals and others, resulting in limited social support and social isolation (Herek, 1999; Lichtenstein, Laska & Clair, 2002; Lee & Craft, 2002).

3.3.1. Individual models of stigma. Individual models attempt to explain how HIV provides a way in which people can express their negative attitudes to groups which are already marginalised (Herek, 1999). Herek

HIV, PTSD AND TRAUMATIC LIFE EVENTS

(1999) concludes that HIV/AIDS consists of four characteristics which are likely to invoke stigma: (a) Stigma is more likely to occur when it is attached to a disease whose cause is seen to be the carrier's fault. He explains that HIV, in particular, fits this parameter perfectly in that the HIV virus is known to have been transmitted mainly via sexual contact, which is presumed to be a voluntary behaviour. (b) Increased stigma occurs in connection with illnesses which are degenerative or unalterable, and may represent a reminder of death and mortality. (c) Greater stigma is attached to illnesses (like HIV) which are seen as dangerous, contagious and life-threatening. (d) Stigma is worsened when it is readily apparent, such as in the latter stages of HIV-illnesses which typically affect the individual's physical appearance as the body deteriorates (Herek, 1999).

It is easy to see why personal beliefs about the origins of HIV and people living with HIV may lead to responses resulting in the stigmatisation of those suffering from this life-threatening illness, but these models do not, however, address the social aspects of HIV-related stigma. Many authors have asserted that stigma is not an individual process, emphasising instead the importance of social power relationships, resulting in the development of social models of stigma (Parker & Aggleton, 2003).

3.3.2. Social models of stigma. Social models of stigma dictate that stigma highlights and reproduces social inequalities (Parker & Aggleton, 2003). Social models postulate two sources for the stigma associated with AIDS, namely the fear and apprehension associated with an HIV-positive diagnosis (Instrumental AIDS-Stigma) and the social meanings which are attributed to AIDS, such as the attitudes directed towards groups of people who are thought to be linked to the disease (Symbolic AIDS-Stigma).

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Instrumental AIDS-stigma refers to the fear and apprehension which one would expect to be associated with having a deadly and transmissible illness (Herek, 1999; Sharma, 2007). It results from the communicability and lethal nature of HIV (fear of infection from casual transmission), and reflects both the fear and apprehension commonly expected with any life-threatening illness (Herek, 1999; Herek, 2002).

Symbolic AIDS-stigma implies the use of HIV/AIDS as a vehicle by which to express attitudes (such as moralistic shaming and blaming) towards certain groups or lifestyles which are perceived to be associated with the illness (Sharma, 2007). AIDS stigma results from the social meanings which are attributed to HIV and AIDS, and manifests in HIV by being the means to express negative attitudes towards the groups or behaviours which are associated with it (Herek, 1999). Sharma (2007) also proposed an additional typology, *Courtesy AIDS-Stigma*, which is the stigmatisation of people who are seen to be associated with the issues of HIV/AIDS or HIV-positive individuals (Sharma, 2007).

Social models do not address individual responses or meanings of the stigma. However, it has been established that the social context of stigma is important in defining the way in which it is expressed and experienced (Deacon, Uys & Mohlanhle, 2009). Deacon (2006) offers a combination of both the social and individual psychological models which appears to be the most comprehensive (Young, 2011). She asserts that the steps leading to stigmatisation include assumptions that: (a) the illness is perceived as preventable or controllable, (b) immoral behaviours which cause the illness are identified, (c) such behaviours are associated with the “carriers” of the illness (who may spread the infection) to other groups of individuals, thus

HIV, PTSD AND TRAUMATIC LIFE EVENTS

exacerbating the social construct of the “other”, (d) certain individuals are, as a result, blamed for their HIV-positive status, and (e) the social status or loss of social status is projected on to the “other”. As a result, HIV-positive people are often faced with feelings of being named, blamed and shamed, and frequently experience a loss of social standing which may well lead to discrimination (Deacon, 2006).

3.4. Stigma and Disclosure

Stigma may affect the physical health and psychological well-being of HIV-positive individuals, and may result in their non-disclosure of status as they view this as being socially unacceptable (Bor, Miller & Goldman, 1993) and fear being ostracised or discriminated against (Herek, 1999; Lee & Craft, 2002). Various studies have examined the negative responses to the disclosure of an HIV-positive status (Alonzo & Reynolds, 1995; Amirkhanian et al., 2003; Black & Miles, 2002) and the adverse implications for the HIV-positive person’s psychological (Bing et al., 2001; Pence, Miller, Whetten, Eron & Gaynes, 2006, Stutterheim et al., 2009) and social functioning (Chesney & Smith, 1999; Lee & Craft, 2002; Vermeer et al., 2009). It follows that non-disclosure curtails opportunities for obtaining support and treatment.

One of the main side-effects of stigma in individuals who are HIV-positive is the fear of the reactions of others (Clark et al., 2003; Nyblade, 2006) that, if they disclose their status, they will not be given the support they desire. A study by Shabalala (2001) examined HIV-positive women in Gauteng and found that the majority of participants kept their HIV-positive status a secret for two or three years as they were afraid of victimisation and stigmatisation. In research by Kylma, Vehvilainen-Julkunen and Lahdevirta (2003), one participant expressed that he was reluctant to access information

HIV, PTSD AND TRAUMATIC LIFE EVENTS

and help from health-care professionals for fear that his HIV-positive status might have been made public. A further study by Olley et al. (2004) found that 78% of their sample had not disclosed their HIV-positive status to their partners.

Reactions to those living with HIV may be influenced by both stigma and stereotyping which may not be typical of other life-threatening illnesses. Self-imposed discrimination sometimes occurs when an individual comes to expect a particular stereotype which is directed at him or her, and from fear of rejection. Such people behave as though they have already been discriminated against (Link & Phelan, 2001; Pinel, 1999). It is advisable for individuals to be careful whom they trust with disclosure as not all people are supportive (Kimberley & Serovick, 1996).

Disclosure ensures that family and friends are aware of the individual's HIV-positive status and may well, as a result, offer assistance allowing access to a social support network which they may not otherwise have (Schlebusch & Cassidy, 1995). Support cannot be made available if an HIV-positive status is not known, so it is important for friends and family to encourage disclosure so that they are able to support the patient and ensure that they are medication-compliant (Heyer & Ogunbango, 2006). Moreover, studies have shown that support from family and friends has a positive influence on medication compliance (Gray, 2006; Williams, Burgess, Danvers, Malone, Winfield & Saunders, 2005) while non-disclosure for fear of stigma may result in HIV-positive individuals skipping treatments to maintain the secrecy of their illness (Sayles, Wong & Cunningham, 2006).

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Bos et al. (2001) found that the stigma of HIV and AIDS may have less of an impact in Western European countries, where people are more likely to disclose their status, than in African and Eastern European countries (Suhrccke, 2005). Research conducted in both Eastern Europe and Central Asia reveals more instances of stigma, typically in discrimination evidenced by being denied health care or being made redundant from their jobs, or by being excluded by their families (Amirkhanian et al., 2003), and such outcomes may be experienced as traumatic by HIV-positive individuals. People may stigmatise their friends and families differently (Maughan-Brown, 2006), hence people who have been diagnosed with HIV may become disadvantaged in a variety of ways, including income, housing, medical treatment and health care (Link, 2001).

According to UNAIDS (2000), disclosing one's HIV-positive status is important for several reasons: it avoids the increased risk of HIV transmission among sexual partners who might otherwise assume a HIV-negative status; it encourages additional support, including treatment access and adherence, family planning, replacement feeding for infants, future care and custody planning; and it influences others who are afraid of disclosure and improves existing knowledge about HIV and its transmission (UNAIDS, 2000). However, when people disclose their HIV-positive status, they run the risk of being stigmatised and discriminated against, which may result in further traumatisation. Overcoming stigma is essential to encourage HIV-positive individuals to access support by disclosing their status.

3.5. Common Stigmas

In light of the above, it is no surprise that people are concerned about the stigma associated with an HIV-positive diagnosis and face a dilemma when deciding whether or not to disclose their status. In South Africa there are a number of common stigmas. For example, in a household survey, findings showed that 26% of participants would not be willing to share a meal with someone who was HIV-positive, 18% would not sleep in the same room as someone who was HIV-positive, and 6% would not speak to someone who they knew was HIV-positive (Shisana & Simbayi, 2002). A further study found that individuals who had not been tested for HIV held greater HIV-related stigmas than those who had been tested (Kalichman & Simbayi, 2003). In particular those who had not been tested were more likely to agree that people diagnosed as being HIV-positive are dirty, should feel both ashamed and guilty, and should not work with children. Moreover, they believed that people who tested HIV-positive had done something wrong in order to have contracted HIV, and they agreed that they would rather not be friends with someone who was HIV-positive (Kalichman & Simbayi, 2003). In a later study investigating HIV-related stigma, 61% of participants believed that HIV-positive individuals have poor moral character, 22% viewed HIV as a punishment for bad behaviour, and 26% blamed the HIV-positive person for being responsible for their HIV-positive status (Visser et al., 2006). In South Africa, there is a common belief that those who are HIV-positive cannot be trusted, should feel guilty, and should not be allowed to work with children (Kalichman & Simbayi, 2003).

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Such stigmas can be more readily seen in the case of an AIDS activist in Soweto: Nyathela was required by his family to buy his own wash basin; his friends would tell him to take cups home after he had drunk from them; and his family threw away a loaf of bread that he had touched (Timberg, 2005). Given the extent of HIV-related stigma, it is not surprising that individuals appraise their HIV-positive status in a negative light. Even the secrecy of HIV testing perpetuates the differences between HIV and other illnesses.

3.6. Coping with HIV-Related Stigma

People who are living with HIV employ a number of coping strategies in an attempt to manage the negative impact of HIV-related stigma. Such strategies include problem-focused coping strategies and emotion-focused coping strategies (Stutterheim, 2011). Problem-focused coping strategies centre on changing the relationship between the HIV-positive person and their environment, and may concentrate on the self, the situation or on other individuals. Such strategies may include selective disclosure, compensating for the stigma during social situations, avoiding situations where stigma is likely, associating oneself with others who are similar, and looking for social support and activism (Stutterheim, 2011). Emotion-focused coping strategies aim to regulate negative emotions by making downward social comparisons, external attributions, denial, distraction, positive reappraisals and dis-identification with the stigmatised body (Crocker, Major & Steele, 1998; Major & O'Brian, 2005; Miller & Kaiser, 2001; Stutterheim, 2011). Not all of the coping strategies employed are useful; at times individuals employ coping mechanisms which serve to exacerbate the trauma already present in being HIV-positive and stigmatised. Different cognitive and trauma models may be

HIV, PTSD AND TRAUMATIC LIFE EVENTS

used to explain reactions to trauma and HIV-related stigma. One such model, that is described and used for the purpose of the present research study, is the Ehlers and Clark (2000) Model. (See Chapter 6).

3.7. Stigma as a Potential Change Agent

However, some researchers feel that stigma may not always be a disadvantage since it may provide the stimulus for group change and resistance (Campbell & Deacon, 2006). It is possible that some individuals gain status or recognition if they disclose their HIV-positive status, as was the case with high court judge Edwin Cameron who publicly disclosed his HIV-positive status in 2005 (Heroes Campaign, 2009).

Campbell, Nair and Maimaine (2006) noted that sometimes people may require support to facilitate change in stigmatised groups. Members of the devalued community may be assisted to develop the skills, support networks and resources to enable them to (a) think critically about the negative social representation, (b) build both confidence and the capacity to challenge the negative social representation, (c) collectively negotiate both individual and group anti-stigma strategies which are realistic and appropriate, and (d) identify and construct alliances which are likely to facilitate action (Campbell et al., 2006).

In South Africa, anti-HIV-stigma campaigns of the past have focused on media coverage aimed at increasing awareness and knowledge of HIV. Such programmes include “LoveLife” and “SoulCity”. However, a systemic review examined the impact of mass communication intervention programmes showing that they make only a minimal impact in reducing risk behaviours (Bertrand, O’Reilly, Denison, Anhang & Sweat, 2006). In fact, despite large scale education programmes, 16% of respondents believed that ARV’s can

HIV, PTSD AND TRAUMATIC LIFE EVENTS

cure HIV and 22% maintained that ARV medication prevents the transmission of HIV (Peltzer & Mlambo, 2013).

Other authors feel that, although stigma is usually considered in a negative light, it may produce positive outcomes for the population (Reidpath & Chan, 2006). Shih (2004) found that positive responses to stigma may be seen, and have been used in therapeutic interventions with HIV-positive women, namely: (a) *Compensation*: HIV-positive people develop skills to compensate for the stigma which allows them to overcome the disadvantages associated with their diagnosis (Miller & Major, 2000; Shih, 2004). One such compensation may be taking particular pride in their physical appearance. (b) *Strategic interpretations of the social environment*: stigmatised people manipulate their interpretations of their social environment to preserve their sense of self-worth (Shih, 2004). For example, they may make selective social comparisons, relating themselves to members of other stigmatised groups as opposed to members of the general population. (c). *Multiple identities help stigmatised individuals cope with prejudice and discrimination*: Stigmatised individuals are able to draw from their alternate identities to protect themselves from the effects of stigma. For example, people may class themselves as Indian, female and Christian. Studies have shown that those with a greater number of self-identities displayed better psychological well-being (Shih, 2004). Such identities may include, ethnicity, job, age, religion, gender, sexual orientation, language. (d) *Adopting an empowerment model in dealing with stigma*: HIV-positive people appear to deal with stigma as a means of empowering themselves rather than seeing stigma as a depleting process (Shih, 2004).

3.8. Summary

One cannot assume that stigma will automatically decrease as HAART accessibility increases. On the other hand, the nature and extent of HIV-stigma changes over time and is affected by death rates within the community, as well as by increased social awareness as more people disclose their status and also as testing becomes more available (Deacon et al., 2009). Research by Freeman, Nkomo, Kafaar and Kelly (2007) suggests that the experiences of discrimination and isolation as a result of an HIV-positive status may lead to a predisposition to mental disorders. Certainly, studies have found high correlations with stigma and PTSD (Katz & Nevid, 2005), as well as with stigma coupled with substance-abuse and depression (Simbayi et al., 2007). Stigma is often discussed in conjunction with other areas of HIV research, but in South Africa it has evolved into a research subject of its own right (Deacon et al., 2009).

Even if one were able to control the mental consequences of HIV, or could predict the acts of stigma and discrimination that HIV-positive individuals might be exposed to, the mental health problems associated with HIV are likely to be worse because of the stigmas associated with HIV. Although the focus of this research is not on the stigma associated with an HIV-positive diagnosis, situations wherein stigma and discrimination take place provide a highly conducive environment for negative appraisals, and may lead to traumatic events. Such events may include isolation, violence or job loss (International Centre for Research on Women, 2010). The traumatic events associated with HIV and possible diagnosis of PTSD will be discussed in the next chapters.

Chapter 4: Traumatic Events and PTSD

A diagnosis of HIV, in addition to the stigma and discrimination often associated with it (Amirkhanian et al., 2003; Kalichman & Simbayi, 2003; Santana & Darcy, 2000; Shisana & Simbayi, 2002; Mahajan et al., 2008, UNAIDS, 2007) is considered to be psychologically traumatic (Kagee, 2008). Indeed, individuals who are HIV-positive have probably been exposed to several traumatic events (Tull, 2012), highlighting the importance of addressing these issues.

It appears that the presence of traumatic life events significantly increases the likelihood of developing a psychiatric disorder such as depression, anxiety or PTSD (Blazer, Hughes & George, 1987; Owe-Larson et al., 2009; Perkonig et al., 2000; Vrana & Lauterbach, 1994;) and even neuro-cognitive disorders such as dementia (Owe-Larson et al., 2009). A study by Vrana and Lauterbach (1994) supports the finding that those who have experienced a trauma become more susceptible to psychiatric illnesses. In their study, higher levels of depression, anxiety, and PTSD symptomology were found in participants who had reported having suffered a traumatic event. Furthermore, symptoms were more intense in subjects who had been exposed to multiple traumatic events.

The word 'trauma' is Greek for wound, and can also mean 'damage', or 'defeat'. In colloquial use in western culture, the term 'trauma' is often used in everyday conversation as an expression of mere distress, However, for the purpose of this study, Baron and Byrne's (2000) definition of trauma is used. This defines trauma as the perception of a personal, physical or psychological threat, and the subsequent stress response. Traumatic events are experiences that involve the threat of injury, or even death, and which may cause shock,

HIV, PTSD AND TRAUMATIC LIFE EVENTS

terror or helplessness (American Psychiatric Association, 2008; American Psychiatric Association, 2000; Edwards, 2005a), and which often results in lasting mental effects and damage to the psychological development of the individual as it overwhelms the individual's coping resources (Hamber & Lewis, 1997). Post-Traumatic Stress Disorder is one possible consequence of such a traumatic event (McNally, 2004).

4.1. The Difficulty in Defining Traumatic Events

Historically, according to American Psychiatric Association's DSM-III, published in 1980, traumatic events were seen to be catastrophic events, outside the range of normal human experience, that included, for example rape, assault, torture, incarceration in a death camp, military combat, natural disasters, industrial/vehicular accidents or exposure to war, civil or domestic violence (American Psychiatric Association, 1980). In the subsequent revised version of DSM-III (DSM-III-R), the definition was expanded to include being exposed to danger oneself and/or witnessing or hearing about friends or family having been exposed to danger (American Psychiatric Association, 1987). These events were considered to result in trauma for almost everybody who experienced them. However, as Friedman (2003) noted, the prevalence of traumatic events is much higher than once thought, while the proportion of those who develop psychiatric disorders as a result of their exposure is lower. Exposure to these sorts of traumatic events is more common in countries and contexts where there is a high instance of war, conflict, terrorism or violence (Friedman, 2003). For example, in South Africa, political, criminal and gender-based violence is not unusual, and there are high frequencies of childhood physical abuse, industrial accidents, burns (Edwards, 2005b; Kaminer & Eagle, 2010), road traffic accidents

HIV, PTSD AND TRAUMATIC LIFE EVENTS

(Peltzer & Renner, 2003), and murder, assault and also robbery (Williams, Williams, Stein, Seedat, Jackson & Moomal, 2007).

That it is not merely the nature of the traumatic event but also the person's subjective response to the event is incorporated into DSM-IV/DSM-IV-TR criteria (American Psychiatric Association, 2000). In 1994, the Fourth Edition (DSM-IV) further revised the criteria for PTSD by including people who had either directly or indirectly experienced an event or events which posed actual or potential threat to their lives, or severe injury to themselves or others. It also provided that an individual's reaction to such an event should be extreme terror, helplessness or shock (American Psychiatric Association, 1994), thereby shifting the concept of trauma from an almost inevitable reaction to an extreme event to a more complex internal response. Events seen as traumatic according to DSM-IV include combat, sexual and physical assault, being held hostage or imprisoned, terrorism, torture, natural and man-made disasters, and accidents, as well as being diagnosed with a life-threatening illness (American Psychiatric Association, 1994). McNally (2004) explained that, although these events have been classified as traumatic, the inclusion of people's reaction to the events in the diagnostic criteria implies that it is the appraisal of the events which largely determines whether or not the individual becomes symptomatic. In other words, people react differently to traumatic events (Breslau, 2002) and it is not just the event itself which results in post-traumatic stress.

Though a step forward to reflect individual responses, the list of qualifying traumatic events has been criticised (Briere & Scott, 2006) for ignoring threats to one's psychological integrity (such as rape or domestic violence), which were previously included in DSM-III-R (American

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Psychiatric Association, 1987). Briere and Scott (2006) also argued that the definition of traumatic events is too narrow and results in an underestimate of the burden of trauma.

In an about turn, the inclusion of a psychological response of intense fear, helplessness or horror has been removed from the most recent edition of the DSM, the DSM-5 (American Psychiatric Association, 2013), on the grounds that this criterion is not an absolute requirement for the development of core PTSD symptoms and does not improve accuracy in diagnosing PTSD (Friedman, Resick, Bryant & Brewin, 2011). It seems that it is not necessary to specify certain emotional reactions at the time of the traumatic event to acknowledge that people's experiences and subsequent reactions are largely subjective. While many may feel shock, horror and/or fear at the time of the event, others might not, or might only, experience one or more of these emotions much later.

The World Health Organisation's current International Classification of Diseases, the ICD-10 (World Health Organisation, 1992), in contrast, classifies a traumatic event as one which is so exceptionally threatening or catastrophic that it would result in distress in almost everyone. Indeed, specifying Criterion A has proved to be very controversial and Brewin, Lanius, Novak, Schnyder and Galea (2009) suggest dropping this altogether and rather narrowing the list of PTSD symptoms (Criteria B, C, D) to the core PTSD symptoms in order to reduce any overlap with other disorders. This appears to be the route that is being followed by the developers of ICD-11, who seem likely to propose fairly non-specific Criterion A events and then fewer overall PTSD symptoms (Brewin et al., 2009).

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Arguments for a broader, looser definition of Criterion A traumatic events are ambivalent: though the claims that PTSD can occur in response to less intense events such as divorce and marital infidelity have been discredited by researchers, there does seem to be good evidence that prolonged stress of less intense events can nevertheless result in valid symptoms of PTSD (Brewin et al., 2009). Additionally, research suggests that traumas of lower intensity can be expected to cause PTSD in people who are especially susceptible where, for example, increased vulnerability may be the result of genetics and/or previous exposure to traumatic life events (Brewin et al., 2009).

The way in which the traumatic event is appraised in light of genetic factors and/or previous exposure to traumatic events will influence vulnerability to PTSD (Ehlers & Clark, 2000; Horowitz, 2001). Appraisals are the cognitive interpretations of information about both the world and the self and include a personal assessment of thoughts, feelings and behaviours (DePrince, Chu & Pineda, 2011). According to Scherer (1999), certain types of appraisals culminate in the generation of certain types of emotion. For example, appraisals of perceived threat or danger lead to fear, and appraisals of loss may result in sadness. Appraisal models focus on the way that a person understands or makes meaning of an event, and recognise that such appraisals may result in a number of emotions such as guilt or fear.

Lazarus and Folkman (1984) classified different types of cognitive appraisals, as either primary or secondary. Their primary appraisal relates to the individual's initial perception of the event, which may be that it is without significance, as a loss (either material or relational), as a threat (at the prospect of loss), or as a challenge (the prospect of benefit). When the

HIV, PTSD AND TRAUMATIC LIFE EVENTS

event is stressful and is seen to be a loss or a threat, negative emotions such as shame or anger are experienced. A secondary appraisal then occurs as the person decides what can be done to cope with the threat to avoid harm.

However, when the internal and external demands of the situation are experienced as too difficult (thus exceeding the resources of the person), the subsequent appraisals result in different coping strategies (Lazarus & Folkman, 1984). For example, people may avoid people or places associated with the trauma. Responses to traumatic events are subjective, and are based on an individual's past experiences and current appraisals of the traumatic event.

Ehlers and Clark (2000) developed a cognitive model to assist with the understanding and assessment of PTSD, which emphasises the role of individual appraisals in the development and maintenance of symptoms following a traumatic event. Research utilising the Ehlers and Clark Model has found that negative beliefs about oneself and the world are risk factors for PTSD (Dunmore, Clark & Ehlers, 2001). This model will be explored more fully in Chapter 6.

4.2. The Burden of Traumatic Events in South Africa

Usually traumatic events are unexpected, specific, and sometimes life-threatening (Flannery, 1999). Some, such as living in poverty or domestic violence are enduring, whereas others, like accidents or violent events, are time-limited. The prevalence of traumatic events and stressors, as defined according to the different DSM and ICD criteria, varies significantly between countries, contexts and communities. Some of these variations can be attributed to different populations, different definitions of traumatic events, or the assessments measures used, but it is also probable that traumatic

HIV, PTSD AND TRAUMATIC LIFE EVENTS

events occur more frequently in some circumstances than in others (Louw, 1997), with particular variations according to the resources available.

Occurrences are most frequent among those who live in low socio-economic contexts (Hamber & Lewis, 1997; Louw & Shaw, 1997).

Despite South Africa's attempt to establish a democratic society based on social justice and human rights (see the Constitution and Bill of Rights, 1996), it continues to be one of the most unequal countries in the world (Husy, 2000; Poverty & Education, 2011), with an environment which readily places people at risk of violence, accidents and illness. This inequality appears to be largely defined by race, with the overwhelming majority of those locked in poverty³ being black South Africans (Husy, 2000; Poverty & Education, 2011; Seekings & Nattrass, 2006). Unable to afford their own transport, it is difficult for the poor to move between townships and suburbs or business areas, and as a result they are forced to make use of public transport like trains, buses and taxis (Arrive Alive, 2012; Houston, 2011; Jeanihess, 2012).

In South Africa there are high rates of the types of trauma which may result in PTSD. These include crime and violence (Hamber & Lewis, 1999; Hirschowitz & Orkin, 1997; Louw, 1997; Statistics South Africa, 2011; Thorpe, 2010), interpersonal traumas such as rape (Jewkes & Abrahams, 2002), motor vehicle accidents, and industrial accidents (Edwards, 2005b; Peltzer & Renner, 2003; Statistics South Africa, 2011).

³ At the United Nations World Summit for Social Development, poverty was defined as a condition characterised by severe deprivation of basic human needs, in particular food, safe drinking water, sanitation facilities, and healthcare. Poverty is not solely determined by lack of income, but also by access to social services, shelter, education and information. (United Nations, 1995).

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Many South Africans are unemployed (Hirschowitz & Orkin, 1997) or work in factories or mines, in difficult and dangerous working conditions. Amongst the lower social-economic classes, people often have to make do without proper shelter (Hirschowitz & Orkin, 1997), making use of coal and/or paraffin to make a fire, which they use both to cook and to keep themselves warm. Many use candles for lighting and have little or no access to electricity or even tap-water and basic sanitation (Anti-Privatisation Forum, 2008; Hirschowitz & Orkin, 1997).

People living in informal settlements are exposed to high rates of crime (Dinan, 2004; Hamber, 1999; Kaminer & Eagle, 2010) which is borne out by the fact that homicide in South Africa is more common in rural areas (Hamber, 1999). In a study based in urban schools in both South Africa and Kenya, it was found that 83% of South African adolescents (under the age of 22) had experienced at least one DSM-IV-TR traumatic event, underlining the high rate of exposure to violence (Seedat, 2004). Moreover, marginalised communities have limited social resources, and are forced into situations where they are more likely to be exposed to traumatic events. Steinberg (1999) found that those who live in poverty are almost 80 times more likely to be killed or injured in an act of crime than those who are well off. In a township sample in South Africa, findings showed that 94% of 201 participants reported exposure to traumatic events, with the average number of events being 3.8 per person. Of this group nearly 20% met the criteria for PTSD (Carey, Stein, Zungu-Dirwayi & Seedat, 2003).

A study of university students in South Africa found that 90% reported having experienced at least one traumatic event in their lifetime, commenting that the high prevalence is a reflection of the broader South African

HIV, PTSD AND TRAUMATIC LIFE EVENTS

environment (McGowan & Kagee, 2013). A study by Williams et al. (2007) commented that, although many people living in South Africa have not directly experienced a trauma, they have however been indirectly traumatised as a result of either hearing about a trauma which affected someone known to them, or bearing witness to a traumatic event; alternatively they may have become traumatised from losing a loved one. Kaminer and Eagle (2010) argued that, due to high crime and trauma statistics, many people who live in South Africa do not have a post-trauma time frame within which to adapt to their most recent traumatic experience before the next traumatic event occurs.

A community study in South Africa found that two-thirds of the women interviewed had suffered traumatic life events, although none of them met the full criteria for PTSD (Dinan, 2004) and, in a review of literature, Berman, Silverman and Kurtines (2000) comment that a person's response to crime and violence is complex and multi-faceted and challenges his or her ability to develop adequate coping skills and access social support. When faced with traumatic and stressful events, some people are resilient whilst others show vulnerability and distress which results in the development of chronic psychological difficulties such as depression or PTSD (Edwards, Sakasa & van Wyk, 2005; Williams et al., 2007).

In conclusion, it seems that traumatic events are common (Breslau et al., 1991; Breslau, Kessler, Chilcoat, Schultz, Davis & Andreski, 1998; Carey et al., 2003; Dinan, 2004; Hamber, 1999; Hamber & Lewis, 1997; Kessler, Sonnega, Bromet, Hughes & Nelson, 1995; Mazza, 1996; Perkonig et al., 2000; Resnick, Kilpatrick, Dansky, Saunders & Best, 1993; Roxburgh, Degenhardt & Copeland, 2006; Seedat, 2004; Statistics South Africa, 2011;

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Thorpe, 2010), yet exact events and exposure to trauma both vary according to different contexts. It is, however, important to not equate previous or current experiences of traumatic events with mental illness (Stein, Seedat & Emsley, 2005), as humans are, on the whole, resilient and may show many levels of functioning. By definition, PTSD only sometimes occurs in response to a qualifying traumatic event, so logically the traumatic events must occur more frequently than the responses which qualify for a diagnosis of PTSD.

The consequences of traumatic stress are varied, and may threaten the individual's personal goals or well-being (Flannery, 1999). A crisis occurs when a traumatic event or incident overwhelms a person's usual coping mechanisms, and results in impaired functioning or evidence of a psychiatric disorder (Everly & Mitchell, 1999). Although some people experience minimal disruption following a traumatic event, common responses are depression, anxiety, psychological disorganisation or somatic pain (Flannery, 1999; Kaminer & Eagle, 2010). Such reactions are usually temporary but, in the case of extreme stressors, characteristic symptoms may develop, such as intrusive recollections of the event, avoidance of the traumatic situation, a numbing of responsiveness and increased physiological arousal (Flannery, 1999).

4.3. Traumatic Events Associated with HIV

Seedat (2012) emphasises that trauma in HIV-positive individuals may result in detrimental mental and physical health consequences, and Brief et al. (2004) found that many people living with HIV have been exposed to a traumatic event during their lives. Indeed, many HIV-positive individuals live in poverty, which increases the likeliness that they will be exposed to multiple traumatic events (Dinan, 2004; Hamber, 1999; Kaminer & Eagle,

HIV, PTSD AND TRAUMATIC LIFE EVENTS

2010). HIV-positive people living in non-metropolitan areas often have fewer resources, experience greater social stigma, and thus face a greater threat of suffering poorer mental health than their counterparts in metropolitan areas (Ullrich, Lutgendorf & Stapleton, 2002). The psychiatric consequences are only one aspect of the psychological challenge presented by HIV (Kaminer & Eagle, 2010), in that some studies have shown that HIV-positive patients display above-average reactions to trauma and may warrant therapeutic intervention (Pedersen & Elklit, 1998).

Environmental factors such as cultural differences and lack of skilled resources combined with traumatic events like violence and displacement may be seen as reasons for the increase in mental health problems (Freeman, 2004). Leserman, Barroso, Pence, Salahuddin and Harmon (2008) stressed that, given the high rates of depression and lifetime trauma amongst those living with HIV, it is important for health-care providers to address these problems as a routine part of their service.

The degree of trauma experienced by those who are HIV-positive is affected by a number of factors, including how they became infected, their personality characteristics, and the level of support available, as well as their knowledge and experience of HIV/AIDS (Weinel, 1990). Furthermore, HIV itself may be perceived as a traumatic event, since, in addition to the stress of receiving an HIV-positive diagnosis, those who live with HIV are constantly confronted with the burden of dealing with a life-threatening disease and its progression (Kelly et al., 2008; Leserman, 2003; Rivkin, Gustafson, Weingarten & Chin, 2006). Some of these stressors include: dealing with one's own mortality, death of a family member, physical limitations and symptom progression (Leserman, 2003; Rivkin et al., 2006),

HIV, PTSD AND TRAUMATIC LIFE EVENTS

domestic violence, loss of relationships, employment or income; as well as childcare and even housing problems (Leserman, 2003; Thom, 2008).

Further factors associated with a positive diagnosis should not be forgotten, including issues of stigma and discrimination (Cao et al., 2006; Deacon et al., 2009; Kalichman & Simbayi, 2003; Leserman, 2003; Shabalala, 2001), negative feelings about being HIV-positive, and family support (Kelly et al., 2008). Such daily stressors may undermine even the most resilient coping strategies and social resources (Schneidman, Ironson & Siegel, 2005). In fact, studies have consistently shown that stressful life events may hasten the progression from an HIV-positive status to full-blown AIDS (Leserman, Whetten, Lowe, Strangl, Schwartz & Thielman, 2005). Furthermore, the experience of a traumatic life event may often lead to poor adherence to medication regimes (Kalichman, Sikkema, DiFonzo, Luke & Austin, 2002; Pence, 2009; Pingo & Seedat, 2009; Whetten et al., 2008).

Leserman et al. (2005) made use of a variety of surveys including a PTSD checklist based on the DSM-IV criteria, and a sample of five clinics serving HIV-positive patients living in rural areas of USA, and found that 53.5% of HIV-positive adults reported a history of either physical or sexual abuse, and 72.4% disclosed having experienced a least two traumatic events during their lifetime. Moreover, 37.8% described having suffered physical abuse, 26% had experienced childhood physical neglect and 23.2% had been subjected to emotional childhood neglect. Such trauma categories were based on previous research and included the murder of a close family member, the death of a child, spouse or partner, or another similar trauma documented by the individual (Leserman et al., 2005).

HIV, PTSD AND TRAUMATIC LIFE EVENTS

A later American study found that 53% of HIV-positive individuals in the sample group had suffered more than two traumas in their lifetime (Leserman et al., 2008). In the same study, 32% reported having been sexually abused, and 8% physically abused, when they were children. As adults, 23% had been sexually abused and 38% had been physically abused.

It is evident that experiencing traumatic stressors may confer a vulnerability to HIV infection, in that people may use a variety of coping strategies to deal with the psychological distress including excessive drinking (Joska et al., 2010; Olley et al., 2005) and unsafe sex practices (Kalichman et al., 2002b; Kalichman, Simbayi & Cain, 2010; Seedat, 2012).

Traumatic events and stressors have also been shown to be strong predictors of HIV-related fatigue (Leserman et al., 2008) and may be related to increased bodily pain, as well as poorer physical and cognitive functioning (Leserman et al., 2005; Owe-Larson et al., 2009). Murphy, Moscicki, Vermund and Muenz (2000) studied a group of HIV-positive adolescents in America, finding that life events that were reported to have had a significant impact were associated with both depression and anxiety, and thus psychological distress. According to this study, the most common negative events included being prescribed medications (74%), such as anti-depressants or anti-anxiety medications (which may in fact reinforce the belief that something is wrong), family financial problems (61%), and parental alcohol abuse (20%).

In a South African study, findings from Joska et al. (2010) demonstrated that patients who showed more lifetime trauma, stressful events and PTSD symptoms, reported poorer cognitive functioning. Furthermore, in common with any other medical illness, the very diagnosis itself must have

HIV, PTSD AND TRAUMATIC LIFE EVENTS

some degree of impact on the individual receiving it, especially in the case of being HIV-positive, which is a life-threatening condition. With the vast numbers of individuals who are directly or indirectly affected by HIV, negative psychological consequences are inevitable.

The impact of the HIV epidemic on South African families has been documented by Richter, Manegold and Pather (2004). They noted that the high rate of HIV contraction in South Africa has resulted in households being headed by adolescents or even children. There has also been an increase in elderly caregivers (and vice-versa, where children are caring for elderly people); a higher household dependency ratio; separation of siblings; family breakdown and child abandonment; and remarriage (Richter et al., 2004). It seems that not only are individuals likely to have a history of trauma, but all the above may be seen as, or may result in, traumatic experiences which may then be further compounded by being diagnosed with a life threatening illness.

A set of influences on the impact of HIV and AIDS in South Africa has been pinpointed by Richter et al. (2004), namely age, gender and household location. Children are more vulnerable to the effects of HIV, which may result in malnourishment, sexual and physical abuse, poor stimulation, and a failure to complete schooling, as well as coping with the loss of a loved one, and separation from their families or community. Females are often required to give up school or work to look after the sick or elderly (Poverty & Education, 2011), and rural households are often poorer than urban households, so children are expected to contribute to the family budget (Richter et al., 2004). Children may be left unsupervised, and social support varies between different communities (Poverty & Education, 2011; Richter et

HIV, PTSD AND TRAUMATIC LIFE EVENTS

al., 2004). HIV and poverty both exacerbate each other, and together impact negatively on mental health. This results in higher levels of mental health difficulties than would be automatically expected amongst those who are either poor, or who have been diagnosed as being HIV-positive (Freeman et al., 2008; Kelly et al., 2008). It is evident that HIV increases both stress and trauma and places both a strain on economic, social and emotional resources.

4.4. Summary

Even if there were consensus about the criteria defining a traumatic event, or the fact that a traumatic event actually occurred, people's subjective experiences of trauma differ. HIV is associated with a range of what one might term 'traumatic stressors', which may become more intense due to a HIV-positive diagnosis or during the course of the HIV-infection. The experience of traumatic events may also increase risky behaviour (Kalichman et al., 2010; Kalichman, Simbayi, Kaufman, Cain & Jooste, 2007; Kiene, Simbayi, Abrams, Cloete, Tennen & Fisher, 2008) including substance abuse and promiscuity (Seedat, 2012) not only after, but also before HIV-infection.

Lazarus and Folkman (1984) have suggested that individual responses may be dependent upon personal resources, the attributes of a situation, cognitive appraisals and coping strategies. The impact of recent stressors, trauma and PTSD on biological markers, physical functioning and access to health care in HIV-positive individuals was examined in 611 individuals in the USA. Findings showed that participants who reported more traumatic events, stressful events and PTSD symptoms experienced more body pains, poorer functioning and increased health-care utilisation (Leserman et al., 2005). Given that HIV is a life-threatening illness, the ramifications of testing HIV-positive are likely to be many (Thom, 2008). An HIV-positive

HIV, PTSD AND TRAUMATIC LIFE EVENTS

diagnosis may lead to questions of fidelity (Harawa, Willians, Ramamurthi & Bingham, 2006) whereas the stigma which surrounds an HIV-positive diagnosis may lead people to feel ostracised and unable to access support when they need it most (Harawa et al., 2006; Kylma et al., 2003; Thom, 2008;).

Chapter 5: The Emergence of PTSD as a Diagnosable Disorder

As stated by Kaminer and Eagle (2010), traumatic situations usually result in brief periods of disequilibrium which are short-lived and disrupt intrapersonal processes. Feelings of distress following a trauma are expected and are part of the process of adjustment. Some sufferers experience depression and anxiety, whereas others have distressing thoughts or memories of the event, have trouble sleeping, and/or are subject to hyper-arousal to potential danger. Many avoid discussing the event or withdraw from friends and family. Reactions typically last from anything between a few days and a few weeks and then fade without impacting significantly on the person's daily life, although in some people they continue to develop ongoing symptoms which result in distress. Post-Traumatic Stress Disorder is the label given to the condition that arises when certain of these symptoms do not naturally resolve in the days or weeks after the traumatic event. Untreated trauma and PTSD may result in disability, legal expenses, increased medical costs, sick leave, increased industrial accidents, lowered productivity and psychological distress (Flannery, 1999).

The current conception of Post-Traumatic Stress Disorder (PTSD) is a western notion which was developed in the late 1970's following the Vietnam War (Baldachin, 2010), though this follows a long history of trying to understand the psychological trauma of war, especially during and after the First World War, when the term 'shell-shocked' was coined. Early indicators of PTSD have been documented in the anti-war movement in the United States (Summerfield, 2001) when it became apparent that military psychiatry focused attention on serving soldiers, rather than on those who had been injured. Consequently activists advocated that veterans receive specialised

HIV, PTSD AND TRAUMATIC LIFE EVENTS

care under a new diagnosis of PTSD, which replaced the old categories of neurosis and battle fatigue (Summerfield, 2001). This new diagnosis was created to facilitate the defining and understanding of the “seemingly bizarre behaviours” exhibited by veterans (Baldachin, 2010), and allowed sufferers to receive moral redemption for their actions and, in some cases, even ensured a disability pension, since PTSD became a recognised and established diagnosable disorder.

PTSD was first introduced as a non-military disorder in 1980 (Bakelaar, Rosenstein, Kagee & Seedat, 2011) when it appeared in the third edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-III). As noted above, Criterion A emphasised the presence of a qualifying stressor that would evoke significant distress symptoms in “almost everyone”. Symptoms in response to these events include persistent avoidance, re-experiencing and hyper-arousal. Individual perceptions, feelings or experiences of an event were not taken into account. As already mentioned, minor revisions were made to the diagnostic criteria of PTSD in 1987 for DSM-III-R (American Psychiatric Association, 1987).

5.1. PTSD in DSM-IV-TR and DSM-5

In 1994, the American Psychiatric Association (APA) expanded the criteria for PTSD by including diagnosis of a life-threatening illness (such as AIDS) as an event significant enough to trigger the symptoms of PTSD (American Psychiatric Association, 1994; American Psychiatric Association, 2000). According to DSM-IV and the DSM-IV-TR (American Psychiatric Association, 2000), there are four conditions which must be fulfilled to establish PTSD: the presence of a stressor, intrusive recollection or re-experiencing of the traumatic event, avoidance and/or numbing behaviour,

HIV, PTSD AND TRAUMATIC LIFE EVENTS

and hyper-arousal. The diagnostic criteria are illustrated in Table 2. To qualify for PTSD, an individual has to satisfy the requirements of Criteria A1 and A2 as well as other symptoms.

Essentially people have to experience symptoms from three separate, yet co-occurring clusters. These clusters include intrusive recollections or the re-experiencing of the trauma with associated psychological distress or physiologic changes, persistent avoidance of activities, thoughts and feelings associated with the event, and increased extreme arousal (American Psychiatric Association, 2000). Often the Criterion A stressors are both physically traumatic and psychologically traumatic (McNally, 2010), and may produce pain in conjunction with fear.

The three symptom clusters mentioned above are seen in Acute Stress Disorder, as well as in acute, chronic and delayed PTSD. Acute stress disorder is diagnosed when victims with the above symptoms also present with a sense of numbing, derealisation, depersonalisation, a reduced awareness of their surroundings, or dissociative amnesia within one month of the traumatic event. Symptoms last for longer than 48 hours, but less than a month. If symptoms are still present after one month, they indicate the onset of PTSD (American Psychiatric Association, 2000; American Psychiatric Association, 2013a).

Table 2

DSM-IV-TR Criteria for PTSD

Criterion A: The person has been exposed to a traumatic event in which both of the following have been present:

- 1 The person has experienced, witnessed, or been confronted with an event or events that involve actual or threatened death or serious injury, or a threat to the physical integrity of himself/herself or others.
 - 2 The person's response involved intense fear, helplessness or horror.
-

Criterion B: The traumatic event is persistently re-experienced in at least one of the following ways:

- 1 Recurrent and intrusive distressing recollections of the event, including images, thoughts, or perceptions.
 - 2 Recurrent distressing dreams of the event.
 - 3 Acting or feeling as if the traumatic event were recurring (includes a sense of reliving the experience, illusions, hallucinations, and dissociative flashback episodes, including those that occur upon awakening or when intoxicated).
 - 4 Intense psychological distress at exposure to internal or external cues that symbolise or resemble any aspect of the traumatic event.
 - 5 Physiologic reactivity upon exposure to internal or external cues that symbolise or resemble any aspect of the traumatic event.
-

Criterion C: Persistent avoidance of stimuli associated with the trauma and numbing of general responsiveness (not present before the trauma), as indicated by at least three of the following:

- 1 Efforts to avoid thoughts, feelings or conversations associated with the trauma.
 - 2 Efforts to avoid activities, places or people who arouse recollections of the trauma.
 - 3 Inability to recall an important aspect of the trauma.
 - 4 Markedly diminished interest or participation in significant activities.
 - 5 Feeling of detachment or estrangement from others.
 - 6 Restricted range of affection (e.g. unable to have loving feelings).
 - 7 Sense of contracted future (e.g. does not expect to have a career, marriage, children, or a normal life span).
-

Criterion D: Persistent symptoms of increasing arousal (not present before the trauma), indicated by at least two of the following:

- 1 Difficulty in falling or remaining asleep.
 - 2 Irritability or outbursts of anger.
 - 3 Difficulty in concentrating.
 - 4 Hyper-vigilance.
 - 5 Exaggerated startle response.
-

Table 2 (continued)
DSM-IV-TR Criteria for PTSD

Criteria E and F: A further qualification is that the duration of the disturbance symptoms outlined in B, C and D above is more than one month and causes significant distress or impairment in social, occupational or other important areas of functioning.

American Psychiatric Association (2000)

In the new DSM-5, the criteria changed slightly with the removal of the earlier criterion A2 requirement that a person's response to the traumatic event was fear, helplessness or horror immediately after the event as studies have shown that this criterion did not improve the diagnostic accuracy for PTSD (Friedman et al., 2011; Friedman, 2013a). It has also been noted that being diagnosed with a life-threatening illness is not necessarily sufficient to qualify as an index trauma, but that the medical illness or trauma must have been sudden or catastrophic, with examples including waking up during surgery, or anaphylactic shock (American Psychiatric Association, 2013a). In other minor amendments, the three symptom clusters were split into four: intrusion, avoidance, negative alterations in cognitions and mood, and alterations in arousal and reactivity (See Table 3) and both PTSD and acute stress disorder are moved into the new diagnostic category of trauma and stressor related disorders (American Psychiatric Association, 2013a; Friedman, 2013b; Kilpatrick, 2013; Schnurr, 2013). This encourages clinicians to take the impact of exposure to traumatic events into account as a risk factor for both PTSD and other disorders (Kilpatrick, 2013). Further changes allow for more than one traumatic event to contribute to the development of PTSD; and the requirement for the presence of at least one avoidance symptom (American Psychiatric Association, 2013a; Friedman, 2013a; Kilpatrick, Resnick, Milanak, Miller, Keyes & Friedman, 2013).

Table 3

New DSM-5 Criteria for PTSD

Criterion A: The person was exposed to death, threatened death, actual or threatened serious injury, or actual or threatened sexual violence, in at least one of the following ways:

- 1 Direct exposure.
 - 2 Witnessing, in person.
 - 3 Indirectly, by learning that a close relative or close friend was exposed to trauma. If the event involved actual or threatened death, it must have been violent or accidental.
 - 4 Repeated or extreme indirect exposure to aversive details of the event(s), usually in the course of professional duties (e.g. first responders, collecting body parts; professionals repeatedly exposed to details of child abuse). This does not include indirect non-professional exposure through electronic media, television, movies or pictures.
-

Criterion B – Intrusion Symptoms: The traumatic event is persistently re-experienced in at least one of the following ways:

- 1 Recurrent, involuntary and intrusive memories. Note: Children older than 6 may express this symptom in repetitive play.
 - 2 Traumatic nightmares. Note: Children may have frightening dreams without content related to the trauma(s).
 - 3 Dissociative reactions (e.g. flashbacks) which may occur on a continuum from brief episodes to complete loss of consciousness. Note: Children may re-enact the event in play.
 - 4 Intense or prolonged distress after exposure to traumatic reminders.
 - 5 Marked physiologic reactivity after exposure to trauma-related stimuli.
-

Criterion C – Avoidance: Persistent effortful avoidance of distressing trauma-related stimuli after the event as indicated by at least one of the following:

- 1 Trauma-related thoughts or feelings.
 - 2 Trauma-related external reminders (e.g. people, places, conversations, activities, objects, or situations).
-

Criterion D – Negative Alterations in Cognitions and Mood: Negative alterations in cognitions and mood that began or worsened after the traumatic event, indicated by two of the following:

- 1 Inability to recall key features of the traumatic event (usually dissociative amnesia not due to head injury, alcohol or drugs).
 - 2 Persistent (and often distorted) negative beliefs and expectations about oneself or the world (e.g. "I am bad," "The world is completely dangerous.").
 - 3 Persistent distorted blame of self or others for causing the traumatic event or for resulting consequences.
 - 4 Persistent negative trauma-related emotions (e.g. fear, horror, anger, guilt or shame).
 - 5 Markedly diminished interest in (pre-traumatic) significant activities.
 - 6 Feeling alienated from others (e.g. detachment or estrangement).
 - 7 Constricted affect: persistent inability to experience positive emotions.
-

Table 3(continued)
New DSM-5 Criteria for PTSD

Criterion E – Alterations in Arousal and Reactivity: Trauma-related alterations in arousal and reactivity that began or worsened after the traumatic event indicated by at least two of the following:

- 1 Irritable or aggressive behaviour.
- 2 Self-destructive or reckless behaviour.
- 3 Hypervigilance.
- 4 Exaggerated startle response.
- 5 Problems in concentration.
- 6 Sleep disturbance.

Criteria F and G: A further qualification is that the duration of the disturbance symptoms outlined in B, C, D and E above is more than one month and causes significant distress or impairment in social, occupational, or other important areas of functioning.

American Psychiatric Association (2013a)

This change means that some people who qualified for a diagnosis of PTSD using the DSM-IV-TR criteria will no longer qualify for a diagnosis of PTSD under DSM-5. A diagnosis of acute PTSD can be made if symptoms are present for longer than one month, but less than three months, while chronic PTSD is indicated if symptoms last for three months or more, while the term “PTSD with delayed expression” implies that the onset of such symptoms occurs six months or more after the traumatic event (American Psychiatric Association, 2000; American Psychiatric Association, 2013a).

5.2. PTSD in ICD-10

PTSD is defined in the tenth edition of the World Health Organisation’s International Classification of Diseases (ICD-10) as a disorder which may develop in response to one or more traumatic events of an exceptionally threatening or catastrophic nature, and which is likely to cause pervasive distress in almost anyone (World Health Organisation, 1992). Examples may include deliberate acts of interpersonal violence, severe accidents, disaster or military action.

Table 4

ICD-10 Criteria for PTSD

Criterion A: Exposure to a stressful event or situation (either short- or long-lasting) of exceptionally threatening or catastrophic nature, which is likely to cause pervasive distress in almost anyone.

Criterion B: Persistent remembering or "reliving" the stressor by intrusive flashbacks, vivid memories, recurring dreams, or by experiencing distress when exposed to circumstances resembling or associated with the stressor.

Criterion C: Actual or preferred avoidance of circumstances resembling or associated with the stressor (not present before exposure to the stressor).

Criterion D: Either (1) or (2)

- 1 Inability to recall, either partially or completely, some important aspects of the period of exposure to the stressor.
 - 2 Persistent symptoms of increased psychological sensitivity and arousal (not present before exposure to the stressor) shown by any two of the following: difficulty in falling or staying asleep; irritability or outbursts of anger; difficulty in concentrating; hyper-vigilance; exaggerated startle response.
-

Criterion E: Criteria B, C and D all occurred within six months of the stressful event, or the end of a period of stress.

World Health Organisation (1992)

In a similarity to the American Psychiatric Association's DSM-IV-TR and DSM-5 diagnostic criteria for PTSD, the ICD-10 classification system requires individuals to satisfy the requirements of their criteria B, C and D, experiencing symptoms from three different, yet co-occurring, clusters within six months of the index trauma. Mirroring the DSM-IV-TR criteria, such clusters include re-experiencing, avoidance and hyper-arousal (See Table 4).

Rosner and Powell (2009) discuss the major differences between DSM-IV-TR and ICD-10, pointing out that the traumatic event in Criterion A of the DSM-IV-TR requires a threat to life, as well as feelings of helplessness, fear

HIV, PTSD AND TRAUMATIC LIFE EVENTS

or horror, whilst in the ICD-10 the event is described as being exceptionally threatening or catastrophic such that it would cause distress in almost everyone. Moreover, the DSM-IV-TR places greater emphasis on Criterion C, the symptoms of avoidance and emotional numbing, requiring three such indications compared with the ICD-10's one symptom.

Furthermore the DSM-IV-TR specifies that symptoms should be present for more than one month, whilst the ICD-10 requires merely that symptoms appear within six months. The DSM-IV-TR's Criterion F emphasises that impairment to the individual's functioning is critical for a diagnosis of PTSD to be made but, in contrast, the ICD-10 criteria does not identify impairment in activities as a significant factor (Rosner & Powell, 2009).

The PTSD criteria are again due for a significant revision in 2015, when ICD-11 is expected to be released. It is anticipated that, in common with DSM-5, PTSD will be moved into a new category of disorders associated with a stressful event or series of events (Friedman, 2013a; Kilpatrick, 2013). However, the new ICD-11 will be including diagnostic criteria for both PTSD and complex PTSD. At this stage it is not clear which symptoms will be retained (Friedman, 2013a).

5.3. Critiques of the Concept of PTSD

Over the years PTSD has been the source of much debate. In the following sections I will investigate some of the different criticisms of PTSD as well as some responses to these criticisms.

5.3.1. The conceptual bracket creep in the definition of trauma.

Originally PTSD was applied to extreme events rarely encountered in everyday life. However, the revised definitions of PTSD lead to possible association with a range of everyday events (Summerfield, 2001). For

HIV, PTSD AND TRAUMATIC LIFE EVENTS

example, people are being diagnosed with PTSD for incidents such as having a difficult labour even after giving birth to a healthy child, disputes with managers at work, or receiving bad news from a doctor (Summerfield, 2001), though it is debatable that these presentations actually qualify for a diagnosis of PTSD. By broadening the criteria in DSM-IV, the American Psychiatric Association initiated a type of conceptual bracket creep in that individuals do not actually have to have been directly exposed to a trauma, they can merely be horrified about what has happened to others (McNally, 2003). McNally further explained that, according to the DSM-IV-TR, there are three types of trauma survivors: firstly, those who have been seriously threatened or harmed directly; secondly, those who have witnessed someone experience a trauma; and thirdly, people who have been presented with information about threats to others (McNally, 2009). These latter two groups would not have qualified for a diagnosis of PTSD according to the original American Psychiatric Association's diagnostic criteria.

So a significant, and a somewhat controversial, change in the conceptualisation of PTSD over the years is that many individuals who have never directly experienced a traumatic event may now be classified as suffering from PTSD. Traditionally, the very definition of a traumatic event is an experience which threatens injury, death or the physical body of an individual, and which may result in shock, terror or helplessness (American Psychiatric Association, 2008) or is so catastrophic that it would cause pervasive distress in almost anyone (World Health Organisation, 1992). Thus a traumatic event, in its clinical sense, is something that a person has to experience directly, which arguably could cast doubt on the clinical validity of the third category. Not surprisingly, this has formed the basis of much

HIV, PTSD AND TRAUMATIC LIFE EVENTS

debate: in fact, in terms of the American Psychiatric Association's DSM-IV-TR's expanded diagnostic criteria, some surveys give the impression that nearly everyone in America, and indeed the rest of the world, is a trauma survivor (McNally, 2009). Conceptually this is problematic, as it makes it more difficult to understand the mechanisms underlying PTSD (McNally, 2009). People who have not been directly exposed to a stressor may display similar symptoms to those who have witnessed or actually experienced a traumatic event, but may not be suffering in the same way (McNally, 2009). Shifting the emphasis away from the stressor undermines the very diagnosis of PTSD, with the result that traditional treatments may fail.

Additionally, there is a danger that clinicians may unnecessarily medicate for conditions which are, in fact, normal emotional reactions. On the other hand, the expansion of the PTSD diagnostic criteria is justified to include a host of clinical presentations which may resemble PTSD in all ways, but did not previously meet the narrow Criterion A (Weathers & Keane, 2007). Research suggests that the previous Criterion A was too narrow to capture the range of qualifying events, and as a result overlooked many individuals who actually did meet the criteria for PTSD (Weathers & Keane, 2007).

In any event, an expanded Criterion A does not present difficulties for a contemporary, dominant model of PTSD like the Ehlers and Clark (2000) Model, which relies on the reciprocal relationship between trauma memories and trauma appraisals to explain the patterns of symptoms associated with PTSD. The event needs only be sufficiently distressing to affect the way in which the experience is encoded at the time of the traumatic event (Ehlers & Clark, 2000). They suggested that the trauma memories subsist because of a

HIV, PTSD AND TRAUMATIC LIFE EVENTS

tendency toward data-driven assimilation rather than the usual conceptual processing under conditions of stress (which may occur more readily for people with previous traumatic experiences) (Ehlers & Clark, 2000). Rather than demanding a narrow definition of what constitutes a qualifying traumatic experience, their model accommodates individual differences in appraisals and processing style. See Chapter 6 for a fuller discussion of the Ehlers and Clark Cognitive Model of PTSD.

5.3.2. Pathologising. It seems that the term “trauma” has been downgraded and has become a reflection of distress in western culture and, is in fact now frequently used in daily conversation. The concept of time is a psychological construct central to traumatic memory (Summerfield, 2001). PTSD in essence works in the opposite mode of causality from other anxiety disorders, in that the assumption is that time and causality move from the traumatic event towards the PTSD diagnostic criteria. Consequently PTSD has been viewed as a preferential diagnosis, since a link between the present and an index event or trigger in the past can be established and “blamed”. Summerfield (2001) felt that this is both scientifically and clinically unsound, as historical studies of people who have been exposed to a variety of man-made and natural stressors have shown that a variation in factors present prior to the traumatic event accounts for more of the symptoms following the trauma (Summerfield, 2001).

Summerfield (2001) also argued that psychology and mental health are social constructs, formulated on collective beliefs and expectations. Employing a western psychiatric diagnosis to frame the normal reactions to a traumatic event explains these experiences in psychological terms, whereas

HIV, PTSD AND TRAUMATIC LIFE EVENTS

previously they may have been accounted for in religious or political connotations.

The usefulness of a diagnosis of PTSD amongst non-western populations has been questioned (Braken, Giller & Summerfield, 1995). In western cultures the concept of the individual is central, and shapes and defines political, cultural and medical discourse. Accordingly, western medicine has adopted the assumption that the individual existed prior to “society and culture” (Braken et al., 1995). This approach to mental illness reflects a cultural perception of individuality and the self, which is not universal among non-western cultures and which runs the risk of victimising and pathologising survivors, categorising them as psychiatric cases. It may in fact convey an expectation of continued psychopathology negating the resilience and empowerment of many who have experienced traumas. Summerfield (2001) expressed concerns that, should it become seen as advantageous to suffer from PTSD, then people will choose to present themselves as victims as opposed to survivors, which may well negate their natural coping skills.

Alternatively, the focus on psychiatric symptomology calls attention to the pain being suffered and enables clinicians to utilise a short description to convey information to one another, which may in turn facilitate the development of psychological and other treatments (Kagee & Naidoo, 2004). Moreover, many find comfort in the diagnosis by knowing that what they are experiencing has a label and must therefore be understood and experienced by others. The diagnosis of PTSD allows many people to access support and treatment that would not occur if the diagnostic criteria did not exist.

5.3.3. Culturally and socially decontextualised. Since the first inclusion of PTSD in DSM-III there have been debates surrounding the impact of pre-morbid personality and the traumatic event (Braken et al., 1995). It is important to take into account environmental factors such as the family and social context as well as social support, psychological factors, cultural values, and biological factors in understanding and explaining psychological distress (Mattis, Bell, Jagers & Jenkins, 1999).

PTSD is frequently used as a tool by humanitarian programmes as a basis on which to address and capture the impact of events such as wars, but it does not take into account other issues like culture, current situation or the subjective meaning given to an experience (Summerfield, 2001). The focus on psychopathology “obviates one’s perspective of the survivor as a complex dynamic aggregate of political, social, cultural and personal factors” (Kagee & Naidoo, 2004, p.48). Theories of post-traumatic responses developed in western countries which are often comparatively peaceful, economically prosperous and stable, might not be applicable in areas that do not have these attributes (Kagee & Naidoo, 2004). Troubled regions like South Africa might frame how traumas are understood, and the meaning gained from them. As such, suffering and distress vary in accordance with social contexts and are shaped by the definitions and interpretations that people apply to such events (Summerfield, 1999). In essence Summerfield argued that, since the majority of those who are exposed to traumatic events are politically oppressed or economically impoverished, it follows that trauma and its consequences are simply symptoms of power inequalities in society and not those of individual disorders (Summerfield, 1995). He further argued that societal suffering and distress should not be seen as psychopathology (Summerfield, 2001).

HIV, PTSD AND TRAUMATIC LIFE EVENTS

The suggestion that PTSD is not a form of individual psychopathology but rather a symptom of social equity is not, however, supported by other researchers, who point out that only a minority of people who have survived traumatic events develop PTSD, and the disorder is associated with particular neuro-cognitive markers that suggests a disruption of the normal stress response (Kaminer & Eagle, 2010). Biological studies have shown that those who have been diagnosed with PTSD following traumatic events have exhibited a significantly smaller hippocampus and an excessively activated amygdala (Van Der Kolk, 1996). The hippocampus is crucial in the categorisation and storage of incoming stimuli into the memory, while the amygdala assists with evaluating the emotional significance of the incoming stimuli (Van Der Kolk, 1996). Individuals with PTSD also display differences in neurochemical responses, for example the brain's receptors for cortisol appear to be more sensitive following a traumatic event, rendering the person more sensitive and hyper-responsive to events (Yehuda, 1999).

Further critiques of the trauma model called attention to the fact that PTSD reflects a western concept of the concerns of those who have suffered a traumatic event (Kagee, 2004b). Braken et al. (1995) further criticised the western notion of mental illness which assumes that the signs and symptoms of mental illness are universal, when in fact many signs and symptoms may be recognisable in a variety of settings, with no guarantee of them representing the same thing across situations (Braken et al., 1995). Frequently in non-western cultures, the physical and psychic are intertwined. As psychiatric diagnoses are developed in western contexts, they incorporate and reinforce western notions of individualism, but such descriptions may not be applicable to those who define themselves differently.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Individualistic cultures value and reward personal accomplishment, autonomy, agency and self-sufficiency (Mesquita & Walker, 2003). Collectivistic cultures, on the other hand, which are traditionally a feature of non-western societies, particularly African and Asian, emphasise duty and relationships to others (Markus & Kitayama, 1991). Sato (2001) suggests that in order to maintain mental well-being, collectivist cultures require relatedness whereas individualistic cultures require autonomy. Consequently, although it is widely accepted that western medicinal treatments are universally appropriate for people of different cultures who present with the same symptoms, it seems unlikely that psychotherapy developed for western cultures will alleviate distress among cultures with different values without adaptations. The experience of mental illness is grounded on a context of cultural, family and orientations which shape both the experience of illness and the interventions used to address it (Braken et al., 1995). PTSD has been criticised for reducing traumatising events, like war, to a technical list of criteria (Summerfield, 2001).

Yet, interestingly, a study that compared the survivors of trauma suggests that, even though cultural differences in how the self is defined shape the negative appraisals formed in response to the trauma (with particular treatment implications), the diagnosis of PTSD is applicable across cultures (Jobson & O’Kearney, 2009). In South Africa, those who have suffered a traumatic event may be familiar with both traditional African and Western beliefs, and thereby draw from a combination of systems when trying to make sense of trauma that they experienced (Kaminer & Eagle, 2010). That there are different meanings associated with and understanding

HIV, PTSD AND TRAUMATIC LIFE EVENTS

of post-traumatic stress reactions does not necessarily negate the cross-cultural validity of the diagnostic category.

Taking symptoms out of their social and cultural context is always a danger when applying necessarily circumscribed psychiatric labels and this danger emphasises the necessity of a detailed case conceptualisation that locate the patient within their social and cultural context (Young, 2011). These should combine the best psychological models, developed to explain particular mental disorders, and the individual's personal experiences to guide interventions (Kuyken, Padesky & Dudley, 2008).

5.3.4. Demand characteristics. A critique of the way in which PTSD is diagnosed and then applied to people is to do with the way in which this information is usually elicited. Kagee and Naidoo (2004b) argue that the nature of the questions asked in an interview may alert respondents to the potential nature of their supposed disorder which is being asked about. Respondents may then endorse items in an attempt to meet the interviewer's expectations, rather than accurately reflecting their phenomenological experiences, perhaps as a deliberate attempt to ensure access to treatment and some form of potential reparation. This is a circular process where symptoms are confirmed as valid because they are endorsed by people, but they are endorsed simply because they are offered as the only or best way to convey their distress. The resulting diagnosis might not reflect the important feature of their experience, which may in turn result in inflated prevalence studies being used to argue the relevance of the diagnostic category in question.

However, in a study specifically designed to circumvent these demand characteristics, Kagee found that South African survivors of political violence reported symptoms of post-traumatic stress, despite the fact that

HIV, PTSD AND TRAUMATIC LIFE EVENTS

these were not the most salient aspects of their experiences. In his study, members spontaneously mentioned PTSD symptoms, discussing them at length (Kagee, 2004b; Kagee, 2004c) which illustrates that, while Summerfield (2001) and colleagues raised important concerns about the validity of PTSD as a universal psychiatric diagnosis, the concept of PTSD need not be discounted. Although too great a focus on traumatic responses may be a problem, “critiques of the trauma discourse as a Western phenomenon need to be tempered with evidence of the lived reality of psychological sequelae experienced by this population” (Kagee, 2004b, p. 323).

It seems that the reality of clinicians over-recording and patients over-emphasising symptoms in research may be a vulnerability of most epidemiological studies, including the present one, which is one of the reasons why this research project complements the structured assessment data with less-structured qualitative data.

5.4. The Question of Whether the Diagnosis of a Life-Threatening Illness Should be Included as a Category A Event that can Result in PTSD

DSM-IV-TR, DSM-5 and the ICD-10 do not give an aetiological description of PTSD, but rather assume that a traumatic event underlies its origins (World Health Organisation, 1992; American Psychiatric Association, 2000; American Psychiatric Association, 2013a; Bakelaar et al., 2011). According to the American Psychiatric Association, PTSD’s diagnostic structure parallels a stimulus response model, making the assumption that a recent past event has occurred and consequently PTSD has developed (American Psychiatric Association, 2000).

HIV, PTSD AND TRAUMATIC LIFE EVENTS

In the old DSM-III, HIV diagnosis was not seen to be a qualifying event sufficient enough to result in PTSD, because being diagnosed with a life-threatening illness was not viewed as being an event “out of the range of normal human experience”. Instead criteria focused on acute events as causes for PTSD, such as war, rape, natural disasters and accidents (Tacon, 2012), but this changed with the publication of DSM-IV in 1994, which included the diagnosis of a life-threatening disease as a qualifying trauma able to precipitate PTSD and subsequent PTSD symptomology (American Psychiatric Association, 1994).

For many years, symptoms resembling those commonly seen in individuals who have experienced traumatic events, such as military combat, violent personal assault (e.g., rape), natural disasters, or other threats to life, were reported among survivors of cancer (Koocher & O’Mally, 1981; Kornblith, et al., 1992). These symptoms were thought to resemble those seen in PTSD and included avoidant behaviours, intrusive thoughts, and heightened arousal (American Psychiatric Association, 1994; Koocher & O’Mally, 1981; Kornblith et al., 1992). As a result of these similarities, the occurrence of trauma-related symptoms in patients with life-threatening cancer has been under increasing scrutiny, culminating in their inclusion in the diagnostic criteria of PTSD in Criterion A in DSM-IV (American Psychiatric Association, 1994). This stressor definition incorporates a more subjective understanding of trauma associated with threat to physical integrity (Talbert, Wagner, Braswell & Husein, 1995; McGrath, 1999), which allows cancer patients and their family or caregivers to be diagnosed with PTSD and included in research (Lerner, 1999).

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Cancer is different from other traumatic stressors in that it is not a discreet event, and the exact nature of the trauma is somewhat blurred, as it consists of a potential range of traumatic experiences that can occur during the course of the illness (Smith, Redd, Peyser & Vogl, 1999). These may include the actual diagnosis, the treatment, information provided about recurrence, negative test results, or another aspect related to their diagnosis (Mundy, Blanchard, Cirenza, Gargiulo, Maloy, & Blanchard, 2000). Research using oncology patients was conducted using the DSM-IV criteria and illustrated the appropriateness of changes in the DSM-IV criteria for examining psychiatric morbidity (Alter, Pelcovitz, Axelrod & Goldenberg, 1996; Baider & DeNour, 1997).

This expansion of the criteria to include chronic illness caused significant alterations to the consideration of events which may cause PTSD. Breslau and Kessler (2001) found that the DSM-IV-TR expanded criteria for PTSD resulted in an increase of 60% in the number of events that could be considered sufficient to precipitate PTSD. Events like a car accident, rape or assault tend to be singular occurrences, restricted to a set time period, whilst a chronic and potentially terminal illness does not have such a definite time-frame (Tacon, 2012). Whereas traditional stressors take place in the past, the stressor for a chronic disease may be seen as bi-directional in that there is also the future threat of further trauma. Tacon (2012) concluded that, regardless of the time of the onset of the stressor, the threat is ongoing. In any chronic illness the perpetrator is internal and is in the form of a disease which may lead patients to believe that their bodies are betraying them. In the case of HIV, the threat is potentially deadly. Nevertheless, the inclusion

HIV, PTSD AND TRAUMATIC LIFE EVENTS

of the diagnosis of life-threatening illnesses as a qualifying traumatic event for the diagnosis of PTSD remains controversial.

5.4.1. Should a diagnosis of HIV be seen as a qualifying event?

Following studies of cancer-related PTSD, researchers have begun to examine other life-threatening illnesses, including HIV. Tacon's (2012) concept of cancer-related PTSD, originally applied to cancer patients, is also relevant to HIV-related PTSD in that the traumatising agent is not external as is the case in assault or rape. A number of studies have examined PTSD and HIV (Botha, 1996; Els et al., 1999; Leserman et al., 2005; Myer et al., 2008; Martin & Kagee, 2008; Olley et al., 2005; Olley, Seedat & Stein, 2006), see Systemic Review, Chapter 7.

However, a diagnosis of HIV needs to be distinguished from a diagnosis of cancer with regards to PTSD symptomology, because of the former's highly-stigmatised nature (Mahajan et al., 2008; UNAIDS, 2007). The question of whether or not HIV/AIDS should be seen as a qualifying event for PTSD has led to prevalence studies attempting to assess the psychological and psychiatric impact of HIV on individuals (Bakelaar et al., 2011). It is apparent that the diagnosis of a life-threatening illness is a significant stressor which triggers responses of fearfulness, helplessness or horror. But unlike most traumatic events, which are time-limited, a life-threatening illness is persistent and can create the possibility for re-traumatisation. Such disease progression may also impact on PTSD symptoms. Among others, Mundy and Baum (2004) mentioned that a separate category of disorder should be developed to accommodate the symptomology of PTSD following a life-threatening illness. Yet a study by Martin and

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Kagee (2008) concluded that receipt of an HIV-positive diagnosis may in itself be considered a stressor significant enough to result in PTSD.

Despite this, the appropriateness of applying a diagnosis of PTSD to the psychological impact of a life-threatening illness has been questioned (Kelly et al., 1998). More recently Kagee (2008) expressed his misgivings about the appropriateness of a PTSD diagnosis when the traumatic event is the diagnosis of HIV. He pointed out that PTSD is a memory disorder that is anchored to a past traumatic event. The traumatic event is re-experienced in the form of intrusive memories and nightmares. In contrast, the intrusive thoughts and imagery of those diagnosed with HIV tend to reflect their concerns about the future, involving the prospect of their physical decline and eventual death.

These sentiments were echoed by Bakelaar et al. (2011) in a guest editorial for the *African Journal of Psychiatry*. They noted that living with HIV involves a multitude of stressors rather than a single event, and represents an ongoing traumatic experience rather than one located at a fixed point in time, arguing that it is the consequence of the diagnosis rather than the notification of status that accounts for what some consider to be indications of PTSD. They doubted that a receipt of a diagnosis of HIV alone, especially in the age of anti-retroviral medications, is enough to culminate in meeting the criteria for PTSD, although they fully acknowledged the presence of significant PTSD symptomology.

Yet researchers such as Brewin and colleagues (Brewin et al., 2009) suggested that prolonged stress of a less intense nature than one would expect of a typical Criterion A event can result in the symptoms of PTSD. Lifelong HIV infection is undoubtedly a prolonged stressful event. They also claimed

HIV, PTSD AND TRAUMATIC LIFE EVENTS

that lower intensity traumatic events can be expected to cause PTSD in people who are vulnerable (Brewin et al., 2009). Again, given that the marginalised are at a heightened risk of HIV, perhaps this marginalisation also renders them at a heightened risk of exposure to other traumatic events and therefore more vulnerable to PTSD when diagnosed with HIV.

Kagee (2008) suggested that people with what many might think is HIV-related PTSD do not actually qualify for such a diagnosis because they are unlikely to experience intrusive reminders of the traumatic event, which must logically be the receipt of the diagnosis of HIV. According to him the intrusive symptomology is more likely to be about the prospect of death and dying.

However, as Young (2011) noted, PTSD researchers have had difficulty distinguishing between intrusive re-experiencing and other intrusive symptomology (Hackmann, Ehlers, Speckens & Clark, 2004). Common features of PTSD include aspects which are not among the criteria, specifically non-re-experiencing intrusions such as evaluative thoughts about the trauma and ruminations which may actually occur far more frequently than the re-experiencing intrusions (Reynolds & Brewin, 1998; Reynolds & Brewin, 1999). Thus, the occurrence of primarily future-orientated intrusions does not necessarily disqualify people from a diagnosis of PTSD. The more pertinent question is whether those individuals who have been diagnosed with HIV-related PTSD also experience intrusive recollections of the moment they were informed of their HIV-positive diagnosis, which would entitle them to fulfil the criteria for PTSD (Young, 2011).

HIV, PTSD AND TRAUMATIC LIFE EVENTS

This is a complicated question because, as Hackmann et al. (2004) noted, most of the intrusive recollections associated with PTSD are not actually about the worst moment of the index trauma, but are sensory experiences that occurred to signal impending danger, or those which surfaced at a later moment when the event took on a traumatic meaning. So the experience of additional stressors that are associated with HIV infection – such as stigma, discrimination, illness, bereavement, the threat of death and other losses – might serve to give the index trauma (the receipt of an HIV-positive diagnosis) a more traumatic meaning (Young, 2011). Thus, with PTSD, whether resulting from the diagnosis of HIV or not, what is re-experienced is not always very obviously associated with the so-called index trauma. Despite their doubts mentioned earlier, Bakelaar et al. (2011) conceded that the actual range of intrusive symptomology occurring with what is currently considered to be HIV-related PTSD requires much more research. Also, the multiple stressors associated with HIV are not unique to this particular trauma. Many traumatic experiences might involve further traumatic sequelae and potentially troubling future outcomes of the trauma. Rape is just one such example.

The debate is far from settled. Those who question the appropriateness of a PTSD diagnosis to capture particular psychological symptoms following the diagnosis of HIV (and by extension all other life-threatening illnesses) do not yet base their concerns on any firm empirical evidence. If such evidence is obtained, then the question would be whether the current PTSD diagnostic criteria should be adapted to include traumatic responses to the news that one has acquired a life-threatening disease, or whether a new diagnostic category needs to be established to accommodate this psychopathology, (as suggested

HIV, PTSD AND TRAUMATIC LIFE EVENTS

by Mundy and Baum (2004). As mentioned, the diagnostic criteria of PTSD have undergone numerous and significant revisions over the years to include a broader range of post-traumatic psychopathology and there will probably be further changes still.

In fact, the new DSM-5 criteria published after the data for the present study had been collected, state that being diagnosed with a life-threatening illness alone no longer qualifies for a diagnosis of PTSD, unless it involves medical events which are seen as sudden or catastrophic (American Psychiatric Association, 2013a). Even though the DSM-5 PTSD criteria are more specific than DSM-IV-TR in specifying traumatic events, (and the interpretation of the DSM-5 is that HIV no longer qualifies as a traumatic event), the South African social context, with pervasive HIV stigma and a seriously under-resourced health service, is one factor alone that is likely to make the diagnosis of HIV a catastrophic event for most South Africans. Life-threatening illness (such as HIV) is still considered a Criterion A traumatic event for ICD-10, which emphasises that the event may be of long or short duration, but must be of a threatening nature (World Health Organisation, 1992) and it seems that it might still qualify as a potential traumatic event for Criterion A in the forthcoming ICD-11. For the time being, although controversial, PTSD diagnostic criteria are routinely applied to those living with the disorder of what appears to be post-traumatic stress resulting from the diagnosis of HIV-infection.

This is the position on which the current research project has been conceptualised. However, in surveying the prevalence of traumatic experiences and HIV-related PTSD and in exploring some of their lived experiences, I will comment, where appropriate on the applicability of the

HIV, PTSD AND TRAUMATIC LIFE EVENTS

DSM and ICD-10 criteria for those seemingly traumatised by learning that they have acquired the HIV virus. Also, the thesis uses the conceptual framework of Ehlers and Clark (2000) which, unlike diagnostic criteria, attempts to describe and explain PTSD and which might allow for some of the variation on symptom profiles that share similar underlying processes.

5.5. Summary

Whetten et al. (2008) found that traumatic events, mental illness, distrust and stigma have all been associated with HIV risk behaviours and poorer medication adherence, and these are essential areas to be addressed. It has been established that HIV infection impacts on quality of life and, when combined with the presence of additional trauma, may also negatively affect functioning (O'Keefe & Wood, 1996). Furthermore, people's approach to stress and trauma may impact on their response to traumatic events, especially when combined with the stigmatised beliefs associated with an HIV-positive diagnosis.

It is evident that in South Africa the experience of traumatic life events is common, and consequently HIV-positive people may negatively appraise both their status and the subsequent events. This may result in a number of maladaptive coping styles and risky behaviours. There are many models which focus on responses to stress and stress tolerance (Simons & Gaher, 2005), but the model adopted for this research is the Ehlers and Clark (2000) Model which is discussed in Chapter 6.

In this chapter I have discussed trauma and PTSD as a diagnosable disorder and have considered whether or not a life-threatening illness is a trauma which may result in PTSD. The debate posed by Braken et al. (1995) and Summerfield (1999) raises questions about the appropriateness of a PTSD

HIV, PTSD AND TRAUMATIC LIFE EVENTS

diagnosis for non-western populations. Furthermore, Kagee (2008) posed a valid question as to whether HIV, as a life-threatening illness, may result in PTSD, as many of the stressors and concerns associated with being HIV-positive are future-orientated.

This research project takes as a starting-point the position that the events and symptomology that meet the requirements of the current diagnostic criteria will qualify for a diagnosis of PTSD. The following chapter provides a model for understanding PTSD and trauma in South Africa.

Chapter 6: Ehlers and Clark Model

The symptoms and course of PTSD can be explained using cognitive theories (Brewin & Holmes, 2003; Edwards, 2005a; Edwards, 2005b; Ehlers & Clark, 2000). Additionally, treatment interventions based on these cognitive models have been shown to be effective in the treatment of PTSD (Edwards, 2005b; Ehlers, Clark, Hackmann, McManus & Fennel, 2005; van Etten & Taylor, 1998).

However, most cognitive models of anxiety involve the expectation of some future threat, whilst PTSD emerges as a response to a dangerous event that has already passed. In an effort to understand this apparent anomaly of PTSD, Ehlers and Clark (2000) have both integrated and expanded earlier cognitive models resulting in a fully comprehensive theoretical perspective which explains both the individual PTSD symptoms and the persistence of such symptoms.

Early cognitive models of PTSD demonstrate the mechanisms underlying and maintaining PTSD symptoms (Brewin & Holmes, 2003; Edwards, 2005b), and the role of trauma-related cues in triggering traumatic memories (Mowrer, 1956). Cognitive therapy aims to bring about changes in cognition, information processing and memory structures, with a focus on the challenging of negative thoughts, and modifying the content of an individual's basic assumptions and schemas (Beck, Rush, Shaw & Emery, 1979). However, Brewin and Holmes (2003) claimed that early theories concerning PTSD did not address the impact of a traumatic event on memory structures. Later models focus on deficits with the encoding, organisation and retrieval of information associated with the traumatic event (Brewin, Dalgleish, & Joseph, 1996; Foa & Kozak, 1986; Foa & Rothbaum, 1998;

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Janoff-Bulman, 1992; Resick & Schnicke, 1996), focusing on the autobiographical memory as a main influence in developing PTSD and its symptoms. The Ehlers and Clark (2000) Model attempts to explain why the actual memory of the event is fragmented, making it difficult to recall accurately in its entirety, despite the fact that a predominant feature of PTSD is the involuntary intrusive memories of the event.

Ehlers and Clark (2000) proposed a cognitive theory to explain the development and persistence of PTSD symptoms, describing too how they continue to distress already-traumatised individuals. Their model differs from other cognitive models addressing PTSD that tend to restrict their focus to either memory disorder or trauma appraisals, in that it fully takes into account the combination of and interaction between trauma memories and appraisals (Ehlers & Clark, 2000; Ehlers et al., 2005).

Discussion of each model of PTSD is beyond the scope of this research but, for the purpose of this study, I shall explore the Ehlers and Clark (2000) Model in detail as it is considered to be the most comprehensive of the cognitive models of PTSD and has already been utilised to understand HIV-related PTSD in South Africa (e.g. see Young, 2011). Furthermore, the model is used to frame and understand the qualitative transcripts (See Qualitative Methodology Chapter 11).

6.1. Understanding PTSD and Trauma Using the Ehlers and Clark Model

According to Ehlers and Clark, PTSD as an anxiety disorder is seen as an anomaly. Anxiety is generally considered to be the result of a perceived future threat, but in the case of PTSD, the threat has usually passed (Brewin & Holmes, 2003; Ehlers & Clark, 2000). PTSD is the result of shortcomings in the processing of the traumatic event (Ehlers & Clark, 2000; Foa & Kozak,

1986), which leads to an over-generalised sense of current threat (Ehlers & Clark, 2000; Ehlers et al., 2005). Building on the theory of Foa and Kozak (1986), Ehlers and Clark (2000) suggested that the nature of the trauma memories combined with the trauma appraisals, which are constructed during and after the traumatic event, leave the person with a sense of current threat.

Consequently, sufferers are unable to realise the trauma's time limitations, and therefore experience it as an ongoing serious threat (Ehlers & Clark, 2000). In the case of persistent post-traumatic stress disorder, required changes to the negative trauma appraisals and traumatic memories are prevented by a series of problematic behavioural and cognitive coping strategies (Ehlers & Clark, 2000; Ehlers et al., 2005). This explains why, for some individuals, traumatic symptoms can be a transient reaction to traumatic stress, while for others it has the potential for becoming a chronic condition.

6.1.1. Deficits in autobiographical memories. Trauma memories differ from autobiographical memories in that they are characterised by poor elaboration and contextualisation (Ehlers & Clark, 2000). The disturbance felt by a person recalling a traumatic event occurs as a result of the way in which the trauma was encoded during a period of intense stress, and then stored and retrieved (McNally 2003). McNally (2003) further argued that during a period of stress our attention narrows as we focus on the most important aspects of the ordeal. It seems that any intentional recall of the trauma often results in a disjointed perspective, in that the central experience is recalled without the peripheral information which might alter the incident's significance (Ehlers, Hackmann & Michael, 2004; Kleim, Wallott & Ehlers, 2008).

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Memories are encoded via conceptual or data-driven processing (Brewin et al., 1996; Ehlers & Clark, 2000). Conceptual processing refers to the encoding of the traumatic event in spatial and temporal order, as well as its integration within the context of previous and subsequent information and other autobiographical memories (Ehlers & Clark, 2000). When under stress, processing tends to be data-driven rather than conceptual, which involves the encoding of sensory impressions resulting in disorganised and fragmented memories (Ehlers & Clark, 2000). Furthermore, when individuals with persistent PTSD recall the traumatic event, their recollection is clouded by their appraisal of it and they selectively retrieve information which is consistent with their evaluation (Ehlers & Clark, 2000); thus the trauma memories may be disjointed. Similarly, because these fragmented memories have not been elaborated and contextualised, they might support problematic appraisals that are contradicted by subsequent events. This interaction of memories and appraisals is the key to understanding PTSD.

People have a powerful associative memory with strong perceptual priming, and this often leads to the involuntary re-experiencing of different aspects of the trauma triggered by cues that are temporarily associated with the traumatic event (Ehlers & Clark, 2000). These might be the sights, smells, sounds or other sensory stimuli that occurred just before or during the traumatic event (Ehlers & Clark, 2000), or an incident which happens to give the experience an even more traumatic connotation (Ehlers et al., 2004). The associated learning which takes place during the trauma results in a powerful connection between various stimuli and the traumatic event. Such cues become warning signals for future dangers and the stimuli become perceptually primed (Ehlers et al., 2004). Consequently the person becomes

HIV, PTSD AND TRAUMATIC LIFE EVENTS

sensitive to stimuli which remind them of the traumatic event, and such triggers may invoke memories of the traumatic event (Ehlers et al., 2004).

Individuals retrieve information using either higher-order meaning-based retrieval strategies (which access autobiographical memory) or by direct retrieval or triggering by stimuli that were associated with the past event (Ehlers & Clark, 2000). If autobiographical memories are encoded normally through conceptual processing, higher-order meaning retrieval is enhanced whilst the ease with which memories are unintentionally retrieved is restricted. If, during the traumatic event, an individual uses predominantly data-driven processing, the trauma memory would be both poorly elaborated and intermingled with other autobiographical memories. This enhances direct retrieval, which may contribute to difficulties in intentionally retrieving memories of the trauma (Ehlers & Clark, 2000), and results in involuntary recollections (intrusive) of trauma or details thereof. Because such intrusions are experienced with the original emotions that the person felt at the time of the traumatic event, and which are perceived to indicate potential future danger (Ehlers, Hackmann, Steil, Clohessy, Wenniger & Winter, 2002), the sense of threat is maintained.

6.2. Appraising Trauma and its Consequences

In persistent PTSD, the nature of the predominant emotional response depends upon the sufferer's appraisal of the trauma (see Beck, 1976). Different individuals will experience a range of negative emotions as the diverse effects and responses take their course (Ehlers & Clark, 2000). This is the fundamental assumption of cognitive models of distress: that the way in which the traumatic event is interpreted largely determines the emotional response. Such appraisals may result in situational fear and avoidance

HIV, PTSD AND TRAUMATIC LIFE EVENTS

behaviours which subsequently maintain over-generalised fear and contribute to the maintenance of both PTSD and PTSD symptoms (Ehlers & Clark, 2000; Foa & Kozak, 1986). The negative appraisals of the symptoms of PTSD maintain the notion of a perceived and impending threat, such as a belief that the individual is weak or that the world is particularly unsafe. Such beliefs cause the hopes and aspirations to appear threatened. Sufferers may over-generalise details of the event and, as a result, may exaggerate the potential for future traumatic events, which can lead to both fear and avoidance behaviour. Such avoidance in turn maintains and exacerbates the over-generalised fear by depriving individuals of opportunities to correct problematic appraisals (Ehlers & Clark, 2000; Clark & Ehlers, 2005).

Ehlers and Clark (2000) proposed that personal history and the characteristics of the traumatic event shape how the traumatic event is appraised. Those who suffer from PTSD have typically appraised the traumatic event in a negative light, perpetuating the sense that the threat is not over and done, but is still present and is able to affect the future. They further suggested that such negative assessments by traumatised individuals are directed towards the self, the world and the future.

Furthermore, appraisals can be categorised as “internal” or “external” threats to the self. Internal threats may include, for example, the way in which the individual behaved during the traumatic event, whilst external threats may incorporate, for example, the person’s feelings about the world. Appraisals frequently take the form of harsh judgements and may present an internal threat to a person’s introspective opinion in that he or she can no longer expect to achieve both a sense of purpose and a worthwhile life goal (Young, 2011). Traumatic appraisals about the world may represent an

HIV, PTSD AND TRAUMATIC LIFE EVENTS

external danger: for example, the individual may feel that the world is a dangerous place (Young, 2011).

These negative appraisals may be based on the behaviour of the survivor or others during and after the trauma (Young, 2011), the consequences of the trauma, and/or simply the fact that the trauma occurred in the first place. Ehlers and Clark (2000) proposed a list of negative appraisals that may reinforce the persistence of PTSD symptoms (see Table 5).

Ehlers and Clark (2000) suggested that some individuals do not view symptoms as being part of the normal recovery process, but rather as an indication that their condition has deteriorated, or as evidence that there is damage to their physical or mental well-being. Such self-appraisals maintain PTSD by producing negative emotions which foster the engagement of dysfunctional coping strategies, subsequently prolonging and exacerbating the PTSD symptoms.

Factors that shape the appraisals that people make during or following the traumatic event include their personal dispositions as well as the social context in which each individual is located. Prior beliefs and experiences, as well as thought processes during the traumatic event may increase the likelihood of negative appraisals (Brewin & Holmes, 2003). Ehlers and Clark (2000) described a type of mental defeat where individuals feel that they are unable to control their future. Such mental defeat may form a risk factor for negative appraisals, including feelings of being weak or helpless or of being unable to act effectively or to protect oneself.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Table 5

Ehlers and Clark's Examples of Negative Appraisals

How it is appraised	What is appraised	Negative Appraisal
Self-Appraisals	Fact that the trauma happened	<ul style="list-style-type: none"> <li data-bbox="868 439 1098 472">[Nowhere is safe <li data-bbox="868 495 1353 528">[The next disaster will strike soon
	The trauma happened to me	<ul style="list-style-type: none"> <li data-bbox="868 562 1107 595">[I attract disaster <li data-bbox="868 618 1347 651">[Others can see that I am a victim
	Behaviour/emotions during the trauma	<ul style="list-style-type: none"> <li data-bbox="868 674 1283 741">[I deserve the bad things that happen to me <li data-bbox="868 752 1206 786">[I can't cope with stress
	Initial PTSD symptoms	<ul style="list-style-type: none"> <li data-bbox="868 819 1273 853">[My personality has changed <li data-bbox="868 875 1251 909">[My marriage will break up <li data-bbox="868 920 1315 987">[I can't be trusted with my own children
	Emotional numbing	<ul style="list-style-type: none"> <li data-bbox="868 1010 1091 1043">[I'm dead inside <li data-bbox="868 1055 1289 1122">[I'll never be able to relate to people again
	Flashbacks, intrusions and nightmares	<ul style="list-style-type: none"> <li data-bbox="868 1133 1078 1167">[I'm going mad <li data-bbox="868 1189 1198 1234">[I'll never get over this
	Difficulty concentrating	<ul style="list-style-type: none"> <li data-bbox="868 1267 1270 1301">[My brain has been damaged <li data-bbox="868 1323 1091 1368">[I'll lose my job
Other people's appraisals of the trauma	Positive responses	<ul style="list-style-type: none"> <li data-bbox="868 1379 1342 1447">[They think I'm too weak to cope on my own <li data-bbox="868 1458 1378 1491">[I am unable to feel close to anyone
	Negative responses	<ul style="list-style-type: none"> <li data-bbox="868 1525 1203 1559">[Nobody is there for me <li data-bbox="868 1581 1289 1626">[I cannot rely on other people
Other consequences of the trauma	Physical consequences	<ul style="list-style-type: none"> <li data-bbox="868 1648 1134 1682">[My body is ruined <li data-bbox="868 1693 1289 1760">[I will never be able to lead a normal life again
	Loss of job, money, etc	<ul style="list-style-type: none"> <li data-bbox="868 1783 1369 1850">[I will lose my children and will be homeless

Other contextual factors may include prior experiences of trauma, feeling that one is the recipient of others hostility, or being vulnerable to danger (Brewin & Holmes, 2003). In South Africa in the case of HIV trauma, appraisals are likely to be strongly influenced by HIV stigma (Young, 2011).

6.3. Strategies to Control the Threat and Symptoms

Ehlers and Clark (2000) described how the adoption of behavioural and cognitive strategies directed at reducing distress may inadvertently maintain and in fact exacerbate PTSD symptoms by preventing the elaboration and integration of trauma memories and the reappraisal of problematic trauma appraisals and by directly causing or exacerbating symptoms associated with PTSD. For most people who experience a traumatic event, recovery is natural, involving a gradual process of reappraising problematic trauma appraisals and the reorganisation and elaboration of the memories of the traumatic event (Young, 2011), but for others this natural process is blocked and therapeutic intervention is warranted.

When sufferers of persistent PTSD perceive a threat, they attempt to control both the threat and consequent symptoms using a range of strategies linked to their personal appraisal of the trauma (Ehlers & Clark, 2000). The intention is to reduce the sense of current threat and, indeed, such strategies may provide temporary relief but typically serve to maintain the PTSD symptoms (Ehlers & Clark, 2000).

Coping strategies may include safety-seeking behaviours that allow individuals to prevent or limit the risk of future traumatic events, but which also prevent the disconfirmation of the problematic beliefs (Salkovskis, 1996). An example of a safety-seeking behaviour is the person who will only leave the safety of his or her home in the company of another person. By

HIV, PTSD AND TRAUMATIC LIFE EVENTS

doing so, he or she preserves the belief that he or she is especially vulnerable. Maladaptive behavioural strategies may include the use of alcohol or medication, as well as avoidance of people, places or situations reminiscent of the trauma. Maladaptive cognitive strategies may include avoiding thinking about the trauma, thought suppression, ruminating about the event, as well as selective attention (Ehlers & Clark, 2000). For example, rumination is one way in which people respond to negative thoughts and beliefs (Brewin, 2006), and may enhance negative emotional reactions and appraisals and may prevent the individual from accepting that the trauma has occurred (Padmanbhanunni, 2010). Typical ruminations include repeatedly thinking about why the traumatic event happened, or whether it could have been prevented (Michael, Halligan, Clark, & Ehlers, 2007).

Thought suppression is another coping strategy, which serves as a temporary mood enhancer, but it tends to increase rather than decrease the frequency of trauma-related thoughts, which in turn increases distress (Shipherd & Beck, 1999). Suppressing thoughts of the trauma may also contribute to the persistence of PTSD symptoms as it inhibits the re-evaluation of a person's experience of the trauma (Geraerts & McNally, 2008; Shipherd & Beck, 1999). For example, individuals may feel that, if they think about the trauma, they may fall apart or go mad. So they try hard not to think about it and instead attempt to keep their minds busy all the time, but the inevitable failure to control intrusive thoughts may only result in self-confirmation that they are in fact losing control (Ehlers & Clark, 2000).

Moreover, selectively attending to cues or stimuli which are perceived as reminders of the traumatic event may serve to produce or increase the frequency of the intrusions of traumatic memories, and may result in both

maintaining and exacerbating PTSD and PTSD symptoms (Ehlers & Clark, 2000; Ehlers et al., 2004).

Another maladaptive coping strategy is hypervigilance whereby individuals tend to be over-alert to signs, sounds or cues that remind them of the trauma, or signal some other threat (Phillips, 2012). (The qualitative findings of this thesis that are presented and discussed in Chapter 12 suggest that hypervigilance might be exacerbated by the demands of anti-retroviral compliance).

6.4. Implications of the Ehlers and Clark Model for the Treatment of PTSD.

Ehlers and Clark (2000) suggested that change is required in three areas in order that sufferers may make progress: the trauma memory needs to be elaborated and integrated into each person's previous experiences, in order to reduce intrusive re-experiencing; the problematic appraisals of the trauma, and the sequelae that maintain the sense of current threat need to be modified; and the dysfunctional behavioural and cognitive strategies which prevent memory elaboration, exacerbate symptoms or inhibit the re-assessment of problematic appraisals need to be changed.

Ehlers, Clark, Hackmann and McManus (2010) explained that the negative appraisals which are used to maintain the PTSD symptoms and other responses to the traumatic event are modified using a variety of means such as providing information, Socratic questioning, and behavioural experiments. Many of those who suffer from PTSD are able to describe a sensation of being "changed" since the incident. Ehlers, Maercker and Boos (2000) described that, in cognitive therapy for PTSD, homework assignments which focus on reclaiming one's life are given, discussed and explained in each

HIV, PTSD AND TRAUMATIC LIFE EVENTS

therapy session, encouraging patients to attend social events and activities which they may have unnecessarily avoided since the event (Ehlers et al., 2010).

The problematic appraisals need to be integrated with the work surrounding the trauma memories, as the disjointed nature of such memories makes assessment of their meanings difficult (simply by discussing the trauma) and may have the effect that the awareness stemming from the cognitive restructuring is insufficient to result in a significant shift in a patient's affect (Ehlers et al. 2010). Ehlers and Clark (2000) developed a way of 'updating trauma memories' which involves: (1) identifying the idiosyncratic appraisals of the trauma, which is effected by determining the moments during the traumatic incident which caused the greatest distress ("hot spots") and sense of 'nowness' when the event is being recalled, and may pinpointed using imaginal reliving, writing a narrative, or discussing the intrusive memories (Ehlers & Clark, 2000; Ehlers et al., 2010); (2) identifying updating information, which involves the identification of the information giving counter-evidence against the idiosyncratic appraisals linked to each hot spot which either arises from the traumatic event itself, without being previously linked to the hot spot, or reaches a new conclusion after cognitive restructuring (Ehlers et al., 2010); and (3) incorporating such updated information into the hot spots, which is achieved by asking patients to think of the hot spot (usually by either reading a narrative or reliving the experience), and then reminding them of the updated information, either verbally, by imagery, or by engaging in movements or actions which are incompatible with the original meaning of the moment of the traumatic incident (e.g. jumping around for the hot spot which involves one's life being

HIV, PTSD AND TRAUMATIC LIFE EVENTS

threatened or harmed), or by incompatible sensations, for example, touching a healed leg (Ehlers et al., 2010).

The second aim of the Ehlers and Clark (2000) Model is to reduce re-experiencing by elaborating the trauma memories and discriminating the triggers. Four main techniques are used in individual treatments: imaginal reliving, where a person visualises and describes the event as well as explaining what he/she is feeling and thinking; writing a narrative; reconstructing the event with diagrams and models; and revisiting the site of the trauma (Ehlers et al., 2010). Because trauma memories are disjointed, frequently lacking important contextual information, the memory elaboration needs to link the hot spots of the traumatic event with new information that updates the meanings of such hot spots (Ehlers & Clark, 2000; Ehlers et al., 2004; Ehlers et al., 2010). The updating trauma memories approach is used in cognitive therapy for PTSD to establish these new links (Ehlers et al., 2010).

The discrimination of the triggers which result in re-experiencing symptoms usually involves two stages. Together, the clinician and patient analyse where and when the intrusions occur. Systemic observation may be necessary for all the triggers to be identified. Once triggers have been noted, the second step is to break the link between the triggers and the trauma memory.

In cognitive therapy for PTSD, several steps are followed: the client learns to distinguish between 'then' and 'now', learning to focus on current stressors and their context, rather than the trauma; next intrusions are triggered in therapy (sometimes triggers are brought to the session) to allow the patient to learn how to apply the 'then' versus 'now' discrimination.

Finally, the third aim of the Ehlers and Clark (2000) Model is to assist the patient to drop dysfunctional behaviours and cognitive strategies. The first step is to discuss the negative consequences of this strategy. This may be achieved by a behavioural experiment, (for example telling a client not to think of an elephant illustrates to the client that sometimes thought suppression serves to increase intrusions); discussing the advantages and disadvantages; and reversing the problematic strategy.

6.5. Support for the Ehlers and Clark Model

The Ehlers and Clark (2000) Model has been chosen as the theoretical model for use in the current study, as it shows both good clinical validity (Ehlers et al., 2003; Ehlers et al., 2005; Gillespie, Duffy, Hackman & Clark, 2002) and is contextual (Gillespie et al., 2002; Young, 2011).

A number of studies have made use of the Ehlers and Clark (2000) Model, illustrating its efficacy in the treatment of PTSD (Gillespie et al., 2002; Ehlers et al., 2003; Ehlers et al., 2005; Ehlers & Clark, 2008). A study by Gillespie et al. (2002) examined 91 cases of individuals who had survived the terrorist bomb blast in Omagh in 1998: the study consisted of cognitive therapy based on the Ehlers and Clark Model for between 5 and 30 sessions and showed a significant reduction in the symptoms of both depression and PTSD in 97% of the participants. Only 3% showed no improvement and no participants showed an increase or worsened symptoms after intervention. No participants dropped out of the treatment and a high effect size was found (2.47) for changes in PTSD symptoms, both pre-and post-treatment.

Another study by Ehlers et al. (2003) found that cognitive therapy using this model was more effective than either self-help booklets or complete lack of intervention, in that after cognitive therapy only 11% still

HIV, PTSD AND TRAUMATIC LIFE EVENTS

met the criteria for PTSD compared to a recovery rate of 12% when intervention consisted of a self-help booklet. Furthermore, there were no drop-outs for the cognitive therapy group. The effect size was 2.0.

A further study by Ehlers et al. (2005) on the efficacy of treatment based on the model showed improvements to the symptoms of depression, anxiety and PTSD, improvements that were maintained at a six-month follow-up. The effect size was 2.70 for the intended to treat sample, and 2.81 for those who completed treatment. Of significance is that the effect sizes for the outcome studies of interventions based on the model are high, when compared to other studies on cognitive therapy. This, combined with a low drop-out treatment rate, illustrates its usefulness as a model for understanding and treating trauma.

A more recent study (Young, 2011) concluded that the Ehlers and Clark (2000) Model provides a useful theoretical model for understanding HIV-related PTSD in South Africa. Furthermore, Young (2011) supported the findings of Gillepsie et al. (2002), who concluded that the Ehlers and Clark Model of cognitive therapy showed good transportability between contexts.

Such transportability further illustrates the usefulness of the Ehlers and Clark Model for the current study, which is based in a developing country in an impoverished area. The model illustrates the link between social contexts and individual appraisals, emphasising personal environments and experiences, all of which are important factors in the development and maintenance of PTSD (Young, 2011).

6.6. The Usefulness of the Ehlers and Clark Model in Understanding HIV-related PTSD

The Ehlers and Clark Model was developed in a developed context where ideas about trauma typically involve single traumatic events (Young, 2011). Despite this, Brewin and Holmes (2003) regarded this model as one of the most useful and comprehensive for treating PTSD and discerning the implications of trauma in different contexts. Furthermore, Young (2011) argued that the Ehlers and Clark Model may be useful in understanding both the prevalence and course of HIV-related PTSD in South Africa, where the experience of multiple traumatic events is common.

An important feature of the Ehlers and Clark (2000) Model is that the meanings or appraisals of traumatic events alongside the nature of the trauma memory maintain a sense of current threat and inspire various adaptive and maladaptive coping responses. It is evident that both the South African health-care system and local social contexts affect the appraisals of receiving an HIV-positive diagnosis (Young, 2011). Studies have shown that cultural differences also influence trauma appraisals (Jobson & O’Kearney, 2009) in the different interpretations of traumatic events, the varied presentation of symptoms following an event, and even alternative norms with regards to societal interventions (Baldachin, 2010). New ideas in the cognitive science suggest that cognition, rather than being purely inner processes detached from the external world, are embodied, embedded in the natural environment and extended beyond the boundaries of the organism (Robbins & Ayded, 2009). The idea of embedded cognition includes not only the immediate natural environment, but also the social and cultural context (Smith & Semin, 2007). Additionally, people’s conscious mental lives generally mirror those

HIV, PTSD AND TRAUMATIC LIFE EVENTS

close to them, like family and friends, who often hold such deprecating beliefs (Robbins, 2008). One prominent feature of the South African social contexts is HIV stigma (Deacon et al., 2009; Olley et al., 2004; Shabalala, 2001; Timberg, 2005). Thus, it is likely that many individuals who are diagnosed with HIV, influenced by their own and other people's stigmatising attitudes towards people who are HIV positive, appraise the event in a particularly negative manner, perhaps seeing themselves as weak, frail, contaminated or dying (Young, 2011). The most anxiety-provoking appraisal is likely to be contemplation of having an incurable life-threatening disease that will result in a painful and lonely death (Young, 2011).

Such appraisals may not just be associated with PTSD but also with other anxiety disorders and depression (Beck, 1987) as well as with substance-use disorders (Freeman et al., 2008), and may in fact maintain and exacerbate a range of trauma-related psychological disorders. Sometimes later events cause a new meaning to be assigned to earlier events, resulting in what appears to be a delayed onset of PTSD. For example, the experience of rejection or discrimination following disclosure, for example may give the original diagnosis of being HIV-positive new traumatic meaning (Young, 2011). As a result, one may see that PTSD symptoms associated with HIV increase over time (e.g. Olley et al., 2006).

As discussed in Chapter 4, South Africa is a country where traumatic events are common (Breslau et al., 1998; Breslau et al., 1991; Carey et al., 2003; Dinan, 2004; Hamber, 1999; Hamber & Lewis, 1997; Kessler et al., 1995; Mazza, 1996; Perkonig et al., 2000; Resnick et al., 1993; Roxburgh et al., 2006; Seedat, 2004; Statistics South Africa, 2011; Thorpe, 2010), so it is quite likely that HIV-positive individuals have already suffered multiple

HIV, PTSD AND TRAUMATIC LIFE EVENTS

traumas. HIV-positive individuals are also continuously confronted with the stigma of such a diagnosis (Amirkhanian et al., 2003; Kalichman & Simbayi, 2003; Mahajan et al., 2008; Santana & Darcy, 2000; Shisana & Simbayi, 2002; UNAIDS, 2007). Previous traumatic experiences are likely to influence the appraisals of new traumatic experiences. People who appraise one traumatic event as an aberration might be less inclined to do so if they experience another traumatic event. Furthermore, additional traumas expand the range of cues that trigger intrusive re-experiencing, and people who are already traumatised might be more inclined to engage in the data-driven processing that disrupts memory encoding and retrieval (Ehlers & Clark, 2000).

Another feature of the social context that might influence trauma appraisals is the state of the South African health-care system (Young, 2011). Being reliant on a health service that is overburdened and under-resourced is likely to add a more threatening meaning to the understanding of a diagnosis of HIV than would be the case in better resourced contexts.

A diagram by Young (2011) clearly illustrates how the Ehlers and Clark (2000) Model can be used to address HIV-related PTSD as it takes into account the high prevalence of other psychological traumas, HIV-related stigma and the health-care context all, of which will impact on the appraisal of an HIV-positive diagnosis. See example Figure 1.

6.7. Summary

In this chapter we have provided an overview of the Ehlers and Clark Model and demonstrated its effectiveness in furthering the comprehension of PTSD symptoms. Dunmore et al. (2001) expressed their view that the model comprehensively identifies the thoughts, appraisals, and beliefs which

HIV, PTSD AND TRAUMATIC LIFE EVENTS

contribute to dysfunction after a traumatic event. Following which feasibility studies (Ehlers et al., 2010; Ehlers et al., 2005) found the Ehlers and Clark (2000) Model to have good acceptability among patients. Furthermore, it was deemed effective and patients made significant improvements which were maintained in follow-up appointments (Ehlers et al., 2010; Ehlers et al., 2005). Based on its proven efficacy in other studies with a focus on PTSD (Ehlers et al., 2003; Gillespie et al., 2002; Young, 2011) the Ehlers and Clark (2000) Model will be the best-suited theoretical model to explain PTSD and frame the responses of participants in the qualitative component of this study (discussed in Chapter 12).

The next chapter contains a systemic review of studies that report the prevalence of PTSD and HIV-related PTSD in Africa and South Africa.

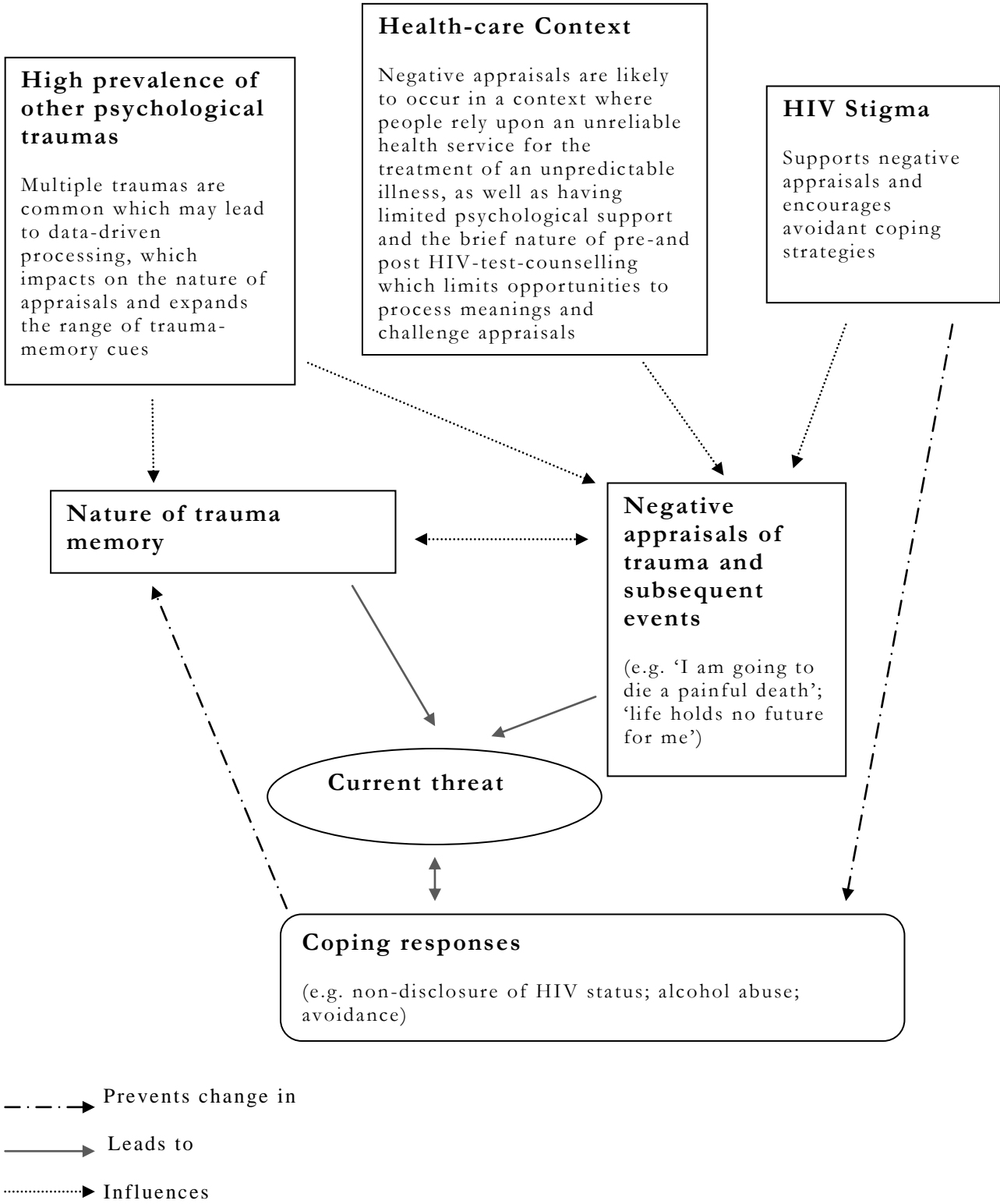


Figure 1. The adapted Ehlers and Clark (2000) Model for HIV-related PTSD

Source: Young (2011).

Chapter 7: A Systemic Review of HIV-related PTSD in Africa and Specifically in South Africa

Though controversial, much research suggests that the diagnosis of HIV is a qualifying event for PTSD and is also implicated in a host of other anxiety disorders. This chapter reviews a great deal of studies that have attempted to estimate the prevalence of PTSD and amongst HIV-positive populations, and provides a systemic review of PTSD in Africa and South Africa.

A systemic review is a summary which serves to identify, appraise, select and synthesise the clinical literature which is relevant to the current study (Centre for Reviews and Dissemination, 2008). The process followed in conducting a systemic review follows five steps. Initially one frames the question for the review, following by identifying the relevant studies. The nature and quality of the studies are assessed, and the studies to be included are presented in a table format. Finally, the results are discussed (Khan, Kunz, Kleijnen & Antes, 2003). At the time of writing, this review is currently the most up-to-date systemic study available. Even the most recent studies (Brandt, 2009; Collins, Holman, Freeman & Patel., 2006; Springer, Dushaj & Azar, 2012; Young, 2011) are not fully inclusive and were already outdated at the time of writing up this research.

In this study, the systemic review aims to estimate the prevalence of PTSD and HIV-related PTSD among HIV-positive individuals in Africa and specifically in South Africa. In order to qualify for inclusion, studies must have involved adult participants (18 years and older) and have been published in 1990 or later, as older studies are thought to be no longer relevant. Computerised searches were conducted using PsychINFO; PsycARTICLES;

HIV, PTSD AND TRAUMATIC LIFE EVENTS

MEDLINE; Google Scholar and PubMed databases and the search terms included different combinations of the words: *prevalence*, *Africa*, *AIDS*, *HIV* and *PTSD*. I also performed a manual search of the reference lists cited in the relevant studies.

7.1. Results

This systemic review includes 16 studies evaluating the presence of PTSD in an HIV-positive population, six of which were in African countries excluding South Africa and ten in South Africa (see Table 6). Several characteristics of the current research limit the comparability of studies.

7.1.1. Assessment measures. The employment of different measures of assessment rendered comparison difficult (Brandt, 2009), and few of the measures have been standardised on an HIV-positive population. A number of studies made use of a structured clinical interview, the Mini-International Neuropsychiatric Interview, commonly referred to as the MINI (Adewuya et al., 2007; Adewuya et al., 2009; Els et al., 1999; Joska et al., 2010; Myer et al., 2008; Olley et al., 2003; Olley et al., 2005; Olley et al., 2006; van den Heuvel et al., 2013), and the PTSD module of the CIDI (Freeman et al., 2008; Martin & Kagee, 2008). Other studies made use of self-report measures such as the Impact of Event Scale (Botha, 1996; Klis, Velding, Gidroy & Peterson., 2011; Peterson, Togun, Klis, Menten & Colebunders, 2012), or a combination of self-report measures (Pence et al., 2012; Wingwood et al., 2008).

The cultural relevance and validity of instruments developed outside Africa for use within Africa and South Africa may affect the quality of research (Brandt, 2009).

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Some instruments have been validated or used in other South African studies. For example, a structured clinical interview, the MINI was used by [redacted] has been used in many studies including a sample of HIV-positive patients in South Africa (Olley et al., 2003; Olley et al., 2005; Olley et al., 2006). Freeman et al. (2008) adapted and made use of a sub-section of the CIDI, the CIDI-PTSD module, for the use and assessment of PTSD symptoms in persons diagnosed or living with HIV in South Africa. This adapted measure was used in later research by Martin and Kagee (2008), and is the structured interview measure chosen for this research.

The study by Myer et al. (2008) established that brief self-report scales may be useful in assessing common mental disorders in people living with HIV in South Africa. The IES-R used by Klis et al. (2011) and Peterson et al. (2012) has been validated and used extensively in Sub-Saharan Africa (Leserman et al., 2008) and this is the self-report measure I have chosen to use in this study to complement the structured interview. (Research measures used in the present study will be discussed in greater detail in Chapter 8).

7.1.1.a. A note on the different diagnostic instruments used in the studies. As mentioned above the many different studies undertaken have used various screening measures and rating scales together with structured clinical interviews to assist in the diagnosis of anxiety and related disorders. These are quick and usually easy to administer, but results should be interpreted with caution as patients usually lack insight into their psychiatric condition and, as these are self-report measures, they may either over- or underestimate their symptoms, based on their own self-assessment (Chen, Chang, Tsui & Juang, 2004). It is important to note the differences between self-report instruments and structured clinical interviews.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

A self-report study involves a type of questionnaire where the interviewees read the questions and select the answer themselves (Barker, Pistrang & Elliot, 2002; Gregory, 2007). This type of screening is viewed as a brief and economical way to assess for pathology and identify individuals who may warrant intervention (Coyne, Thompson, Palmer & Kagee, 2000). The advantages of this approach include the fact that the interviewer cannot affect the results and, as questions may be open-ended or closed, this method can be useful in obtaining opinions, beliefs and attitudes. Access to phenomenological data may be gained from the respondents' perceptions of themselves and their world (Barker et al., 2002). However, disadvantages are that participants may not answer truthfully, or that they may attempt to represent themselves in a more positive light (Barker et al., 2002; Gregory, 2007;). Results frequently show large numbers of people without a psychiatric diagnosis being identified as at risk (false positives) and many individuals who have a psychiatric disorder not being identified (false negatives), and consequently not receiving the intervention they need (Coyne et al., 2000). There is also no guarantee that they have even understood the question, so the resultant responses may not be valid.

An example of a self-report measure is the 17-item Post-Traumatic Stress Diagnostic Scale (PDS) (Foa, Cashman, Jaycox & Perry, 1997). This scale assesses the 17 symptoms of PTSD according to the DSM-IV diagnostic criteria, and consists of 17 questions about how the individual has been feeling following a stressful life event. Respondents have to grade the severity of a variety of PTSD symptoms, indicating the degree to which the symptom has bothered them over the last week, using one of four possible answer choices ("0" indicating not at all or only one time; "1" indicating

HIV, PTSD AND TRAUMATIC LIFE EVENTS

once a week or once in a while, “2” reflecting two to four times a week or half of the time, and “3” showing five or more times a week or almost always). Each answer is awarded points, on a scale of 0 to 3, which are then totted up. The total score can range from 0-51, with higher scores indicating higher PTSD symptomology (Foa et al., 1997).

Another example of a self-report instrument is the IES-R, which has been used in other African research (Myer et al., 2008; Peterson et al., 2012). This measure lists potential difficulties which may have been experienced over the past week, which people sometimes have following stressful life events (Weiss & Marmar, 1997). The IES-R is the measure which will be used in the current research, and will be discussed in detail in Chapter 8.

Structured clinical interviews, by contrast, are administered by a researcher or clinician (Barker et al., 2002). The clinician poses questions, which may be open or closed, and respondents’ answers are recorded (Gregory, 2007). Interviews may be structured or unstructured: in the case of a structured clinical interview the questions are pre-determined (Barker et al., 2002). One of the most widely-used structured clinical interviews, designed to gauge anxiety as well as a variety of other psychiatric disorders, is the Structured Clinical Interview for DSM-IV (SCID). The SCID is interviewer-administered and is designed to be conducted by a clinician or someone with mental health training (Segal, Maxfield & Coolidge, 2008).

An alternative clinical interview is the Composite International Diagnostic Interview (CIDI), used by the World Health Organisation, whereby the clinician asks the participant a number of fixed choice questions which demand yes or no answers (Kessler & Ustun, 2004; Robins et al., 1988). In this manner the interviewer is able to establish the presence or

HIV, PTSD AND TRAUMATIC LIFE EVENTS

absence of a number of symptoms which indicate whether or not they meet the clinical ICD-10 criteria for a range of disorders. The CIDI is able to diagnose 22 mental disorders among adults in different cultures (Kessler & Ustun, 2004). For the purpose of this research, the PTSD sub-section of the CIDI has been used and will be discussed in greater detail later in the Quantitative Methodology section (Chapter 8).

7.1.2. Demography. Despite all studies focusing on an adult population of HIV-positive individuals, research to date has tended to focus on specific types of HIV-positive individuals: for example Adewuya et al. (2007), Adewuya et al. (2009) and Pence et al. (2012) looked at HIV-positive patients taken from community samples, while Peterson et al. (2012) examined a sample of HIV-positive individuals who were compliant on ARV medication. Many of the South African studies were based at HIV clinics (Freeman et al., 2008; Martin & Kagee, 2008; Myer et al., 2008) or hospital clinics (Els et al., 1999; Olley et al., 2005; Olley et al., 2006). Van den Heuvel et al. (2013) studied a combination of individuals taken from both rural and urban primary health-care centres. Most studies used mixed samples of men and women (Adewuya et al., 2007; Adewuya et al., 2009; Botha, 1996; Els et al., 1999; Freeman et al., 2008; Joska et al., 2010., Martin & Kagee, 2008; Myer et al., 2008; Olley et al., 2003; Olley et al., 2005; Olley et al., 2006; Pence et al., 2012; Peterson et al., 2012; van den Heuvel, 2013), while in contrast Wingwood et al. (2008) examined sample of 120 women attending one of five primary health-care clinics in Cape Town, South Africa.

7.1.3. Time-frame. The length of time since diagnosis varied from study to study. The participants in Botha's (1996) research had been recently diagnosed as HIV-positive, whereas Olley et al.'s (2005) sample had known

HIV, PTSD AND TRAUMATIC LIFE EVENTS

about their HIV status for almost six months. Martin and Kagee (2008) analysed 85 adults who had been diagnosed for less than a year, while Myer et al (2008) focused on those who had been HIV-positive for more than two years. One study focused on a varied sample (Freeman et al., 2008) and others did not report this information.

7.1.4. Geography. Excluding the studies in South Africa, there appears to be a paucity of country-specific research. Two studies were based in Gambia (Klis et al., 2011; Peterson et al., 2012), two in Nigeria (Adewuya et al., 2007; Adewuya et al., 2009), one in Zambia (van den Heuvel et al, 2013) and one in Tanzania (Pence et al., 2012). In South Africa research has been restricted to hospitals or HIV clinics, thus limiting comparisons with the wider population. Furthermore, such studies took place in different provinces which, in the multi-cultural environment of South Africa, are home to vastly different populations. Six studies took place in the Western Cape (Olley et al., 2003; Olley et al., 2005; Olley et al., 2006; Martin & Kagee, 2008; Myer et al., 2008; Wingwood et al., 2008), and one was in the Free State Province (Els et al., 1999). Several were conducted over multiple sites (Freeman et al., 2008; Joska et al., 2010; Martin & Kagee, 2008; Myer et al., 2008; Wingwood et al., 2008). The largest South African study examined 900 HIV-positive adult individuals at 18 HIV treatment centres spread across five provinces (Freeman et al., 2008).

7.1.5. Design. The majority of studies employed a cross-sectional design, aside from Olley et al. (2006) who examined a longitudinal study of 149 HIV-positive individuals, 65 of whom were followed-up after six months, forming a comparison group. Three international studies made use of an HIV-negative control group (Adewuya et al., 2007; Pence et al., 2012; van den

Heuvel et al., 2013), whilst of the South African studies, none made use of an HIV-negative control group.

7.1.6. Sample size. The sample sizes ranged from small, 24 HIV-positive individuals (Botha, 1996), through medium, 149 participants (Olley et al., 2005) to large, 926 men and women (Pence et al., 2012). The smallest study is also the earliest research, by Botha (1996), whose participants had been recently diagnosed as being HIV-positive, and findings showed elevated scores on the Impact of Events Scale (IES) indicating that participants had experienced their HIV-positive status as traumatic. Another small study used the Impact of Events Scale-Revised (IES-R) and examined a sample of only 44 outpatients at a clinic in Gambia (Klis et al., 2011), while the largest research by Pence et al. (2012) utilised an adult sample of 228 ARV compliant, and 267 recently-diagnosed HIV-positive participants, as well as 182 HIV-negative and 249 randomly-sampled community individuals (totalling 926 participants) from multiple sites in Tanzania. The most recent study by van den Heuvel et al. (2013) examined a total sample of 649 individuals, of whom 269 suffered from both HIV and tuberculosis, while a further 149 were only HIV-positive, and 231 were HIV-negative with tuberculosis.

7.1.7. Findings. The findings of the review are reported under two sections. The self-report checklists discussed first, are considered to be less reliable and therefore less valid than the structured interviews which are reviewed afterwards. In this study, PTSD refers to PTSD that occurs as a result of any qualifying traumatic event, whilst HIV-related PTSD refers to PTSD as a result of a diagnosis or living with HIV.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

7.1.7.a. Prevalence of PTSD using symptom checklists. Estimates of the prevalence of PTSD varies between 7.1% in those with an established HIV-positive status, and 8.4% in recently diagnosed individuals (Pence et al., 2012) to 43.2% (Klis et al., 2011) amongst a mixed sample of outpatients, which is certainly high enough to illustrate the importance of addressing such mental health issues. An early South African study which examined only 24 HIV-positive individuals who had been recently diagnosed in an effort to explore the rates of distress associated with an HIV-positive diagnosis, and findings showed an elevated score on the IES scale reflecting a high level of PTSD symptoms (Botha, 1996).

7.1.7.b. Prevalence of PTSD using structured clinical interviews. The prevalence of PTSD was seen to vary from 0.7% in Freeman et al.'s (2008) large scale study to 54.1% in a smaller sample taken from three HIV clinics (Martin & Kagee, 2008). Interestingly enough, both these studies use the same diagnostic tool to examine PTSD, namely the PTSD module of the CIDI. Amongst African studies (excluding South Africa) the prevalence of PTSD was examined by Adewuya et al. (2007) and van den Heuvel et al. (2013), both made use of the MINI. Adewuya et al. (2007) found that PTSD was present in 12.5% of their sample, while van den Heuvel et al. (2013), found a lower prevalence. In participants who were diagnosed with both tuberculosis and HIV, 4.4% met the criteria for PTSD. Of those who were diagnosed as only being HIV-positive (no tuberculosis), 7.4% met the criteria for PTSD.

Amongst research in South Africa, the prevalence of HIV-related PTSD was examined with results ranging from 4.2% (Freeman et al., 2008) to 40% (Martin & Kagee, 2008). A Nigerian study of an all HIV-positive adult

HIV, PTSD AND TRAUMATIC LIFE EVENTS

community sample found that HIV-stigma related PTSD (PTSD following stigmatising events and situations) was at 27.4% (Adewuya et al., 2009).

7.2. Discussion

Although the prevalence of PTSD across different countries and communities was high, results were variable. Each study used different measures and populations and therefore assimilation of findings needs to be done with caution. Ideally studies need to be performed using the same diagnostic tool and should use control groups to compare them with the general population rates (Thom, 2008) and with each other. As stated by Makoae et al. (2005) “physical and psychological symptoms are profoundly disruptive and impact almost every aspect of daily life” (p 22). In any event, it is evident that anxiety disorders, like PTSD are common, and that such anxiety causes distress which should be addressed if the mental health of HIV-positive individuals is to be enhanced.

With regards to African research conducted outside South Africa, two studies at the same ARV clinic in Gambia focused on PTSD and depression, using translated versions of a self-report measure (IES-R) combined with a depression scale (Klis et al., 2011; Peterson et al., 2012). The earlier study assessed 44 HIV-positive outpatients, finding that the prevalence of PTSD was high at 43.2% (Klis et al., 2011), whereas the later research employed a larger sample of 252 HIV-positive participants (169 women and 83 men who were already taking ARV medication), and found that 30% screened positive for PTSD (Peterson et al., 2012). No relationship was seen between the participants’ ages, the length of time they had been taking ARV medication, their viral load or their CD4 counts.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

In a large sample study of Tanzanian adults, utilising a combination of self-report measures, PTSD was seen in 8.4% of individuals who had recently been diagnosed with HIV, and 7.1% of individuals with an established HIV-positive diagnosis. The sample included 267 patients (84 males and 182 females)⁴ who had recently tested HIV-positive, as well as 228 (76 males and 147 females) who had an already established HIV-positive diagnosis. In this study, women were seen to present with more PTSD symptoms than men (Pence et al., 2012), a result that was also reported in the Gambian research (Peterson et al., 2012).

A Nigerian study using a structured questionnaire, the MINI, examined a sample of 190 HIV-positive individuals (54.7% female) and conclusions asserted that HIV-stigma-related PTSD was present in 27.4% of individuals. Of this sample, the mean time since first being diagnosed with HIV was 2.26 years, and 43.2% had been receiving ARV medications for less than one year (Adewuya et al., 2009).

A large-scale Zambian study also used the MINI. It took place across 16 rural and urban primary health-care clinics which allowed for comparisons between those suffering from tuberculosis and HIV, and findings showed that patients with only HIV showed more PTSD symptoms (7.4%), than those who suffered from only tuberculosis (4.6%), or those who were diagnosed with both (4.4%). PTSD was not shown to be associated with clinical stage or treatment status (van den Heuvel, 2013).

In contrast to the dearth of research in Africa (excluding South Africa), there is a growing body of literature targeting HIV and PTSD and its symptoms in South Africa, where studies found that the prevalence of PTSD

⁴ The data of this study does not add up, presumably due to missing information in the data sets.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

varied between 0.7% (Freeman et al., 2008) and 54.1% (Martin & Kagee, 2008), whereas the prevalence of HIV-related PTSD (HIV being the significant traumatic event) varied between 4.2% in HIV-positive adults (Freeman et al., 2008) and 40% in recently-diagnosed HIV-positive adults (Martin & Kagee, 2008).

The only longitudinal study was that by Olley et al. (2006) who investigated the persistence of psychiatric disorders in HIV-positive adults over 6 months, and found that PTSD at baseline was originally reported at 14.8, and had increased to 20% after six months, which could demonstrate that PTSD symptoms become pronounced as time passes and individuals adjust to being HIV-positive. Of the participants who met the criteria for PTSD at baseline testing, 36% reported that being diagnosed as being HIV-positive constituted their most traumatic event (Olley et al., 2006). This study concludes that the increased rate of PTSD between the baseline assessment and 6-month follow up may be the result of a delayed onset of PTSD symptoms or being exposed to another traumatic event. The possibility that living with HIV itself may be traumatic and could result in PTSD was not been addressed by Olley et al.'s (2006) research, and it may be that the traumatic events were consequences of the HIV-positive diagnosis, for example stigma or victimisation. According to Young (2011), in the case of multiple traumatic events, attempting to identify the single index trauma is pointless.

This highlights the importance of the present study which focuses on a population of HIV-positive people who are 'living with HIV'. In an effort to make the varied South African studies both accessible and comparable, I will present the findings region by region:

HIV, PTSD AND TRAUMATIC LIFE EVENTS

The Western Cape appears to be the most popular site for research, and showed varied results. Olley et al. (2003), used the structured MINI, to assess psychiatric morbidity, coping responses and disability amongst a sample of 149 recently-diagnosed HIV-positive patients (44 male and 105 female). This study found the PTSD prevalence at 14.8%, and concluded that women were more likely to suffer PTSD than men. Later research using the same sample examined noted PTSD at 14.8% and HIV-related PTSD (HIV being the index trauma) at 5.4% (Olley et al., 2005). In this study, individuals who met the criteria for PTSD reported greater work impairment and tended to use alcohol as a coping mechanism. At a six-month follow-up using 65 of the 149 original adult sample (discussed above), the prevalence of PTSD had increased to 20% (Olley et al., 2006). This may show that, after living with HIV for some time, PTSD symptoms either increase or become more apparent.

Myer et al. (2008), one of the larger studies, utilised the MINI, and reported one of the lowest prevalence rates, finding that PTSD prevalence was 5%. The sample included 465 HIV-positive adults recruited from three separate primary health-care facilities, 75% of the sample was female and the time since they were diagnosed varied. Only 18% of the study participants were receiving ARV medication at the time of the study. This study was not able to establish a causal relationship between a diagnosis of HIV and PTSD.

In the same year, a study at public health clinics reported one of the highest prevalences: 54% met the criteria for PTSD in their lifetimes, 40% met the diagnostic criteria for HIV-related PTSD (with HIV as the qualifying event), whilst 81.2% reported experiencing the A2 (a response involving fear, helplessness or terror) criterion of DSM-IV-TR, thus concluding that 45.8%

HIV, PTSD AND TRAUMATIC LIFE EVENTS

of participants experienced mild PTSD symptom severity (Martin & Kagee, 2008). Using the PTSD module of the CIDI previously adapted by Freeman et al. (2008) for use with HIV patients, this study made use of 85 HIV-positive patients, 75% of whom were female, who were attending one of three HIV clinics. Not all participants were taking ARV treatment, but they had all been diagnosed with HIV within the past year (Martin & Kagee, 2008). In contrast to the study by Myer et al (2008), Martin and Kagee's findings are suggestive of a causal relationship between hearing about one's HIV-positive status and the development of PTSD.

More recent research which focused on neuro-cognitive disorders amongst HIV-positive adults in three separate treatment centres, using the MINI, illustrated that 30.6% of the 536 participants met the cut-off for PTSD (Joska et al., 2010), thus demonstrating that people may experience living with their HIV-positive status as traumatic. Of this sample, 73.3% were female, and approximately half were taking ARV medication. Findings also show that more than a third of the sample disclosed that they abused alcohol, which supports the earlier finding of Olley et al. (2005) who found that alcohol was frequently used as a coping mechanism. The study by Joska et al. (2010) also found a correlation between education level and PTSD, concluding that individuals who are better educated may be more resilient, and consequently better equipped to deal with PTSD. A further correlation was found between PTSD and HIV-associated neuro-cognitive disorders, possibly linking PTSD symptom severity and the extent of cognitive impairment, such as memory deficits (Joska et al., 2010).

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Also in the Western Cape was a study by Wingwood et al. (2008) which used a variety of self-report measures with a sample of 120 female participants at five rural health-care clinics. Most of the sample were single (70.6%) and 5% had no education. Although the focus of the study was not specifically PTSD symptoms, but rather on stigma and the mental health of black South African women living with HIV, 34.7% met the criteria for PTSD. This revealed that those who divulged greater levels of HIV-related stigma also reported more PTSD symptoms. Despite the fact that the results of this study are not really comparable to other South African studies who used structured clinical interviews and focused on PTSD rather than stigma, it can be compared to the Nigerian study by Adewuya et al. (2009) which used a mixed-sex sample of 190 individuals and found a similar result, in that HIV-stigma related PTSD was seen in 27.4% of their participants.

The Bloemfontein study in the Free State province was one of the earliest studies. Els et al. (1999) examined the prevalence of psychiatric disorders amongst HIV-positive participants using the structured MINI, establishing that the prevalence of PTSD was 6%. This research was conducted at a hospital clinic and made use of a sample of 100 HIV-positive adults. The sample was predominantly female (57%) and not receiving ARV medication (recall that HAART was not available then, and the few ARV medicines that existed then were not available in the public health system for another 14 years). However, 73% had a CD4 count of less than 200. The length of time since they were diagnosed was not reported.

The largest South African study, which examined a cross-sectional sample of 900 individuals across 5 provinces and 18 clinics, arrived at the lowest rates of PTSD and HIV-related PTSD, which were 0.7% and 4.2%

HIV, PTSD AND TRAUMATIC LIFE EVENTS

respectively (Freeman et al., 2008). This finding may be due to the use of different measures and populations, as well as the researchers being primarily interested in the presence of absence or anxiety disorders within the cohort. This study used the CIDI-PTSD module which was adapted for use with HIV-positive patients. Of this sample, 74% was female, and 18% was taking ARV medication. The length of time since they were diagnosed varied.

Despite the growing body of literature in South Africa addressing issues surrounding HIV-positive populations and mental health, there is little research covering KwaZulu-Natal, which is reputed to be the “AIDS epicentre” of South Africa. The present research aims to redress this deficit by examining PTSD, HIV-related PTSD, and the combined prevalence of PTSD and HIV-related PTSD, as well as the total prevalence of PTSD in a rural setting in KwaZulu-Natal. Of the limited research conducted to date, all studies showed a high prevalence of both PTSD and HIV-related PTSD amongst HIV-positive participants, although a consistent limitation of most studies is the lack of a control group, which is clearly an area for further research and comparison. Despite the different rates of PTSD among those who are HIV-positive, it can be concluded that the prevalence is high (Brief et al., 2004), and that such individuals are vulnerable to traumatic events (Martin & Kagee, 2011), which suggests an important area of intervention for mental health practitioners. The lowest South African estimate (0.7%), as seen in the study by Freeman et al. (2008), can be contrasted to the lifetime prevalence of PTSD (2.3%) described amongst a general population (Stein, Seedat, Herman, Moomal, Heeringa, Kessler & Williams, 2008). Such comparisons imply that at the very least living with HIV can be seen as an additional traumatic stressor (Young, 2011).

HIV, PTSD AND TRAUMATIC LIFE EVENTS

There are only three published South African studies on HIV-related PTSD, and none at all which report on the combined prevalence of PTSD and HIV-related PTSD. Therefore the present study will be able to make a valuable contribution to this impoverished area of research, more especially since this project is based in a province where there has been limited investigations and medical intervention to date. It is clear from the above discussion that there appear to be only a few African studies targeting HIV and PTSD and the symptoms thereof. Due to the use of different measures, different populations and various countries, the generalisability and comparability of results is poor.

7.3. Summary

Research on anxiety and PTSD shows a link to HIV “milestones” such as initial diagnosis, first opportunistic infection, a declining CD4 count and the onset and progression of AIDS (Freeman et al., 2008). Difficulties may emerge shortly after diagnosis, which have been attributed to the receipt of an HIV-positive test result; or may develop during the course of illness, possibly due to stress or traumatic events (Olley et al., 2006).

In this chapter I have looked at the importance of addressing PTSD among those who are suffering a life-threatening illness, specifically of HIV/AIDS. Using a systemic review, I have also looked at the prevalence PTSD in Africa and South Africa and noted the high numbers of HIV-positive individuals who are affected by such problems and thus the importance of addressing them. This is, at the time of writing, the most up-to-date systemic review available and at the time of this research was fully-inclusive.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

The differing estimates of prevalence from such a variety of studies may be the result of a number of methodological dissimilarities, including sample sizes, selected groups, the measuring and reporting of individual symptoms not syndromes (Thom, 2008), the diagnostic criteria used to define the disorder, the assessment procedures employed, sample characteristics, and the definition of qualifying traumatic events (Breslau, 2001). In addition, one would expect the prevalence of PTSD to vary across contexts and to be higher where people cannot easily access good health care (Young, 2011).

It is clear that not everyone develops PTSD after experiencing a traumatic event. However, its prevalence is elevated, both in the general population and even more so among HIV-positive individuals, and further treatment and intervention should be made available to those who require it. The following chapter introduces the quantitative methodology used.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Table 6
Selected Studies of PTSD in Africa

Study	Study Site	Study Design	Sample Size	Diagnostic Measure	PTSD Prevalence
Botha, 1996	South Africa	Quantitative methodology Cross-sectional	24 HIV-positive individuals (recently diagnosed)	Self-report: IES	Above-average scores on the IES scale indicating PTSD symptoms
Els et al., 1999	South Africa: Hospital clinic, Free State Province	Quantitative methodology Cross-sectional No controls	100 HIV-positive individuals	Structured interview: MINI	Anxiety 21% Panic disorder 37% Social phobia 15% Agoraphobia 9% PTSD 6%
Olley et al., 2003	South Africa: Western Cape	Quantitative methodology Cross-sectional	149 HIV-positive individuals	Structured interview: MINI	Anxiety 9.7% Panic disorder 7.5% Social anxiety disorders 6.5% PTSD 14.8%
Olley et al., 2005	South Africa: Hospital Clinic, Cape Town, Western Cape Province	Quantitative methodology Cross-sectional No controls	149 patients	Structured interview: MINI	PTSD anxiety symptoms 14.8% HIV-related PTSD 5.4%
Olley et al., 2006	South Africa: Hospital Clinic, Cape Town, Western Cape Province	Quantitative methodology 6-month follow-up Longitudinal study	65 patients	Structured interview: MINI	PTSD Anxiety present in 14.8% of participants at baseline and increased to 20% after 6-month follow-up.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Table 6 (continued)
Selected Studies of PTSD in Africa

Study	Study Site	Study Design	Sample Size	Diagnostic Measure	PTSD Prevalence
Adewuya et al., 2007	Nigeria	Quantitative methodology Cross-sectional with Control Group	88 HIV-positive and 89 HIV-negative individuals	Structured interview: MINI	PTSD 12.5%
Freeman et al., 2008	South Africa: 18 sites across 5 provinces	Quantitative methodology Cross-sectional No control group	900 participants	Structured interview: 14 categories of the CIDI, incl. the PTSD module	Anxiety 0.4% Panic disorder 0.1% Social phobia 0.9% PTSD 0.7% HIV-related PTSD 4.2%
Martin & Kagee, 2008	South Africa: 3 HIV clinics, Western Cape Province	Quantitative methodology Cross-sectional No control group	85 adults	Structured interview: PTSD module of CIDI	Lifetime prevalence of PTSD 54.1% HIV-related PTSD 40%
Myer et al., 2008	South Africa: 3 HIV clinics, Western Cape Province	Quantitative methodology Cross-sectional No control group	465 adults	Structured interview: MINI	PTSD 5%
Wingwood et al., 2008	South Africa: 5 Primary Health-care Clinics, Western Cape Province	Quantitative methodology	120 women	Combination of self-report measures	HIV-stigma-related PTSD 34.7%

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Table 6 (continued)
Selected Studies of PTSD in Africa

Study	Study Site	Study Design	Sample Size	Diagnostic Measure	PTSD Prevalence
Adewuya et al., 2009	Nigeria	Quantitative methodology Cross-sectional No control group	190 HIV-positive patients	Structured interview: MINI	HIV-stigma-related PTSD 27.4%
Joska et al., 2010	South Africa: HIV clinics at various sites in South Africa	Quantitative methodology	536 HIV-positive patients	Structured interview: MINI	PTSD 30.6%
Klis et al., 2011	Gambia	Quantitative methodology Cross-sectional No control group	44 outpatients	Self-report measure: IES-R	PTSD 43.2%
Pence et al., 2012	Tanzania	Quantitative methodology Cross-sectional with Control Group	926 participants (incl. 182 HIV-negative)	Combination of self-report measures	PTSD in recently-diagnosed HIV patients 8.4%
					PTSD in established HIV-positive patients 7.1%
Peterson et al., 2012	Gambia	Quantitative methodology Cross-sectional No control group	252 HIV-positive individuals compliant on ART	Self-report measure: IES-R	PTSD 30%

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Table 6 (continued)
Selected Studies of PTSD in Africa

Study	Study Site	Study Design	Sample Size	Diagnostic Measure	PTSD Prevalence
van den Heuvel et al., 2013	Zambia	Quantitative methodology Cross-sectional with Comparison Group	649 participants (231 TB only patients, 269 HIV & TB patients, and 149 HIV-positive only)	Structured interview: MINI	PTSD in HIV only patients 7.4% PTSD in HIV and co-morbid TB patients 4.4%

Chapter 8: Quantitative Methodology

This chapter provides an overview of the quantitative methodology, starting with a description of the objectives of the quantitative section of the study (an outline of the qualitative methodology is presented in Chapter 11). Then the sample group is described, followed by detailed accounts of the measures used, procedure taken, and the analysis of the data. Ethical issues are discussed at length.

8.1. Objectives

The primary aim of the study was to investigate the lifetime prevalence of HIV-related PTSD and the lifetime prevalence of PTSD that is not necessarily related to living with, or being diagnosed with HIV, amongst a sample of ARV-compliant HIV-positive patients receiving treatment at G J Crookes Hospital, a primary health-care facility on the south coast of KwaZulu-Natal.

Based on the review of the literature, it was anticipated that in comparison to the lifetime PTSD prevalence of 2.3% for the general population (Stein et al., 2008), the lifetime prevalence of HIV-related PTSD and the lifetime prevalence of PTSD amongst the sample of ARV-compliant, HIV-positive individuals would both be high.

Secondary aims included an exploration of the associations between a lifetime diagnosis of HIV-related PTSD and various clinical, demographic and personal variables. Additionally, the study aimed to explore the frequency of different traumatic events (whether or not these result in PTSD) and the proportion of these that resulted in a lifetime diagnosis of PTSD.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Lastly, a receiver-operated curve is plotted to compare the performance of the IES-R, an easily administered self-report checklist, in relation to the adapted CIDI module that is used to diagnose lifetime HIV-related PTSD.

8.2. Participants

The sample included 159 HIV-positive, ARV-compliant adults who fell within the range of 18-50 years, and who were judged to be physically and psychologically capable of completing the assessment when they were seen at the anti-retroviral clinic at G J Crookes Hospital.

8.3. Measures

Measures included an intake questionnaire, the CIDI-PTSD module, an adapted version of the CIDI-PTSD module for HIV, and the IES-R, each of which will be described below. Interview times per participant varied from 45 minutes for the initial consent forms and intake questionnaire, to 3 hours for completion of the three quantitative measures. Patients were seen once and those who were part of the qualitative study were seen a second time (The qualitative methodology is discussed in Chapter 11).

8.3.1. Consent form and intake questionnaire. The complete quantitative interview schedule consisted of a form which gave information about the study (Appendix A), and which participants were required to sign before taking part. An intake questionnaire was used to gather information on age, gender, racial group, highest level of education obtained, length of time diagnosed with HIV, CD4 count, doctors' recorded symptoms, and other personal details (Appendix B). An additional question, whether participants were ever involved in political violence was asked. This was considered necessary given the violent history of apartheid in South Africa (Kaminer,

Grimsrud, Myer, Stein & Williams (2008), and particularly in the province of KwaZulu-Natal where the study was located.

8.3.2. The Composite International Diagnostic Interview (CIDI).

The World Health Organisation (1997) developed the Composite International Diagnostic Interview (CIDI) as a structured interview to assess whether or not symptoms meet both the DSM-IV and ICD-10 diagnostic criteria for various psychiatric disorders (Andrews & Peters, 1998). Since its development, it has been translated into 18 languages and is being used for epidemiological surveys worldwide (Andrews & Peters, 1998). Studies have shown the CIDI to display good reliability and validity (Andrews & Peters, 1998). Janca, Robins, Cottler and Early (1992) found that the CIDI provided all the data needed to form a diagnosis in accordance with the ICD-10 criteria, and it is designed to be administered by interviewers with no clinical training (Breslau, 2002). A limitation of the CIDI is its administration time, which is lengthy (approximately 75-90 minutes for the full interview) and necessitates additional clerical time for data entry and scoring. It has been used for studies such as the South Africa Stress and Health Study (SASH), which assessed both lifetime and 12-month prevalence of mental disorders amongst adults (Williams et al., 2004). The version used in this research is 2.1 (a new version, version 3.0, has since been released).

The PTSD module of the CIDI (CIDI-PTSD) (Appendix C) has been previously employed as a useful measure of PTSD in patients diagnosed with HIV (Martin & Kagee, 2008; Martin, Fincham & Kagee, 2009; Tsao Dobalian, Moreau & Dobalian, 2004) and was used in South Africa as part of the SASH study, to determine the prevalence of lifetime trauma in a sample

HIV, PTSD AND TRAUMATIC LIFE EVENTS

of adults (Williams et al., 2007). Further studies have been performed using samples of individuals suffering mild traumatic brain injury in Australia (Bryant & Harvey, 1998) and survivors of political discord in post-conflict settings in Africa (de Jong et al., 2001).

The CIDI-PTSD module is interviewer-administered and enquires about eleven potentially-traumatic events which individuals may have experienced in their lifetime: war, a life-threatening accident, fire, flood or other natural disaster, witness to someone being injured or killed, rape or molestation, serious attack, threat with a weapon, being held captive, kidnap or torture; and, for the purpose of this study, political violence was added to the list of possible traumatic events (see Kaminer et al., 2008). If they respond positively to having experienced any of the events, interviewees are then asked which event was the most traumatic (Andrews & Peters, 1998). This event is then examined more closely using a variety of questions which reflect the DSM-IV and ICD-10 criteria for PTSD (Table 7) and some additional questions to establish clinical distress or impairment as per the DSM-IV requirement that clinical distress must be present for the classification of PTSD. All questions require only a “yes” or “no” answer. If, after various sub-sections, it transpires that the participant does not meet the diagnostic criteria for PTSD (quantified by negative responses to all items in the section), then progress is discontinued. If, on the other hand, the participant meets the criteria, then the diagnosis is made accordingly. In the current study, the CIDI- PTSD module was used to determine the lifetime prevalence of diagnosable PTSD, and additionally granted the interviewer the opportunity to examine exposure to traumatic events.

Table 7
Composite International Diagnostic Interview, PTSD Module (CIDI-PTSD)
Sample Items

Domain	Sample Item
Intrusion	<p>Did you keep remembering (the event) when you didn't want to?</p> <p>After it, did you keep having bad dreams or nightmares about it?</p> <p>Did you suddenly act or feel as though (the event) was happening again even though it wasn't?</p> <p>Did you get upset when you were reminded of it?</p>
Avoidance	<p>Did you deliberately try not to think or talk about (the event)?</p> <p>Did you avoid places or people or activities that might have reminded you of it?</p> <p>After (the event) was your memory blank for all or part of (the event)?</p> <p>After (the event) did you lose interest in doing things that were once important or enjoyable for you?</p> <p>After (the event) did you feel more isolated or distant from other people?</p>
Hyper-arousal	<p>Did your heart beat fast or did you tremble when you were reminded about (the event)?</p> <p>After (the event) did you have trouble sleeping?</p> <p>After it, did you feel unusually irritable, or lose your temper a lot more than is usual for you?</p> <p>After it, did you have trouble concentrating?</p> <p>After (the event) did you become very much more concerned about danger or very much more careful?</p> <p>After (the event) did you become easily jumpy or easily startled by ordinary noises or movements?</p>

8.3.3. The adapted PTSD module of the Composite International Diagnostic Interview (CIDI-HIV-PTSD). As part of a larger study focusing on the prevalence of individuals with mental disorders amongst a population of persons living with HIV, Freeman et al. (2007) adapted the CIDI-PTSD module for the use and assessment of PTSD symptoms in persons diagnosed or living with HIV in South Africa (CIDI-HIV-PTSD). The CIDI-HIV-PTSD was used to determine the prevalence of diagnosable PTSD and PTSD symptomology associated with being HIV-positive or in receipt of an HIV-positive diagnosis (Appendix D).

The CIDI-HIV-PTSD module is introduced by the interviewer stating “I am now going to ask you some questions around your reactions to hearing that you were HIV-positive, and to being HIV-positive” (Martin et al., 2009). Mirroring the questions asked in the CIDI-PTSD module, the items asked reflect the DSM-IV and ICD-10 criteria for PTSD, with the qualifying event being living with HIV, and if, after various sub-sections, it becomes apparent that the participant does not meet the criteria for HIV-related PTSD (quantified by his or her responding negatively to all items in the section), then the questionnaire is discontinued. If, however, the participant meets the criteria for PTSD, then he or she qualifies for a diagnosis of HIV-related PTSD (Martin et al., 2009).

8.3.4. The Impact of Event Scale Revised (IES-R). The Impact of Event Scale Revised (IES-R) is classified as a self-report measure which assesses PTSD symptoms over the last week stemming from exposure to a traumatic stressor (Appendix E). In this research, the traumatic event was ‘Being diagnosed and living with HIV’. It has been used in previous research

HIV, PTSD AND TRAUMATIC LIFE EVENTS

focusing on PTSD amongst those who are HIV-positive in Sub-Saharan Africa (Klis et al., 2011; Peterson et al., 2012). The IES-R was developed by Weiss and Marmar in 1997 to reflect the DSM-IV criteria for PTSD and assesses current distress for any specific life event and is based on the original Impact of Event Scale (IES) (Horowitz, Wilner & Alvarez, 1979), which was published in 1980 prior to PTSD being established in the DSM-III as a diagnostic category (Weiss & Marmar, 1997).

The IES-R examines PTSD symptomology according to the three different domains of PTSD symptoms (intrusion, avoidance and numbing, and hyper-arousal) and uses various questions to target these differences (Table 8). There are 22 items, which is seven more than the original IES (Weiss & Marmar, 1997). Eight measure intrusion (reminders evoking feelings, experiencing strong feelings, intrusive thoughts, things triggering thoughts, difficulty staying asleep, nightmares, imagery, and acting as though they were back at the time of the trauma), another eight evaluate avoidance and numbing (numbing of responses, avoidance of feelings, feelings of derealisation, avoidance of situations, trying to forget, trying not to speak of it, avoidance of reminders of the trauma, being aware that one has many feelings surrounding the trauma but not dealing with them) and six indicate hyper-arousal (anger, irritability, heightened startle response, hypervigilance, and difficulties with concentration).

Respondents are asked to rate each item on a scale of 0 (not at all), 1 (a little bit), 2 (moderately), 3 (quite a bit), and 4 (extremely) according to how they were feeling over the previous seven days. Combining these provides a total subjective stress score. The IES-R is normally a five point

HIV, PTSD AND TRAUMATIC LIFE EVENTS

scale. However, for the purpose of this research, the original points 1 and 2, “not at all” and “a little bit” were combined to mean “not applicable”. Similarly, points 4 and 5, “quite a bit” and “extremely” were grouped together indicating to mean “definitely did apply”. This modified analysis method was previously employed by Lakaje (2005) in research on HIV.

According to Weiss and Marmar (1997), there is no cut-off score or normative data for the IES-R, but this measure is rather intended as an indication of symptomatic status over the last seven days with regards to exposure to a traumatic stressor. In other words the IES-R was not designed to be a diagnostic tool and the administrator and the participant both need to be sure what traumatic stressor is being discussed.

The score for the intrusive sub-scale is the mean of scores on items 1, 2, 3, 6, 9, 14, 16 and 20 (Appendix E). The score for the avoidance sub-scale is the mean of scores on items 5, 7, 8, 11, 12, 13, 17 and 22. The score for the hyper-arousal sub-scale is the mean of scores on items 4, 10, 15, 18, 19, and 21 (Weiss & Marmar, 1997).

The IES-R has been shown to display good internal consistency on the three domains of PTSD (Weiss & Marmar, 1997). Briere (1997) and Weiss and Marmar (1997) found the hyper-arousal sub-scale to have good predictive validity with regards to trauma, whilst the intrusion and avoidance sub-scale have shown sensitivity to changes in respondents’ clinical status over time, as well as in detecting differences in reactions to traumatic events of varying severity (Horowitz et al., 1979; Weiss & Marmar, 1997).

Table 8
Impact of Event Scale-Revised (IES-R) Sample Items Grouped According to Domain

Domain	Sample Item
Intrusion	<p>Any reminder brought back feelings about it.</p> <p>I had trouble staying asleep.</p> <p>Other things kept making me think about it.</p> <p>I thought about it when I did not mean to.</p> <p>Pictures about it popped into my mind.</p> <p>I found myself acting or feeling as though I was back at that time.</p> <p>I had waves of strong feelings about it.</p> <p>I had dreams about it.</p>
Avoidance	<p>I avoided letting myself get upset when I thought about it or was reminded of it.</p> <p>I felt as if it had not happened or was not real.</p> <p>I stayed away from reminders about it.</p> <p>I tried not to think about it.</p> <p>I was aware that I still had a lot of feelings about it but I did not deal with them.</p> <p>My feelings about it were kind of numb.</p> <p>I tried to remove it from my memory.</p> <p>I tried not to talk about it.</p>
Hyper-arousal	<p>I felt irritable and jumpy.</p> <p>I was jumpy and easily startled.</p> <p>I had trouble falling asleep.</p> <p>I had trouble concentrating.</p> <p>Reminders of it caused me to have physical reactions such as sweating, trouble breathing, nausea or a pounding heart.</p> <p>I felt watchful and on guard.</p>

8.4. Procedure

8.4.1. Responsibilities of the researcher. The researcher, a registered clinical psychologist, ensured that she was familiar with the administration of the CIDI and IES-R, both of which can be administered by individuals with clinical training. The researcher also ensured that the student nurses assisting with the study were familiar with the consent form, initial interview and the measures being used so that the interviews could run smoothly when assisted with translation. The researcher was responsible for obtaining informed consent from participants, conducting interviews and analysing results.

8.4.2. Data collection. Quantitative data collection took place over a period of six months (August 2009 to January 2010 inclusive). Every morning the patients attending the clinic gave their patient number to the ward clerk who located the patient file. Random sampling of every tenth referral from the ARV clinic was used, and a white sticker was placed on every tenth patient file to signal to staff that the patient be approached to participate in the study. These patients were informed by the counsellors at the HIV treatment centre that the psychologist was conducting a study. If patients indicated an interest in the study they were referred to the researcher.

The study was described and explained to participants and the psychologist assessed participants for eligibility, taking into consideration age (being between the ages of 18 and 50 years) and ARV adherence. Exclusion criteria included being diagnosed with HIV for less than one month (to exclude Acute Stress Disorder), but in fact no participants were excluded from the study on this basis. A further exclusionary factor was that participants could not include prisoners because they are only allowed to

HIV, PTSD AND TRAUMATIC LIFE EVENTS

participate in research with consent of the Correctional Services Department.

When this became known, doctors and staff of the HIV clinic were informed that prisoners could not be included in the study.

Questions were asked by the psychologist in English and, in the case of first-language isiZulu-speaking patients, this was then repeated in their mother-tongue by a student nurse acting as a translator. This was done for all isiZulu speaking patients, even though all respondents were able to understand spoken English. Using trained student nurses from the local community obviated any extraneous factors thrown up by language barriers. Ample opportunity to ask questions about the study was provided before consent forms and the intake interview were completed by the clinical psychologist conducting the study.

Overall, the majority of the ARV clinic patients approached responded positively to being invited to participate in the study. However, of the 501 individuals who indicated an initial interest to the HIV counsellors, only 165 actually came to see the psychologist. This potential sample group was further reduced by six patients who then refused to become involved, leaving a total sample of 159 patients (Table 9, for a summary of attendance), a response rate of 32%. Reasons for this response rate may be attributed to a variety of factors such as: transport difficulties, not wanting to spend additional waiting time to see the psychologist, not wanting to see a psychologist, work or family commitments, or the psychologist being temporarily unavailable. This last factor could indicate a shortcoming in that the study was conducted by a single researcher who may have been busy,

HIV, PTSD AND TRAUMATIC LIFE EVENTS

sometimes for three hours at a time, with other participants or hospital patients when potential participants tried to make contact.

Following the consent form and intake interview the CIDI-PTSD module, CIDI-PTSD-HIV, and IES-R were administered consecutively by the researcher, assisted by one of two student nurses who were trained by the psychologist with regards to the procedure. All items were administered in the same sequence for all participants. One trained student nurse was present at all times, and participants were encouraged to talk and explain their answers as much as possible. Any participants who were perceived to be malnourished were referred to the dietician, while those who displayed psychological distress were encouraged to attend a further session with the clinical psychologist.

Table 9
Summary of Attendance

Potential & Actual Participants	Number	%
Number of individuals expressing initial interest in the study	501	100.0%
Number of patients failing to turn up	336	67.1%
Number of patients refusing to take part in the study	6	1.2%
Number of patients taking part in the study	159	31.7%

8.5. Statistical Analysis

All measures were hand-scored and placed onto an Excel spread sheet for analysis. The means (M), standard deviations (SD), percentages (%) and ranges were calculated for the variables relevant to the present study, as were

HIV, PTSD AND TRAUMATIC LIFE EVENTS

the prevalence of PTSD, HIV-related PTSD and the combined prevalence of PTSD and HIV-related PTSD.

The 95% confidence interval for the lifetime prevalence rates for PTSD, HIV-related PTSD and the combined prevalence of PTSD in the participants was estimated using the Wilson score method without continuity correction (Newcombe, 1998). An advantage of this method is that it is not considered to be overly conservative and is able to provide coverage for close to 95% of nominal 95% intervals. A disadvantage is that this method is cumbersome; however a number of online calculators are available for assistance. The calculations were performed using a downloaded excel script and checked against two online calculators (<http://www.vassarstats.net/prop1.html> and <http://www.measuringusability.com/wald.htm>). The results produced by all three calculators were identical.

The prevalence of each of the different categories of traumatic events was reported and compared across genders. The rates of PTSD for the different traumatic events were calculated and compared.

8.5.1. Bivariate analysis. Initial descriptive statistics were run, followed by chi-square analyses (with Yates' correction when appropriate) to determine the association between selected variables (more specifically, age, gender, length of time since diagnosis, CD4 count, disclosed status, reason for HIV test and previous experience of trauma) and the diagnosis of HIV-related PTSD.

8.5.2. Multivariate analysis. A multiple regression analysis was performed to assess the relationship between the certain variables and post-traumatic symptomology as measured by the IES-R (Tabachnick & Fidell, 2007). Following this, a binary logistic regression analysis was conducted to examine the relationship between the same variables and diagnosis of HIV-related PTSD as the dichotomous dependent variable as determined using the adapted CIDI module. As there is no theoretical model that would justify a particular sequence of variables, the actual number of predictor variables was small (4), and similarly, the number of cases was relatively small (159), a forced entry method was used for both regression analyses.

According to Field (2000), a rule of thumb for multiple regressions is that the sample size should be at least 15 participants per independent variable. Previous research suggests that HIV-related PTSD is associated with having a history of previous traumatic events other than the diagnosis of HIV, negative life changes, social support, stigma, and HIV symptomology (Katz & Nevid, 2005). The variables that were entered, in sequence, into the regression analyses were: (1) whether or not participants had told their families or friends about their HIV-positive diagnosis, which was expected to correlate with internalised or attributed stigma and social support; (2) whether CD4 counts were higher or lower than 200, which was likely to correspond with HIV symptomology; and (3) whether or not participants had experienced other traumatic events.

8.5.3. Receiver Operating Characteristic (ROC) curve. A ROC graph was plotted to calculate the performance of the IES-R in relation to the CIDI, which, as a structured diagnostic interview, is considered the gold standard of assessment instruments.

The methodology employed in this ROC analysis is consistent with that used by Martin et al. (2009), who compared the 17-item Post-traumatic Stress Diagnostic Scale (PDS) with the same adapted CIDI to assess HIV-related PTSD that was used for this study.

ROC graphs are a two-dimensional plot of a true-positive rate on the Y axis, and the false-positive rate of the X axis (Fawcett, 2006). The area under the ROC curve (AUC) offers a single value for the average performance of a classifier (the IES-R). This is calculated as a proportion of the total ROC space, and ranges from 0 to 1. Random performance is illustrated by diagonal line ($y = x$) from the lower left quadrant to the upper right quadrant, which is an AUC of 0.5. Any classifier is expected to achieve an AUC of greater than 0.5 (Fawcett, 2006). The sensitivity and specificity values were calculated in an attempt to identify the cut-off point that maximised both. The Youden index (J) refers to the maximum vertical difference between the ROC curve and the diagonal line, and illustrates the cut-off point that optimises the measure's differentiating ability when equal weight is given to both sensitivity and specificity (Schisterman, Perkins, Liu & Bondell, 2005). The ROC graph and AUC are calculated using MedCalc, a computerised statistical software package developed for health research.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

As noted, Martin et al. (2009) published the ROC of the Post-traumatic Stress Diagnostic Scale (PDS) against the same adapted PTSD module of the CIDI that was used in the present study. The AUC of the IES-R as obtained in the present study was statistically compared to the AUC of the PDS obtained by Martin et al. (2009).

Like the IES-R, the PDS assesses PTSD symptoms reported by the interviewee over the past week, which Martin et al. (2009) compared to a lifetime diagnosis of HIV-related PTSD. But, because all of their participants had been diagnosed with HIV only within the 12 months preceding their research interviews, their reported lifetime prevalence of HIV-related PTSD is equivalent to a 12-month prevalence. Thus, to remain consistent with Martin et al. (2009), for the purpose of the ROC analysis and comparison, only those who reported PTSD symptoms as assessed by the adapted CIDI within the 12 months prior to the research interviews were considered to be HIV-related cases. (As it turned out, all of those who met the criteria for a lifetime diagnosis of HIV-related PTSD had reported symptoms within the previous six months – some much more recently – so all could be considered HIV-related PTSD cases. See the following chapter).

It should be noted, however, that even this reduced time frame might have included people who would have met the diagnosis for HIV-related PTSD in the past, but who no longer fulfilled the diagnostic criteria at the time of the interview. Identifying the exact end-point or remission of symptoms of any psychological disorder is complicated, but perhaps especially so for symptoms of PTSD that typically wax and wane over time (American Psychiatric Association, 1994). Thus, to identify current PTSD

symptomology, a too-narrow time frame may result in false negatives, while a too-wide time frame might result in false positives. Importantly, the present study used the same time frame as that of Martin et al. (2009). Nevertheless, results should be treated with some caution.

8.6. Ethical Considerations

Due to the sensitive nature of the information regarding this study, and because the participants had been diagnosed with a life-threatening illness, subjects were considered to be vulnerable. Once ethical approval had been obtained from both the Rhodes University RPERC, and the psychiatry department at the hospital, the nature of the study was described to staff at the hospital. The researcher ensured that selected patients understood their rights and what was expected if they agreed to participate in the study. Those who were interested were informed about the nature, risks and benefits of the study as well as given ample opportunity to ask questions, following which they were allowed time to decide whether or not they wanted to take part and sign the consent form.

8.6.1. Informed consent. According to Foxcroft (2011), obtaining informed consent is paramount in conducting research in an ethical way. The consent form and information letter were read out aloud, explained, and a copy was given to each participant. The researcher ensured that the study was described and understood, and that the risks and benefits of the study were transparent. Additionally it was explained to participants that they were free to withdraw from the study at any time without giving reasons, and without suffering any negative consequences. Participants were told that taking part

HIV, PTSD AND TRAUMATIC LIFE EVENTS

in the research project would not have any positive or negative impact on their medical treatment at the hospital.

Evans (2007) stressed that consent should be given formally, viz. a consent form. Written informed consent was obtained from each participant for all aspects of the study. A number of the participants had achieved only a very low or elementary level of education and were illiterate. In these cases extra care was taken to explain, and participants' agreement to partake in the study was witnessed by an independent person. For people who have no previous experience of psychological testing, having the project explained using both concrete and colloquial terms may be most effective in ensuring that they fully understand enough to give consent (Foxcroft, 2011).

8.6.2. Privacy and confidentiality. Respect for the dignity of individuals involves maintaining the value of confidentiality of the personal details that are disclosed (Evans, 2007). Evans (2007) noted how participants' confidentiality can be maintained by removing any identifying information and replacing it with a code. In this research, all identifying data has been coded to ensure privacy, and no names or other identifiable details have been used. All source data remains in a locked cabinet with the primary researcher.

Foxcroft (2011) argued that with regards to ethical testing practices, it is best to test such an individual in familiar surroundings. To maintain confidentiality, a private office adjacent to the ARV clinic was used for the duration of the study, and staff advised patients of the study prior to them being approached by the researcher.

8.6.3. Risks and benefits. It is important for researchers to minimise the risks associated with research, thus protecting participants as far as possible from harm (Gillepsie, 2013). Although there were no anticipated risks for the individuals who agreed to take part in the study, the researcher considered the potential for re-traumatisation due to the intrusive nature of questioning. To ensure the psychological wellness of participants, all participants were seen by the HIV counsellors during their monthly hospital follow-ups. They were also invited see the psychologist without an appointment on the date of their monthly visit.

8.6.4. Compensation. Participants did not obtain any financial compensation for their participation in the study. This was to ensure that individuals who did participate, did so of their own free will and not for financial gain.

8.6.5. Conflicts of interest. A conflict of interest may occur when a researcher becomes caught between two or more concerns (American Psychiatric Association, 2013b). These generally refer to financial or other interests that might compromise the judgement of the researcher or at least create the impression that the researcher's integrity may have been compromised. No such conflict of interests was identified in this study.

8.7. Summary

In this chapter, the method utilised in the quantitative research section has been comprehensively discussed with details of the participants, and the measures which were used. This was followed by an in-depth discussion of the procedure taken, the statistical analysis and the ethical concerns which

HIV, PTSD AND TRAUMATIC LIFE EVENTS

were considered. In the next chapter the quantitative results will be analysed and presented.

Chapter 9: Quantitative Analysis

This chapter presents the results of the quantitative analysis. It starts with a description of the sample, followed by a description of the IES-R and CIDI responses, the lifetime prevalence of HIV-related PTSD and PTSD, the frequencies of the different traumatic events and their rates of PTSD. Results of the bivariate analyses are reported followed by the multivariate analyses. Finally, the ROC analysis is reported and compared with those reported by Martin et al. (2009).

9.1. Demographic Characteristics

The sample consisted of 159 HIV-positive South African participants who were all compliant on anti-retroviral medication. A frequency distribution was conducted for age, gender, length of time since diagnosis, CD4 count, and the reason that participants went for an HIV test, as well as particulars of disclosure to family and friends. Each of these will be discussed separately below.

9.1.1. Age. All 159 participants were adults, aged 18 and older. The mean age of the sample was 34 years with a standard deviation of 6.97 years, and the actual ages ranged from 20 years to 50 years, with 101 participants (63.5%) falling into the 18-35 years age category, and the remaining 58 participants (36.5%) being aged 36 or older (Table 10).

9.1.2. Gender. Of the 159 participants, 47 (29.6%) were male, and 112 (70.4%) were female (Table 9). This split is in accordance with national statistics which have established that more women than men are diagnosed as being HIV-positive (HSRC, 2005), perhaps partly due to the fact that women are often routinely referred for HIV-testing and treatment as part of anti-

HIV, PTSD AND TRAUMATIC LIFE EVENTS

natal health care, or that they tend to access health-care more frequently than men, whose culture of masculinity limits help-seeking behaviours (Lindegger & Quayle, 2009).

9.1.3. Race. In this study Black African participants comprised the majority at 150 (94.3%), while six (3.8%) were identified as Indian, two (1.3%) as white and one (0.6%) as coloured⁵.

9.1.4. Marital status. The majority of participants (83.0%) in this study were single (i.e. not married or co-habiting), 22 (13.8%) were married, and five (3.1%) were widowed.

9.1.5. Education. The participants' educational backgrounds were varied: three (1.9%) had received no formal education at all, whereas 116 individuals (73.0%) had attended school for between 6 and 10 years. Only five (3.1%) went on to tertiary studies. Twelve (7.5%) participants were unsure how many years of schooling they had completed.

9.1.6. Employment. Of the 159 participants, only 46 (28.9%) were employed at the time of the study. One participant did not answer the question and the remaining 112 (70.4%) were unemployed.

9.1.7. Reason for HIV test. Individuals are tested for HIV for a variety of reasons (Fischer, Reynolds, Yacobson, Barnett & Schueller, 2005). Of the participants in this study, 67 (42.1%) went for an HIV-test of their own volition, and 66 (41.5%) were referred by their doctors for testing due to

⁵ The use of race as a variable in South African research is surrounded by controversy due to the country's history of racial segregation, discrimination and oppression. Bowman, Seedat, Duncan and Burrows (2006) explained that though an emphasis on race contradicts the commitment to non-racialism, the consensus for the time being is that race continues to be a significant demographic variable in South Africa as it is an important indicator of life opportunities and remains a social reality for most individuals (Bowman et al., 2006). The usages of these persistent apartheid-era categories in no way condones the ideology on which the apartheid system was based (Durrheim, Mtose & Brown, 2011).

HIV, PTSD AND TRAUMATIC LIFE EVENTS

being ill. The remaining 26 (16.4%) were tested as a routine consequence of being pregnant (Table 10).

9.1.8. Length of time since diagnosis. Nearly one-quarter of participants reported that they had been diagnosed with HIV within the past 12 months, of which one-third (8.2% of the total sample) had been diagnosed within the last 6 months. The proportions of those notified earlier were fairly evenly distributed across the time frames of 1-2 years, 2-5 years and 5 years or more, which suggests that individuals may go for a long time without knowing their HIV-positive status. Six participants (nearly 4%) were unable to recall when they had been originally diagnosed (see Table 10).

9.1.9. Disclosure. In the sample, 150 (94.3%) participants had disclosed their life-threatening HIV-positive diagnosis to a family member and 88 (55.3%) had revealed their HIV-positive status to their friends.

9.1.10. CD4 Count. Of the 159 participants, only 77 were aware of their CD4 counts when questioned: the CD4 count data was verified from the hospital files. Two individuals (1.3%) had a count of less than 50; whilst 12 (7.5%) reported having CD4 counts of between 51 and 200 and 63 participants (39.6%) had a CD4 count of over 200. The remainder (51.6%) were still awaiting their results.

9.2. Frequency of Item Responses

9.2.1. The IES-R. The mean IES-R score was 16.6 and the standard deviation, 11.6. Internal consistency was adequate, with a Cronbach alpha of 0.84. The frequency distribution of the various answers to each item was examined (Table 11).

Table 10
Selected Variables

Category	Variable	No.	%
Gender	Male	47	29.6%
	Female	112	70.4%
Age	18 - 35 years	101	63.5%
	36 - 50 years	58	36.5%
Length of time since diagnosis	Less than 6 months	13	8.2%
	6 - 12 months	26	16.4%
	1 - 2 years	36	22.6%
	2 - 5 years	38	23.9%
	More than 5 years	40	25.2%
	Unknown	6	3.8%
CD4 Count	< 50	2	1.3%
	51 – 200	12	7.5%
	> 200	63	39.6%
	Awaiting results	82	51.6%
Had disclosed HIV+ Status	to Family	150	94.3%
	to Friends	88	55.3%
Reason for HIV test	Pregnancy	26	16.4%
	Referred by GP	66	41.5%
	Tested Voluntarily	67	42.1%

It is apparent from Table 11 below that most participants consistently attempted to forget about their HIV-positive status. The three highest statements which were endorsed were “I tried to forget about it” (66.0%), “I tried not to think about it” (60.4%) and “I tried not to talk about it” (52.8%). Moreover 20.1% of respondents said that they “Thought about it unintentionally”.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Table 11

The IES-R Frequency Distribution of Responses

Item	Did Not Apply (points 1 & 2)		Applied Moderately (point 3)		Definitely Did Apply (points 4 & 5)	
	No.	%	No.	%	No.	%
Brought back feelings	119	74.8%	22	13.8%	18	11.3%
Trouble staying asleep	124	78.0%	8	5.0%	27	17.0%
Thinking about it	87	5.7%	30	18.9%	42	26.4%
Irritability/anger	136	85.5%	7	4.4%	16	10.1%
Avoided getting upset	145	91.2%	4	2.5%	10	6.3%
Thought about it unintentionally	109	68.6%	18	11.3%	32	20.1%
Felt as though it wasn't real	150	94.3%	2	1.3%	7	4.4%
Stayed away from reminders	144	90.6%	4	2.5%	11	6.9%
Pictures popped into my head	152	95.6%	3	1.9%	4	2.5%
I was jumpy	129	81.1%	7	4.4%	23	14.5%
I tried not to think about it	41	25.8%	22	13.8%	96	60.4%
I was aware I had feelings but didn't deal with them	151	95.0%	4	2.5%	4	2.5%
Feelings were numb	153	96.2%	3	1.9%	3	1.9%
Found myself acting like I was back at that time	154	96.9%	2	1.3%	3	1.9%
I had trouble falling asleep	125	78.6%	7	4.4%	27	17.0%
I had strong feelings about it	138	86.8%	11	6.9%	10	6.3%
I tried to forget about it	39	24.5%	15	9.4%	105	66.0%
I had trouble concentrating	153	96.2%	1	0.6%	5	3.1%
Experienced physical reactions	142	89.3%	8	5.0%	9	5.7%
Dreamt about it	140	88.1%	6	3.8%	13	8.2%
Felt watchful or on-guard	151	95.0%	4	2.5%	4	2.5%
I tried not to talk about it	57	35.8%	18	11.3%	84	52.8%

HIV, PTSD AND TRAUMATIC LIFE EVENTS

9.2.2. The CIDI-PTSD module. The CIDI- PTSD module was examined for individual response to items, as well as for total PTSD prevalence. In the CIDI-PTSD module, the participants were asked if each of the symptoms had been experienced as a result of an earlier traumatic event (Table 12). The most common responses were “Keeps remembering the event” (42.1%) , “Becomes upset when they are reminded of the event” (40.9%) and “Is concerned about danger” (39.6%). Although those questioned were forthcoming in their assessments, 26.4% said they “Try not to talk about it”.

Many symptoms consistent with depression and PTSD were reported as having been experienced, including: “Irritable or angry” (37.1%), “Has trouble sleeping” (29.6%), “Feeling despondent about their future” (20.8%) and “Loss of interest in activities” (12.6%). Over one-third of participants reported “Experiencing physical symptoms” (36.5%), and a high number continued to be “Easily startled” (29.6%).

9.2.3. CIDI-HIV-PTSD module. The CIDI-HIV-PTSD module was examined for individual response to items, as well as for total HIV-related PTSD prevalence. Table 12 illustrates the frequency distribution of individual responses to items.

In the CIDI-HIV-PTSD module adapted for use with HIV-positive, a very high proportion was “Concerned about danger” (78.0%) and two-thirds of participants “Kept remembering the event”. The majority (61.6%) of those interviewed “Became upset when reminded about the event” and 59.8% felt “Terrified” and “Try not to talk about it”.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Table 12

Frequency of Individual Responses, CIDI-PTSD and CIDI-HIV-PTSD

Cluster	Item	% of respondents who endorsed item	
		CIDI-PTSD	CIDI-HIV-PTSD
Intrusion	Feeling terrified	48.4%	59.8%
	Feeling helpless	43.4%	45.3%
	Keep remembering the event	42.1%	66.0%
	Experience dreams or nightmares	27.0%	26.4%
	Feel as though it is recurring	26.4%	Not included
	Become upset when reminded about the event	40.9%	61.6%
Hypervigilance	Experience physical symptoms	36.5%	57.2%
	Have trouble sleeping	29.6%	39.0%
	Irritability/anger	37.1%	50.9%
	Trouble concentrating	3.1%	3.8%
	Are concerned about danger	39.6%	78.0%
	Easily startled	29.6%	27.7%
Avoidance	Try not to talk about it	26.4%	59.8%
	Avoid places/people associated with the traumatic event	20.8%	11.3%
	Memory blank for the time of the event	5.7%	20.8%
	Loss of interest in activities	12.6%	18.2%
	Feel distant	16.4%	34.0%
	Avoid meetings and social activities	7.6%	10.1%
Distress	Difficulty expressing love	13.2%	47.2%
	Feel despondent about the future	20.8%	46.5%
	Have received assistance from a health-care professional	10.1%	58.5%
	Have used drugs/alcohol or medication to cope	5.7%	10.7%
	Feel that it has changed their life	25.8%	55.4%
	Blame themselves	12.6%	42.8%

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Neuro-vegetative symptoms appeared to be common and included “Irritability and angry” (50.9%), “Feeling despondent about their future” (46.5%) and “Has difficulty sleeping” (39.0%). Moreover, 57.2% reported that they “Experience physical symptoms” when they thought about their HIV-positive status. In support of this, 55.4% of participants felt that being HIV-positive had “Changed their lives” and many “Blame themselves” (42.8%) for acquiring their status. 58.5% of participants described having “Received assistance from a health-care professional”.

9.3. Total Prevalence of PTSD, HIV-Related PTSD and the Combined Prevalence of PTSD and HIV-Related PTSD

9.3.1. Lifetime Prevalence of HIV-related PTSD according to the CIDI-HIV-PTSD module. The prevalence according to the CIDI-HIV-PTSD module adapted for HIV showed that 40.9% (95% CI = 33.5 to 48.7%) met the criteria for lifetime HIV-related PTSD (Table 13). A 95% confidence interval was calculated using the Wilson score method without continuity correction.

9.3.2. Lifetime Prevalence of PTSD according to CIDI-PTSD module. The total prevalence of PTSD was assessed by examining which participants met the criteria for PTSD using the CIDI-PTSD module of assessment. Results showed that 29.6% (95% CI = 23.0 to 37.1%) of participants met the criteria for lifetime PTSD (Table 13).

HIV, PTSD AND TRAUMATIC LIFE EVENTS

9.3.3. Total and Combined Lifetime Prevalence of PTSD and HIV-Related PTSD. Using the CIDI-PTSD and CIDI-HIV-PTSD modules, the total and combined prevalence of PTSD and HIV-related PTSD was calculated. The combined prevalence, or number of individuals who met the criteria for both PTSD and HIV-related PTSD, was 20 individuals (12.6%; 95% CI = 8.3 to 18.6%).

The total number of individuals who met the criteria for either regular PTSD or HIV-related PTSD was 92 participants (57.9%; 95% CI = 50.1 to 65.1%). As far as the researcher is aware, this is currently the only study which reports on the total individual, and combined prevalence of PTSD and HIV-related PTSD of an ARV complaint, HIV-positive sample (Table 13).

Table 13

***Prevalence of PTSD, HIV-Related PTSD
and the Combined Prevalence of PTSD and HIV-Related PTSD***

Lifetime Prevalence	Participants		95% Confidence Interval
	No.	%	
PTSD	47	29.6%	23.0 - 37.1
HIV-related PTSD	65	40.9%	33.5 - 48.7
Combined Prevalence of HIV-related PTSD	20	12.6%	8.3 - 18.6
Total Prevalence of PTSD and HIV-related PTSD	92	57.9%	50.1 - 65.1

9.4. Frequency of Traumatic Events

In the current study 62.3% reported having experienced at least one traumatic event in their lifetime, excluding being HIV-positive, as determined according to their responses to the CIDI-PTSD module (Table 10). These included being violently attacked (18.2%), robbed/hijacked (7.6%), involved in a car accident (7.6%), diagnosed with a life-threatening illness (6.9%), or raped (6.3%). A further 7.6% described having witnessed to something traumatic affecting either a friend or family member, and a few individuals (2.5%) reported being victim to a natural disaster. Two participants (1.3%) stated that they had experienced more than one trauma, excluding being HIV-positive. The additional question asked by the researcher found 11 respondents having been caught up in political violence (6.9%).

A comparison of the gender proportions for each of the different trauma categories (see Table 14), including the category of no reported trauma, indicates that the only statistically significant gender difference is that men are more likely to report having been violently attacked than women ($\chi^2 (1) = 7.98$; $p = .005$; Yates' correction).

Table 14

Frequency Distribution of Traumatic Events other than the Diagnosis of HIV Event

Traumatic Event	Male	Female	Total	
			No.	%
No reported traumatic events	16	44	60	37.7%
Being violently attacked*	17	12	29	18.2%
Being robbed or hijacked	1	11	12	7.5%
Being involved in a car accident	6	6	12	7.5%
Being caught up in political violence	1	10	11	6.9%
Being notified of a life-threatening illness (other than HIV)	2	9	11	6.9%
Being raped	0	10	10	6.3%
Witnessing another person's trauma	3	9	12	7.5%
Being the victim of a natural disaster	1	3	4	2.5%
Reporting more than 1 traumatic event	0	2	2	1.3%

* statistically significant

9.4.1. Comparison of traumatic events. Table 15 presents the rate of PTSD (in the case of HIV infection, this is HIV-related PTSD) for each of the different traumatic events.

The table reveals that rape and political violence are most strongly associated with PTSD. Because some of the numbers are small, related traumatic events are clustered together into three categories that are reported at the bottom of the table. 'Interpersonal Violence' includes violent attack, rape, political violence, robbery and hijacking and witnessing, while the others (car accident, life-threatening illness and natural disaster are clustered into a category called 'Disaster'. The third cluster is 'Living with HIV' and

HIV, PTSD AND TRAUMATIC LIFE EVENTS

includes the diagnosis of HIV. As the table reveals, Interpersonal Violence is most strongly associated with PTSD, and Disaster, which includes the diagnosis of a life-threatening illness other than HIV, is least strongly associated with a lifetime diagnosis of PTSD. Being diagnosed and Living with HIV falls between these two categories.

Table 15
Rate of PTSD

Traumatic event	No PTSD	PTSD	Total	% with PTSD
Being involved in a car accident	7	5	12	41.7%
Being notified of a life-threatening illness (other than HIV)	10	1	11	9.1%
Being the victim of a natural disaster	2	2	4	50.0%
Being caught up in political violence	3	8	11	72.7%
Being raped	1	9	10	90.0%
Being robbed/hijacked	7	5	12	41.7%
Being violently attacked	14	15	29	51.7%
Witnessing another person's trauma	8	4	12	33.3%
Living with HIV	94	65	159	40.9%
Clusters				
Interpersonal Violence	33	41	74	55.4%
Disaster	19	8	27	29.6%
Living with HIV	94	65	159	40.9%

9.5. Bivariate Statistical Analysis

Chi-square tests were performed to determine whether any of the categorical variables are associated with a lifetime diagnosis of HIV-related PTSD. For a breakdown of variables and frequencies see Table 9.

9.5.1. Gender. Gender is not associated with a lifetime diagnosis of HIV-related PTSD ($\chi^2(1) = 1.72$; $p = .189$; Yates' correction).

HIV, PTSD AND TRAUMATIC LIFE EVENTS

9.5.2. Age. Using two age categories, 18 to 35, and 36 to 50, findings showed that age is not associated with a lifetime diagnosis of HIV-related PTSD ($\chi^2 (1) = 0.87$; $p = .350$; Yates' correction).

9.5.3. Length of time since diagnosis. Whether or not an individual has been diagnosed with HIV for longer than a year is not associated with a lifetime diagnosis of HIV-related PTSD ($\chi^2 (1) = 0.16$; $p = .688$; Yates' correction).

9.5.4. CD4 Count. The participants' CD4 count (either below 50, between 51 and 200, or greater than 200) at the time of the assessment is not associated with a lifetime diagnosis of HIV-related PTSD ($\chi^2 (2) = 0.63$; $p = .731$).

9.5.5. Disclosed their HIV-positive status to their family. Whether or not participants had told their families of their HIV-positive status, is not associated with a lifetime diagnosis of HIV-related PTSD ($\chi^2 (1) = 1.62$; $p = 0.204$; Yates' correction). As one of the cells has fewer than 5 cases, a Fisher's exact test was also run, and the result was also not significant ($p = 0.161$).

9.5.6. Disclosed their HIV-positive status to their friends. Whether or not participants had told their friends about their HIV-positive diagnosis is not associated with a lifetime diagnosis of HIV-related PTSD ($\chi^2 (1) = 0.671$; $p = 0.413$; Yates' correction).

9.5.7. Reason for HIV test. The reason for the HIV test (because the participant was pregnant, or was referred by a doctor, or voluntary) was not related to a lifetime diagnosis of HIV-related PTSD ($\chi^2 (2) = 1.25$; $p = 0.536$).

HIV, PTSD AND TRAUMATIC LIFE EVENTS

9.5.8. Previous experience of traumatic events. Previous exposure and experience of traumatic events in addition to that of being diagnosed with HIV are not associated with a lifetime diagnosis of HIV-related PTSD ($\chi^2 (1) = 1.80$; $p = 0.180$; Yates' correction).

9.6. Multiple Regression Analysis

A multiple regression analysis was run to determine the relative contributions of the four variables to PTSD symptomology as measured by the IES-R. Two cases had missing data, which brought the sample down to 157. Using the enter method, a significant model emerged ($F (4; 152) = 3.26$, $p = 0.013$). The R square = 0.079, and significant variables are reflected below.

Predictor Variable	Beta	p
Traumatic events	0.2790	0.0005

On average, those who report previous traumas report IES-R scores that are 6.7 points higher than those who do not report previous traumas. Whether or not the participants had told their family, their friends, and whether or not their CD4 count was greater or less than 200 were not shown to be significant predictors in this model.

9.7. Logistic Regression Analysis

A logistic regression was conducted in an attempt to determine the relative contributions of the same variables as predictors for a lifetime diagnosis of HIV-related PTSD as measured by the CIDI-HIV-PTSD. However, this model was not statistically significant ($p = 0.267$).

9.8. ROC Curve

Though identifying symptom time-frames proved to be difficult for most participants, all 65 participants who met criteria for a diagnosis of HIV-related PTSD reported symptoms within the previous six months of the interview, while 61 reported symptoms in the previous month, 49 in the previous week, and a little less than half reported symptoms on the day of the interview. Symptoms of PTSD are known to vary over time, waxing and waning depending on internal and external factors (American Psychiatric Association, 1994). Thus, for the large majority, if not all, of the participants, the diagnosis of HIV-related PTSD is most likely to be current. Because all 65 participants with a lifetime diagnosis of HIV-related PTSD fall well within the implicit symptom timeframe utilised by Martin et al., (2009), no cases of lifetime HIV-related PTSD were recorded as not having a diagnosis for the purpose of the ROC analysis.

Analysis of the ROC curve shows that the IES-R would discern between HIV-related PTSD caseness 60.3% of the time (AUC= 0.603, 95% CI = 0.52 to 0.68, $p = 0.02$). The curve is graphically illustrated in Figure 2.

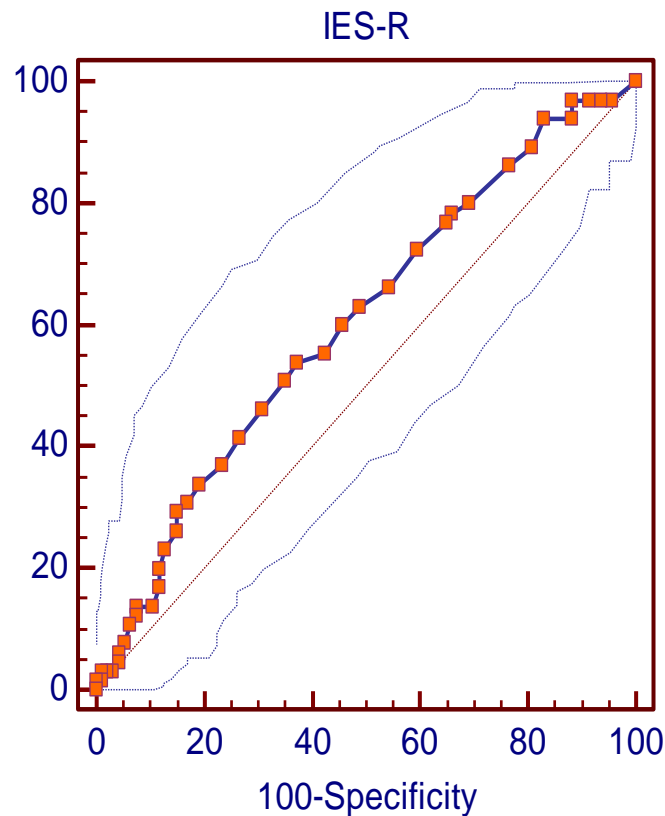


Figure 2: ROC Curve Analysis

The Youdin Index J , which is the maximum vertical distance between the ROC curve and the diagonal line (Perkins & Schisterman, 2006), is 0.166 (95% CI = 0.064 to 0.249) which is associated with a score of greater than 16 on the IES-R. This optimal cut-off score (Perkins & Schisterman, 2006) yields a sensitivity and specificity of 53.85 and 62.77 respectively. A chi-square analysis using the cut-off value of >16 indicates a non-significant association between the CIDI and IES-R ($\chi^2(1) = 3.66$; $p = 0.056$; Yates' correction). The difference between the mean IES-R scores to determine whether participants meet the criteria for HIV-related PTSD or not is statistically significant ($t = -2.10$, $df = 117.2$, $p = 0.038$), but the effect size of this difference ($d = 0.35$) is small to medium. The relatively small AUC,

HIV, PTSD AND TRAUMATIC LIFE EVENTS

non-significant test of association and the non-significant difference between the mean IES-R scores all suggest that the IES-R does not perform as well as one might have hoped as a HIV-related PTSD screening instrument when compared to the CIDI.

To compare the performance of the IES-R and PDS scale, another self-report measure for PTSD, in detecting cases of HIV-related PTSD that meet diagnostic criteria, the AUC obtained in the present study was compared to that reported by Martin et al. (2009). These authors compared the PDS against the same adapted PTSD module of the CIDI that was used in the present study. They reported an AUC of 0.749 (95% CI = 0.64 to 0.85), which is more impressive than the AUC obtained in the comparison between the IES-R and the CIDI. Though they did not report the Standard Error of their ROC analysis, which is needed to make a statistical comparison between the two results, the corresponding author provided their raw data so that the Standard Error could be calculated (A. Kagee, personal communication, November 2013). The difference between the two ROC curves is 0.146, which is statistically significant ($Z = 2.063$, $p = 0.039$). This suggests that as a clinical screening measure for HIV-related PTSD, the PDS performs significantly better than the IES-R.

9.9. Summary

This chapter clearly illustrates that there is a high prevalence of both PTSD and HIV-related PTSD among an HIV-positive, ARV compliant sample in rural South Africa. Furthermore this is the only study which comments on the combined incidence of both PTSD and HIV-related PTSD among HIV-positive, ARV compliant individuals.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Additionally, the findings also reveal that nearly two-thirds of the participants have experienced another major traumatic event other than their diagnosis of HIV. The multiple regression analysis suggests that the experience of previous trauma contributes to PTSD symptomology that is related to the diagnosis and living with HIV, but logistic regression analysis suggests that this variable does not predict a diagnosis of HIV-related PTSD.

Of the different categories of traumatic events, those involving interpersonal violence show the strongest association with PTSD, followed by the diagnosis of and living with HIV, followed by those events that involve disaster.

In fact, none of the variables as tested individually appears to be associated with a diagnosis of HIV-related PTSD. Finally, although the IES-R may be a useful screening measure of PTSD symptomology, it does not fare well as a diagnostic tool when compared to the CIDI.

Chapter 10: Discussion

The quantitative results that were presented in the previous chapter are discussed in this chapter. This discussion starts with the various demographic characteristics of the sample, then the lifetime prevalence of PTSD and HIV-related PTSD, followed by a discussion of the traumatic events reported by the sample, and ending with a discussion of the performance of the IES-R as a screening measure for HIV-related PTSD.

10.1. Demographic Characteristics

10.1.1. Race, gender and marital status. The vast majority (94%) of participants in this research were identified as “black” South Africans, which reflects the fact that black South Africans comprise the largest of the different South African race groups and that this is the group that also reports the highest prevalence of HIV (Shisana et al., 2009; South Africa HIV and AIDS Statistics, n.d.). For a variety of socio-economic and cultural reasons, sexual concurrency is common in many African communities, which greatly facilitates the transmission of HIV (Halperin & Epstein, 2007). Moreover, the large proportion of black participants is expected, given that the study was undertaken at a public health facility, as opposed to a private clinic or hospital, and income inequalities in South Africa continue to be highly racialised after decades of apartheid, where the overwhelming majority of those locked in poverty are black (Seekings & Nattrass, 2006).

Of 159 HIV-positive participants, 70% were female, which again is consistent with other similar research in South Africa, where greater numbers of women participants were seen than men (e.g., Els et al., 1999; Freeman et al., 2007; Louwagie, Bachmann, Meyer, Booysen, Fairall, & Heunis, 2007;

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Martin & Kagee, 2008; Olley et al., 2005; Thom, 2008). In the study by Martin and Kagee (2008) on lifetime PTSD and HIV-related PTSD among recently-diagnosed HIV-positive adults, 75% of their sample was female. Another South African study that examined factors associated with the occurrence of mental disorder among HIV-positive adults reported that 74% of their sample was female (Freeman et al., 2007). While women are more likely to seek testing and treatment (Lindegger & Quayle, 2009), they are also more vulnerable to HIV infection (WHO, 2001). In fact, the South African HIV adult prevalence in females is almost double that of males (HSRC, 2005), being 20% compared to 11.7% respectively for the 15 to 49 years age category. The result is that women seem to face higher rates of mortality as a result of AIDS (Machtiger, Wilson, Haberger & Weiss, 2012).

One reason for the greater vulnerability of women is physiological: the larger surface area of the vagina and frequency of tears during intercourse confer a particular susceptibility on women, and transmission of HIV is therefore more likely from men to women than from women to men (Jewkes, 2009; Reyes, 2001).

Other reasons for women's greater vulnerability are social, cultural and economic. In South Africa the traditional roles of men and women are still deeply entrenched: women usually assume the role of care-giver and are often financially dependent on their husbands or other family members (Peterson et al., 2012). Foreman (1999) believes that young black South African women are among the most economically marginalised of the population. This notion is supported and elaborated upon by Jewkes (2009), who argues that women remain vulnerable throughout their lives. There is an unequal distribution of

HIV, PTSD AND TRAUMATIC LIFE EVENTS

power between the two sexes in favour of males (WHO, 2002), in that men are generally afforded better education, and earn more money, resulting in greater social status. The upshot of this is that, in comparison to men, many women are disempowered, which is reflected in terms of their sexual decision making (Jewkes, 2009).

The social construct of hegemonic masculinity illustrates how male privilege and social power is produced and maintained through a number of ideas, beliefs and practices that normalise and demand male dominance (Lindegger & Quayle, 2009). Many African communities are structured in ways that reinforce hegemonic masculinity, with patriarchal governance and female subordination commonplace, placing women at an even greater risk for HIV infection (Clüver, Elkonin & Young, 2013). Hegemonic masculinity may lead to several risky HIV practices, including multiple sex partners, unprotected sex, alcohol abuse and even sexual violence (Jewkes, 2009; Lindegger & Quayle, 2009). A South African qualitative study found that adolescent participants had all experienced instances where they felt coerced, pressured or manipulated by their boyfriends into having sex, and were in fact afraid of being raped (Clüver et al., 2013). There is an expectation of men to maintain and live up to such masculine behaviour, and considerable pressure is brought to bear to encourage them to act accordingly (Lindegger & Quayle, 2009). Men may use physical violence to exercise control over women and ensure sexual submission (Jewkes, 2009). Such acts of control can include demanding to know the whereabouts of girlfriends or wives, accusing them of infidelity, rejecting challenges to their own infidelity and refusing to use condoms (Jewkes, 2009). Such overbearing features of

HIV, PTSD AND TRAUMATIC LIFE EVENTS

masculinity may also limit male help-seeking behaviours (Lindegger & Quayle, 2009), which also explains why you might expect to see far more women at an ARV clinic than men.

Young African women are seen to be the poorest and most economically marginalised (Foreman, 1999). Such women are frequently placed in positions where they are inferior, dependent and passive and where attributes such as sexual ignorance and motherhood are idealised (Clüver et al., 2013). Whilst it is acceptable for men to be sexually experienced, women are expected to be virgins when they get married (Buve, Bishikwabo-Nsarhaza & Mutangadura, 2002). Getting married after virginity has been lost results in the reduction of the bride's worth (traditionally this is called lobola) (Jewkes, 2009) and it has been claimed that some women engage in unprotected anal sex as a method of satisfying their boyfriends yet retaining their virginity, thus putting themselves at an even greater risk of contracting HIV (McKerrow, 2000).

Olley et al. (2003) argued that HIV-positive women show an increased vulnerability to psychopathology, poor coping skills and disability as they face greater stigmatisation and more traumatic life events. Being HIV-positive and living with HIV means that women may be faced with HIV-related stigma at a time when they are most in need of social support, medical care and mental health services (Wingwood et al., 2008). Peterson et al. (2013) emphasised the need for the provision of social support for women living with HIV who often experience intrusive thoughts and anxiety about not being able to meet the basic needs of their family. However, men living with HIV may also require support, as they often have more difficulty in

HIV, PTSD AND TRAUMATIC LIFE EVENTS

coming to terms with their deteriorating physical health (Freeman et al., 2008) which again may be related to their concept of male masculinity.

Economic and social vulnerability is exacerbated by the fact that so many women must head households without the support of a co-habiting partner. The Department of Health (2007a) found that just over 42% of households in South Africa are female-headed. The great majority of participants in the present study were single, which is consistent with similar findings by Lakaje (2005) and Thom (2008). Whether a risk factor for, or a consequence of, HIV infection, the fact that most participants are single suggests that one possible source of social support for those most in need of it is curtailed.

10.1.2. Education and employment. In the current study the majority (73%) of participants had attended school for between 6 and 10 years. These results are consistent with Freeman et al. (2007), who found that 74% of their sample had attended but not completed school. Similarly Louwagie et al. (2007) examined ARV treatment and the quality of life among 371 adult participants, finding that 67% had completed less than 10 years of schooling.

Moreover, in the current study, 70% of participants were unemployed, a proportion which is roughly consistent with the research of Lakaje (2005), who found that less than 22% of individuals involved in his study (on the PTSD symptoms following a diagnosis of HIV) were employed, as well as with Louwagie et al., (2007) who reported that only 25% were in work. Another study over multiple sites in South Africa examining depression and anxiety in HIV-positive individuals found that almost 70% were unemployed, nearly 20% were in part-time employment, self-employed or had “piece

HIV, PTSD AND TRAUMATIC LIFE EVENTS

jobs”; and only just over 10% were in full-time employment (Thom, 2008).

Given this high rate of unemployment, it is perhaps surprising that only 40% of people in the same study believed that their income was not enough to provide for the most basic needs (food and clothing). Freeman et al. (2007) reported that 77% of their participants were unemployed, which is a similar statistic found in the present study. In contrast to Thom (2008), almost all of Freeman et al.’s (2007) respondents felt that they did not have enough money for basic necessities such as food and clothing.

The statistics in all studies suggest that the majority of HIV-positive individuals are mainly single and unemployed. In other words, those who are most vulnerable seem to carry the burden of HIV infections. As mentioned, these factors may be a consequence of their HIV-positive status. But, it also seems likely that these factors confer a risk for HIV infection.

The burden of unemployment rests most heavily on vulnerable women. Due to the traditionalist views commonly found in South Africa, more women than men may be forced to leave educational institutions early (Jewkes, 2009), either for financial reasons or to care for their families. Similarly, they may be unable to maintain gainful employment due to such commitments. Such gender inequalities detract from education and employment opportunities, and place women at increased risk of poverty (Reyes, 2001). In these contexts, many women may be forced into transactional or commercial sex, selling their bodies to earn enough money to buy food. Such women may be particularly vulnerable, and may face violence at the hands of their clients or loss of income if they insist on using protection during sex (Reyes, 2001).

HIV, PTSD AND TRAUMATIC LIFE EVENTS

While unemployment and poverty might place people at risk of HIV infection, the financial impact of HIV can be severe on families that are already under financial strain. It is apparent that HIV affects entire households as breadwinners become ill, potentially dying. The increased financial burden of transport costs for travel to and from hospitals combined with medical and funeral expenses, as well as loss of income, may result in deeper poverty among already poor families.

These figures discussed above, together with the current study, serve to emphasise the condition of poverty and unemployment that affects those suffering from HIV/AIDS, and further supports the hypothesis that HIV/AIDS and poverty go hand-in-hand and that the combination of the two have a detrimental impact on mental health (Freeman et al., 2008).

10.1.3. Reasons for being tested. In the present study, 42% of the sample reported that they voluntarily went for their HIV test. The remainder of participants were tested for HIV either as routine procedure after becoming pregnant (16%) or because an HIV test was recommended by their doctor (41.5%). Another South African study conducted over multiple sites found that nearly 60% were tested as a result of falling ill (with a condition considered likely to be related to being HIV-positive), whilst the remainder were tested as part of anti-natal care and voluntary testing (Thom, 2008).

It is of concern that so few of the participants sought voluntary testing for HIV. Although testing centres are now widely available in South Africa (Pembrey, 2007), too few South Africans at risk for HIV have taken advantage of such facilities without being encouraged to do so by health-care practitioners (Kalichman & Simbayi, 2003).

HIV, PTSD AND TRAUMATIC LIFE EVENTS

There are many reasons that individuals may not want to be tested for HIV, including the negative perceptions of testing services (Kalichman & Simbayi, 2003). Fear of stigma and discrimination is the major barrier to testing, especially if people think that their HIV status may become known within the community (Kalichman & Simbayi, 2003). Kalichman and Simbayi (2003) also revealed that participants who had not been tested, or did not have their test results back, held many more negative beliefs about HIV-testing than those who had been tested. Such apparent reluctance to undergo HIV testing without being prompted by a health-care practitioner at least partly explains why many of the participants only received their HIV-positive diagnosis late, once their CD4 counts had already dropped quite significantly.

There is also the likelihood that many people received their diagnosis of HIV without expecting it, sometimes only because they were seeking routine anti-natal care during pregnancy. That so few people seek HIV testing and only learn of their HIV-positive status when they are already ill or pregnant must contribute to a sense of shock on receipt of the diagnosis.

10.1.4. Length of time since diagnosis. A little over half of the participants had received their HIV-positive diagnosis within the previous two years. By definition, all of the participants in this study qualified for ARV treatment, and recall also that those who had received a diagnosis in the month prior to their interviews were excluded from the study (to rule out acute-stress disorder), suggesting that most people only receive a diagnosis of HIV infection very late in the disease course. This does not necessarily apply to the women who were diagnosed with HIV while pregnant and who were started on ARV medication immediately, but this is a relatively small

HIV, PTSD AND TRAUMATIC LIFE EVENTS

proportion of the sample. It clearly suggests that efforts to encourage early testing should be maintained and, even bolstered, as delayed diagnosis can have a severe impact on a patient's prognosis (Castilla, Sobrino, De La Fuente, Noguer, Guerra & Parras, 2002).

That the diagnosis of HIV is often delayed until people become symptomatic might negatively impact on the burden of HIV-related PTSD. Research suggests that permanent physical injury as a result of a traumatic event is associated with poorer outcomes for the treatment of PTSD. Young (2011) proposed that this is because the physical symptoms support negative trauma appraisals. Physical symptoms resulting from HIV infection might serve the same function and confirm for people all manner of negative appraisals. Earlier diagnosis and ARV treatment might, then, result in better mental health outcomes.

10.1.5. Disclosure. While almost all of the participants had disclosed their HIV-positive status to relatives, only a little more than half had confided in their friends. These statistics appear to be more or less consistent with findings of Thom (2008), who found that nearly 90% of her sample population had disclosed their status to someone outside the health services, and Wong et al. (2009) whose results showed that 87% had disclosed their status to at least one person. A study on the factors associated with the prevalence of mental disorders found that 85% of HIV-positive individuals had disclosed their status to someone outside the realms of their HIV-clinic, and nearly 45% reported that they are fully open about their HIV-positive status (Freeman et al., 2007).

HIV, PTSD AND TRAUMATIC LIFE EVENTS

These findings suggest that disclosing to a family member is possibly both easier and safer than disclosing to a friend. Another possibility for these participants, who are all ARV-compliant, is that disclosure to family members is unavoidable as the adherence to the medicine regime would be difficult to conceal from them. Furthermore, those who are enrolled on ARV treatments are encouraged to disclose their status to significant others. Thom (2008) found that the participants of her study were most likely to disclose their status to mothers, partners, siblings, relatives or to other people who were known to be similarly HIV-positive, and concluded that patients found it beneficial to disclose their status to someone else. The high rate of at least partial disclosure as reported in this study and others suggests that this may be a sign that communities are becoming more knowledgeable about and accepting of HIV (Van Dyk & Van Dyk, 2003).

Disclosure is important as it allows access to social support, and it may also form part of one's personal acceptance of the reality of having been diagnosed with a life-threatening illness. UNAIDS have stated that disclosing one's HIV-positive status is important for a number of reasons: (1) it avoids the increased risk of HIV transmission among sexual partners due to concealment of one's status; (2) it encourages additional support, including treatment access and adherence, family planning, replacement feeding for infants, future care and custody planning; and (3) it influences others who are afraid of disclosure and improves existing knowledge about HIV and its transmission (UNAIDS, 2000).

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Yet there might be a downside to disclosure that is not often acknowledged: while disclosure is a precondition to accessing social support and other types of support, it might also increase the likelihood of bearing the brunt of stigma and discrimination. Findings by Freeman et al. (2008) suggest that, while most people report that their experiences of disclosure were helpful, those who were fully open about their status were more likely to meet diagnostic criteria for a mental disorder than those who did not fully disclose their diagnosis. They speculate that many of those with pre-existing mental conditions might have been prompted to disclose their status because they needed the support. But it is also possible that some who had disclosed their status received negative reactions that directly or indirectly detracted from their mental health (Freeman et al., 2008). Recall that Adewuya et al. (2009) reported that more than a quarter of their Nigerian sample met criteria for a diagnosis of PTSD resulting from stigma-related traumatic events.

10.2. The Lifetime Prevalence of HIV-Related PTSD

In the current study, the lifetime prevalence of HIV-related PTSD was almost 41%. This result was obtained using the CIDI-HIV-PTSD module. Each item in this structured questionnaire asks participants whether they have experienced certain symptoms after hearing that they were HIV-positive and to being HIV-positive, to ensure that the PTSD symptoms reported are anchored to this event. That people report symptoms that are diagnostic of PTSD suggests that HIV diagnosis is a valid Criterion A event, even though the latest edition of the DSM (American Psychiatric Association, 2013a) no longer considers the diagnosis of a life-threatening illness to be necessarily

HIV, PTSD AND TRAUMATIC LIFE EVENTS

of sufficient intensity to qualify as a Criterion A event unless it involves a medical event that is sudden and catastrophic.

These findings are almost identical to those of Martin and Kagee (2008), who reported a prevalence of HIV-related PTSD of 40% amongst a sample of people recently diagnosed with HIV. This is in contrast to Freeman et al. (2008), who reported a HIV-related PTSD prevalence of 4.2% after using the same adapted CIDI module, so the difference in results cannot simply be attributed to different assessment measures.

A more likely explanation is to do with the differing sample characteristics: the present study is the only one that only involves participants who are ARV compliant. As Young (2011) noted, the act of taking ARV medications daily may confirm negative trauma appraisals and act as a daily reminder of the traumatic event that prolongs or enhances HIV-related PTSD. (The impact of ARV compliance is further discussed when discussing the qualitative findings). A study of gay men living with HIV in the UK suggests that receiving medical treatment, experiencing physical symptoms and witnessing HIV-related death were the variables most strongly associated with symptoms of HIV-related PTSD (Theuninck, Lake & Gibson, 2010). Assuming this is also true of HIV-positive people in South Africa, each of these variables is most likely amongst people in the advanced stages of HIV illness, and so one would expect a higher prevalence of HIV-related PTSD amongst people who are ARV compliant than HIV-positive people yet to qualify for and receive ARV treatment.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Another explanation, as already suggested, is to do with the fact that the recent sample carries a high burden of other traumatic events and PTSD not related to the diagnosis of HIV. The occurrence of multiple traumas amongst individuals is associated with increased vulnerability to PTSD (Brewin, Andrews & Valentine, 2000). The mechanism of this increased vulnerability however, is not well understood. A number of hypotheses have been offered: Young (2011) suggested that it is likely that negative trauma appraisals are reinforced by the accumulation of adversity while healthy appraisals are repeatedly undermined. Similarly, Ehlers and Clark (2000) contended that new traumatic events might give a more traumatic meaning to earlier traumas. In other words, the experience of traumatic stigma might give a new meaning to the experience of an HIV-positive diagnosis, for example, which perhaps accounts for the delayed onset of PTSD reported by Olley et al. (2006). Young also suggested that different traumas expand the range of trauma-related cues that trigger re-experiencing symptoms, while Ehlers and Clark asserted that those who have endured previous traumatic events might be more inclined to engage in the data-driven processing that probably increases the risk of PTSD.

The fact that the sample comprised multiply-traumatised individuals makes it difficult to connect PTSD symptoms to a specific traumatic event (Kaminer et al. 2008). According to these authors, this is true even when individuals attribute symptoms to specific events, as it is likely that the other traumatic events may have played a causal role in the development of PTSD and may be represented in their symptoms of PTSD. Indeed, that so many people suffer multiple traumatisation, not only in South Africa, but even in

HIV, PTSD AND TRAUMATIC LIFE EVENTS

developed contexts (Kaminer & Eagle, 2010), calls into question the utility of diagnostic criteria that attempt to link trauma symptoms to a single event.

It was surprising that none of the various variables of gender, age, length of time since diagnosis, CD4 count, whether they had told their family of their diagnosis, whether they had told their friends of their diagnosis, their reason for having an HIV test and previous traumas seemed to be associated with a diagnosis of HIV-related PTSD according to either the various bivariate analysis, or the logistic regression analysis. This may be because the sample was relatively homogenous in that all the participants represented a vulnerable socio-economic class that is reliant on the state for their health care, and all were at a particularly vulnerable stage of their HIV illness. Another factor is that the sample size was relatively small (though a larger sample size might have resulted in a more powerful analysis, the danger could have been that small differences that are statistically significant have very little clinical significance).

The only significant finding was that a history of at least one previous traumatic event seems to contribute to PTSD symptomology as measured by the IES-R, but not to the actual diagnosis of HIV-related PTSD as measured by the adapted CIDI module. This is partial support for the suggestion above, that previous trauma might be one factor in explaining the high prevalence of PTSD and HIV-related PTSD reported by this study. However, to fully explore this issue further, it would be necessary to conduct a study using a sample that is representative of all people, across the full continuum of HIV illness, and across various geographical and social-economic contexts in

HIV, PTSD AND TRAUMATIC LIFE EVENTS

South Africa. The findings reported here are specific to a particular sub-set of people who were HIV-positive.

Given the difficulty of connecting PTSD symptoms to a specific event when all of the participants in the sample had been through the traumatic experience of being diagnosed with HIV and had endured medical treatment, and while many had experienced HIV-related physical symptoms and/or in all likelihood had witnessed the deaths of others from HIV and had encountered stigma and discrimination as a result of the HIV status, and while most had experienced some other form of traumatic experiences not necessarily related to HIV, it is probably more useful to combine the diagnoses of HIV-related and ordinary PTSD to provide an indication of the overall burden of traumatic stress amongst the sample of people who are HIV-positive and ARV-compliant.

The high rate of HIV-related PTSD within the current study, together with supporting evidence from prior research (Martin & Kagee, 2008), as obtained by an instrument that very specifically asks about symptoms in response to the diagnosis of HIV, suggests that the diagnosis of HIV and being HIV-positive should remain as valid a Criterion A event as any of the others.

10.3. The Lifetime Prevalence of PTSD

Findings from the current study are that nearly 30% of the sample met the criteria for PTSD that appears to be independent of their actual HIV diagnosis, lending support to previous suggestions that the rate of PTSD is high amongst HIV-positive individuals (Brief et al., 2004). The prevalence of PTSD in this research is higher than that found in overseas studies (e.g. Katz

HIV, PTSD AND TRAUMATIC LIFE EVENTS

& Nevid, 2005), which may be attributed to population and environmental differences.

In comparison with other South African studies, the current research took place in rural KwaZulu-Natal, and reports a prevalence of PTSD that is higher than the Free State study conducted by Els et al. (1999) and those in the Western Cape by Olley et al. (2003), Olley et al. (2005), and Myer et al. (2008), where the prevalence of PTSD was 6%; 12.9%; 14.8% and 5% respectively. It was certainly higher than the research by Myer et al. (2008) and Freeman et al. (2008) who found comparatively low rates of PTSD (5% and 7% respectively) amongst HIV-positive participants. The only study that reported a similarly high prevalence was Martin and Kagee (2008), who used the same CIDI modules as this study and who reported a lifetime prevalence of PTSD of 54%.

The question is how one might explain a PTSD prevalence amongst HIV-positive people that is significantly higher than all the other South African studies bar one. Unlike all of the other studies, the sample employed in the present study included only participants who were ARV compliant, which means that, apart from those prescribed ARV medicines while pregnant, all were already at an advanced stage of HIV illness. Other research suggests that the longer people are HIV-positive, the more likely they are to report symptoms of PTSD: in 2006, a study by Olley et al. found PTSD rates had increased from 14.8% to 20% at a 6-month follow-up, which they attributed either to a delayed onset of PTSD symptoms, or to new traumatic events. Support for the claim that HIV-positive individuals are vulnerable to new traumatic events is provided by Adewuya et al. (2009),

HIV, PTSD AND TRAUMATIC LIFE EVENTS

who found that over a quarter of their sample in Nigeria met the diagnostic criteria for PTSD as a result of experiencing stigma-related traumatic events. Though not necessarily specific to PTSD, a study by Freeman et al. (2008) indicated that the later the stage of disease, the higher the prevalence of mental disorder. This suggests that heightened physical vulnerability and the experience of HIV-related physical symptoms, greater exposure to stigma and reduced resiliency as a result of the on-going stress of living with HIV may increase vulnerability to all psychological disorder, including PTSD. Thus, it seems that samples that include advanced cases of HIV infection are likely to report a higher prevalence of PTSD and other disorders than those that include more recent cases of HIV infection.

Furthermore, the present sample was obtained from a rural hospital in the KwaZulu-Natal Province, which endured the burden of political violence during the final decade of apartheid, conflict that still flares up 20 years after the end of the apartheid system (Longford, 2012). The friction saw thousands of politically-motivated assaults and killings, and arson attacks. Many thousands were detained without trial and tortured and sometimes murdered by the state security forces. It is likely that many of the participants would have been exposed to horrific occurrences of political violence that could directly result in PTSD. Additionally, enmity has undermined family and community structures that provide social support and, therefore some protection from the psychological consequences of traumatic events. The suggestion that people in the rural areas of the KwaZulu-Natal province carry a higher burden of politically-related traumatic events is supported by the finding that almost 7% of participants reported having experienced political

HIV, PTSD AND TRAUMATIC LIFE EVENTS

violence as a previous traumatic event, which is considerably higher than 2.3% of a nationally representative sample that had experienced some form of politically-motivated violence (Kaminer et al., 2008). Williams et al. (2007) confirmed that different forms of violence are more or less common amongst different segments of the South African population.

The relationship between PTSD and HIV-related PTSD might be circular: The high incidences of traumatic events and PTSD may predispose individuals to develop HIV-related PTSD after being notified of their HIV-positive status or after living with HIV for some time, while HIV status might result in the erosion of resiliency and create opportunities for additional stigma-related traumas that result in PTSD (Adewuya et al., 2009).

10.4. Total and Combined Lifetime Prevalence of PTSD and HIV-Related PTSD

To the best of my knowledge, the present study is the only one to date that reports the prevalence statistics for those who meet the criteria for HIV-related and other PTSD (in other words, a double diagnosis of PTSD) and the combined prevalence of HIV-related PTSD and other PTSD (the prevalence of those who meet the criteria for either HIV-related PTSD or other PTSD, or both). The latter statistic is an indication of the total burden of traumatic stress amongst the sample of ARV-compliant participants. This study suggests that almost 60% of the sample met criteria for a diagnosis of PTSD (of one sort or the other), which suggests that psychiatric and psychological services should be integrated into the physical care of HIV patients receiving ARV medication. ARV programmes are designed to screen for mental disorders and other risk factors which may affect adherence (Department of

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Health, 2004), but this research highlights the gap between policy and practice as there is very little screening or treatment available for these HIV-positive patients with PTSD and other likely mental disorders (see Freeman et al. 2008). Apart from detracting from the quality of the lives of HIV-positive people in South Africa, the failure to detect and treat mental disorders is likely to affect adherence and increase behaviour that risks re-infection and transmission.

10.5. The Lifetime Prevalence of Traumatic Life Events

Findings in this study show that nearly two-thirds of the participants report at least one traumatic event in their lifetime other than being diagnosed with HIV. This high experience of traumatic events may be due to the high rate of violent crime and of community violence in South African society (McGowan & Kagee, 2013), and household, industrial and road traffic accidents (Edwards, 2005b; Kaminer & Eagle, 2010; Peltzer & Renner, 2003). The high prevalence of traumatic events is consistent with other similar studies. Leserman et al. (2005) reported that almost three-quarters of their sample experienced at least one lifetime traumatic event. Williams et al. (2007) declared that three-quarters of their sample in the large-scale SASH study had suffered a traumatic event.

The only significant gender difference between the different traumatic events reported in the present study was that men are more likely to experience interpersonal violence than women, consistent with notions of hegemonic masculinities (Lindegger & Quayle, 2009).

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Interestingly, the rate at which these traumatic events are associated with PTSD was highest for rape followed by political violence (which also highlights the importance of including political violence as a possible traumatic event when assessing PTSD in countries like South Africa (Kaminer et al., 2008). However, because the different types of traumatic events are many and the sample size relatively small, it is probably more reliable to consider the rate of PTSD that is associated with the three clusters of events: 'Interpersonal Violence', 'Disaster' and 'Living with HIV' (which includes the HIV-positive diagnosis). As one would expect, Interpersonal Violence is associated with the highest rate of PTSD (Kaminer et al., 2008); but perhaps a little more surprising is that this is followed by Living with HIV, which has a higher rate of PTSD than Disasters, such as car accidents, other life-threatening illnesses and natural disasters. Again, this suggests that the diagnosis of and living with HIV, certainly in a South African context, is sufficiently traumatic to warrant inclusion as a Criterion A event.

10.6. The IES-R as a Screening Measure for HIV-Related PTSD

The performance of the IES-R as a screening measure for HIV-related PTSD is poor. A major difference between the IES-R and the HIV-related PTSD CIDI module (CIDI-HIV-PTSD) is the phrasing of each CIDI item, which specifically asks about symptoms related to being told that one is HIV-positive, whereas the IES-R asks respondents at the start to comment on a series of symptoms during the past seven days with respect to the identified traumatic events (for this study, this was being diagnosed and living with HIV). Also, the IES-R takes a snapshot of symptoms over the previous week rather than the fuller picture that is obtained using the CIDI. The IES-R may

HIV, PTSD AND TRAUMATIC LIFE EVENTS

offer a reasonable estimate of current PTSD-related symptomology, but it is not a reliable diagnostic instrument, nor is it meant to be.

However, taking into account that the IES-R is a screening rather than a diagnostic measure, and is therefore unlikely to perform as effectively as a diagnostic instrument, it is useful to consider the performance of the IES-R against a competing, similar screening measure, such as the PDS. A comparison with the ROC analysis reported by Martin et al. (2009) suggested that the PDS is a superior screening instrument and should therefore rather be used than the IES-R as a screening measure for HIV-related PTSD. No other data on the performance of any other screening measures that could be used to screen for HIV-related PTSD could be located and so no other comparisons are possible.

10.7. Summary

It is clear that a significant number of individuals in this study displayed symptoms of both PTSD and HIV-related PTSD, and there was also a high combined prevalence of PTSD and HIV-related PTSD, as well as a high proportion of individuals having suffered traumatic events without necessarily developing PTSD. Living with HIV (including its diagnosis) features strongly alongside other traumatic events in the rate at which it is associated with PTSD. Interpersonal Violence has a higher rate of PTSD but Disasters have a lower rate of PTSD.

Overall, the findings show that it is imperative that mental health-care interventions be incorporated in the health care of HIV-positive patients to prevent or alleviate PTSD and other mental disorders. While the challenges of offering such treatments in under-resourced and overburdened health-care

HIV, PTSD AND TRAUMATIC LIFE EVENTS

settings are major, research shows that complex mental disorders can be effectively treated in such an environment (e.g., Patel, Saraceno & Klienman, 2006). In fact, Kalichman et al. (2002a) found that patients not on ARV treatment showed greater depression and pessimism in comparison with those receiving such treatment, illustrating the benefit of early intervention (even if the act of taking ARV medicine reminds people of their illness or confirms negative trauma appraisals). It is apparent that those who are HIV-positive may experience both PTSD and HIV-related PTSD, or a number of the symptoms thereof, and it is essential that trained health-care professionals are available to manage the mental health difficulties of this vulnerable population.

Not everyone who experiences a traumatic event develops PTSD (Keane, Marshall & Taft, 2006), but this does not make the trauma of HIV, or traumatic events which occur before or after an HIV-positive diagnosis, any less important. Untreated PTSD and sub-clinical post-traumatic stress are likely to further erode resilience and increase vulnerability to other psychological disorders and social problems. The next section of this thesis explores the lived experiences of such people and further contextualises the quantitative findings.

Qualitative Study

Individual responses to trauma and PTSD vary according to sufferer's age, the nature of the trauma, the response to the trauma and the social support that is provided to the person after the stressful event (Rothschild, 1997). In the following section I discuss details of the qualitative methodology and its analysis.

Chapter 11: Qualitative Methodology

This chapter describes the collection and analysis of the qualitative data. Initially the theoretical underpinnings of Interpretative Phenomenology Analysis (IPA), a qualitative approach concerned with the lived experiences of participants, are introduced in order to provide an overview of the IPA approach and to demonstrate its value in assessing the aims of this component of the research. This is followed by a step-by-step discussion of the methods and the analytical procedures that were followed. The chapter ends with a discussion of the measures taken to enhance the validity of the analysis.

11.1. Using an IPA Methodology with a Theoretical Model of Interpretation

The individual experiences of patients have received little attention in both the psychotherapy process and outcome-based research, including that of the cognitive therapies (McManus, Peerbhoy, Larkin & Clark, 2010).

However, the current mental health policy advocated by the Department of Health (2007b) emphasises the importance of involving patients in research and of eliciting their personal experiences of illness and treatment. The active involvement of individuals in evaluating their treatment is consistent

HIV, PTSD AND TRAUMATIC LIFE EVENTS

with cognitive-behavioural interventions (McManus et al., 2010). Qualitative methodologies are receiving recognition for their ability to help us understand the experiences of patients and therefore contribute towards improving their care (Elliot, 2008; McManus et al., 2010).

IPA methodology is particularly appropriate for use in this research as it is committed to understanding people's experiences within the broader framework of mainstream psychology (Smith et al., 2009). The approach is thought to mediate both the opposing positions of social cognition in that, while it is concerned with an individual's perception and cognition, it emphasises the role of both context and language in sharing people's lived experiences (Smith, 1996).

11.2. Interpretative Phenomenological Analysis

Qualitative research includes a number of diverse approaches, such as grounded theory, discourse analysis, conversational analysis and phenomenology. Each qualitative approach aims to understand the phenomenon which is being studied, and can be distinguished by having its own theory and methodology (Elliott et al., 1999). For the purpose of this research I have used an Interpretative Phenomenological Analysis (IPA). IPA is a fairly new and fast-growing approach to qualitative research (Smith et al., 2009) that is developed within psychology (Smith & Osborn, 2004) by Jonathan Smith and colleagues to rigorously explore idiographic, subjective experiences and, specifically, social cognitions (Smith, Harre & Van Langenhove, 1995). It is now being used by researchers in health, clinical and social psychology as a methodology in its own right (Brocki & Wearden, 2006; Reid et al., 2005; Smith, 2004), and it examines how people make

HIV, PTSD AND TRAUMATIC LIFE EVENTS

sense of their major life experiences, while regarding cognitions as their main component (Eatough & Smith, 2006).

The value of any research method should be measured according to its ability to provide meaningful and useful answers to the research topic of interest (Elliot et al., 1999). It is particularly suited to this research, as the qualitative study aims to increase understanding and awareness of living and being HIV-positive. IPA is able to address in-depth questions about participants' experiences, exploring their accounts and perception of events (Willig, 2001; Giorgi & Giorgi, 2003; Smith, Jarman & Osborne, 1999). This type of methodology is suited to complement the quantitative findings reported and discussed in the previous chapters, as it brings a different insight into understanding health and illness (Yardley, 2000).

In contrast to making definitive and objective statements, IPA involves detailed examinations of people's significant experiences (Shaw, 2001; Smith, 2004; Smith & Osborne, 2003; Willig, 2001). As a result of this, IPA is suitable for small sample sizes (Smith & Osborne, 2003; Willig, 2001) where, using an interpretative micro-analysis, IPA is able to emphasise the variability and diversity of human experience (Eatough & Smith, 2008; Willig, 2001). IPA is idiographic in nature (Reid et al., 2005) and focuses on the individual rather than on a larger sample. By applying an analysis to a set of semi-structured interviews, the researcher is able to gain rich, valuable insights into individuals and examine the emerging themes, as opposed to merely reducing the sample responses to a set of quantitative categories (Smith, 1995; Smith & Dunworth, 2003). In this way qualitative research has an advantage over quantitative studies (Yardley, 2000).

11.3. The Origins of IPA

IPA has roots in both phenomenology (Giorgi, 1995) and symbolic interactionism (Denzin, 1995). Smith et al. (1999) described IPA as an approach reflecting these two facets: namely phenomenology (as applied to an individual) and symbolic interactionism (the evolution of social interactions and the need for interpretation to access it). These concepts are derived from the idea that people are not bystanders in an objective reality, but are individuals who take an active part in formulating their biographical stories in a way that makes sense to them, based on their understanding and interpretation of their experiences and the world around them (Brocki & Wearden, 2006). The theoretical underpinnings of IPA stem from the phenomenology, hermeneutics and symbolic-interactionism. Phenomenology originated with Husserl's science of consciousness (Smith et al., 2009), while hermeneutics is the theory of interpretation, and symbolic-interactionism contends that the meanings an individual ascribes to events, which, while important, are in fact accessible only through an interpretative process (Smith et al., 2009). As such, IPA takes into account that the researcher's engagement with the subject's text has an interpretative element, but it takes an epistemological stance, whereby through careful and explicit interpretative methodology, it becomes possible to access an individual's inner cognitive world and the connotations given to feelings (Smith et al., 2009). IPA explores how people ascribe meaning to their experiences in their interactions with the environment (Smith et al., 1999). The three key areas, namely *phenomenology*, *hermeneutics* and *idiography* (Smith, 2004; Smith et al., 2009) of the IPA approach will be described in more detail below.

11.3.1. Phenomenology. Phenomenology is a philosophical approach towards the study of experience (Langdridge, 2007; Smith et al., 2009) and is influenced by different figures. Husserl argued that experiences should be studied in the same way that they occur, and became concerned with human psychological processes, such as perception, awareness and consciousness (Smith et al., 2009). The researcher tries to bracket (set aside) personal knowledge of theory and assumptions, allowing the data collection to be exploratory (Smith & Osborne, 2008). Heidegger proposed that, since every person has been born into a world of objects, relationships and language, living in this world will always be relative to something temporal and perspectival (Smith et al., 2009). It is the meaning ascribed by that person (Smith, 1996) and the development of this meaning which is seen as central to phenomenology (Smith et al., 2009).

This theory is expanded by Merleau-Ponty who described the concept of “body-subject”, the body being seen as a means of communication with the rest of the world. Thus we can never completely engage in other people's experiences, because they belong to and are influenced by their own perceptions which, in turn, are based on their differing embodied life experiences. Kierkegaard explained that this is due to the fact that every person is constantly in the process of evolution. (Smith et al., 2009).

IPA is phenomenological in that it aims to explore an individual's personal perception or account of an event, as opposed to attempting to develop an objective record of it (Smith et al., 1999; Smith et al., 2009). Simultaneously, while attempting to understand the participant's personal world, IPA realises that this cannot in fact be done completely. Access is

HIV, PTSD AND TRAUMATIC LIFE EVENTS

dependent on the researcher's own experiences and conceptions, and these are necessary to make sense of the other person's world via a process of interpretative activity. Giorgi (1997) found that people are complex and multi-faceted, which enables them to hold their own unique perceptions and prejudices.

11.3.2. Hermeneutics. Hermeneutics is the theory of interpretation (Rennie, 1999; Smith et al., 2009). Schleiermacher proposed that interpretation can be classified as either *grammatical* or *psychological* (what was said and how it was said). Grammatical interpretation involves exact and textual meaning, whilst psychological interpretation may vary according to the individuality of the writer (Smith et al., 2009). Therefore the role of interpretation is extended to include understanding the writer as well as the text itself. In IPA research there is added value in the systematic and detailed analysis of text. Further value may be obtained from connections which emerge within the context of the larger data set and contextualising in psychological theory (Smith et al., 2009). In this study I have attempted to understand the participants' experiences of '*being HIV-positive*' and '*living with HIV*' using an IPA methodology. These experiences will be understood and contextualised using the established Ehlers and Clark cognitive model.

Heidegger believes that phenomenology is in fact interpretative, and highlights the "fore-conception" by explaining that the interpreter always needs to be aware of the preconceptions, assumptions and prior experiences which they bring to the encounter. As researchers cannot escape the bias of their own experiences, what is gained from another's experience will always be indicative and provisional as opposed to absolute (Larkin, Watts &

Clifton, 2006). This observation is mirrored by Gadamer, who emphasised the importance of history and tradition on the interpretative process (Smith et al., 2009).

The concept of the hermeneutic circle is central to hermeneutic theory and relates to the importance of understanding both the part and the whole (Moran, 2000; Smith et al., 2009). To understand any one part, it must be seen in the context of the whole. And the converse is also true: to understand the whole, it is important to look at the individual parts (Smith et al., 2009). In IPA analysis, this means that understanding a text may be made at a number of different levels, all of which are related, and all of which offer different perspectives on the whole (Smith, 1996; Smith et al., 2009). Smith et al. (2009) summarised the co-dependency of interpretation and phenomenology, stating that without phenomenology, there would not be anything to interpret, following which, without hermeneutics, the phenomenon would not be seen. IPA researchers claim to access a version of an experience, as the participant makes sense of it through their narrative account (Smith et al., 2009; Smith & Osborn, 2008).

11.3.3. Idiography. Idiography is concerned with the particular, the distinct experiences of particular people and the particular contexts in which those experiences occur (Eatough and Smith, 2008; Flowers & Larkin, 2009; Smith et al., 2009). Consequently any analysis should be both thorough and systematic. Idiography may refer to a single case, or may apply to the examination of further cases, each with a similarly detailed analysis (Smith et al., 2009). Consistent with the idiographic approach, small samples are commonly advocated for IPA studies (Smith et al., 2009; Smith & Osborn,

2008). The IPA method utilises the idiographic approach by considering a detailed analysis of each case in isolation, before moving on to similarly comprehensive analyses of other cases and making more general claims (Smith et al., 2009).

11.4. The Aim of the Qualitative Study

In the case of this research project, the experiences being considered are to do with being HIV-positive and living with HIV. The employment of IPA in this study illustrates the exploration of people's perception and experiences of living once they have been diagnosed as HIV-positive. Using detailed analyses, mapping of individual accounts, experiences and perceptions by means of interview transcripts, the underlying thinking (Smith et al., 1999) and cognitions (Smith, 1995) concerning an HIV-positive status will be revealed. This in turn will be informed by the researcher's psychological knowledge, explicitly the Ehlers and Clark (2000) cognitive model developed for understanding trauma. While it seems that the IPA researchers do not often specify the psychological theory they bring to the interpretive process, the approach adopted for this research is to describe this model in detail (see the earlier chapter describing the Ehlers and Clark Model) in order to make the interpretative process more explicit and thorough. The commitment to both cognition and the importance of context is shared by Ehlers and Clark (2000), who offer a comprehensive understanding of PTSD. As such, IPA and Ehlers and Clark are ontologically compatible.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Several characteristics of IPA made it a suitable methodological approach for the purpose of this study: IPA studies are usually conducted with approximately 5 to 15 participants (Smith & Osborn, 2003). Having a smaller number of participants, facilitates focus on the similarities, differences and experiences of individuals (Reid et al., 2005; Smith et al., 2009) as opposed to larger quantitative sample groups. They aim to illustrate detailed perceptions and interpretations without needing to generalise the findings (Smith & Osborn, 2003). In the case of this study, six individuals who were compliant on ARV treatment were encouraged to tell their stories.

IPA focuses on people's experiences and allows participants to remember and talk about their ordeals, and encourages them to think about their understanding of them, as well as to share their perspectives and opinions. The IPA methodology is descriptive in nature and involves the individual's appraisal of reality as well as the researcher's perception of it. This is interpretive and influenced by language (Giorgi & Giorgi, 2003) since, without language, it would not be possible to describe or explain any experience. Given that in this study, many participants spoke English only as a second language, the researcher and reader need to both be aware that some participants may have had difficulty finding the right words to express their experiences. The addition of a translator was deemed unsuitable as the process already involved a double hermeneutic whereby the researcher tried to make sense of the participants who tried to make sense of their experiences; another layer of interpretation would have served only to stifle the interviews.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

IPA is participant-centred and, in this study, focuses on the subjects' separate accounts of their experiences of being diagnosed with and living with a life-threatening illness. By adopting an IPA approach to semi-structured interviews, attempts can be made to pinpoint the unique emerging themes which become apparent throughout the participants' narratives, instead of merely reducing the data to a list of quantitative categories (Smith, 1995). This was deemed suitable for the qualitative section of the research, where substantial narratives were considered to be desirable in order that the quantitative data could be enhanced and put into context.

Within IPA, the researcher becomes an active participant, with the result that his or her views, preconceptions and perspectives inevitably influence the meaning and interpretation of the data. Goals of the researcher include facilitating a safe space for the participants' voices to be heard, and encouraging them to tell their stories of life with HIV. The researcher then attempts to empathise with their experiences in an effort to understand their points of view, even though this may ultimately prove to be impossible. Willig (2001) highlighted that the interaction between the participant and researcher is always seen in the interpretation.

Furthermore, IPA is particularly suitable for new topics which have hitherto been under-researched (Smith & Osborn, 2004). In the case of *this* study, although there are a limited number of studies on HIV and PTSD, there are no studies which use a qualitative approach to explore individual experiences of HIV-positive participants who are compliant on ARV medication.

11.5. Researcher as Active Participant

In traditional qualitative research, participant verification is often used to ensure understanding. This is not used in an IPA methodology as the analysis is the result of the researcher making sense of the participants who are in turn making sense of their world (Conroy, 2003), the double hermeneutic mentioned above. The interpretation of their experiences is therefore a combined effect, as influenced by both myself and the participants, which has resulted in uniquely detailed accounts of their experiences of living with, and being diagnosed with, HIV.

11.6. Limitations of IPA

IPA adopts the position that language is central as it shapes experiences and the way in which they are expressed to the researcher. However, some people may have difficulties in expressing themselves clearly and may not be able to relay their experiences to the researcher (Willig, 2001). In this study, I aimed to make use of participants who were able to understand and speak English, even if only as their second or third language. The language barrier is recognised by Smith (2004), who reported that it is common for most qualitative IPA studies to make use of English-speaking adults. The disadvantage, of course, is that it excludes many people from participating in this sort of research, people who may have unique insights into the topic. So, while language barriers might have prevented the participants in the present study from fully expressing themselves, this is seen as less important than giving them the opportunity to voice their experiences.

Furthermore, a criticism by Willig (2001) was that language constructs reality: the same experience can be described in various ways using different words. Larkin (2008) responded to Willig (2001) by highlighting that IPA is a means to access the account of an experience, and does not claim to directly access the experience itself.

A further criticism of IPA is that it describes the lived experiences of individuals, but does not attempt to explain them (Willig, 2001), which may in turn inhibit understanding. It appears however that this is a common criticism of most qualitative research which aims to describe (Larkin, 2008; Smith et al., 1999). A distinction, however, can be made between the hermeneutics of meaning-recollection, which is the faithful description of experiences, and of the hermeneutics of suspicion, which emphasises a deeper understanding in which participants may not necessarily recognise themselves (Ricoeur, 1970 as cited in Ashworth, 2003). While the former is emphasised in IPA research, the latter is also considered in coming to a fuller understanding of people's experiences (Smith, 2004).

11.7. Qualitative Data Collection

The in-depth, semi-structured interview-based qualitative data was collected after the quantitative dataset and took place in February and March 2010. Subjects who indicated on the quantitative data interview schedule that they would be available for follow-up were contacted by telephone and invited to come in for a scheduled audio-taped session. The semi-structured interviews were recorded and transcribed verbatim.

11.8. The Sample

The qualitative sample consisted of six participants from the G J Crookes Hospital Anti-Retroviral Clinic who, as mentioned previously, had completed the quantitative data collection phase of the research, and who had indicated on the quantitative data demographic questionnaire that they would consent to a follow-up appointment. Exclusion criteria consisted of being diagnosed with HIV for less than one month (to exclude Acute Stress Disorder), and not being able to communicate in English (to exclude translation difficulties). Despite 28 people indicating on the demographic data form that they would be prepared to attend a follow-up session, only fourteen participants were able to provide contact numbers to enable such sessions to be organised. Furthermore, six patients subsequently indicated that they were unable to attend a follow-up appointment because they had been transferred to community health clinics nearer to their homes. Two participants were happy to attend a follow-up but did not wish to be audio-recorded and were therefore not used for the IPA study, with the result that six participants compromised the qualitative sample.

11.9. Data Collection

IPA researchers attempt to elicit rich personal accounts from participants and may use in-depth interviews or diaries which facilitate the telling of stories, thoughts and feelings surrounding the event or phenomenon. Semi-structured interviews are considered the ideal method of collecting data in IPA research (Smith & Osborne, 2003) as they are useful in obtaining details about participants' beliefs, perceptions or feelings about a particular topic (Smith, 1995).

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Bogdan and Biklen (2003) described an interview as being a purposeful conversation, usually between two people, but directed by one person in order to obtain information. One can assume that the material provided by the participants in a semi-structured interview has some significance to them (Smith, 1995). Such interviews provide the researcher with flexibility to ask questions and pursue different avenues of questioning which may have been omitted in a structured questionnaire (Smith, 1995). Using semi-structured interviews as a data collection method maintains the aim of IPA, in that it allows the researcher to guide the conversation while enabling the participant to be the expert on the topic they are discussing (Smith & Osborne, 2003).

Roulston (2011) stated that one-to-one interviews allow for the participant and interviewer to develop rapport, and give the interviewee the space to think, speak and be heard. However, they are influenced by a number of contextual, situational and personal factors, all of which make analysis complex (Hargie & Tourish, 1999) and, while interviews can provide rich data, Anderson (2011) pointed out that their disadvantages are that they can be time-consuming and are dependent on the skill of the interviewer. For the purpose of this research, an Interview Schedule of Questions was drawn up in order to target people's experiences of diagnosis, adjustment, stigma, various challenges and social support (see Table 16), and to facilitate a comfortable interaction with the participants, which in turn should encourage them to provide a detailed account of their experiences and encourage discussion (Smith et al., 2009).

Table 16

IPA Schedule of Questions

Schedule of Questions	
1. Tell me about your family 2. Who do you stay with now? 3. What traumas or difficulties have you experienced in your life? 4. How have these changed/impacted or affected you? 5. What was your life like before your diagnosis? 6. Why did you get tested? - What prompted you? 7. How has your life changed since you found out your HIV status?	8. Do you feel any different? - in your body? - from other people? 9. Has your HIV-positive status changed your perception of yourself? 10. How did you tell people? - Why did you tell people? - What were their reactions? - Were you worried about what other people thought? 11. How have you coped? - What advice would you give other people suffering from HIV?

The opening question “Tell me about your family” was considered to be non-threatening and gave participants the chance to get acclimatised to the interview setting and also allowed me to establish whether or not they had family support. While the ‘Schedule of Questions’ was used as a guide, the interviews were semi-structured, allowing the researcher to probe, and to facilitate the telling of the participants’ stories. Questioning progressed to enquiries about previous traumas and how these affected and changed their

HIV, PTSD AND TRAUMATIC LIFE EVENTS

lives, why they were tested for HIV, how they found out their status, and how their lives had changed in the process of living with HIV. This was then explored further using questions such as “Has HIV changed your perception of yourself?” and “Has HIV changed the way you feel about body?” The interview closed on a positive note asking participants how they had coped with their HIV status, and what other advice they would offer to others who may have had to deal with such difficult experiences. As Smith et al. (2009) explained, the IPA studies can be used to obtain detailed analyses of specific instances of lived experience which explore each participant’s relationship with or involvement in a particular event.

11.10. Data Analysis

According to Roulston (2011), the researcher's task is not limited to recording descriptive data and analysing it, but also includes making sense of the data. With IPA, the analysis is developed on substantive verbatim extracts (Reid et al., 2005). Meaningful segments were coded and grouped into themes with common characteristics throughout the participants’ stories. Similarly those displaying significant variations were identified and treated separately. This is a unifying process of coding, organising, integrating and interpreting the data.

The analysis of the IPA data is a process in which there are several levels of interpretation. The researcher investigates the details, descriptions, and experiences of the participants’ worlds and simultaneously attempts to examine the meanings attributed to their experiences in order to speculate on alternative understandings and interpretations (Eatough & Smith, 2008). In this study the data was analysed manually by the researcher in accordance

with the procedure described by Reid et al. (2005) and Smith and Osborne (2003), who suggested the six iterative steps discussed below:

11.10.1. Step One: Reading and re-reading. In the first step, the researcher pores over the original data and carefully goes through the participant responses in order to understand their full meanings. This may involve re-reading notes, listening again to audio recordings and re-evaluating the IPA transcriptions.

11.10.2. Step Two: Initial noting. During this step the researcher maintains an open mind and notes anything of interest within the transcript. Different individuals will probably use different terms and types of language to express themselves, and examining this allows identification of the particular way in which the participant talks about, understands and thinks about an event.

11.10.3. Step Three: Developing emergent themes. Step 3 is achieved by going through the researcher's notes in an attempt to consolidate them into a concise statement of salient points. These themes are then carefully written down.

11.10.4. Step Four: Searching for connections across emergent themes. Step 4 involves looking for and establishing connections or patterns in each participant's narrative. This can be done in many ways, including typing the themes into a chronological list and then moving them into related clusters.

11.10.5. Step Five: Moving on to the next case. The next step involves putting the work aside and moving on to the next participant's transcript to repeat the process. It is important to treat each case separately in order to do justice to the specific individual's experience.

11.10.6. Step Six: Looking for patterns across cases. The final stage involves looking for patterns and emergent themes throughout all the case-notes. This could be achieved by logging all the data on a table and looking across them to see which themes are recurrent. Group themes can then be illustrated using examples from individual cases. The qualitative analysis seeks to contextualise the quantitative results and is discussed in relation to the existing literature.

11.11. Validity

11.11.1. Validity in Theory. It is inappropriate to assess the validity of qualitative research using a quantitative framework (Smith & Dunworth, 2003). The validity of qualitative research is dependent upon the researcher's ability and efforts. As the aim of IPA is to gain an insider's perspective about a particular phenomenon while using the researcher as an analytic tool (Smith et al., 1999), the researcher's beliefs and viewpoints are not seen as bias, and do not therefore need to be set aside or discounted as they might be in traditional research. On the contrary, the researcher's perspective is viewed as being essential for making sense of other people's experiences, and his or her reflection is seen as a tool by which an interpretive role may be acknowledged (Fade, 2004).

Yardley (2000) presents four principles for assessing the quality of qualitative research:

11.11.2. *Sensitivity to context.* Sensitivity to context can be displayed in a number of ways including the selection of IPA as a methodology. A great number of verbatim extracts from participants' accounts should be used to illustrate the purposed themes and arguments made (Yardley, 2000).

Researchers should also be aware of existing literature and should use this to illustrate sensitivity to context by paying attention to the idiography and nature of the lived experience of the person (Smith et al., 2009).

This study showed sensitivity to context in taking note of the socio-economic factors of participants and the community as well as the context of being HIV-positive in KwaZulu-Natal. My study also examined the testing procedures and ARV requirements in an effort to gain a better understanding of what participants had to experience. The information obtained was examined in the context of the hermeneutic circle (as discussed previously), and in the reporting of findings a substantial number of verbatim quotes is used, giving the participant a voice (Smith et al., 2009).

11.11.3. *Commitment and rigour.* Yardley (2000) believed the degree of commitment can be shown in the amount of attention paid to the participant during the data collection stage, and the care with which the analysis is executed. The term "rigour" refers to the analysis being conducted thoroughly and systematically (Smith et al., 2009). Similar to Yardley, Golafshani (2003) revised traditional definitions of validity in quantitative research, emphasising that, for a qualitative study to be considered reliable and valid, it should display trustworthiness, rigour and quality.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Commitment and rigour is shown in this study's approach to the research topic, *HIV-Related PTSD, Traumatic Life Events, and the Personal Experiences of Living with HIV*. As language is a central feature of IPA (Smith et al., 2009; Willig, 2001), participants were chosen using the inclusion criteria that they were able to express themselves reasonably comfortably in English. As such, interviews were conducted in a language the participants were able to understand, without the presence of an interpreter, to allow participants to express themselves freely, encouraging discussion. To be even more rigorous, multiple methods were employed during data collection (Begley, 1996), interviews were recorded by means of audio tapes, and extensive field notes were kept at all times.

11.11.4. Transparency and coherence. Transparency refers to the degree of clarity in which the stages of the research process are described in the study (Smith et al., 2009; Yardley, 2000). This may be seen in explaining the steps of the study, how the participants were selected and how the interviews were conducted. Coherence suggests the fit between the completed research and the theoretical assumptions of the approach which is being used.

In this study, the theoretical model used to inform the researcher's interpretation of the participants' meanings, is the Ehlers and Clark (2000) Model of trauma. Furthermore, transparency and coherence has been shown in explanations both to the participants and to the reader. This ensures that the reader is aware of all the steps that I have taken to ensure that this study makes a valuable contribution to research on HIV.

11.11.5. Impact and importance. Yardley makes the point that the real validity of research lies in whether or not it tells the reader anything interesting, important and useful (Smith et al., 2009; Yardley, 2000). Research should be evaluated according to how informative it is about a specific case on a micro-level (Smith, 1999).

My study is unique and demonstrates both that it will have an impact upon and that has importance for the future management and care of PTSD and mental health amongst HIV-positive individuals. This study provides an inner look into the experiences of six individuals who are living with HIV, and in addition, it contains the most up-to-date literature review of PTSD, it discusses the prevalence of both PTSD and HIV-related PTSD, and also includes a description and comparison of the traumatic events.

11.12. Ethical Considerations

Because all the participants were classified as “vulnerable”, a secure office adjacent to the ARV clinic was used for the duration of the study. Following guidelines by Strydom (2002), participants were assured that information would be treated confidentially and used only in accordance with the purposes that were outlined by the study. Confidentiality has been ensured by treating all quotations anonymously. All data has since been coded to ensure privacy, and no names or other identifiable details have been used. The IPA transcriptions are identifiable only by a reference code of the participant, the key to which is known only to the researcher.

Patients were invited to participate in the study and were informed about the nature, risks and benefits of the study at the time of the quantitative data collection, and again prior to the IPA interviews.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Individuals were given an opportunity to ask questions. The psychologist ensured that patients understood their rights, and what was expected of them, prior to signing the consent form. As one of the inclusion criteria was ability to communicate in English, no interpreter was present, further ensuring confidentiality and encouraging more frank discussion.

11.13. Summary

This chapter describes interpretative phenomenological analysis, the qualitative methodology chosen to complement the quantitative findings. Qualitative research to examine PTSD and traumatic life events in HIV-positive populations is scarce, and the combination of both qualitative and quantitative research to explore the topic in this study is unique to this study. In the next chapter the findings of the qualitative analysis will be reported and discussed.

Chapter 12: Qualitative Findings and Discussion

This chapter presents the results of the interpretative phenomenological analysis of the interview transcripts. A brief description of each participant allows the reader better understanding of their experiences. The themes that have been identified will be described and explained, often by drawing on the Ehlers and Clark (2000) Model, described in Chapter 6, as an explanatory framework (Young, 2011).

12.1. Participants

The qualitative sample consisted of six participants who were patients at the G J Crookes Hospital anti-retroviral clinic, drawn from the initial quantitative sample. Inclusion criteria include those that were stated for the quantitative analysis and possessing an ability to express themselves in English. Initially 28 people indicated on the demographic data form that they would be prepared to attend a follow-up session, but it transpired that only fourteen participants were able to provide contact numbers to enable such sessions to be organised. Of these, six patients were in fact unable to attend a follow-up appointment because they had been transferred to community health clinics nearer their homes, and a further two were happy to attend a follow-up but did not wish to be audio-recorded and were therefore excluded from this phase of the study. The demographic data of these participants is summarised in Table 17.

To preserve their anonymity, the six participants have been assigned labels from A to F.

Table 17
Demographic Data of Qualitative Sample

Demographic	Category	No. of Participants
Race	Black	4
	White	1
	Indian	1
	Coloured	0
Gender	Male	2
	Female	4
Age	18 - 35 years	4
	36 - 50 years	2

12.1.1. Participant A. Participant A was a 50-year old white man who was born in Zimbabwe. He was single and lived with his mother whom he described as very supportive. His first language was English and he was semi-retired at the time of the interview. He had found out about his HIV-positive status only 6 weeks earlier, after he fell ill and was referred for testing by his doctor. He had been compliant on ARV-medication from the outset. His CD4 count at the time of this study was 85 and appeared to be gradually rising. He stated that he had disclosed his HIV-positive status to his brothers and mother, but had not told his friends for fear of their reactions.

Participant A fought in the apartheid border war, and so was exposed to a great deal of violence and the deaths of a number of people. During his life he had endured many traumatic experiences including being physically

HIV, PTSD AND TRAUMATIC LIFE EVENTS

attacked and arrested. However, it was his opinion that being diagnosed with HIV was one of the most stressful.

12.1.2. Participant B. Participant B was a 26-year old unemployed black woman whose home language was isiZulu. She had a boyfriend and found out about her HIV-positive status in 2008 when her son fell ill and was tested. Her seven-year-old son subsequently died due to HIV-related complications. She had disclosed her positive status only to a friend as she felt that her family would not understand. She had been taking ARV medication since January 2010 and her CD4 count at the time of the testing was 92.

When questioned about the traumatic events that she had endured in her lifetime she described the death of her son and finding out about her HIV-positive status. Her son's biological father knew that he was HIV-positive and withheld this information from her. Had she known about it earlier, she and her son might have received treatment earlier. For a long time this participant ruminated about her son's death and how things may have been different.

12.1.3. Participant C. Participant C was a 28-year old Indian man who was single and unemployed. His home language was English and he lived with his parents. He found out about his HIV status in 2007 after he went for a voluntary HIV test, and started taking anti-retroviral medication in 2009. His CD4 count at the time of the assessment phase was 26. He had disclosed his status to both family and friends.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

When describing the traumatic events which had occurred in his life, this participant mentioned that he had been physically threatened and also involved in a taxi accident in which he was knocked unconscious and taken to hospital. He reported that he often had flashbacks of the accident and had visions of the other vehicle coming towards him. He does not like driving now and said that he tries to avoid leaving the house. The car accident had serious repercussions on his social life and continues to trouble him:

Participant C: “Ever since then I’ve been having flashbacks as well... like this morning when I got into the taxi. The taxi was like smoking inside and I was scared.”

He declared that having tested positive for HIV and taking anti-retroviral treatment was extremely stressful.

12.1.4. Participant D. Participant D was a 32-year old black woman whose first language was isiZulu. She was single and had a child. She found out about her HIV-positive status at voluntary testing station in 2008, and began taking treatment later that year. Her CD4 count at the time of the study was 190. She had disclosed her status to both her family and friends.

This participant reported that she had experienced the death of many family members which she found very stressful. Her mother died after an illness, and her brother was murdered.

12.1.5. Participant E. Participant E was a 31-year old African male with a girlfriend and two children. His home language was isiZulu and he was unemployed. He found out about his HIV-positive status in 2003 when the mother of his first child tested positive. He went for a voluntary test shortly afterwards and later began treatment in 2009. His CD4 count at the time of

HIV, PTSD AND TRAUMATIC LIFE EVENTS

the assessment was 103. He had disclosed his status to his family, but had decided against telling his friends as he did not want them to know.

Participant E described having been involved in political conflict and he had witnessed another person being injured. He himself had been physically assaulted and had been threatened with a weapon. His half-brother was murdered and he was asked to identify the body. When questioned about additional stressors he described that the death of his mother and sister were extremely traumatic for him. He is left with what is a very sad appraisal: “Now I have to think...that maybe they pass away ’cos they are in my life.”

12.1.6. Participant F. Participant F was a 36-year old African female with a boyfriend and two children. Her home language was isiZulu and she was employed at the time of the interview. She was diagnosed as being HIV-positive in 2005 and began taking treatment that same year. Her CD4 count at the time of the study was 987. She had disclosed her status to her friends but had not told her family.

This participant recounted having been raped, physically attacked, threatened with a weapon and mugged. In addition, her employer was murdered while she was present in the house. She stated that all of these, as well as finding out that she was HIV-positive, had deeply affected her.

Of the six participants who recounted their experiences during the qualitative interviews, all described having been exposed to major traumatic events in their past and five live with dangerously low CD4 counts.

12.2. Themes

The analysis was informed by the Ehlers and Clark (2000) Model of traumatic stress, and themes are grouped into clusters of stigma experiences, appraisals, emotions and coping strategies. Individual themes are supported by direct quotes from the participants in order to lend greater insight and understanding (Smith et al., 2009).

Table 18
Group Themes

	Themes	Sub-Theme
Theme 1	Stigma	Rejection and Discrimination
Theme 2	Negative Appraisals	My life is not worth living My life is being threatened I am cursed I am contaminated This creature is inside me
Theme 3	Emotions	Fear, helplessness and horror Anger, sadness, guilt and frustration
Theme 4	Coping Strategies	Social withdrawal Denial Rumination Hypervigilance Embracing Responsibility Having a positive outlook Religion Social support and disclosure

12.2.1. Theme 1: Stigma. For the participants of this study, the experience of stigma and associated fear of discrimination due to their HIV-positive diagnosis was a very real issue with which they had to contend. Participant F, for example, seemed surprised that her family continued to treat her as if nothing had changed, implying that she had expected them to treat her differently. Indeed, the expectation of negative reactions from others, termed perceived stigma (Deacon et al., 2009), whether or not corroborated by actual experiences, is a powerful influence on the behaviour of HIV-positive people.

Researcher: “Your family, have you told them?”

Participant F: “My family, I couldn’t tell my mother. My father, father he drinks, so I got no problem, but I didn’t tell my father, I didn’t tell my mother. But all my sisters know.

Researcher: “All your sisters know, good.”

Participant F: “Yea, and they treat me, they treat me like nothing is wrong, everything is still the same. We share one bed, we share everything in the kitchen...”

The experience of support from her family made it easier for her to speak about medication and hospital visits, and ask for assistance as and when it became necessary. Freeman et al. (2007) suggested that the perception by HIV-positive individuals of available support can assist in alleviating mental disorders. According to the Ehlers and Clark Model, such support may assist in refuting the negative self-appraisals that they are unworthy of love and support (see Theme 2).

HIV, PTSD AND TRAUMATIC LIFE EVENTS

What was a shock for this participant was that she had voluntarily sought testing with a group of friends in the expectation that her test would prove negative. She revealed that, when she received the result, she felt like a different person and felt very isolated:

Researcher: “So, you went there trying to be an example for other women to get tested and encourage them to go. Thinking that you were negative, and you were going to be fine. It must have been a big shock.

Participant F: “Yes, yes it was, when I came out of that vehicle, as if the world is going to be a new place, without friends. I felt different...”

Researcher: “You did feel different?”

Participant F: “Yes, but I pretended like there was nothing wrong...”

A world without friends can be experienced as a threatening and frightening place. Her perceived stigma, that she would be rejected and abandoned by her friends, seems to have influenced her appraisals of her situation.

Another example of perceived and felt stigma is associated with the common assumption that those who are HIV-positive must have had many sexual partners. This was clearly stated by Participant B:

Participant B: “...People they don’t understand... because they... they say that you have HIV because you have had many partners...”

She asserted that becoming HIV-positive is not about having had multiple partners but rather about having had unprotected sex, and also declared that you never know how many previous sexual partners your current partner has had.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Similarly, participant C explained that he was reluctant to disclose his status for fear that other people would discriminate against him:

Researcher: “Your mum, how did you tell her?”

Participant C: “My sister told her.”

Researcher: “Your sister told her, okay, okay... what did she say? how did it all go?”

Participant C: “She started crying, but later in the evening she said that everything would be okay.”

Researcher: “Mmmm, she was also supportive. Were you worried about what people might think?”

Participant C: “Yes, I thought that people would think bad about me... that I deserved it...”

Researcher: “But that hasn’t happened?”

Participant C: “It did at the beginning...”

Researcher: “What happened, with who?”

Participant C: “My friends.”

Researcher: “Your friends didn’t want anything to do with you.”

Participant C: “Yes, they were like they kept away and obviously it hurted...”

This excerpt clearly demonstrates his belief that many people would assume that he must have been promiscuous and therefore deserved retribution. His statement “People would think bad about me...” is an example of perceived stigma, perhaps even felt stigma in that he might easily have come to believe that he is bad and therefore can only expect people to shun him. The difference between this and the previous example is that his

HIV, PTSD AND TRAUMATIC LIFE EVENTS

friends did initially keep away from him, which would certainly have supported his initial negative appraisal of his HIV-positive status, possibly reinforcing the belief that he is unworthy. He did confide in his family and, he found them to be understanding, but Participant C did not enjoy the same level of support from his friends.

It is also likely that his initial experiences would make him wary of disclosing his status to others. Partial disclosure seems to be a coping strategy to access some support while minimising the risk of rejection.

What these excerpts suggest is that the social context, characterised by widespread stigma (Deacon et al., 2009; Shisana & Simbayi, 2002; Kalichman & Simbayi, 2003; Visser et al., 2006; Timberg, 2005), profoundly shapes and in turn is shaped by individuals' appraisals. It seems that these negative appraisals are pre-loaded in that they are possibly held by people long before they discover their own HIV-positive status. Additionally, people's conscious mental lives generally mirror those close to them (Robbins, 2008), like family and friends, who often hold such deprecating beliefs. One implication is that, alongside the efforts to challenge in counselling contexts the negative appraisals held by people who are HIV-positive, much more should be done to challenge HIV stigma more generally (Deacon et al., 2009). Some of the appraisals that result from this internalised or felt stigma are described in the section below.

12.2.2. Theme 2: Negative Appraisals of the Self, World and Future.

A consistent theme for the participants includes negative self- and other appraisals in response to their HIV-positive diagnosis. As discussed in Chapter 6, according to Ehlers and Clark (2000), negative appraisals may

HIV, PTSD AND TRAUMATIC LIFE EVENTS

occur at the time of the traumatic event, and have the potential to contribute to a sense of ongoing threat. For example, people may believe that they are socially tainted and therefore unable to disclose their status to their friends and family for fear of negative reactions or rejection. After being diagnosed as HIV-positive, individuals may over-generalise this initial sense of threat, believing that their death is imminent, regardless of their response to ARV treatment. Some examples of these negative appraisals are described below.

12.2.2.a. *My life is not worth living.* In certain cases, given the news that they suffer from a life-threatening illness, some people lose the will to live and the will to fight. In terms of the Ehlers and Clark (2000) Model, the appraisal that they suddenly no longer have a future is likely to result in sadness and anxiety, and social withdrawal. Participant C divulged to his sister that he did not want to take the anti-retroviral medication and would rather die than have to deal with living with HIV:

Researcher: “Were you eating?”

Participant C: “Yes, I was, the first time I was here. Then a few days later, I said to my sister, you know what – I can’t take it anymore. I didn’t want the medication. I didn’t eat.”

Researcher: “You wanted to die..?”

Participant C: “I had decided.”

Luckily his sister and parents were able to provide support and encouragement that enabled the participant to find the will to carry on. The support they offered is likely to have contradicted his own beliefs about the worth of his life. However, despite being on anti-retroviral medication and

HIV, PTSD AND TRAUMATIC LIFE EVENTS

having good social support at the time of the interview, Participant C disclosed that he still sometimes questioned whether life was worth living:

Researcher: “Do you feel different?”

Participant C: “At times I sit and think, is it worth the way I live? And I go on praying I speak to my family. Well I think a lot.”

Perhaps Participant C coped by thinking, but it is more likely that he was ruminating about his status. Such ruminations may serve to maintain the negative appraisals of the trauma of being diagnosed HIV-positive (see Theme 4). When speaking about the future, his answer was negative and fatalistic:

Participant C: “Well, I say to myself that that’s life and you just have to deal with it.”

Researcher: “How do you see your future...?”

Participant C: “I don’t...”

Despite the support he receives, and that he is taking ARV medication, it would seem that his appraisal that his life is less worth living is largely unchanged, an appraisal likely to be reinforced by his social withdrawal and a vow to avoid all romantic relationships.

12.2.2.b. My life is being threatened. Another assumption which commonly made of a HIV-positive diagnosis is the belief that the person is dying and that their death is imminent (Meursing, 1999). Such appraisals no doubt mirror the views of many people in communities that have been devastated by AIDS. The conviction that one is going to die sustains a current sense of threat. This is especially frightening prospect for those diagnosed with HIV as they must cope both with their own fears and with the

HIV, PTSD AND TRAUMATIC LIFE EVENTS

misconceptions of others. Kelly et al. (2008) found that the negative appraisals related to individuals' HIV-positive status tend to be based on the view of HIV as a death sentence, combined with the expectation of encountering stigma and discrimination for the duration of their lives. One participant, who attempted to tell her extended family members about her HIV-positive status, found that although they tried to be understanding, they automatically expected her to die soon. Participant B echoed their words, and repeated the questions that were asked of her:

Participant B: "Most of my family, they did understand a lot, because they have it. But some of them, they wonder, hawu, you are going to die now. But no, I do understand if they go hawu, you have it, wooh!"

Researcher: "You look fine..."

Participant B: "...how many is your CD4 count? It was negative mine – okay you are on the way, you are going to heaven now..."

Her family knew enough about HIV to enquire about her CD4 count, but not enough to know that with anti-retroviral medications the CD4 count can improve significantly.

What is central to the understanding of the Ehlers and Clark (2000) Model of trauma is that negative appraisals are often maintained, even in the face of overwhelming contradictory information, by the often fragmented nature of trauma memories and by the cognitive and behavioural coping responses that people employ. Because it is common for people to assume that HIV is a terminal illness, HIV-positive people might hold this view despite their engagement with the health services and improving CD4 counts following the initiation of ARV therapies.

12.2.2.c. I am cursed. While Participant B had to contend with thoughts of her own death, Participant E seemed to appraise his own HIV-positive status as a curse that has brought misfortune and death to so many who were dear to him.

Researcher: “How has this changed you, how does it change your life?”

Participant E: “When it happens... sometimes I just think that maybe there is a curse on me. 'Cos every time each and every person that I would befriend, they pass away...”

Kalichman and Simbayi (2004) reported that the conviction that AIDS is caused by spirits or the supernatural is relatively common in some segments of South African society. In contexts like this, it would not be surprising that people link their HIV infections with a host of unrelated misfortunes. The belief that HIV will bring disaster to the self and others would of course maintain a sense of current threat. Furthermore, it is possible that this presumption would support another belief that the person is bad or worthy of such misfortune, as Participant E seems to hint.

Similarly, participant F suggests that she is being punished by God or that she is unworthy of his protection.

Researcher: “How have these things changed you?”

Participant F: “...I get very angry and um... I thought um... that I was different from the other people...”

Researcher: “You felt different?”

Participant F: “I felt different, but it’s over now.”

Researcher: “It almost feels like bad things keep happening to you...”

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Participant F: “Yes! I keep wondering why God doesn’t love me... what keeps happening...”

12.2.2.c. I am contaminated. Some people believe that they are contaminated, as though there is something in them which drives others away, and this is made worse by the stigma and discrimination surrounding the diagnosis. One participant attributes human characteristics to the disease (anthropomorphism), comparing the multiplication of the virus in the body with global overpopulation that is consuming all of the world’s natural resources. The belief that one is contaminated brings two threatening possibilities: one is that the body will succumb and the other is that one will be marked and rejected by others.

One of the most striking examples of this came from Participant A.

Participant A: “I think to myself that I should feel dirty.”

Researcher: “Okay.”

Participant A: “Because um, lots of people keel away when they say someone is HIV, or keep away from them you know. And um, you feel contaminated somehow.”

Researcher: “Like you can’t? Something you can’t get rid of...?”

Participant A: “...it’s a strange thing you know, it’s like there is this little tiny creature that lives inside me, you know. And, you know, it’s like you want to tell this creature to stop multiplying because you will kill me and then we’ll all die. But if you think about it – humanity is exactly the same, I mean in this world people are just breeding out of control and destroying this world...”

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Participant A revealed that others avoided him because of his status and this made him feel contaminated. This is interesting because it suggests that the source of the belief was his experience of disclosing his status to others. As noted previously, while disclosure is often encouraged so that HIV-positive people can access social support, it also brings the possibility of rejection, perhaps explaining Freeman et al.'s (2007) suggestion that there is a positive association between the presence of a mental disorder and the disclosure of an HIV-positive status.

By associating the HIV virus with the whole of humanity, Participant A illustrated how big and important the virus was to him. His frustration was evident in his choice of phrases such as “out of control” and “destroying this world”. This participant continued with the theme of being contaminated, and went on to explain:

Researcher: “Does it feel like there is something living with you? Do you feel like the virus is alive? Or...”

Participant A: It’s funny, it’s like I’m not alone anymore, it’s like I’ve got like...”

Researcher: “There is something with you all the time?”

Participant A: “Yes, there are millions and millions of tiny things inside me and I wish I could talk sense to them and say to them... ‘listen, yea, like take it easy... stop breeding you know like uncontrollably you know’, like you know a ... are they like, are they having, are they having sex?...”

This mental image is an example of a negative appraisal that is not verbal. He imagines millions of tiny organisms having sex and multiplying,

HIV, PTSD AND TRAUMATIC LIFE EVENTS

despite the fact that he is on anti-retroviral medication that should suppress almost all viral activity.

12.2.3. Theme 3: Emotional Responses. According to Ehlers and Clark (2000) and a mass of other researchers in the field of cognition and emotion, the negative emotions individuals experience are as a result of how they appraise their HIV-positive status. The emotional responses are the result of the recurring thoughts of death and dying, sickness, being unable to care for oneself, and so on, influenced by the fact that HIV infection is a highly stigmatised, life-threatening illness. Individuals may encounter a sense of gloominess and helplessness which one would expect with a degenerative disease (Morin, Charles, & Maylon, 1984). While many of the appraisals of being HIV-positive in a low resource context are realistic, the point made by Ehlers and Clark (2000) and other cognitive theorists is that often the trauma appraisals made during or after a traumatic event are exaggerated or even completely untrue, and so the corresponding emotional responses are excessive or inappropriate.

After receiving an HIV-positive diagnosis, people may have any number of reactions and emotions. In this IPA study the participant reactions varied from individual to individual, and included depression, sadness, anger, shame and guilt. Some participants displayed more than one reaction, and others found that their reactions to diagnosis changed over time. Some felt that they were damaged in some way and blamed themselves for their HIV-positive diagnosis, while others, on the basis of a belief that no-one would want to be involved with or love them again, felt afraid of having relationships.

12.2.3.a. Fear, helplessness and horror. Most people are likely to have negative emotions following a diagnosis of a potentially deadly illness, due to the very nature of it being life-threatening. They may experience feelings of fear about death and dying.

Thoughts of death and dying may become intrusive and may overwhelm the person concerned. Niehaus (2007) viewed the construction of HIV and AIDS as being “dead before dying” as the individual is caught in a place where they feel that they are between life and death. Repeated concerns about, or fears of, death and dying would be seen as a consequence of the negative appraisal that the person is about to die, regardless of the reality that they are all receiving ARV medication.

On first receiving the diagnosis, a reaction of fear, shock and horror was common. This was demonstrated by Participant F's early response to her HIV diagnosis:

Participant F: “When I came out of that vehicle, as if the world is going to be a new place, without friends... I felt different.”

Researcher: “You did feel different?”

Participant F: “Yes, but I pretended that there was nothing wrong, and I failed. I went to the big house where my boss was and I started crying a lot. And they were asking – what is wrong. And I didn’t want to talk. Eventually I said to madam that “I’m going to die” and she said “What’s wrong? Who said? Who’s going to kill you?”. I couldn’t tell her. I was crying and crying, crying and crying. She said “You are not going anywhere; you tell me what is wrong with you.” And then later on I tell her that I went for a test and I tested positive. And she said

HIV, PTSD AND TRAUMATIC LIFE EVENTS

“No, you are not going to die now, who said you were going to die? We are here for you, and we will make sure that you eat well, you take your medication. So that is that.”

As an aside, the remarkable, uplifting aspect of this experience is the support offered by her employer.

Participant A admitted to fearing that the virus was going to kill him by destroying his immune response and making him vulnerable to other diseases. For him, his HIV-positive status is like a ticking time-bomb, counting down the hours and minutes that he had left.

Participant A: “... I used to be carefree. I can’t just take off and go camping, or...”

Researcher: “Yeah.”

Participant A: “I have to sit there and count out pills and go to the clinic you know and I have to make sure I’m back in time for all that. And so it does... and also, okay look, the doctor told me that overseas you can take 1 pill. 1 ARV a day, that’s how good it is and you can live for like 25 years, 30 years you know. And I feel like, I feel now there is a clock ticking, although there always is a clock ticking. There always is a clock ticking isn’t there?...”

Indeed, the fear that their ARV medicine might fail is a pervasive one, understandable given that five of the six participants still have CD4 counts that are dangerously low. The fear seems to be managed to some extent by adopting various mechanisms to ensure that the medication is taken at the right time every day, and by minimising stress that might put strain on their immune systems. Thus participants adopt an approach to life that is

hypervigilant and also embrace responsibility and a positive outlook (see Theme 4).

12.2.3.b. Anger, sadness, guilt and frustration. Alongside fear, participants also described feelings of anger, sadness, guilt and frustration. In a study by Kelly et al. (2008) respondents appraised their status with disappointment and despondency for their future, following which many expressed either depression or anger. Participant B describes her unbearable sadness at the tragic death of her son, combined with anger directed at her son's father, who was the person from whom she believed she had contracted the virus. The following excerpt illustrates the tragic and devastating impact of HIV in South Africa:

Participant B: “The hardest thing - my child that passed away, this year in March.”

Researcher: “This year?”

Participant B: “Mmmm, I found out that he was HIV-positive.”

Researcher: “Okay....”

Participant B: “Because he was infected by me at birth”.

Researcher: “He got infected at birth...”

Participant B: “Because I got infected by his father – and he, he never told me. Then I found out what he gave us. I asked the father of the child that he knows about that and then he says he knows. And I asked him - You?... He never told me.”

Researcher: “Yes.”

Participant B: “He said that he was afraid and very embarrassed.”

Researcher: “So you...?”

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Participant B: “ I was angry with him, really angry, sometimes I cry a lot.”

This quote illustrates how angry this individual was with her partner, who failed to inform her of his own status which ultimately resulted in her infection and the death of her young son. She went on to further reveal her anger and sadness.

Participant B: “I was so very angry with God, trust me. The way that I don’t understand. He knows everything that I don’t know about. He knows me, the way that I don’t know myself, but he knows...”

Researcher: “He knows...?”

Participant B: “So I must accept that he, he called him and then he answered him, go away. So I have to accept it, I have to live, I have to pray, I have to concentrate for him, not for myself. Maybe he passed away, maybe for my sins. Maybe for the time has come when I passed away I will see him someday. I don’t know, but I’m accepting it.”

Researcher: “I see, that’s good, but after you found out about your status, how did your life change?”

Participant B: “Mmmm, I was, I was stressed and I was depressed. I lost a lot of weight because I was thinking about it night and day...”

Researcher: “Really?”

Participant B: “I used to cry, I said why did I get this disease. I never slept with anybody, I only had the one boyfriend. Why did God do this to me?”

HIV, PTSD AND TRAUMATIC LIFE EVENTS

She questioned whether her son died for her 'sins', implying that she was being punished. This suggests that she carried a great deal of guilt over her son's death, which might have been avoided had his HIV infection been known earlier. She also spoke of being very stressed and depressed, but also indicated that she was slowly coming to terms with what has happened.

12.2.4. Theme 4: Cognitive and Behavioural Coping Strategies.

According to Ehlers and Clark (2000), individuals cope with the negative appraisals, fragmented trauma memories and negative emotions following a traumatic event like being diagnosed with, and living with HIV, in a variety of ways. Some coping strategies are more effective than others. Those that are effective serve to assist individuals in reassessing their negative appraisals, elaborating their trauma memories, and curtailing any unhelpful 'coping' responses. In some cases, being a recipient of a devastating diagnosis of HIV may be the trigger for individuals to make healthy changes to their lives, which include safer sex, having only one sexual partner, eating more healthily, lowering alcohol intake, reducing smoking, taking moderate exercise and focusing on the positive. A South African study found that as time passed many of the HIV-positive respondents realised that they were able to continue with their lives with minimal disruption and rejection (Kelly et al., 2008). In this study many positive changes and coping behaviours were displayed by individuals.

Yet it is also possible that in some cases many seemingly healthy coping strategies might impede the psychological healing process by serving as compensatory strategies that leave the underlying appraisal unchanged. While these might be helpful over the short-term, the concern is that they are

sometimes unsustainable and ultimately fail (Young, Klosko & Weishaar, 2003).

12.2.4.a. Social withdrawal. It seems the norm for individuals to withdraw socially after receiving a life-threatening diagnosis of HIV. Participant A physically withdrew from everyone after finding out about his HIV-positive status. He spent six weeks taking ARV treatment and gaining weight before he could face people again:

Researcher: “How has your life changed since you found out about your HIV status?”

Participant A: “Well I hid for about was 6 weeks until I put on weight and I looked normal.”

Researcher: “Okay, you locked yourself away?”

Participant A: “Yes, I hid away, cos I I looked like, I looked like a ... death warmed up and um... I hid away for 6 weeks. And um... My mum told everyone that I had leukaemia...”

He socially isolated himself to avoid rejection but in doing so, he excluded himself from social situations where he might have gained a sense of acceptance to dispel the negative appraisals of his HIV-positive status. This self-enforced isolation probably only served to bolster his negative appraisal of himself as unworthy of love and support. What is particularly interesting about this excerpt is that his mother preferred to lie by telling people that her son had leukaemia, another life-threatening illness, but without the same stigma as HIV. While this may have been to protect him, the action may have been misguided, as it probably confirmed his negative appraisal that his status was something for which he should be ashamed of.

12.2.4.b. Denial. A stigmatising belief is that those who suffer from HIV are socially and physically tainted (Kalichman & Simbayi, 2003). One way in which people might cope with this appraisal is to assert their normality by denying that their lives are any different post-diagnosis. This could at times become a maladaptive compensatory mechanism, whereby the person thinks, feels and behaves as if the opposite of their appraisal is true without actually changing the appraisal (Young et al., 2003). Participant A states that:

Researcher: “So you worry about the stigma attached to it?”

Participant A: “To being HIV-positive?”

Researcher: “Yes.”

Participant A: “Not really, I think what I find is like ...I wake up in the morning and I feel normal you know...”

A similar need to emphasise his normality is echoed by Participant E:

Researcher: “Does the HIV change the way you think about yourself? When you look in the mirror do you still see the same person, or does it change things for you?”

Participant E: “Not that much hey, when I’m looking at the mirror I see the same guy”.

Researcher: “You see the same guy...?”

Participant E: “And I don’t see myself different, but yet I know that I got it. But I haven’t changed that much.’Cos, I understand that because I was diabetic now I know it’s one and the same thing. You have to take the treatment in order to live, but it hasn’t changed me that much...”

HIV, PTSD AND TRAUMATIC LIFE EVENTS

The other interpretation is, of course, that this reflects a healthy outlook. But this viewpoint is weakened by the fact that both participants have CD4 counts that are still dangerously low after having lived with HIV for years. They would have experienced a decline of their own immune systems and witnessed HIV stigma and discrimination, if not directed at them, then almost certainly at others. Given this, it is argued here that ultimately the assertion of normality is quite likely an compensatory that ultimately leaves the negative appraisals intact.

Another participant seems to acknowledge the distress associated with his diagnosis, but then seems to have adopted what is possibly an avoidant, forward-looking approach to dealing with his situation:

Participant C: “It really hurted, but there was nothing I could do about it, it’s part of life, so I just got on.”

12.2.4.c. Rumination. Rumination may be defined as a preoccupation with thinking about past events which may result in feelings of anxiety, sadness, regret, shame or guilt (Tull, 2013). Sometimes individuals cope with their HIV-positive status by over-thinking and ruminating over aspects of their lives, but such coping strategies can result in them becoming stressed, anxious, depressed and, in some instances, even ill. Michael et al. (2007) reported that rumination is a common feature of post-traumatic stress and can be a precursor to the development and maintenance of PTSD. Rumination is thought to strengthen problematic appraisals and prevent the formation of more complete and elaborated trauma memories, as well as increase intrusive remembering and dysphoria (Ehlers & Clark, 2000). Participant C described that he became ill and was subsequently admitted to hospital:

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Participant C: “I did get sick thereafter, landed inside and she helped.”

Researcher: “Okay, what happened?”

Participant C: “...I thought too much about it and it like, it made me ill. I couldn't walk ... I was being pushed by wheelchair. I even got sent to hospital...”

Despite being on anti-retroviral medication and having good social support at the time of the interview, Participant C went on to express that he frequently sat and contemplated his diagnosis, still finding himself thinking about not being alive any more:

Researcher: “Do you feel different?”

Participant C: “At times I sit and think, is it worth the way I live? And I go on praying I speak to my family. Well I think a lot.”

Rumination is one of the ways in which individuals respond to the negative thoughts and beliefs (Brewin, 2006). As seen above, it is thought that it is difficult for people to break the cycle of ruminating, as they may have fewer associative links between their negative thoughts and other memories (Brewin, 2006). In the case of HIV this will clearly play a role in maintaining individuals' negative appraisals and subsequent emotions.

Another participant, who has appraised himself to be a problem to others, seems to demonstrate a ruminative style of thinking as he responds to the researcher's questions about whether he worries about being a burden:

Participant A: “And in a way it's like someone should do something, maybe I should stop this because I'm becoming a burden. You know, um....”

Researcher: “Okay. Do you worry about becoming a burden?”

Participant A: “Well, to a certain degree, you know because I mean, if everybody became HIV positive, I mean, how would this country cope? But then I’m discriminated because I’m white. And there is BEE, and there is affirmative action. I can’t get any job I want. You know, I’m discriminated against. Why should I be discriminated against – you know I have always been good to people, black and white. I’ve always been really decent to people. But I get punished because of of of... of the colour of my skin, its not fair.”

His response quickly cascaded from a concern about being a burden on others, to a concern about the overall health burden of the HIV hyper-epidemic, to a fear of racial discrimination. This is an example of how in ruminating he is able to quickly generate a series of possible though unlikely negative outcomes and in doing so, giving himself more about which he is able to ruminate. This vicious, negative spiral of thinking can generate support for negative appraisals and prevent opportunities for reappraisal.

12.2.4.d. Hypervigilance. Hypervigilance which involves a bias in attention toward the detection of threat, is included among the diagnostic criteria for PTSD in the DSM-IV-TR (American Psychiatric Association, 2000) and new DSM-5 (American Psychiatric Association, 2013a). But hypervigilance for threat is not only a diagnostic symptom of PTSD, but is also implicated in the aetiology and maintenance of all the anxiety disorders (Wells and Mathews, 1994), including, of course, post-traumatic stress disorder (Thrasher & Dalgleish, 1999). The relationship between anxiety and hypervigilance is circular: hypervigilance is a feature of anxiety that results in greater threat detection and, therefore, further anxiety. As Ehlers and

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Clark (2000) explain, hypervigilance, which they describe as a selective attention to threat cues, contributes to the maintenance of a sense of current threat and may increase the frequency of intrusions. Such hypervigilance has been seen in PTSD studies to be adversely related to symptom improvement (Schell, Marshall & Jaycox, 2004).

Yet hypervigilance also appears to be a noteworthy feature of compliance with ARV medication. This hypervigilance is twofold: patients need to carefully monitor time to ensure they do not miss doses, and they also need to monitor their bodies for side effects of the medicines as well as for any symptoms of HIV infection. Though this might be associated with good ARV outcomes, the unanticipated and possibly unavoidable cost might be both increased for and stronger maintenance of post-traumatic stress and other anxiety disorders. Participant A referred to the hypervigilance of ARV compliance:

Participant A: “Ya and it takes a huge burden’ cos you, I used to worry about you know, I must keep watching and I mustn’t forget and being distracted ...it’s ten minutes before my time, and now I have this thing that vibrates in my pocket and I... you can set this thing, to keep reminding you every five minutes so it keeps performing and carrying on and buzzing...and all that.”

Researcher: “and so you take...”

Participant A: “and so you don’t slip, and that good,’ cos now I can relax a bit more...”

Later the same participant referred to the danger of complacency:

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Participant A: "...The danger, like the doctor told me was that you start feeling so well and normal that you stop..."

Researcher: "That you stop taking..."

Participant A: "Taking the pills and you can't forget you are taking them. That's the thing that I don't like, you know. I'm on TB which stops in two months' time. But the anti-retrovirals go on forever, forever and on..."

Another participant alluded to the importance of remaining hypervigilant when emphasising that there was no break from the treatment regimen:

Participant B: "...you must take the treatment. You must take the treatment everyday, as you were told by your doctor. There is no holiday with the treatment. There is no weekend. Wherever you go, go with the treatment..."

Similarly, Participant A talked about the loss of freedom that a hypervigilant monitoring of compliance requires:

Participant A: "It sort of structured me ...ya, I told the sister as well – I don't want to give this to anybody. I know what it...how it's changed my life. I'm not so free, like I used to be carefree. I can't just take off and go camping or ... I ..."

Researcher: "Yes"

Participant A: "I have to sit there and count out pills and go to the clinic you know and I have to make sure I'm back in time for all that..."

Hypervigilance has also been seen as one of the first symptoms to develop in delayed onset PTSD (Andrews, Brewin, Stewart, Philpott & Hejdenberg, 2009) and strongly influences the other symptoms (Schell et al., 2004) in that it leads individuals to pay attention to body sensations, as well as continuously scanning their environments for potential threats.

In addition to managing the fear of the ARVs failing, patients' strict, hypervigilant adherence to the regime of anti-retroviral medicine that might serve to counteract any lingering appraisals of having been irresponsible. In other words, it is possible that it also serves a compensatory function.

12.2.4.e. Embracing responsibility. Because HIV is transmitted primarily via sexual intercourse, people with HIV are held by many to be responsible for their own infections (Herek, 1999). But, by being especially responsible in maintaining a healthy approach to life that includes absolute adherence to the medication programme, any suggestions that the person is irresponsible, could well be mitigated, or at least compensate for perceived past failings.

Thus, embracing responsibility appears to be a common response to coping with the diagnosis of HIV. In addition to the rigorous anti-retroviral regime and strict diet, there are monthly clinic appointments and follow-up sessions with counsellors. Patients are encouraged to look after themselves both physically (Shapiro & Ray, 2007; Seeley, Russel, Khana, Ezati, King & Bunnell, 2009) and emotionally (McCain & Gramling, 1992; Ehman, Ott, Short, Ciampa & Hansen-Flaschen, 1999). The emphasis on living responsibly may for some be a compensatory coping strategy for the negative appraisal that he or she has been irresponsible. Some cognitive therapy

HIV, PTSD AND TRAUMATIC LIFE EVENTS

research has suggested that the successful alleviation of mental distress is achieved by making positive self-representations more accessible to the individual, rather than by necessarily only refuting negative self-representations (Brewin, 2006). So, if the act of taking ARV medications strengthens positive self-representations (positive self-appraisals), this would be a positive influence on people's mental health. If, however, the negative appraisal remains unchallenged, the benefits of such an approach might not be particularly sustainable.

In this study Participant B made the important point that patients need to organise their lives in order to make circumstances more manageable and to allow more time to reduce stress. This enabled her to control the present and take responsibility for her future. She said:

Participant B: "Cry, it's okay to cry. Because you, you, you... we feel angry inside you gonna cry, cry if you feel like crying. And as time goes on think about yourself, what do you want, who you are and then accept yourself that I'm who I am today. Yesterday I was somebody else. Today I found out that I'm positive so my life changes a little bit...not all of it. No, a little bit. So I'm going to go on. It's not ended now so continue with things, just try to sort things. Don't run around and do everything that's going to make yourself a mess, like having more than one partner, like don't want to use condoms. People they do hate condoms but they gotta use them.

Researcher: "It's better?"

Participant B: "Yes, now think about things before doing them. Don't jump into conclusion and do things in a rush...no, in life it's not about

HIV, PTSD AND TRAUMATIC LIFE EVENTS

rushing. Don't be silly, organise your life, maybe you can live longer...”

This participant believed that by organising her life, staying positive and reducing stress, it was possible to live longer, which may have been her way of coping with the fear associated with being HIV-positive. When she encouraged others to organise their lives, we can assume that this was to accommodate the strict anti-retroviral regime. In stating that people must “think about things before doing them”, she may have referred to having unprotected sex, not eating properly, or not taking the medication as prescribed. It seems that helping others allowed this participant to feel better about herself. Making changes and assisting others may be viewed by the Ehlers and Clark (2000) Model as re-appraising negative appraisals by gaining acceptance and having a new purpose. On the other hand, as noted earlier, it could serve as a compensatory behaviour that leaves the negative appraisal intact.

Another participant stated that he had made many changes since he found out that he was HIV-positive, one of which was having only one girlfriend as opposed to many partners. A new approach to life might be partly motivated by the lingering sense of guilt and blame. Participant E stated:

Researcher: “How has your life changed since you found out about your status? Since 2003?”

Participant E: “It has changed ‘cos from the life I was living by that time, now I have to cut some things out, no more girlfriends.”

Researcher: “No more girlfriends, only one girlfriend now?”

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Participant E: “ And I have to be taking my life serious. I know what I have to live, in order to be a good dad. That is important to me...”

This participant describes a finding a new identity is a good father as an alternative to having a sick or tainted identify, imposed on him by the stigmatising views of many others. The interview continued:

Researcher: “How have you coped with your status and what advice would you give other people, people that have HIV or that are going to get tested... what would you tell them?”

Participant E: “I... the only thing to say to them is that if you are testing and you find yourself positive you need to realise that it is not the end of ...the world...”

Researcher: “Yes”

Participant E: “You know, but yet it’s like some challenge and now it’s like you have to be serious and take care of your life...the more you do that, the more chances of you living...”

This participant seems to have come to terms with his status. Perhaps part of the reason that it is not the end of the world for him, is that he has developed a strong identity as a good, responsible father, which is a powerful alternative to an identity based solely on his HIV status.

However, the emphasis on responsibility can also motivated by a desire to avoid further negative judgements of others. Participant B suggested that people would be held accountable for not complying with the ARV regimes in the court of public opinion, the same court that deems HIV-positive individuals as irresponsible.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Participant B: "...Should you have failed to take the treatment, you must be prepared to explain why the HIV-virus has grown stronger..."

12.2.4.f. Having a positive outlook. Having a positive outlook and avoiding negative feelings is a coping strategy which is strongly advocated by doctors, nurses and HIV counsellors, especially with regards to patients who test HIV-positive (McCain & Gramling, 1992). Patients are encouraged to suppress negativity, which may lead them to believe that they should not entertain pessimistic thoughts. But the maintenance of a constant positive outlook also implies deliberate efforts not to think about the distressing aspects of their lives. Ehlers and Clark (2000) note that these efforts to try not to think about the traumatic event as an avoidant behaviour that can prevent necessary changes to the trauma appraisals and the nature of the trauma memories.

For example, Participant B described the importance of staying happy:

Researcher: "So it's about looking after yourself and looking after your life... and then everything else?"

Participant B: "If you make yourself happy, you must assess your heart and go ahead and don't always be sad because if you are always sad you are going to get ill, ill, ill everytime. I must be happy because I know that I am HIV-positive. By 8'o clock I must take my treatment. Early in the morning I must take my treatment So, ... um ... in the afternoon or in the day I can do my thing. I can do anything in the day that the people who are negative can do. I can do that."

Similarly, Participant A struck a similar note:

Participant A: “This has changed my whole attitude you know, like, I am a lot more positive about life. I don’t feel that I have to be intimate to ... to feel good. Because that can happen to you when you are depressed as well. You feel, you know...”

The belief that if you are not happy, then you will die is of course particularly problematic as it must involve immense efforts to suppress everything that might be negative.

12.2.4.g. Religion. Spirituality is a coping strategy that might facilitate social support (Clarke, 2002b), and allow people to re-appraise their traumatic appraisals and better elaborate their traumatic memories (Ehlers & Clark, 2000). Research suggests that people who are religious or spiritual appear to respond better to illness, showing improved adjustment and quality of life (Konstam, Moser & de Jonk, 2005) and show lower anxiety levels (Vance & Woodley, 2008).

Ehman et al. (1999) found that those suffering a serious illness often turn to their religious and spiritual beliefs as a source of comfort, and to help them feel more positive about their future. Church attendance and other spiritual practices may contribute to individual health (Parsons, Cruise, Davenport & Jones, 2006) as well as assisting HIV-positive people to make sense of their worlds. In a study conducted in KwaZulu-Natal, spirituality was found to be one of the coping strategies employed to deal with an HIV-positive status (Demmer, 2007).

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Participant B had a particularly difficult time during the period in which her HIV status was discovered, in that her son died as a result of being HIV-positive. This woman appeared to have found comfort in her belief that the death of her son was preordained, and thus not her fault:

Participant B: "...I was angry with him, really angry, sometimes I cry a lot and I pray to God that maybe it was supposed to happen. It was going to happen anyway. Everybody dies when your time comes. You not die because you are HIV-positive, you die when your time comes."

Believing that his death was preordained helps her let go of appraisals that she was blameworthy or responsible for her son's death. It was no doubt also very comforting for her to believe that her son was now in a better place, where he was healthy and happy. She went on to explain that the answer to her question about why she had to become infected with HIV was that this has brought her closer to God:

Participant B: "I used to cry, I said why did I get this disease? I never slept with anybody. I only had one boyfriend. Why did God do this to me?"

Researcher: "Okay."

Participant B: "You know, but as time comes I think that everybody got it, not because it's a bad thing. Maybe God gave it, gave it to me. I never went to church until that month but now I know that I have to go to church and pray to God..."

Various researchers have argued that churches play a critical role in assisting and supporting the communities affected by AIDS, by providing material and emotional support, and by also changing attitudes to those who

HIV, PTSD AND TRAUMATIC LIFE EVENTS

are HIV-positive (Visser & Forsyth, 2009; Weaver, 2004). Church attendance and a virtuous life may counteract or compensate for some of the possible negative appraisals associated with a diagnosis of HIV and divert attention of those who are judgemental and stigmatising. Such appraisals might include the belief that the person is bad, irresponsible and blameworthy.

But churches have also, unfortunately, been the source of many stigmatising claims about those who are affected with HIV. Maughan-Brown (2004) compared the stigmatising beliefs between those who were affiliated and those who were not associated with a church group and found that it was the religious individuals who held more rigid stigmatising beliefs. As such, church affiliation may also have the potential to reinforce the negative appraisals associated with an HIV-positive diagnosis.

12.2.4.h. Social support and disclosure. HIV-positive patients are encouraged to disclose their status to others so that they can access essential social support (UNAIDS, 2000). Certainly from the perspectives of Ehlers and Clark (2000), social support might counteract many negative appraisals and provide opportunities for the elaboration of trauma memories and the discontinuation of problematic coping responses. According to Brewin and Holmes (2003), lack of social support has been found to be a significant risk factor for PTSD intensity.

Participant C describes below his experience of his supportive sister after learning that he was HIV-positive.

Participant C: “I actually went up to her and I started crying.”

Researcher: “Okay...”

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Participant C: "...she asked me what's wrong and I just continued crying, for maybe an hour. And she was still supportive. Still sitting with me. And I said 'How do I tell you?' She said 'Just go ahead...'"

Researcher: "you can trust me... but it took an hour, an hour of you sitting there, and her reaction. How did she react?"

Participant C: "She started crying and so. But she was there and she saw me through and she saw the results."

This transcript demonstrates how disclosure can lead to the acceptance and support that most people desire, and is in fact encouraged, for medication compliance (Williams et al., 2005; Gray 2006). It is obviously useful to have other people to encourage and support those on life-saving medication, even if this only means that those taking the medication do not have to hide the fact that they are doing so. Similarly, Fogarty, Roter, Larson, Burke, Gillepsie and Levy (2002) advocated that social support can be a buffer against stress, and suggested that a positive attitude to the future, coupled with long-term goals, bodes well for adherence to treatment regimes. This support might not be solely emotional, but may also involve assistance with the more practical aspects of HIV treatment, such as hospital visits, monitoring medication, and even, depending on the treatment stage, assisting with childcare, shopping, or cooking, thus enabling patients to cope better with everyday life and their HIV-positive status. According to Gilbert and Walker (2009), respondents in their study found social support from their immediate family but were reluctant to disclose their status to others. Deciding upon who to tell and how to tell can present a real dilemma, even

HIV, PTSD AND TRAUMATIC LIFE EVENTS

with family members, and some of the participants in this study decided against telling others for fear of their reactions.

One participant did not tell her mother because she did not want to upset her, using the excuse that the older woman suffers from many medical conditions which might have been aggravated by the stress. Indeed, another South African study found that HIV-positive respondents expressed mixed feelings with regards to disclosure. Some individuals felt that the risk of disclosure outweighed the benefits, in that being open about their HIV-positive status may have exposed them to further emotional trauma, while others felt that open disclosure about their status was essential for both self-acceptance and living a positive life (Kelly et al., 2008). As mentioned previously, Freeman et al. (2007) reported that disclosure was associated with the presence of mental disorder. A compromise for many is a partial disclosure to minimise the risk of encountering stigma and discrimination whilst enabling access to support and treatment.

All six participants had disclosed their status to somebody. These experiences were mostly positive in that they gained support and encouragement after disclosing their status to family members, friends and even employers.

Positive acceptance following disclosure assists with coping by boosting their confidence and self-esteem and allowing some of the mystery associated with the diagnosis to fall away indicating a type of personal acceptance (Thom, 2000). Emotional support has consistently shown benefits for those suffering from HIV in that it provides them with a source of support for medication compliance (Williams et al., 2005; Gray, 2006; UNAIDS,

HIV, PTSD AND TRAUMATIC LIFE EVENTS

2000; Schlebush & Cassidy, 1995), gives them someone with whom to discuss their hopes and fears, and lowers their stress levels. Moreover, having someone to confide in may improve their general quality of life (Thom, 2008), as well as assist them to find a reason to carry on living.

Support may be available from a variety of different sources, including family, friends and intimate partners. After receiving their diagnosis, some participants found that they were able to help and support others within the community, thus feeling empowered, which may allow them to re-evaluate their own negative appraisals and find some purpose to their experiences.

After his disclosure, Participant C's sister accompanied him to the hospital to confirm the results and to find out his CD4 count. He emphasised that she went back with him the same day, thus demonstrating the significance he attached to the event. The revelation of his diagnosis came as such a shock that he was unable to speak about it at first. His sister's attendance at the hospital may be interpreted as supportive, but can also be viewed as an expression of disbelief and perhaps a need to see the truth for herself. Participant C continues:

Researcher: "Your status, why did you decide to go and get tested? What happened?"

Participant C: "It was like on the TV. Love yourself, get tested..."

Researcher: "One of those safe sex, the Love Life adverts?"

Participant C: "So I said it is part of life isn't it so ..."

Researcher: "So you chose to go by yourself, did you go with friends, did you take anybody with you?"

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Participant C: “Yes, by myself, I went there by myself, after I got the results I went home and I told my sister. I think I was in shock.”

Researcher: “So you went and told your sister?”

Participant C: “Yes, and thereafter she came back with me all the way here...”

Although he was at first encouraged by his sister's support, a few days later he decided that living with his HIV-diagnosis was too difficult and he told his sister that he didn't think that he could continue living, implying that perhaps he was ready to end his life prematurely. She again provided him with support and was able to convince him not to do anything drastic. When I asked Participant C who he views as his closest friend, he stated that it would be his sister.

Not all experiences of disclosure were positive, however at least not initially. Participant C went on to describe what happened when he told his friends, after the support he received from his sister:

Researcher: “Your friends didn't want anything to do with you?”

Participant C: “Yes, they were like they kept away and obviously it hurted. Then obviously when I got back and they spoke to me. Visited, like all that you know.”

Given these mixed experiences, it is understandable why people often choose partial over full disclosure. Fortunately for this respondent, things did improve with his friends, but the initial disappointment is probably enough to discourage many from disclosing to their friends.

According to Young (2011), from the perspective of the Ehlers and Clark (2000) Model, while positive experiences of support and care might undo some of the worst appraisals, rejection and isolation can work in the opposite direction.

12.3. Summary

In this chapter I have presented the themes that emerged from the interpretative phenomenological analysis of the interview transcripts. The resulting cataloguing of some of the important experiences of these participants certainly helps to contextualise the quantitative findings. The findings support the idea that people's negative self appraisals following a diagnosis of HIV are supported by widespread HIV stigma. It appears that the results of these negative appraisals are a range of troubling emotions. In response, participants employ a host of coping strategies.

Interestingly, ARV compliance seems to imply or even require a degree of hypervigilance that probably confers vulnerability to anxiety. Because hypervigilance is a risk factor and symptom of PTSD, it is possible that this hypervigilance artificially elevates the estimates of the prevalence of PTSD amongst ARV-compliant patients. These and related symptoms are mistakenly thought of as symptoms of PTSD rather than separate aspects of ARV compliance. Alternatively, for those who would have qualified for a diagnosis of PTSD without the added symptoms of hypervigilance, this feature of ARV compliance is likely to exacerbate their traumatic stress. This and some of the other coping mechanisms seem to be attempts to avoid, or alleviate the negative judgements of others as well as their own negative self-judgements.

Chapter 13: Conclusion

In this chapter I begin with a summary of the main findings: the systemic review, the quantitative study and the qualitative study, which brings the different strands of this thesis together and demonstrates the advantages of a mixed-method approach.

I then discuss the implications of and limitations of the study. This is followed by a comment on the debate about the inclusion of a life-threatening illness as a qualifying event for a Criterion A diagnosis of PTSD and the changes introduced by DSM-5.

The thesis is then concluded by a short reflection on my experiences during this project.

13.1. Findings of the Systemic Review

The systemic review presented in this study is currently fully inclusive and is the most up-to-date available (as at February 2014). Findings showed 16 studies which examined the presence of PTSD in an HIV-positive population, six of which were in African countries excluding South Africa.

Results differed due to the varied diagnostic criteria used to define the disorder and the assessment procedures employed, as well as the diverse sample sizes, selection of groups, and the measuring and reporting of individual symptoms not syndromes. This is consistent with the findings of Young, (2011) who explained that it is expected for the prevalence of PTSD to vary across contexts, and to be higher where people cannot easily access good health care.

Amongst African studies (excluding South Africa) the prevalence of PTSD, as measured using structured interviews, ranged from 4.4% (van den

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Heuvel et al., 2013) to 12.5% (Adewuya et al., 2007). In South Africa the prevalence of PTSD varied between 0.7% (Freeman et al., 2008) and 54.1% (Martin & Kagee, 2008), and the rates of HIV-related PTSD varied between 4.2% in HIV-positive adults (Freeman et al., 2007) and 40% in recently-diagnosed HIV-positive adults (Martin & Kagee, 2008).

These findings demonstrate that, although not everyone develops PTSD after experiencing a traumatic event, its prevalence is definitely elevated and further treatment and intervention should be made available to those who require it. The findings also suggest that the prevalence of various mental disorders, including PTSD, seems to increase with each advancing stage of HIV infection.

13.2. Quantitative Findings

The quantitative study consisted of a mixed gender sample of 159 adults (aged between 18 and 50) who were complaint on ARV medication. Results of this study showed that 29.6% of participants met the criteria for lifetime PTSD, and 40.9% met the criteria for lifetime HIV-related PTSD. In a further comparison, 12.6% met the criteria for both PTSD and HIV-related PTSD, while 57.9% of individuals met the criteria for some form of PTSD (either regular PTSD or HIV-related PTSD), all of which confirms that there is a high prevalence of both PTSD and HIV-related PTSD among an HIV-positive, ARV-compliant sample in rural South Africa. This is the only study which comments on the combined incidence of both PTSD and HIV-related PTSD among HIV-positive, ARV-compliant individuals.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

At first glance it may not seem that important to know whether or not the PTSD seen in participants is a direct result of the HIV-positive diagnosis, as long as the person with PTSD is treated (Matacotta, 2010). However, for patients who do not present with a previous history of trauma, it is essential to know whether a diagnosis of HIV will potentially result in PTSD symptomology so that the appropriate treatment may be provided. Such interventions are needed to assist those living with HIV to better adapt to their life-threatening illness and social environment (Simbayi, Skinner, Letlape & Zuma, 2005). If PTSD can be the result of learning about one's HIV status, then it would be important to explore whether pre- and post-test counselling could be adapted in such a way as to address the traumatic appraisals that are implicated in the development and maintenance of the PTSD.

Additionally, the findings also reveal that nearly two-thirds of the participants had experienced another major traumatic event other than their diagnosis of HIV. The majority of such traumatic events were divided between men and women roughly proportionately, with the only statistically significant gender difference being that men are more likely to report having been violently attacked than women. The trauma of rape and political violence appear to be events which are most strongly associated with PTSD. In fact, those events involving interpersonal violence show the highest rate of PTSD, followed by the diagnosis of and living with HIV, and then followed by those events that involve disaster.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

The multiple regression analysis suggests that the experience of previous trauma contributes to PTSD symptomology (which is related to the diagnosis of and living with HIV), but logistic regression analysis suggests that this variable does not predict a diagnosis of HIV-related PTSD. Of the different categories of traumatic events, none of the variables as tested individually appears to be associated with a diagnosis of HIV-related PTSD. Finally, the IES-R was compared for its usefulness as a screening measure for PTSD against both the CIDI and the PDS. Findings reflected that although the IES-R may be a useful diagnostic tool for PTSD symptomology, it does not perform as well as the PDS, which is a similar screening measure.

13.3. Qualitative Findings

The qualitative study attempted to understand the experiences of six participants who were living with HIV. I used an IPA methodology informed by the Ehlers and Clark (2000) cognitive model of trauma. It is evident from examining the IPA transcripts that traumatic events other than the diagnosis of HIV are common.

Participants recalled vivid imagery in the form of intrusive thoughts associated with feelings of death and dying as well as the feeling of contamination and worry about the reactions of others when their HIV-positive status became common knowledge. Other people's actions and attitudes may also have served to maintain these intrusive thoughts and negative appraisals, based on assumptions and questions about death and dying. Following their diagnosis, the participants reported experiences of stigma, rejection and discrimination. A number of coping behaviours were seen, such as social avoidance and withdrawal, denial, embracing

HIV, PTSD AND TRAUMATIC LIFE EVENTS

responsibility, turning to religion, or having a positive outlook. Sometimes these coping mechanisms seem to be compensatory strategies that are used to avoid negative judgements from the self and others. The danger is that they may prevent the negative appraisals from changing.

Additionally, many of the participants described feelings of hypervigilance. Compliance to ARV medication, which requires absolute adherence, may serve to increase hypervigilance, which may in turn heighten and exacerbate PTSD symptoms (Schell et al., 2004), conferring an added vulnerability on an already vulnerable population, thus possibly accounting for some of the high prevalence of PTSD in the quantitative study.

13.4. The Usefulness of a Mixed-Method Approach

This study is unique in that it used a mixed-method approach to understanding HIV-related PTSD, PTSD and traumatic events amongst an ARV-compliant hospital sample. The qualitative section emphasises that individual experiences are in fact rich and varied, which would be lost if only quantitative data was considered. The use of both *qualitative* and *quantitative* methodologies is sometimes regarded as being inconsistent. However, Pope and Mays (1995) argued that such an approach may in fact be complimentary, particularly when employed in health-related research projects. Furthermore, psychology, being a human science, is distinct from natural sciences and should therefore be treated as such.

The qualitative sample size is small, so it would be inadvisable to apply the same principles to larger groups. On the other hand, it is likely that most people will be able to identify with at least some of the experiences of others, thereby rendering a theoretical generalisability (Smith et al., 2009). In this context, the qualitative data set adds value to the quantitative data.

13.5. Implications

As discussed in this research, individuals suffering from HIV may be faced with stigma, PTSD and indeed HIV-related PTSD. The challenge of living with HIV and HIV-related PTSD appears to be a significant one for the health-care professionals in South Africa. It seems that, in developed countries, mental health treatment and awareness have been integrated into HIV/AIDS programmes (Freeman et al., 2008). The findings of this study indicate that screening for PTSD, among other mental disorders, should be incorporated into treatment programmes in South Africa, and other developing countries.

It is apparent from this study that some individuals appear to adopt compensatory strategies that leave problematic appraisals intact. It would be useful for psychotherapists and other mental health professionals to adopt an approach which would focus on challenging such negative appraisals, perhaps during pre- and post-test counselling and whilst they are in the readiness phase for ARV treatment. (The Ehlers and Clark (2000) Model, used in this research, is one such model which may be used for intervention).

Given the high prevalence of PTSD and HIV-related PTSD among the participants in the current study, it is evident that health practitioners working with HIV-positive patients should be able to recognise mental health

HIV, PTSD AND TRAUMATIC LIFE EVENTS

difficulties so that their patients receive intervention timeously. In turn, mental health practitioners need to consider HIV as a differential diagnosis which may exacerbate or compromise patient's mental health.

The current research also shows a great need for counselling and making psychological services accessible to patients. It would be advantageous to have a dedicated HIV-designated psychologist in the main ARV roll-out centres to whom the HIV counsellors can refer should they feel that patients need further intervention. Furthermore, ARV counsellors and home-based carers should be made aware of the signs and symptoms of PTSD, and should be given referral guidelines and details of treatment procedures. In addition to these individual strategies, structural changes to reduce the burden of stigma and trauma are required.

13.5.1. Recommendations. Simbayi et al. (2005) recommended the strengthening of the anti-discrimination laws in Southern Africa in an effort to change the social climate of AIDS. They suggested that treating HIV as a purely medical condition will reduce the social stigma associated with the diagnosis. From my own findings it is apparent that further education and information about the realities of HIV could assist in the reduction of the stigma attached to its acquisition, following which new policies may need to be bolstered to protect the rights of HIV-positive individuals (for example, the right to employment, health care and education, and the right not to be discriminated against on the basis of an HIV-positive status).

Additionally, future similar studies should use instruments which have been standardised or previously used within South Africa. If all studies use the same measures, results will be easily comparable and this will improve policy-making and the planning of future treatment regimes.

Moreover, the validity of rating scales for a South African rural population needs to be standardised to facilitate closer comparison in future studies. To provide continuity, the same measures which had already been employed in prior HIV-related research were utilised in this study, and translators were made available to assist both the researcher and participants as and when required.

13.6. Limitations

This was a cross-sectional descriptive-analytic study of occurrence of PTSD, HIV-related PTSD, and traumatic life events in an HIV-positive population. The study is unable to be generalised to the general population as the sample group was restricted to people attending a particular HIV-treatment site. Although this study may be compared to other quantitative and qualitative studies conducted within South Africa, it was conducted at a site where HIV-positive patients have access to care and support and therefore may not be representative of all HIV-positive individuals within the country.

The sample size of the present study is small (necessitated by the limited capacity of a single researcher collecting the data while also working within the health-care system) and may lack the power to detect some of the variables associated with a PTSD diagnosis. However, other research has also established that none of the differences were significant (age, gender, length

HIV, PTSD AND TRAUMATIC LIFE EVENTS

of time since diagnosis, CD4 count, and reason for HIV test, disclosed their status to friends or family, and previous experience of traumatic event).

The current study includes only those who were both HIV-positive and compliant on treatment. It does not take into account individuals within the community who had not been tested, or who had been tested but were not on treatment. Moreover, no comparison was made with a control group (either of HIV-negative or untreated HIV-positive).

As an English speaking clinician, working with a mixed language (but primarily Zulu-speaking) sample, language barriers may have detracted from my ability to obtain rich accounts from participants in the qualitative study. However, it is important to give such participants a voice (no matter how small), and the qualitative findings aid our understanding of the individual experiences of participants. As far as I am aware, this is the first study that suggests that ARV compliance and the hypervigilance that it requires (as seen in the qualitative study) may lead to a psychiatric vulnerability in that these individuals are more likely to be aware of body sensations, and they may consequently have a tendency to report more PTSD symptoms. This important finding comes despite the limitations of the qualitative interviews and is an issue that warrants further investigation.

13.7. A Note of the Changes Introduced by DSM-5

The latest edition of the DSM, the DSM-5, which was published once this study was already at an advanced stage, has adopted a more specific description of the qualifying traumatic events than those listed in the DSM-IV edition (American Psychiatric Association, 2013a). In the new version, a life-threatening illness or a debilitating medical condition is no longer

HIV, PTSD AND TRAUMATIC LIFE EVENTS

necessarily considered to be of sufficient intensity to qualify as a Criterion A traumatic event, which is an about-turn on all the evidence that was considered by the DSM-IV task team. Medical events that could be considered traumatic for the purpose of Criterion A are specifically those that are sudden and catastrophic. The examples given in the DSM-5 include anaphylactic shock or waking during surgery, both of which are situations that involve very intense and immediate threats.

Although HIV infection could be considered to be not only sudden but also catastrophic, it is not yet clear whether the flexibility afforded by the recognition of culture-related diagnostic issues would allow the inclusion of a diagnosis of HIV in the impoverished, stigmatising context of South Africa, which obviously results in quite a different psychological impact for the patient than for a person similarly diagnosed in a developed environment with access to efficient health care. In this connection, research is needed to identify the triggers that can influence the progression of traumatic stress in South Africans diagnosed with HIV. The understanding of the idioms of distress that influence the expression of traumatic stress would be an important step forward.

DSM-5 advises that an Adjustment Disorder should be diagnosed for those who exhibit the full symptom profile of PTSD but who do not meet Criterion A. However, this raises a further problem in that while adjustment disorder offers the diagnostic label necessary to access mental health treatment and support, HIV-positive patients who would have received a diagnosis of PTSD in terms of the DSM-IV criteria must now be allocated a diagnostic label that does not include their full spectrum of symptoms. DSM-

HIV, PTSD AND TRAUMATIC LIFE EVENTS

5 seems to have returned to the stricter definitions used in DSM-III, overlooking evidence that prolonged stress can result in the symptoms of PTSD and that traumatic events of lower intensity can be expected to cause PTSD in people who are vulnerable (Brewin et al., 2009).

An additional complication is that, as at February 2014, it is not clear whether or not the World Health Organisation's ICD-11 will follow the American Psychiatric Association in itemising the qualifying traumatic events necessary before a diagnosis of PTSD can be established. It is possible that instead the emphasis will be on the presence of core PTSD symptoms to improve the specificity of diagnoses (Brewin et al., 2009) with the potential consequence that those who are traumatised by receiving a diagnosis and living with HIV might qualify for a diagnosis of PTSD according to ICD-11 but not DSM-5. The debate about whether or not life-threatening illnesses such as HIV should be considered a Criterion A event is thus unlikely to be settled by the changes brought about in DSM-5.

Whatever the outcome of this debate, it should not be allowed to detract from the need to provide mental health services to those often traumatised HIV-positive people in South Africa. The toll that HIV places on individuals is an emotional, physical and psychological one. Any person who is suffering from this life-threatening illness has to deal not only with the shock of such a diagnosis, but also with the stigma, health complications, and financial implications, together with the possibility of an early death. Furthermore, individuals who suffer from mental illness are frequently stigmatised (Satatorius, 2007). One can see that the diagnosis of HIV (a

highly stigmatised condition), combined with PTSD (a mental illness) requires assistance and intervention.

13.8. My Reflections

In 2009, when I first decided that I wanted to do my PhD, I couldn't find a research topic which attracted me. I was at that time working at G J Crookes Hospital and my office was adjacent to the HIV ARV roll-out centre. As a result I frequently saw those patients about whom the doctors, nurses and HIV lay counsellors were most concerned.

As time passed it became evident that one of the most pressing issues was right in front of me. There appeared to be a great deal of research on depression, but only a limited amount of material on the effects of PTSD. Rhodes University, and Dr Charles Young in particular, were enthusiastic about the concept, and so the study rapidly began to take shape, and then matured as more aspects of living with HIV appeared.

During the course of this study I have met some incredibly uplifting individuals who have gone out and assisted others in their communities. I have also met others whose CD4 counts were so low that they appeared emaciated, and I was amazed that they managed to function at all. In fact, over the course of the research, I took it upon myself to refer three patients with low CD4 counts to the hospital dietician, who assisted with dietary supplements and monitored their weight gains.

Unfortunately, long-term follow-up of these patients was not possible because, as soon as they became stable and their CD4 counts were seen as adequate, they were transferred to satellite clinics closer to their homes. I often wonder what participants thought of this white woman conducting this

HIV, PTSD AND TRAUMATIC LIFE EVENTS

study, whether or not they have any faith in the health-care system, and if they believe that things will improve. The majority of participants were fantastically helpful, even though it was apparent that their HIV-positive status was not something that they could easily speak about.

I know that there appear to be many aspects of HIV-related PTSD which require further attention and research, but I would like to think that this study has assisted health-care professionals in their treatment of HIV-positive patients, and will continue to do so. I know that the experience and contact with these participants has allowed me greater insight into the lives of those living with HIV.

References

- Abah, S. J., Addo, E., Adejei, P. C., Arhin, P., Barami, A.A.S., Byarugaba, M. A.,...Zeeman, H. (2004). There`s Hope - Early observations of ARV treatment roll out in South Africa. *Draft Paper for PRDUC fieldwork for comment*. 22 (39), 1-6.
- Adewuya, A. O., Afolabi, M. O., Ola, B. A., Ogundele, O. A., Ajibare, A. O., & Oladipo, B. F. (2007). Psychiatric disorders among the HIV-positive population in Nigeria: A control study. *Journal of Psychosomatic Research*, 63, 203-206.
- Adewuya, A. O., Afolabi, M. O., Ola, B. A., Ogundele, O. A., Ajibare, A. O., & Oladipo, B. F, & Fakande, I. (2009). Post-traumatic stress disorder (PTSD) after stigma related events in HIV infected individuals in Nigeria. *Social Psychiatric Journal of Epidemiology*, 44 (9), 761-766.
- AIDS.gov (2012). Retrieved on July, 15, 2013, from <http://aids.gov/hiv-aids-basics/hiv-aids-101/what-is-hiv-aids/>
- Aidsmeds. (2010). *PTSD symptoms common among people with HIV*. Retrieved August 15, 2012, from http://www.aidsmeds.com/articles/hiv_pstd_stress_1667_18966.shtml
- Alcorn, K. (2010, July). *Prevention of mother to child transmission. Malawi plans 'test and treat' approach for pregnant women to cut mother-to-child HIV transmission*. Retrieved October 17, 2012, from <http://www.aidsmap.com/Malawi-plans-test-and-treat-approach-for-pregnant-women-to-cut-mother-to-child-HIV-transmission/page/1494940/>

HIV, PTSD AND TRAUMATIC LIFE EVENTS

- Alonzo, A. A., & Reynolds, N. R. (1995). Stigma, HIV and AIDS: An exploration and elaboration of a stigma trajectory. *Social Science and Medicine, 41* (3), 303-315.
- Alter, C., Pelcovitz, D., Axelrod, A., & Goldenberg, B. (1996). Identification of PTSD in Cancer Survivors. *Journal of Psychosomatics, 37* (2), 137-43.
- American Psychiatric Association. (1980). *Diagnostic and statistical manual of mental disorders (3rd ed.)*. Washington, DC: Author.
- American Psychiatric Association. (APA) (1987). *Diagnostic and statistical manual of mental disorders: DSM III-R. (3rd ed. revised.)*. Washington, D. C.: APA.
- American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders (4th ed.)*. Washington, DC: Author.
- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders, (4th ed., text revision)*. Washington, D C: Author.
- American Psychiatric Association (2013a). *Diagnostic and Statistical Manual of Mental Disorders (5th ed.)*. Arlington, VA: American Psychiatric Publishing. pp. 5–25.
- American Psychiatric Association. (2013b). *Conflicts of Interests and Commitments*. Retrieved May 18, 2013, from <http://www.apa.org/research/responsible/conflicts/index.aspx>
- American Psychological Association. (2008). Children and trauma: update for mental health professionals. *2008 Presidential Task Force on Post-*

HIV, PTSD AND TRAUMATIC LIFE EVENTS

traumatic Stress Disorder and Trauma in Children and Adolescents.

Retrieved July 18, 2012, from

<http://www.apa.org/pi/families/resources/update.pdf>.

Amirkhanian, Y. A., Kelly, J. A., & McAuliffe, T. L. (2003). Psychosocial needs, mental health, and HIV transmission risk behaviour among people living with HIV/AIDS in St Petersburg, Russia. *Journal of Epidemiology and Social, 17* (16), 2367-2374.

Anderson, C. (2011). Presenting and evaluating qualitative research. *American Journal of Pharmacy and Education, 74* (8), 141.

Andrews, B., Brewin, C. R., Stewart, L., Philpott, R., & Hejdenberg, J. (2009). Comparison of Immediate-Onset and Delayed-Onset Post-traumatic Stress Disorder in Military Veterans. *Journal of Abnormal Psychology, 118* (4) 767 - 777. Doi:10.1037/a0017203.

Andrews, G., & Peters, L. (1998). The psychometric properties of the Composite International Diagnostic Interview. *Social Psychiatry and Psychiatric Epidemiology, 33* (2), 80-88.

Anti-Privatisation Forum. (2008). *Press Release: Electricity is a right and the poor must have access to clean, alternative energy, South Africa needs democratic control of energy for all*. Published online on 20th March, 2008. Retrieved September 20, 2012, from <http://contrarytoauthority.blogspot.com/2008/03/press-release-electricity-is-right-and.html>

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Arrive Alive. (2012). *Minibus Taxis and Road Safety*. Retrieved August 15, 2012, from <http://www.arrivealive.co.za/pages.aspx?i=2850>

Ashworth, P. (2003). The origins of qualitative psychology. In J. A. Smith (Ed.), *Qualitative Psychology: A Practical Guide to Research Methods* (pp. 4-24). London: Sage.

Baider, L., & DeNour, A. (1997). Psychological Distress and Intrusive Thoughts in Cancer. *Journal of Nervous and Mental Disease*, 185 (5), 346-348.

Baingana, F., Thomas, R., & Comblain, C. (2005). *HIV/AIDS and mental health*. Washington, DC: World Bank.

Bakelaar, S. Y., Rosenstein, D., Kagee, A., & Seedat, S. (2011). HIV as an index stressor for PTSD challenges and pitfalls in applying DSM criteria. Guest editorial. *African Journal of Psychiatry*, September, 2011. doi.org/10.4314/ajpsy.v14i4.2

Baldachin, J. (2010). *The Problematic Nature of Using Western Treatments for PTSD in Non-Western Settings and a Discussion of Culturally Sensitive Interventions: Introduction to Cultural Psychology*, December 13, 2010. Retrieved January 15, 2013, from academiccommons.columbia.edu/download/fedora_content/download/ac:132370/CONTENT/75-Baldachin_Cultural_Treatment_for_Trauma.pdf

Barker, C., Pistrang, N., & Elliot, R. (2002). Chapter 6: Self-Report Methods. In *Research Methods in Clinical Psychology: An Introduction for Students and Practitioners*, 2nd Edition. John Wiley LTD.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

- Baron, R. A., & Byrne, E. (2000). *Social Psychology, 9th Edition*. Boston: Allyn and Bacon.
- Beck, A. (1976). Meaning and emotions. In A. T. Beck (Ed.), *Cognitive therapy and the emotional disorders* (pp. 47–75). London: Penguin.
- Beck, A. (1987). Cognitive models of Depression. *Journal of Cognitive Psychotherapy, 1* (1), pp 5-37.
- Beck, A. T., Rush, A. J., Shaw, B. F., & Emery, G. (1979). *Cognitive Therapy of Depression*. New York: Wiley.
- Begley, C. M. (1996). Using triangulation in nursing research. *Journal of Advanced Nursing, 24* (1), 122-128.
- Berman, S. L., Silverman, W. K., & Kurtines, W. M. (2000). Children's and adolescents exposure to community violence, post-traumatic stress reactions and treatment implications. *The Australasian Journal of Disaster and Trauma Studies, 1*.
- Bertrand, J .T., O' Reilly, K., Denison, J., Anhang, R., & Sweat M. (2006). Review Systematic review of the effectiveness of mass communication programs to change HIV/AIDS-related behaviours in developing countries. *Journal of Health, Education and Research, 21* (4), 567-97.
- Bing, E. G., Burnam, M. A., Longshore, D., Fleishman, J. A., Sherbourne, C. D., London, A.S., ... & Shapiro, M. (2001). Psychiatric disorders and drug use among human immunodeficiency virus-infected adults in the United States. *Archives of General Psychiatry, 58*, 721-728.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

- Black, B. P., & Miles, M. S. (2002). Calculating the risks and benefits of disclosure in African American women who have HIV. *Journal of Obstetric, Gynaecologic and Neonatal Nursing, 31* (6), 688-697.
- Blazer, D., Hughes, D., & George, L.K. (1987). Stressful life events and the onset of a generalized anxiety syndrome. *American Journal of Psychiatry, 144*, 1178-1183.
- Bogdan, R. C., & Biklen, S. K. (2003). *Qualitative research for education: An introduction to theory and methods (4th ed.)*. Boston, MA: Allyn and Bacon.
- Bor, R., Miller, R., & Goldman, E. (1993). HIV/AIDS and the family: a review of research in the first decade. *Journal of Family Therapy, 15*, 187-204.
- Bos, A. E. R., Kok, G., & Dijker, A. J. (2001). Public reactions to people with HIV/AIDS in the Netherlands. *AIDS Education and Prevention, 13* (3), 219-228.
- Botha, K., (1996). Post-traumatic stress disorder and illness behaviour in HIV positive patients. "A prospective examination of delayed onset". *Psychological reports, 79* (3), 843-845.
- Bouzagloul, H., (2006, November 30). Living with Aids, not Depression. *Mail and Guardian*.
- Bowman, B., Seedat, M., Duncan, N., & Burrows, S. (2006). 'Race', Social Transformation and Redress in the South African Social and Health

HIV, PTSD AND TRAUMATIC LIFE EVENTS

- Sciences. In G. Stevens, V. Franchi & T. Swart (Eds.), *A Race against Time: Psychology and Challenges to Deracialisation in South Africa*. (pp. 91 - 103). Pretoria: Unisa Press.
- Braken, P. J., Giller, J. E., & Summerfield, D. (1995). Psychological responses to war and atrocity: the limitations of current concepts. *Social Science and Medicine*, 40 (8), 1073-1082.
- Brandt, R. (2009). The mental health of people living with HIV/AIDS in Africa: A systematic review. *African Journal of AIDS Research*, 8 (2), 123-133.
- Breslau, N. (2001). The epidemiology of post-traumatic stress disorder: What is the extent of the problem? *The Journal of Clinical Psychiatry*, 62 (17), 16-22.
- Breslau, N. (2002). Epidemiological studies of trauma, post-traumatic stress disorder, and other psychiatric disorders. *Canadian Journal of Psychiatry*, 47, 923-930.
- Breslau, N., Davis, G. C., Andreski, P., & Peterson, E. (1991). Traumatic events and post-traumatic stress disorder in an urban population of young adults. *Archives of General Psychiatry*, 48, 216-222.
- Breslau, N., & Kessler, R. C. (2001). The stressor criterion in DSM-IV post-traumatic stress disorder: An empirical investigation. *Biological Psychiatry*, 50, 699-704.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

- Breslau, N., Kessler, R. C., Chilcoat, H. D., Schultz, L. R., Davis, G.C., & Andreski, P. (1998). Trauma and post-traumatic stress in the community: The 1996 Detroit Area Survey of Trauma. *Archives of General Psychiatry*, *55*, 626-632.
- Brewin, C. R. (2006). Understanding cognitive behaviour therapy: A retrieval competition account. *Journal of Behaviour Research and Therapy*, *44*, 765-784.
- Brewin, C. R., Andrews, B., & Valentine, J. D. (2000). Meta-analysis of risk factors for post-traumatic stress disorder in trauma-exposed adults. *Journal of consulting and clinical psychology*, *68* (5), 748.
- Brewin, C. R., Dalgleish, T., & Joseph, S. (1996). A dual representation theory of post-traumatic stress disorder. *Psychological Review*, *103*, 570-686.
- Brewin, C. R., & Holmes, E. A. (2003). Psychological theories of post-traumatic stress disorder. *Clinical Psychology Review*, *23*, 339-376.
- Brewin, C. R., Lanius, R. A., Novac, A., Schnyder, U., & Galea, S. (2009). Reformulating PTSD for DSM-V: Life after Criterion A. *Journal of Traumatic Stress*, *22* (5), 366-373.
- Brief, D. J., Bollinger, A. R., Vielhauer, M. J., Berger-Greenstein, J. A., Morgan, E. E., Brady, S. M., ... & For The HIV/AIDS Treatment Adherence, Health Outcomes And Cost Study Group. (2004). Understanding the interface of HIV, trauma, post-traumatic stress

HIV, PTSD AND TRAUMATIC LIFE EVENTS

disorder, and substance use and its implications for health outcomes. *AIDS Care*, 16 (1), 97-120.

Briere, J. (1997). *Psychological assessment of adult post-traumatic states*. Washington, D.C. American Psychological Association.

Briere, J., & Scott, C. (2006). *Principals of Trauma Therapy: A guide to Symptoms, Evaluation, and Treatment*. SAGE Publications.

Brocki, J., & Wearden, A. (2006). A critical evaluation of the use of Interpretative Phenomenological Analysis (IPA) in health psychology. *Psychology and Health*, 21 (1), 87-108.

Broder, S., & Gallo, R. C. (1984). A pathogenic retrovirus (HTLV-III) linked to AIDS. *New England Journal of Medicine*, 311, 1292-7.

Brouard, P., & Wills, C. (2006). *A closer look: The internalization of stigma related to HIV*. Washington DC: POLICY Projecct/Futures Group.

Retrieved March 28, 2012, from

http://www.policyproject.com/pubs/generalreport/GEN_Internal_Stigma.pdf

Brown, L., Trujillo, L., & Macintyre, K. (2001). Interventions to reduce HIV stigma: What have we learned? *Horizons Population Council*. Retrieved

October 29, 2011, from

<http://www.popcouncil.org/pdfs/horizons/litrwstigdisc.pdf>

HIV, PTSD AND TRAUMATIC LIFE EVENTS

- Bryant, R. A., & Harvey, A. G. (1998). Acute Stress Disorder after mild traumatic brain injury. *Journal of Nervous and Mental Disorders*, 186, 333-337.
- Buve, A., Bishikwabo-Nsarhaza, K., & Mutangadura, G. (2002). The spread and effect of HIV-1 infection in sub-Saharan Africa. *Lancet*, 359, 2011–2017.
- Cabaj, R. P. (1996). Management of anxiety and depression in HIV-infected patients. *Journal of International Association of Physicians AIDS Care*, 2 (6), 11-16.
- Campbell, C., & Deacon, H. (2006). Unravelling the contexts of stigma: from internalisation to resistance to change. *Journal of Community & Applied Social Psychology*, 16 (6), 411-417.
- Campbell, C., Nair, Y., Maimaine, S. (2006). AIDS Stigma, Sexual Moralities and the Policing of Women and Youth in South Africa. *Feminist Review: Sexual Moralities*, 83, 132-138.
- Castilla, J., Sobrino, P., De La Fuente, L., Noguer, I., Guerra, L., & Parras, F. (2002). Late diagnosis of HIV infection in the era of highly active anti-retroviral therapy: consequences for AIDS incidence. *AIDS (London, England)*, 16 (14), 1945.
- Cao, X., Sullivan, S. G., Xu, J., Wu, Z., China CIPRA Project 2 Team. (2006). Understanding HIV-related stigma and discrimination in a "blameless" population. *AIDS Education and Prevention*, 18 (6), 518-28.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

- Carey, P., Stein, D., Zungu-Dirwayi, N., & Seedat, S. (2003). Trauma and Post-traumatic Stress Disorder in an Urban Xhosa Primary Care Population: prevalence, comorbidity and service use patterns. *Journal of Nervous and Mental Disease*, 191 (4), pp 230-236.
- Cele, S. (2008). Inkosi rolls up his sleeves to fight AIDS. *Igula Logu*. Retrieved June 26, 2012, from: <http://www.kznhealth.gov.za/ugu/news2.pdf>
- Centre for Reviews and Dissemination. (2008). *Systematic reviews: CRD's guidance for undertaking reviews in health care*. York: University of York.
- Chen, T, Chang, S., Tsai, C., & Juang, K. (2004). Prevalence of depressive and anxiety disorders in an assisted reproductive technique clinic. *Journal of Human Reproduction*, 19 (10), 2313-2318.
- Chesney, M. A., Morin, M., & Sherr, L (2000). Adherence to HIV combination therapy. *Journal of Social Science and Medicine*, 50, 1599-1605.
- Chesney, M. A., & Smith, A. W. (1999). Critical delays in HIV testing and care: The potential role of stigma. *American Behavioral Scientist*, 42 (7), 1162-1174.
- Chigwedere, P., Seage, G., Gruskin, S., Lee, T. H., & Essex, M. Z. (2008). Estimating the lost benefits of anti-retroviral drug use in South Africa. *Journal of Acquired Immune Deficiency Syndromes*. 49, 410-415.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

- Clark, S. (2002a). HIV/AIDS in Africa. *The Lancet*, 359, 2047-2124.
- Clarke, D. (2002b). Faith and Hope. *Journal of Australian Psychiatry*, 11 (2), 164-168.
- Clark, D. M., & Ehlers, A. (2005). Post-traumatic stress disorder: From cognitive theory to therapy. In R. L. Leahy (Ed.), *Contemporary cognitive therapy* (pp. 141-160). New York, NY: Guilford Press.
- Clark, H. J., Linder, G., Armistead, L., Austin, B.J. (2003). Stigma, disclosure, and psychological functioning among HIV infected and non-infected African-American women. *Journal of Women and Health*, 38, 57–71.
- Clüver, F., Elkonin, D., & Young, C. (2013). Experiences of sexual relationships of young black women in an atmosphere of coercion. *SAHARA-J: Journal of Social Aspects of HIV/AIDS*, (ahead-of-print), 1-9.
- Collins, P. Y., Holman, A. R., Freeman, M. C., & Patel, V. (2006). What is the relevance of mental health to HIV/AIDS care and treatment programs in developing countries? A systematic review. *AIDS*, 20 (12), 1571–1582. doi:10.1097/01.aids.0000238402.70379.d4
- Conroy, S. A. (2003). A pathway for interpretive phenomenology. *International Journal of Qualitative Methods*, 2 (3), 1-43.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Coovadia, H., Jewkes, R., Barron, P., Sanders, D., & McIntyre, D. (2009).

The health and health system of South Africa: Historical roots of current public health challenges. *The Lancet*, 374, 817-834.

Corrigan, P. W., & Watson, A. C. (2002). Understanding the impact of stigma on people with mental illness. *World Psychiatry*, 1(1), 16.

Cote', J., Delmas, P., Delpierre, C., Sylvain, H., Delon, S., & Rouleau, G. (2009). Factors Relating to Quality of Life in Treatment Adherence, Successfully Treated HIV Patients in France. *Journal of Open Nursing*, 3, 10-17.

Cournos, F., McKinnon, K., & Wainberg, M. (2005). What can mental health interventions contribute to the global struggle against HIV/AIDS? *Official Journal of the World Psychiatric Association*, 4 (3), 135-141.

Coyne, J. C., Thompson, R., Palmer, S, C., & Kagee, A. (2000). Should we screen for depression? Caveats and potential pitfalls. *Applied and Preventative Psychology*, 9, 101-121.

Crocker, J., Major, B., & Steele, C. (1998). Social stigma. In D. T. Gilbert, S. T. Fiske & G.Lindzey (Eds.), *The Handbook of Social Psychology (4th ed)*. Vol. 1 & 2, pp. 504-553). New York, NY: McGraw-Hill.

de Jong, J. T., Komproe, I. H., Van Ommeren, M., El Masri, M., Araya, M., Khaled, N., ... & Somasundaram, D. (2001). Lifetime events and post-traumatic stress disorder in 4 post-conflict settings. *JAMA: the journal of the American Medical Association*, 286 (5), 555-562.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

- Deacon, H. (2005) *Understanding HIV/ AIDS Stigma*. Human Sciences Research Council Press, Cape Town, South Africa.
- Deacon, H. (2006). Towards a sustainable theory of health-related stigma: Lessons from the HIV/ AIDS literature. *Journal of Community & Applied Social Psychology*, 16, (6), 418-425
- Deacon, H., Uys, L., & Mohlanhle, R. (2009). In Rohleder, P., Swartz, L., Kalichman, S & Simbayi, L (Eds.), *HIV/AIDS in South Africa 25 years on. Psychosocial Perspectives*. Springer
- Demi. A., Bakerman, R., Moneyham, L., Sowell, R., Seals, B. (1997). Effects of resources and stressors on burden and depression of family members who provide care to an HIV-infected woman. *Journal of Family Psychology*, 11, 35–48.
- Demmer, C. (2007). Coping with AIDS-related bereavement in Kwa-Zulu Natal, South Africa. *AIDS Care*, 19 (7), 866-870.
- Denzin, N. (1995). Symbolic interactionism. In J. A. Smith, R. Harre, & L. van Langenhove (Eds.), *Rethinking Psychology*. London: Sage.
- Department of Health. (2004). *National Anti-retroviral Treatment Guidelines: National Department of Health South Africa*. Retrieved July 20, 2011, from <http://www.kznhealth.gov.za/arv/arv5.pdf>
- Department of Health. (2007a). *South Africa Demographic and Health Survey 2003*. Pretoria: Department of Health.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Department of Health. (2010). *The South African Anti-retroviral Treatment Guidelines*. Pretoria. South Africa: Department of Health.

Department of Health. (2011). *The 2010 national antenatal sentinel HIV and syphilis prevalence survey in South Africa*. Pretoria. South Africa: Department of Health.

Department of Health. (2012a). Ugu Health District. Retrieved April 12, 2012 from <http://www.kznhealth.gov.za/ugu.htm>

Department of Health. (2012b). Ugu Health District: *Additional information about Ugu health district*. Retrieved April 12, 2012, from <http://www.kznhealth.gov.za/ugu/info.htm>

Department of Health. (2012c). *G J Crookes Hospital*. Retrieved May 30, 2012, from: <http://www.kznhealth.gov.za/gjcrookeshospital.htm>

Department of Health London. (2007b). *Commissioning framework for health and wellbeing*. London. Department of Health.

De Prince, A. P., Chu, A. T., & Pineda, A. S. (2011). Links between specific Post-trauma Appraisals and Three Forms of Trauma-Related Distress. *Journal of Psychological Trauma, Theory, Research, Practice and Policy*, 3 (4), 430-441. Doi 10.1037/a00215576

Dinan, B. A. (2004). Community violence and PTSD in selected South African Townships. *Journal of Interpersonal Violence*, 19 (6), 727-742.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

- Donenberg, G. R., & Pao, M. (2005). Youth and HIV/AIDS : Psychiatry's role in the changing epidemic. *Journal of American Academic of Child and Adolescent Psychiatry, 44* (8), 728-747.
- Dorrington, R. E., Johnson, L. F., Bradshaw, D., & Daniel, T. (2006). *The Demographic Impact of HIV/AIDS in South Africa. National and Provincial Indicators for 2006*. Cape Town: Centre for Actuarial Research, South African Medical Research Council and Actuarial Society of South Africa.
- Dunmore, E., Clark, D., & Ehlers, A. (2001). A prospective investigation of the role of cognitive factors in persistent post-traumatic stress disorder (PTSD) after physical or sexual assault. *Behaviour Research and Therapy, 39*, 1063-1084.
- Durante, A. J., Bova, C., Fennie, K. P., Danvers, K. A., Holness, D. R., Burgess, J. D., & Williams, A. (2003). Home-based study of anti-HIV drug regimen adherence among HIV-infected women: Feasibility and preliminary results. *AIDS Care. 15* (1), 103-115.
- Durrheim, K., Mtose., X. & Brown, L. (2011). *Race Trouble: Race, Identity and Inequality in Post-apartheid South Africa*. South Africa: University of KwaZulu-Natal Press.
- Eatough, V., & Smith, J. (2006). I was like a wild wild person: Understanding feelings of anger using interpretative phenomenological analysis. *British Journal of Psychology, 97* (4), 483-498.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

- Eatough, V., & Smith, J. A. (2008). Interpretative phenomenological analysis. In C. Willig & W. Stainton-Rogers (Eds.), *The Sage Handbook of Qualitative Research in Psychology* (pp. 165-178). London: SAGE.
- Edwards, D. (2005a). Critical perspectives on research on post-traumatic stress disorder and implications for a South African context. *Journal of Psychology in Africa, 15* (2), 117-224.
- Edwards, D. (2005b). Treating PTSD in South African contexts: A theoretical framework and a model for developing evidence based practice. *Journal of Psychology in Africa, 15* (2), 209-220.
- Edwards, D., Sakasa, P., & van Wyk, G. (2005). Trauma, resilience and vulnerability to PTSD: a review and clinical case analysis. *Journal of Psychology, 15* (2), 143-153.
- Ehlers, A., & Clark, D. M. (2000). A cognitive model of post-traumatic stress disorder. *Journal of Behavioural Research and Therapy, 38*, 319-345.
- Ehlers, A., & Clark, D. M. (2008). Post-traumatic stress Disorder: The development of effective psychological treatments. *Nordic Journal of Psychiatry, 62* (47), 11-18. Doi: 10.1080/08039480802315608
- Ehlers, A., Clark, D. M., Hackmann, A., & McManus, F. (2010). Intensive cognitive therapy for PTSD: A feasibility study. *Behavioural and Cognitive Psychotherapy, 38*, 383-398.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Ehlers, A., Clark, D. M., Hackmann, A., McManus, F., & Fennell, M. (2005).

Cognitive therapy for post-traumatic stress disorder: development and evaluation. *Behaviour Research and Therapy*, *43*, 413-431.

Ehlers, A., Clark, D. M., Hackmann, A., McManus, F., Fenell, M., Herbert,

C., & Mayou, R. (2003). A randomized controlled trial of cognitive therapy, a self-help booklet, and repeated assessment as early interventions for post-traumatic stress disorder. *Archive of General Psychiatry*, *60*, 1024-1032.

Ehlers, A., Hackmann, A., & Michael, T. (2004). Intrusive re-experiencing in

post-traumatic stress disorder: Phenomenology, theory, and therapy. *Memory*, *12* (4), 403-415.

Ehlers, A., Hackmann, A., Steil, R., Clohessy, S., Wenninger, K., & Winter,

H. (2002). The nature of intrusive memories after trauma: The warning signal hypothesis. *Journal of Behavioural Research and Therapy*, *40*, 1021-1028.

Ehlers, A., Maercker, A. and Boos, A. (2000). PTSD following political

imprisonment: the role of mental defeat, alienation, and permanent change. *Journal of Abnormal Psychology*, *109*, 45-55.

Ehman, J. W., Ott, B. B., Short, T. H., Ciampa, R. C., & Hansen-Flaschen, J.

(1999). Do patients want physicians to enquire about their spiritual or religious beliefs if they become gravely ill? *Archives of Internal Medicine*, *159* (15), 1803-1806.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

- El-Khatib, Z., & Richter, M. (2009). (ARV-) Free State? The moratorium's threat to patients, adherence and the development of drug-resistant HIV. *South African Medical Journal*, 99 (6), 412-4.
- Elliot, R. (2008). Research on client experiences of therapy: introduction to the special section. *Journal of Psychotherapy Research*, 18, 239-242.
- Elliott, R., Fischer, C., & Rennie, D. (1999). Evolving guidelines for publication for qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*, 38, 215-229.
- Els, C., Boshoff, W., Scott, C., Strydom, W., Joubert, G., & van der Ryst, E. (1999). Psychiatric co-morbidity in South African HIV/AIDS patients. *South African Medical Journal*, 89 (9), 992-995.
- Evans, J. (2007). Chapter 2: Ethics for Research in Psychology. *Your Psychology Project: the essential guide*. Sage Publishers
- Everly, J. R., & Mitchell, J. T. (1999). *Critical Incident Stress Management (CISM): A new era and standard of care in crisis intervention (2nd Ed.)*. Ellicott City, MD: Chevron.
- Fade, S. (2004). Using interpretative phenomenological analysis for public health nutrition and dietetic research: a practical guide. *Proceedings of the Nutrition Society*, 63, 647-653.
- Fawcett, T. (2006). An Introduction to ROC analysis. *Pattern Recognition Letters*, 27 (8), 861-874.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

- Field, A. (2000). *Discovering Statistics: Using SPSS for Windows. Advanced Techniques for the beginner*. SAGE publications. London, Thousand Oaks, New Delhi.
- Fischer, S., Reynolds, H., Yacobson, I., Barnett, B. & Schueller J. (2005). HIV Counseling and Testing for Youth; a Manual for providers. Family Health International. Retrieved on November 10, 2013 from http://pdf.usaid.gov/pdf_docs/PNADD624.pdf
- Flannery, R. B., (1999). Psychological trauma and post-traumatic stress disorder: a review. *International Journal of Emergency Mental Health*, 2, 135-140.
- Flowers, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research*. SAGE Publications Limited.
- Foa, E. B., & Kozak, M. J. (1986). Emotional processing of fear: Exposure to corrective information. *Psychological Bulletin*, 99 (1), 20-35. 419
- Foa, E. B., Cashman, L., Jaycox, L., & Perry, K. (1997). The validation of a self-report measure of post-traumatic stress disorder: the Post-traumatic Diagnostic Scale. *Psychological Assessment*, 9(4), 445.
- Foa, E. B., & Rothbaum, B. O. (1998). *Treating the Trauma of Rape: Cognitive-Behavioral Therapy for PTSD*. New York, NY: Guilford Press.
- Fogarty, L., Roter, D., Larson, S., Burke, J., Gillespie, J., & Levy, J. (2002). Patient adherence to HIV medication regimes: A review of published and abstract reports. *Patient Education and Counselling*, 46 (2), 93-108.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

- Foremen, M. (1999). *Men and AIDS: Taking risks, taking responsibility*. London, Zed Press.
- Fox, M. P, & Rosen, S. (2010). Patient retention in anti-retroviral therapy programs up to three years on treatment in Sub-Saharan Africa, 2007-2009: systematic review. *Tropical Medicine and International Health*, 15 (1), 1-15.
- Foxcroft, C. D. (2011). Ethical Issues Related to Psychological Testing in Africa: What I Have Learned (So Far). *Online Readings in Psychology and Culture*, 2 (2). <http://dx.doi.org/10.9707/2307-0919.1022>
- Freeman, M. (2004). Hiv/Aids in developing countries: Heading towards a mental health and consequent social disaster? *South African Journal of Psychology*, 34 (1), 139-159.
- Freeman, M., Nkomo, N., Kafaar, Z., & Kelly, K. (2007). Factors associated with prevalence of mental disorder in people living with HIV/AIDS in South Africa. *AIDS Care*, 19 (10), 1201-1209.
- Freeman, M., Nkomo, N., Kafaar, Z., & Kelly, K. (2008). Mental disorder in people living with HIV/AIDS in South Africa. *South African Journal of Psychology*, 38, 489-500.
- Freeman, M., Patel, V., Collins, P., & Bertolote, J. (2005). Integrating mental health in global initiatives for HIV/AIDS. *British Journal of Psychiatry*, 187, 1-3.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

- Friedman, M. J. (2003). Pharmacologic management of post-traumatic stress disorder. *Primary Psychiatry, 10*, 66–73.
- Friedman, M. J. (2013a). Finalizing PTSD in DSM-5: Getting Here From There and Where to Go Next. *Journal of traumatic stress, 26* (5), 548-556.
- Friedman, M. J. (2013b). PTSD in the DSM-5: Reply to Brewin (2013), Kilpatrick (2013), and Maercker and Perkonigg (2013). *Journal of traumatic stress, 26* (5), 567-569.
- Friedman, M. J., Resick, P. A., Bryant, R. A., & Brewin, C. R. (2011). Considering PTSD for DSM-5. *Depression and Anxiety, 28* (9), 750-769.
<http://www.ptsd.va.gov/professional/articles/article-pdf/id35490.pdf>
- Frith, A. (2011). Ugu. Retrieved on 12 December 2013, from www.census2011.adrianfrith.com
- Geraerts, E., & McNally, R. J. (2008). Forgetting unwanted memories: Direct forgetting and thought suppression methods. *Acta Psychologica, 127* (3), 614-622.
- Gilbert, L., & Walker, L. (2009). “They (ARVs) are my life, without them i’m nothing”- experiences of patients attending a HIV/AIDS clinic in Johannesburg, South Africa. *Health and Place, 15*, 1123-1129.
- Gillespie, D. (2013). *Ethical Issues in Research*. Retrieved on May 18, 2013, from http://www.uncp.edu/home/marson/ethical_issues.html
- Gillespie, K., Duffy, M., Hackmann, A., & Clark, D. M. (2002). Community-based cognitive therapy in the treatment of post-traumatic stress disorder

HIV, PTSD AND TRAUMATIC LIFE EVENTS

- following the Omagh bomb. *Behaviour Research and Therapy*, 40 (4), 345-357.
- Giorgi, A. (1995). Phenomenological Psychology. In J.A. Smith, R. Harre, & L. van Langenhove (Eds.), *Rethinking Psychology* (pp.24–42). London: Sage.
- Giorgi, A. (1997). The theory, practice, and evaluation of the phenomenological method as a qualitative research procedure. *Journal of Phenomenological Psychology*, 28 (2), 235-260.
- Giorgi, A., & Giorgi, B. (2003). The descriptive phenomenological psychological method. In P.M. Camic, J.E. Rhodes, and L. Yardley, (Eds.), *Qualitative research in psychology: Expanding perspectives in methodology and design* (pp. 243-273). Washington, D.C: American Psychological Association.
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. Englewood Cliffs (NJ): Prentice-Hall.
- Golafshani, N. N. (2003). Understanding reliability and validity in qualitative research. *The Qualitative Report*, 8 (4), 1-10.
- Gonzalez, J. S., Penedo, F. J, Llabre, M. M., Duran, R. E., Antoni, M. H., Schneiderman, N., & Horne, R. (2007). Physical symptoms, beliefs about medications, negative mood, and long-term HIV medication adherence. *Annals of Behavioural Medicine*, 34 (1), 46-55.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

- Granich, R., Kahn, J. G., Bennett, R., Holmes, C. B., Garg, N., Serenata, C., ... & Williams, B. G. (2012). Expanding ART for treatment and prevention of HIV in South Africa: estimated cost and cost-effectiveness 2011-2050. *PLoS One*, 7 (2), e30216.
- Grant, A. D., & De Cock, K. M. (1998). The growing challenge of HIV/AIDS in developing countries. *British Medical Bulletin*, 54 (2), 369-381.
- Gray, J. (2006). Becoming adherent: Experiences of persons living with HIV/AIDS. *Journal of the Association of Nurses, in AIDS Care*, 17 (3), 47-54.
- Green, G., & Smith, R. (2004). The psychosocial and health-care needs of HIV-positive people in the United Kingdom: a review. *Journal of HIV Medicine*, 5, 4-46.
- Gregory, R. J. (2007). *Psychological Testing: History, Principles, and Applications* (5th ed.). Boston: Pearson Education.
- Groh, K., Audet, C. M., Baptista, A., Sidat, M., Vergara, A., Vermund, S. H., & Moon, T. D. (2011). Barriers to anti-retroviral therapy adherence in rural Mozambique. *BMC Public Health*, 11. 650. doi:10.1186/1471-2458-11-650
- Hackmann, A., Ehlers, A., Speckens, A., & Clark D. M. (2004). Characteristics and content of intrusive memories in PTSD and their changes with treatment. *Journal of Traumatic Stress*, 17, 211–240.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

- Halperin, D. T., & Epstein, H. (2007). Why is HIV prevalence so severe in southern Africa? the role of multiple concurrent partnerships and lack of male circumcision-implications for HIV prevention: opinion. *Southern African Journal of HIV Medicine*, (26), 19-23.
- Hamber, B. (1999). *"Have No Doubt it is Fear in the Land": An Exploration of the Continuing Cycles of Violence in South Africa*. Johannesburg: Centre for the Study of Violence and Reconciliation.
- Hamber, B., & Lewis, S. (1997). *An overview of the consequences of violence and trauma in South Africa*. Centre for the Study of Violence and Reconciliation. Research report written for the Centre for the Study of Violence and Reconciliation, August, 1997. Retrieved August 20, 2008, from http://www.csvr.org.za/index.php?option=com_content&task=view&id=617&Itemid=164
- Harawa, N. T., Willians, J. K., Ramamurthi, H. C., & Bingham, T. A. (2006). Perceptions towards condom use, sexual activity and HIV disclosure among HIV-positive African American men who have sex with men: implications for heterosexual transmission. *Journal of Urban Health*, 83 (4), 682-694.
- Hargie, O., & Tourish, D. (2000) Auditing professional practice. In O. Hargie & D. Tourish (Eds.), *Handbook of communication audits for organisations*. London: Routledge.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Herek, G. M. (1999). AIDS and Stigma. *American Behavioural Scientist*, 42 (7), 1106-1116.

Herek, G. M. (2002). Thinking about AIDS and Stigma: a psychologist's perspective. *Journal of Law, Medicine, and Ethics*, 30, 594-607.

Heroes Campaign. (2009, October 19). Retrieved September 18, 2012, from <http://www.aidsconsortium.org.za/heroes.html>

Heyer, A., & Ogunbanjo, G. A. (2006). Adherence to HIV anti-retroviral therapy. Part 1: A review of factors that influence adherence. *South African Family Practice*, 48 (8), 5-9.

Hirschowitz, R., & Orkin, M. (1997). *Central Statistical Service: South Africa for presentation at Seminar on Poverty Statistics: Santiago, 7-9 May 1997*. Retrieved September 18, 2012, from <http://www.ibge.gov.br/poverty/pdf/southafrica.pdf>

HIV and AIDS in South Africa. (n. d.). Retrieved June, 19, 2012, from www.avert.org/aidssouthafrica.htm

Hodes, R., & Grimsrud, A. (2011). *The anti-retroviral moratorium in the Free State Province of South Africa: Contributing factors and implications*. Centre for Social Science Research. Aids and Society Research Unit. CSSR Working Paper No. 290. March 2011.

Horowitz, M. J. (2001). *Stress Response Syndrome*. (4th ed). New Jersey: Jason Aronson Inc.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Horowitz, M. J., Wilner, N. R., & Alvarez, W. (1979). Impact of Event Scale.

A measure of subjective stress. *Psychosomatic Medicine*, 41, 209-218.

Houston, C. (2011). How decent public transport can strike a blow to

poverty. Retrieved September 20, 2012, from

<http://allafrica.com/stories/201109300983.html>

HSRC. (2005). *South African national HIV prevalence, HIV incidence,*

behaviour and communication survey, 2005. Cape Town: HSRC Press

HSRC. (2006). Retrieved November 14, 2010, from

<http://www.hsrc.ac.za/Document-2180.phtml>

Husy, D. (2000). *Growth, Poverty and Inequality. Published by Social Watch,*

poverty eradication and gender justice. Retrieved September 20, 2012,

from <http://www.socialwatch.org/node/10709>

Hutton, H. E., Lyketsos, C. G., Zenilman, J. M., Thompson, R. E., &

Erbelding, E. J. (2004). Depression and HIV risk behaviors among

patients in a sexually transmitted disease clinic. *American Journal of*

Psychiatry, 161, 912-914.

Impumelelo. (2008). *Umdoni and Vulamehlo HIV/AIDS association:*

Nakhimpilo-Care for Life. Retrieved June, 16, 2012, from

[http://www.impumelelo.org.za/what-we-do/impumelelo-innovations-](http://www.impumelelo.org.za/what-we-do/impumelelo-innovations-awards/2008/silver/nakimpilo-care-for-life-1)

[awards/2008/silver/nakimpilo-care-for-life-1](http://www.impumelelo.org.za/what-we-do/impumelelo-innovations-awards/2008/silver/nakimpilo-care-for-life-1)

International Centre for Research on Women. (2010). *Scaling up the*

Response to HIV Stigma and Discrimination. Retrieved October 2, 2012,

HIV, PTSD AND TRAUMATIC LIFE EVENTS

from <http://www.icrw.org/files/publications/Scaling-Up-the-Response-to-HIV-Stigma-and-Discrimination.pdf>

Irin. (2011). South Africa: Government moves to earlier HIV treatment.

Retrieved September 16, 2012, from Irin,%20Plus%20News%202011.htm

Irin/Plus News. (2009). *South Africa: Waiting to hear if treatment will start earlier*. Retrieved September 14, 2012,

Irin,%20Plus%20news,%202009.htm

Janca, A., Robins, L. N., Cottler, L. B., & Early, T. S. (1992). Clinical observation of assessment using the Composite International Diagnostic Interview (CIDI). An analysis of the CIDI Field Trials--Wave II at the St Louis site. *British Journal of Psychiatry*, *160*, 815-818.

Janoff-Bulman, R. (1992). *Shattered assumptions: Towards a new psychology of trauma*. New York, NY: Free Press.

Jeanihess. (2012). *Explore Politics and Social Issues: Life on the taxis*.

Retrieved on December 05, 2012, from

<http://hubpages.com/topics/politics-and-social-issues/africa-political-and-social-issues/4692>

Jewkes, R., & Abrahams, N. (2002). The epidemiology of rape and sexual coercion in South Africa: An overview. *Journal of Social Science and Medicine*. *55*, 1231-1244.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

- Jewkes, R., (2009). *Chapter 3: HIV and Women*. In Rohleder, P., Swartz, L., Kalichman, S. C., Simbayi, L. C (eds.), *HIV/AIDS in South Africa 25 Years On, psychosocial perspectives*. Springer Science and Business Media.
- Jobson, L., & O' Kearney, R. T. (2009). Impact of cultural differences in self of cognitive trauma appraisals in post-traumatic stress disorder. *Behavioural and Cognitive Psychotherapy*, 37 (3), 249-266.
- Joska, J. A., Fincham, D. S., Stein, D. J., Paul, R. H., & Seedat, S. (2010). Clinical Correlates of HIV-Associated Neurocognitive Disorders in South Africa. *AIDS Behaviour*, 14 (2), 371-378.
- Kagee, A. (2004a). Treatment adherence in South African primary health care. *South African Family Practice*, 46 (10), 26-30.
- Kagee, A. (2004b). Do South African former detainees experience post-traumatic stress? Circumventing the demand characteristics of psychological assessment. *Journal of Transcultural Psychiatry*, 41 (3), 323-336.
- Kagee, A. (2004c). Present concerns of survivors of human rights violations in South Africa. *Social Science and Medicine*, 59, 625-635.
- Kagee, A. (2005). Symptoms of distress and post-traumatic stress among South African former political detainees. *Journal of Ethnicity and Health*, 10 (2), 169-179.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

- Kagee, A. (2008). Application of the DSM-IV criteria to the experience of living with AIDS. Some concerns. *Journal of Health Psychology, 13*, 34–37.
- Kagee, A., & Naidoo, A. V. (2004). Reconceptualizing the sequelae of political torture: Limitations of a psychiatric paradigm. *Transcultural Psychiatry, 41*, 46-61.
- Kalichman, S. C., Graham, J., Luke, W., & Austin, J. (2002). Perceptions of Health Care among Persons Living with HIV/AIDS Who Are Not Receiving Anti-retroviral Medications. *AIDS Patient Care and STDs, 16* (5), 233-240. doi:10.1089/10872910252972285
- Kalichman, S. C., Sikkema, K. J., DiFonzo, K., Luke, W., & Austin, J. (2002). Emotional adjustment in survivors of sexual assault living with HIV-AIDS. *Journal of Traumatic Stress, 15*, 289 –96.
- Kalichman, S. C., & Simbayi, L. C. (2003). HIV testing attitudes, AIDS stigma, and voluntary HIV counselling and testing in a black township in Cape Town, South Africa. *Journal of Sex, Trauma and Infection, 79*, 442-447.
- Kalichman, S. C., & Simbayi, L. (2004). Traditional beliefs about the cause of AIDS and AIDS-related stigma in South Africa. *AIDS Care, 16* (5), 572-580.
- Kalichman, S, C., Simbayi, L. C., & Cain. D. (2010). HIV transmission risk behaviours among HIV seropositive sexually transmitted infection clinic

HIV, PTSD AND TRAUMATIC LIFE EVENTS

- patients in Cape Town, South Africa. *European Journal of Public Health*, 20 (2), 202–206.
- Kalichman, S. C., Simbayi, L. C., Jooste, S., Toefy, Y., Cain, D., Cherry, C., & Kagee, A. (2005). Development of a brief scale to measure AIDS-related stigma in South Africa. *AIDS Behaviour*, 9 (2), 135–143.
- Kalichman, S. C., Simbayi, L. C., Kaufman, M., Cain, D., & Jooste, S. (2007). Alcohol use and sexual risks for HIV/AIDS in sub-Saharan Africa: systematic review of empirical findings. *Prevention Science*, 8 (2), 141–151.
- Kaminer, D., & Eagle, D. (2010). *Traumatic Stress in South Africa*. Wits University Press.
- Kaminer, D., Grimsrud, A., Myer, L., Stein, D. J. & Williams, D. R. (2008). Risk for post-traumatic stress disorder associated with different forms of interpersonal violence in South Africa. *Social Science and Medicine*, 67 (10), 1589-1595.
- Katz, S., & Nevid, J. S. (2005). Risk Factors Associated with Post-traumatic Stress Disorder Symptomatology in HIV-Infected Women. *AIDS Patient Care & Stds*, 19 (2), 110-120.
- Keane, T. M., Marshall, A. D., & Taft, C. T. (2006). Post-traumatic stress disorder: etiology, epidemiology, and treatment outcome. *Annual Reviews in Clinical Psychology*, 2, pp. 161-197.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Kelly, B., Raphael, B., Judd, F., Perdices, M., Kernutt, G., Burnett, P., ...

Burrows, G. (1998). Post-traumatic stress disorder in response to HIV infection. *General Hospital Psychiatry*, 20(6), 345-352.

Kelly, K. (2003a). Day I: An overview of the key themes. *Summary presented at Round Table discussion on Mental health and HIV/AIDS*. Retrieved on July 10, 2010, from www.hsrcpress.ac.za

Kelly, K. (2003b). Day II: Areas requiring further research, policy and service development. *Summary presented at Round Table discussion on Mental health and HIV/AIDS*. Retrieved on July 12, 2010, from www.hsrcpress.ac.za

Kelly, K., Freeman, M., Nkomo, N., & Ntlabati, P. (2008). Chapter 13: The Vicious Circularity of Mental Health Effects of HIV/AIDS: Symptom and Cause of Poor Responses to the Epidemic. In Moller, V., & Huschka, D. (eds), *Quality of Life and the Millenium Challenge*. Springer Science and Business Media.

Kessler, R. C., & Ustun, T. B. (2004). The World Mental Health (WMH) Survey Initiative Version of the World Health Organization (WHO) Composite. International Diagnostic Interview (CIDI). *International Journal of Methods in Psychiatric Research*, 13, 93–121.

Kessler, R. C., Sonnega, A., Bromet, E., Hughes, M., & Nelson, C. B. (1995). Post-traumatic stress disorder in the National Comorbidity Survey. *Archives of General Psychiatry*, 52, 1048–1060.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

- Khan, K. S., Kunz, R., Kleijnen, J., & Antes, G. (2003). Five steps to conducting a systematic review. *JRSM*, *96* (3), 118-121.
- Kiene, S. M., Simbayi, L. C., Abrams, A., Cloete, A., Tennen, H., & Fisher, J. D. (2008). High rates of unprotected sex occurring among HIV-positive individuals in a daily diary study in South Africa: the role of alcohol use. *Journal of Acquired Immune Deficiency Syndrome*, *49* (2), 219–226.
- Kilpatrick, D. G. (2013). The DSM-5 Got PTSD Right: Comment on Friedman (2013). *Journal of traumatic stress*, *26* (5), 563-566.
- Kilpatrick, D. G., Resnick, H. S., Milanak, M. E., Miller, M. W., Keyes, K. M., & Friedman, M. J. (2013). National Estimates of Exposure to Traumatic Events and PTSD Prevalence Using DSM-IV and DSM-5 Criteria. *Journal of traumatic stress*, *26* (5), 537-547.
- Kimberley, J. A., & Serovich, J. M. (1996). Perceived social support among people living with HIV/AIDS. *The American Journal of Family Therapy*, *24* (1), 41-53.
- Kleim, B., Wallott, F., & Ehlers, A. (2008). Are trauma memories disjointed from other autobiographical memories in post-traumatic stress disorder? An experimental investigation. *Behavioural and Cognitive Psychotherapy*, *36* (2), 221-234.
- Klis, S., Velding, K., Gidroy, Y., & Peterson, K. (2011). Post-traumatic stress and depressive symptoms among people living with HIV in the Gambia. *AIDS Care*, *23*, 426-434.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

- Knight, R. (2006). *South Africa Delegation Briefing Paper, November 2006, South Africa 2006: Population and HIV/AIDS*. Retrieved May 10, 2012, from <http://richardknight.homestead.com/files/SouthAfrica2006-PopulationandHIV-AIDS.pdf>
- Konstam, V., Moser, D. K., & De Jong, M. J. (2005). Depression and anxiety in heart failure. *Journal of Cardiac Failure, 11*, 455-463.
- Koocher, G., & O'Malley, J. (1981). *The Damocles Syndrome: Psychosocial Consequences of Surviving Childhood Cancer*. New York: McGraw-Hill.
- Kornblith, A. B., Anderson, J., Cella, D. F., Tross, S., Zuckerman, E., Cherin, E., ... Holland, J. C. (1992). Hodgkin disease survivors at increased risk for problems in psychosocial adaptation. *Cancer, 70* (8), 2214-2224.
- Kuyken, W., Padesky, C.A., & Dudley, R. (2008). The science and practice of case conceptualization. *Behavioural and Cognitive Psychotherapy, 36*, 757-768.
- Kylma, J., Vehvilainen-Julkunen, K., & Lahdevirta, J. (2003). Hope, despair and hopelessness in living with HIV/AIDS: A grounded theory study. *Journal of Advanced Nursing, 33* (6), 764-775.
- Lakaje, T. S. (2005). *A Comparative Study of Post Traumatic Symptoms in Men and Women Newly Diagnosed with HIV Infection* (Master's Thesis). Retrieved from: <https://ujdigispace.uj.ac.za/handle/10210/1512>

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Langdrige, D. (2007). *Phenomenological psychology: theory, research and method*. Harlow: Pearson Prentice Hall.

Larkin, M. (2008). *IPA Analysis. Interpretative Phenomenological Analysis Research Interest Group*. Retrieved on April 26, 2012, from <http://groups.yahoo.com/group/ipanalysis>

Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in Interpretative Phenomenological Analysis. *Qualitative Research in Psychology*, 3 (2), 102-120.

Lawn, S. D., & Wood, R. (2006) How can earlier entry of patients into anti-retroviral programs in low-income countries be promoted? *Clinical Infectious Diseases*, 42, 431–432.

Lazarus, R. S., & Folkman, S. (1984). *Stress appraisal and Coping*. New York: McGraw-Hill.

Leclerc-Madlala, S. (2006). "We will eat when I get the grant": AIDS, poverty and anti-retroviral treatment in South Africa. *African Journal of AIDS Research*, 5 (3), 249-256.

Lee, J. D., & Craft, E. A. (2002). Protecting one's self from a stigmatized disease...once one has it. *Deviant Behavior*, 23 (3), 267-299.

Lerner, M. (1999). Post-traumatic Stress and the Experience of Cancer: A Literature Review. *Journal of Rehabilitation*, July-September.

Leserman, J. (2003). HIV disease progression: Depression, stress and possible mechanisms. *Journal of Biological Psychiatry*. 54, 295-306.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Leserman, J., Barroso, J., Pence, B. W., Salahuddin, N., & Harmon, J. L.

(2008). Trauma, stressful life events and depression predict HIV-related fatigue. *AIDS Care*, 20 (10), 1258-1265.

Leserman, J., Whetten, K., Lowe, K., Strangl, D., Schwartz, M., & Thielman,

N. (2005). How trauma, recent stressful life events, and PTSD affect functional health status and health utilization in HIV-infected patients in the South. *Psychosomatic Medicine*, 67, 500-507.

Lichtenstein, B., Laska, M. K., & Clair, J. M. (2002). Chronic sorrow in the

HIV-positive patient: Issues of race, gender, and social support. *AIDS Patient Care and STDs*, 16 (1), 27-38.

Lindegger, G., & Quayle, M. (2009). Masculinity and HIV/AIDS. In

Rohleder, P., Swartz, L., Kalichman, S. C., Simbayi, L. C. (eds.), *HIV/AIDS in South Africa 25 Years On, psychosocial perspectives*.

Springer Science and Business Media.

Link, B. G. (2001). Stigma: many mechanisms require multifaceted

responses. *Epidemiologia e Psichiatria Sociale*, 10 (1), 8-11.

Doi: <http://dx.doi.org/10.1017/S1121189X00008484>

Link, B. G., & Phelan, J. C. (2001). Conceptualising Stigma: On stigma and

its public health implications. *Annual Review of Sociology*, 27, 363-385.

Longford, C (2012). South Africa: still an apartheid state. Essay: The roots of

the Marikana massacre lie in the ANC's deep antipathy to those it relied

upon to rise to power: the black working classes. Retrieved December 22,

HIV, PTSD AND TRAUMATIC LIFE EVENTS

2013, from <http://www.spiked->

[online.com/newsite/article/12910#.UsA9U9IW2YE](http://www.spiked-online.com/newsite/article/12910#.UsA9U9IW2YE)

Louw, A. (1997). Surviving the transition: Trends and perceptions of crime in South Africa. *Social Indicators Research, 41*, 137-168.

Louw, A., & Shaw, M. (1997). *Stolen Opportunities: The impact of crime on South Africa's poor*. Occasional Paper, Unpublished.

Louwagie, G. M., Bachmann, M. O., Meyer, K., Booysen, F. R., Fairall, F., & Heunis, C. (2007). Highly active anti-retroviral treatment and health related quality of life in South African adults with human immunodeficiency virus infection: A cross sectional analytical study. *BMC Public Health, 7*, 244.

Machtiger, E. L., Wilson, T. C., Haberer, J. E., & Weiss, D. S. (2012). Psychological trauma and PTSD in HIV-positive women: a meta-analysis. *AIDS and Behavior, 16* (8), 2091-2100.

Mahajan, A. P., Sayles, J. N., Patel, V. A., Remien, R. H., Ortiz, D., Szekeres, G., & Coates, T. J. (2008). Stigma in the HIV/AIDS epidemic: A review of the literature and recommendations for the way forward. *AIDS, 22* (2), S67-S79. doi: 10.1097/01.aids.0000327438.13291.62

Major, B., & O' Brien, L. T. (2005). The social psychology of stigma. *Annual Review of Psychology, 56*, 393-421.

Makoe, L. N., Sebont, N. M., Molosiwa, K., Moleko, M., Human, S., Sukati, N., & Holzemer, W. L. (2005). The symptom experience of people living

HIV, PTSD AND TRAUMATIC LIFE EVENTS

- with HIV? AIDS in Southern Africa. *Journal of the Association of Nurses in AIDS Care*, 16 (3).
- Markus, H. R., & Kitayama, S. (1991). Culture and the self: implications for cognition, emotion, and motivation. *Psychological Review*, 98, 224–253. doi: 10.1037/0033-295X.98.2.224.
- Martin, L., & Kagee, A. (2008). Lifetime and HIV-related PTSD among persons recently diagnosed with HIV. *Aids and Behaviour*, 15 (1), 125-131.
- Martin, L., Fincham, D., & Kagee, A. (2009). Screening for HIV-related PTSD: sensitivity and specificity of the 17-item Post-traumatic Stress Diagnostic Scale (PDS) in identifying HIV-related PTSD among a South African sample. *African Journal of Psychiatry*, 12 (4), 270-4.
- Matacotta, J. J. (2010). *Post-traumatic Stress Disorder in Patients with HIV: A Review of the Current Literature*. Retrieved November 15, 2012, from www.nlm.nih.gov/medlineplus/ency/article.htm
- Mattis, J. S., Bell, C. C., Jagers, R. J., & Jenkins, E. (1999). A Critical Approach to Stress-Related Disorders in African Americans. *Journal of the National Medical Association*, 91 (2), p 80-85.
- Maughan-Brown, B. (2004). *Measuring HIV/AIDS stigma. CSSR Working Paper*, (74).

HIV, PTSD AND TRAUMATIC LIFE EVENTS

- Maughan-Brown, B. G. (2006). Attitudes towards people with HIV/AIDS: stigma and its determinants among young adults in Cape Town, South Africa. *South African Review of Sociology*, 37 (2), 165-188.
- Mayosi, B. M., Lawn, J. E., van Niekerk, A., Bradshaw, D., Abdool Karim, S. S., & Coovadia, H. M. (2012). Health in South Africa: changes and challenges since 2009. *The Lancet*, 380 (9858), 2029 - 2043.
- Mazza, J. J. (1996). *Exposure to violence in inner-city school-based adolescents*. Retrieved July 15, 2011, from www.vincentre.org/96/mazza.html
- McCain, N. L., & Gramling, L. F. (1992). Living with dying: Coping with HIV disease. *Issues in Mental Health Nursing*, 13 (3), 271-284.
- McGowan, T. C., & Kagee, A. (2013). Exposure to traumatic events and symptoms of post-traumatic stress among South African university students. *South African Journal of Psychology*, 43 (3), 327-339.
- McGrath, P. (1999). Post-traumatic Stress and the Experience of Cancer: A Literature Review. *Journal of Rehabilitation*, 17-23.
- McKerrow, N. (2000). *At Risk Groups*. Paper presented at the Second Annual HIV/AIDS Conference. Pietermaritzburg, UKZN.
- McManus, F., Peerbhoy, D., Larkin, M., & Clark, D. (2010). Learning to change a way of being: An interpretative phenomenological perspective on cognitive therapy for social phobia. *Journal of Anxiety Disorders*, 24 (6), 581-589.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

- McNally, R. J. (2003). Progress and Controversy in the Study of Post-traumatic Stress Disorder. *Annual Review of Psychology*, 54, 229-252.
- McNally, R.J. (2004). Conceptual problems with the DSM-IV criteria for post-traumatic stress disorder. In G.M. Rosen (Ed.), *Post-traumatic stress disorder* (pp.1–14). Chichester: Wiley.
- McNally, R. J. (2009). The Cutting Edge: Can we Fix PTSD in DSM-V. *Journal of Depression and Anxiety*, 26, 597-600
- McNally, R. J. (2010). Can we salvage the concept of psychological trauma? *The Psychologist*, 23 (5), 386-389. Retrieved on September 15, from http://www.thepsychologist.org.uk/archive/archive_home.cfm?volumeID=23&editionID=188&ArticleID=1669
- Meiberg, A. E., Bos, A. E., Onya, H. E., & Schaalma, H. P. (2008). Fear of stigmatization as barrier to voluntary HIV counselling and testing in South Africa. *East African Journal of Public Health*, 5 (2), 49-54.
- Mesquita, B., & Walker, R. (2003). Cultural differences in emotions: a context for interpreting emotional experiences. *Journal of Behaviour, Research and Therapy*, 41, 777–793. doi: 10.1016/S0005-7967(02)00189-4.
- Meursing, K. (1999). *Barriers to sexual behavior change after an HIV diagnosis in sub-Saharan Africa*. Macfarlane Burnet Centre for Medical Research.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

- Michael, T., Halligan, S. L., Clark, D. M., & Ehlers, A. (2007). Rumination in post-traumatic stress disorder. *Depression and Anxiety, 24* (5), 307-317.
- Miller, C. T., & Kaiser, C. R. (2001). A theoretical perspective on coping with stigma. *Journal of Social Issues, 57* (1), 73-92.
- Miller, C. T., & Major, B. (2000). Coping with stigma and prejudice. In T. F. Heatherton, R. E. Kleck, M. R. Hebl, & J. G. Hull (Eds.), *The social psychology of stigma*. New York: Guilford.
- Moran, D. (2000). *Introduction to phenomenology*. London, Routledge, Taylor & Francis Group.
- Morin, S. F., Charles, K. A., & Malyon, A. K. (1984). The psychological impact of AIDS on gay men. *American Psychologist, 39* (11), 1288.
- Mowrer, O. H. (1956). Two-factor learning theory reconsidered, with special reference to secondary reinforcement and the concept of habit. *Psychological Review, 63*, 114-128.
- Mundy, E. A., Blanchard, E. B., Cirenza, E., Gargiulo, J., Maloy, B., & Blanchard, C. G. (2000). Post-traumatic stress disorder in breast cancer patients following autologous bone marrow transplantation or conventional cancer treatments. *Behaviour research and therapy, 38* (10), 1015-1027.
- Mundy, E., & Baum, A. (2004). Medical disorders as a cause of psychological trauma and post-traumatic stress disorder. *Current Opinion in Psychiatry, 17*, 123-127.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Murphy, D. A., Masicicki, A. B., Vermund, S. H., & Muenz, L. R. (2000).

Psychological distress among HIV (+) adolescents in the REACH study: effects of life stress, social support and coping. The Adolescent Medicine HIV? AIDS Research Network. *Journal of Adolescent Health*, 27 (6), 391-398.

Myer, L., Smit, J., Le Roux, L., Parker, S., Stein, D., & Seedat, S. (2008).

Common mental disorders among HIV-infected individuals in South Africa: Prevalence, Predictors and validation of Brief Psychiatric Rating Scales. *AIDS Patient Care*, 22 (2), 147-158

Nattrass, N. (2006). Trading off income and health? AIDS and the disability grant in South Africa. *Journal of Social Policy*, 35 (1), 3-19.

Newcombe, R. G. (1998). Two-sided confidence intervals for the single proportion: Comparison of seven methods. *Statistics in Medicine*, 17, 857-872.

Niehaus, I. (2007). Death before Dying: Understanding AIDS Stigma in the South African Lowveld. *Journal of Southern African Studies*, 33 (4), 845-860.

Nordqvist, O., Sodergard, B., Tully, M. P., Sonerborg, A., & Kettis Lindblad, A. M. (2006). Assessing and achieving readiness to initiate HIV medication. *Patient Education and Counselling*, 61 (1), 21-30.

Nyblade, L. C. (2006). Measuring HIV stigma: existing knowledge and gaps. *Psychology, Health & Medicine*, 11, 335-345.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

- Nyblade, L., Pande, R., Mathur, S., MacQuarrie, K., & Kidd, R. (2003). *Disentangling HIV and AIDS stigma in Ethiopia, Tanzania and Zambia*. Washington, DC: International Center for Research on Women.
- O' Cleirigh, C., Ironson, G., & Smits, J. A. J. (2007). Does distress tolerance moderate the impact of major life events on psychosocial variables and behaviours important in the management of HIV? *Journal of Behavioural Therapy*, 38 (3), 314-323.
- O'Keefe, E. A., & Wood, R. (1996). The impact on the human immunodeficiency virus (HIV) infection on quality of life in a multiracial South African population. *Quality of Life Research*, 5, 275-280.
- Olley, B. O., Gxamza., F. & Seedat, S., Theron, H., Taljaard, J., Reid, E., ... Stein, D. J. (2003). Psychopathology and coping in recently diagnosed HIV/AIDS patients – the role of gender. *South African Medical Journal*, 93, 928-931.
- Olley, B. O., Seedat, S., & Stein, D. J. (2004). Self-disclosure of HIV serostatus in recently diagnosed patients with HIV in South Africa. *African Journal of Reproductive Health*, 8 (2), 71-76.
- Olley, B.O., Seedat., S. & Stein, D.J. (2006). Persistence of psychiatric disorders in a cohort of HIV/AIDS patients in South Africa: A 6-month follow-up study. *Journal of Psychosomatic Research*, 61, 479-484.
- Olley, B. O., Zeier, M. D., Seedat, S., & Stein, D. J. (2005). Post-traumatic stress disorder among recently diagnosed patients with HIV/AIDS in South Africa. *AIDS Care*, 17, 550–557.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

- Owe-Larsson, B., Säll, L., Salamon, E., & Allgulander, C. (2009). HIV infection and psychiatric illness. *African Journal of Psychiatry, 12*, 115-128.
- Padmanbhanunni, A. (2010). *A Series of Systematic Case Studies on the Treatment of Rape-related PTSD in the South African Context: Implications for Practice and Policy*. (Unpublished Masters Thesis).
- Palitza, K. (2009, April, 2) South Africa: Nurses should be backbone of ARV treatment. *Inter Press Service News Agency*. Retrieved April 14, 2011, from <http://www.ipsnews.net/2009/04/south-africa-nurses-should-be-backbone-of-arv-treatment/>
- Paoli, M. M., Mills, E. A., & Gronningsaeter, A. B. (2012). The ARV roll out and the disability grant: a South African dilemma? *Journal of the International AIDS Society, 15* (6). doi:10.1186/1758-2652-15-6
- Parker, R., & Aggleton, P. (2003). HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. *Journal of Social Science and Medicine, 57* (1), 13-24.
- Parsons, S. K., Cruise, P. L., Davenport, W.M., & Jones, V. (2006). Religious beliefs, practices and treatment adherence among individuals with HIV in the southern United States. *AIDS Patient Care and STDs, 20* (2), 97.
- Patel, V., Saraceno, B., & Kleinman, A. (2006). Beyond evidence: the moral case for international mental health. *American Journal of Psychiatry, 163* (8), 1312-1315.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

- Paterson, D. L., Swindells, S., Mohr, J., Brester, M., Vergis, E. N., Squier, C., ... Singh, N. (2000). Adherence to protease inhibitor therapy and outcomes in patients with HIV infection. *Annals of Internal Medicine*, *133* (1), 21-30.
- Pedersen, S., & Elklit, A. (1998). Traumatization, psychological defence style, coping, symptomatology, and social support in HIV-positive: A pilot study. *Scandinavian Journal of Psychology*, *39*, 55-60.
- Peltzer, K., & Mlambo, G. (2013). Sexual HIV risk behaviour and associated factors among pregnant women in Mpumalanga, South Africa. *BMC Pregnancy and Childbirth*, *13*, 57.
- Peltzer, K., Mngqundaniso, N., & Petros, G. (2006) HIV/AIDS/STI/TB knowledge, beliefs and practices of traditional healers in Kwa-Zulu Natal, South Africa. *AIDS Care*, *18* (6) 608-613.
- Peltzer, K., & Renner, W. (2003). Superstition, risk-taking and risk perception of accidents among South African taxi drivers. *Journal of Accident Analalysis and Prevention*, *35* (4), 619-23.
- Pembrey, G. (2007). *The impact of HIV & AIDS in Africa*. Retrieved on July 12, 2008, from <http://www.avert.org/aidsimpact.htm>
- Pence, B. (2009). The impact of mental health and traumatic life experiences on anti-retroviral treatment outcomes for people living with HIV/AIDS. *Journal of Antimicrobial Chemotherapy*, *63* (4), 636–640. doi: 10.1093/jac/dkp006

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Pence, B. W., Miller, W. C., Whetten, K., Eron, J. J., & Gaynes, B. N.

(2006). Prevalence of DSM-IV-defined mood, anxiety, and substance use disorders in an HIV clinic in the Southeastern United States. *AIDS Journal of Acquired Immune Deficiency Syndromes*, 42 (3), 298-306.

Pence, B. W., Shirley, K., Whetten, K., Agala, B., Itemba, D., Adams, J., ...

Shao, J. (2012). Prevalence of Psychological Trauma and Association with Current Health and Functioning in a Sample of HIV-infected and HIV-uninfected Tanzanian Adults. *PLoS One*, 7 (5).

Doi:10.1371/journal.pone.0036304

Perkins, N. J., & Schisterman, E. F. (2006). The inconsistency of “optimal”

cutpoints obtained using two criteria based on the receiver operating characteristic curve. *American Journal of Epidemiology*, 163 (7), 670-675.

Perkonig, A., Kessler, R. C., Stortz, S., & Wittchen, H. U. (2000).

Traumatic events and post-traumatic stress disorder in the community: prevalence, risk factors and comorbidity. *Scandinavian Journal of Psychiatry*, 101 (1), 46-59.

Peterson, K., Togun, T., Klis, S., Menten, J., & Colebunders, R. (2012).

Depression and Post-traumatic Stress Disorder Among HIV-Infected Gambians on Anti-retroviral Therapy. *AIDS Patient Care and STDs*, 26 (10), 589-596.

Phillips, A. (2012, July). *Anthropomorphizing PTSD Symptoms Part II:*

Triggers & Hypervigilance. Retrieved August 08, 2012, from

HIV, PTSD AND TRAUMATIC LIFE EVENTS

<http://www.goodtherapy.org/blog/ptsd-symptoms-triggers-hypervigilance-0712125>

Pinel, E. C. (1999). Stigma consciousness: the psychological legacy of social stereotypes. *Journal of Personality Social Psychology*, 76, 114-128.

Pingo, J., & Seedat, S. (2009). The management of trauma and post-traumatic stress disorder in HIV-infected individuals. *Southern African Journal of HIV Medicine*, 35, 14-19.

Policy project, Centre for the study of AIDS, USAID & the Department of Health South Africa. (2003). *Siyam'kela: Measuring HIV/AIDS related stigma. A report on the fieldwork*. Retrieved October 21, 2011, from http://pdf.usaid.gov/pdf_docs/PNACY685.pdf

Pope, C., & Mays, N. (1995). Qualitative Research: Researching the parts other methods cannot reach. An introduction to qualitative methods in health and health services research. *British Medical Journal*, 311, 42-45.

Poverty and Education. (2011). *Poverty in South Africa: Youth Group fact sheet*. Retrieved August 16, 2012, from http://www.equaleducation.org.za/sites/default/files/Fact%20Sheet%205_Poverty%20and%20Education.pdf

Pryor, J. B., & Reeder, G. D. (2011). HIV-related stigma. In B. Hall, J. Hall & C. Cockerell (Eds.), *AIDS: The first 30 years*. Shelton, CT: People's Medical.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Rehle, T., Shisana, O., Pillay, V., Zuma, K., Puren, A., & Parker, W. (2007).

National HIV incidence measures – new insights into the South African epidemic. *South African Medical Journal*, 7 (2), 194-199.

Reid, K., Flowers, P., & Larkin, M. (2005). Exploring lived experience. *The Psychologist*, 18 (1), 20-23.

Reidpath, D. D., & Chan, K. Y. (2006). HIV, Stigma and rates of Infection: A Rumour without Evidence. *PLoS Med*, 3 (10).

Doi:10.1371/journal.pmed.0030435

Rennie, D. L. (1999). Qualitative research: a matter of hermeneutics and the sociology of knowledge. In: Kopala M and Suzuki LA (Eds.), *Using qualitative methods in psychology*, (pp 3-13). Thousand Oaks: Sage.

Resick, P. A., & Schnicke, M. K. (1996). *Cognitive processing therapy for rape victims*. London: Sage Publications

Resnick, H. S., Kilpatrick, D. G., Dansky, B. S., Saunders, B. E., & Best, C.

L. (1993). Prevalence of civilian trauma and post-traumatic stress disorder in a representative national sample of women. *Journal of Consulting and Clinical Psychology*, 61 (6), 984-991.

Reyes, H. (2001). Chapter 9: Women in Prison and HIV. In Bollini, P (Ed),

HIV in Prisons, A reader with particular relevance to the Newly Independent States. World Health Organisation.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

- Reynolds M., & Brewin C. R. (1998). Intrusive cognitions, coping strategies and emotional responses in depression, post-traumatic stress disorder, and a non-clinical population. *Behaviour Research and Therapy*, *36*, 135–147.
- Reynolds M., & Brewin C. R. (1999). Intrusive memories in depression and post-traumatic stress disorder. *Behaviour Research and Therapy*, *37*, 201–215.
- Richter, L., Manegold, J., & Pather, R. (2004). *Family and community interventions for children affected by AIDS*. Cape Town, South Africa: Human Sciences Research Council.
- Rivkin, I. D., Gustafson, J., Weingarten, I., & Chin, D. (2006). The effects of expressive writing on adjustment to HIV. *AIDS and Behaviour*, *10* (1), 13–26.
- Robbins, P. (2008). Consciousness and the social mind. *Cognitive Systems Research*, *9* (1), 15–23.
- Robbins, P., & Ayded, M. (2009). *The Cambridge Handbook of Situated Cognition*. New York: Cambridge University Press.
- Robins, L. N., Wing, J., Wittchen, H. U., Helzer, J. E., Babor, T. F., Burke, J., ... Towle, L. H. (1988). The Composite International Diagnostic Interview: an epidemiologic instrument suitable for use in conjunction with different diagnostic systems and in different cultures. *Archives of general psychiatry*, *45*(12), 1069.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

- Rosner, R., & Powell, S. (2009). Does ICD-10 overestimate the prevalence of PTSD. Effects of differing diagnostic criteria on estimated rates of post-traumatic stress disorder in war zone exposed civilians. *Trauma und Gewalt, 1*, 46-57.
- Rothschild, B. (1997). Post-traumatic Stress Disorder: Identification and Diagnosis. *Swiss Journal of Social Work, February, 1998*.
- Roulston, K. (2011). *Reflective interviewing: a guide to theory and practice*. Sage Publications Limited.
- Roxburgh, A., Degenhardt, L., & Copeland, J. (2006). Post-traumatic stress disorder among female based sex workers in the greater Sydney area, Australia. *BMC Journal of Psychiatry, 6*, 24.
- Salkovskis, P. M. (1996). The cognitive approach to anxiety: threat, beliefs, safety-seeking behaviour and the special case of health anxiety and obsessions. In P. M. Salkovskis, *Frontiers of Cognitive Therapy* (pp 48-74). New York: Guilford
- Santana, M. A., & Dancy, B. L. (2000). The stigma of being named “AIDS carriers” on Haitian American Women. *Health Care for Women International, 21*, 161-171.
- Satatoruis, N. (2007). Stigma and Mental Health. *The Lancet: Global Mental Health, 2-3*.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Sato, T. (2001). Autonomy and relatedness in psychopathology and treatment:

A crosscultural formulation. *Genetic Social and General Psychology Monographs*, 127 (1), 89-127.

Sayles, J. N., Wong, M. D., & Cunningham, W. E. (2006). The inability to take medications openly at home: does it explain gender disparities in HAART use? *Journal of Women's Health*, 15, 173-181.

Schell, T., Marshall, G., & Jaycox, L. (2004). All symptoms are not created equal: The prominent role of hyper-arousal in the natural course of post-traumatic psychological distress. *Journal of Abnormal Psychology*, 113, 189-197.

Scherer, K. S. (1999). Appraisal theory. In T. Dalgleish & M. J. Power (Eds.), *Handbook of cognition and emotion* (pp. 637-664). Chichester, UK: Wiley.

Schisterman, E. F., Perkins, N. J., Liu., A. & Bondell, H. (2005). Optimal cut-point and its corresponding Youden Index to discriminate individuals using pooled blood samples. *Epidemiology*, 16 (1), 73-81.

Schlebusch, L., & Cassidy, M. J. (1995). Stress, social support and biopsychosocial dynamics in HIV/AIDS. *South African Journal of Psychology*, 25 (1), 27-30.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

- Schneiderman, N., Ironson, G., & Siegel, S. D. (2005). Stress and Health: psychological, behavioural and biological determinants. *Annual Review of Clinical Psychology, 1*, 607-628.
- Schnurr, P. P. (2013). The Changed Face of PTSD Diagnosis. *Journal of traumatic stress, 26* (5), 535-536.
- Scott-Sheldon, L. A. J., Kalichman, S. C., Carey, M. P., & Fielder, R. L. (2008). Stress management interventions for HIV+ Adults: A meta-analysis of randomised controlled trials, 1989 to 2006. *Health Psychology, 27* (2), 129-139.
- Seale, A. (2004). Breaking the cycle of HIV/AIDS-related stigma and discrimination: Addressing stigma. *Journal of Sexual Health, 2*, 2.
- Seedat, S., (2004). Trauma exposure and post-traumatic stress symptoms in urban African schools. *The British Journal of Psychiatry, 184*, 169-175.
- Seedat, S. (2012). *Interventions to improve psychological functioning and health outcomes of HIV-infected individuals with a history of trauma or PTSD. Current HIV/AIDS report. Current HIV/AIDS Report*. Retrieved December 06, 2012, from <http://www.ncbi.nlm.nih.gov/pubmed/23007792>. DOI 10.1007/s11904-012-0139-3.
- Seekings, J., & Nattrass, N. (2006). *Class, Race, and Inequality in South Africa*. Durban: UKZN Press, James Heintz. Originally published in 2005 by Yale University Press
- Seeley, J., Russell, S., Khana, K., Ezati, E., King, R., & Bunnell, R. (2009).

HIV, PTSD AND TRAUMATIC LIFE EVENTS

- Sex after ART: sexual partnerships established by HIV-infected persons taking anti-retroviral therapy in Eastern Uganda. *Culture, health & sexuality*, 11 (7), 703-716.
- Segal, D. L., Maxfield, M., & Coolidge, F. L. (2008). Diagnostic interviewing. In M. Hersen & A. M. Gross (Eds.), *Handbook of clinical psychology, Vol. I: Adults* (pp. 371–394). Hoboken, NJ: Wiley.
- Shabalala, T. S. (2001). *Once you reveal that you are HIV positive they only see you as the virus itself: Experiences of women living with HIV/AIDS in Gauteng, South Africa*. Paper presented in the Aids in Context conference 4 -7 April. University of Witwatersrand, Johannesburg.
- Shapiro, K., & Ray, S. (2007). Sexual health for people living with HIV. *Reproductive health matters*, 15 (29), 67-92.
- Sharma, N. (2007). *HIV-AIDS in women and Children of India*. Delhi: Pearl
- Shaw, R. (2001). Why use Interpretative Phenomenological Analysis in Health psychology. *Health Psychology Update*, 10 (4), 48-52.
- Shih, M. (2004). Positive stigma: examining resilience and empowerment in overcoming stigma. *Annals of American Academy of Political and Social Sciences*, 591, 1175-1185.
- Shipherd, J. C., & Beck, J. G. (1999). The effects of suppressing trauma-related thoughts in women with rape-related post-traumatic stress disorder. *Behaviour Research and Therapy*, 37, 99–112.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

- Shisana, O., Rehle, T., Simbayi, L. C., Zuma, K., Jooste, S., Pillay-van-Wyk, V., ... the SABSSM III Implementation Team. (2009). *South African national HIV prevalence, incidence, behaviour and communication survey 2008: A turning tide among teenagers?* Cape Town: HSRC Press
- Shisana, O., & Simbayi, L. (2002). *Nelson Mandela/HSRC Study of HIV/AIDS: South African national HIV prevalence, behavioural risks and mass media, household survey, 2002*. Cape Town South Africa: Human Sciences Research Council.
- Simbayi, L. C., Kalichman, S., Strebel, A., Cloete, A., Henda, N., & Mqeketo, A. (2007). Internalized stigma, discrimination, and depression among men and women living with HIV/AIDS in Cape Town, South Africa. *Social Science and Medicine*, *64*, 1823–1831.
- Simbayi, L. C., Skinner, D., Letlape, L., & Zuma, K. (2005). Workplace policies in public education. A review focusing on HIV AND AIDS. Retrieved July 9, 2011, from <http://www.hsrbpress.ac.za>
- Simons, J. S., & Gaher, R. M. (2005). The Distress Tolerance Scale: Development and validation of a self-report measure. *Motivation and Emotion*, *29*, 83–102.
- Siyam'kela, (2004). *Siyam'kela: Measuring HIV/AIDS related stigma*. A joint project of the POLICY project, South Africa; Centre for the study of AIDS, University of Pretoria; United States Agency for International Development (USAID); and Chief Directorate: HIV/AIDS and TB,

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Department of Health, March. Retrieved August 17, 2012, from www.policyproject.com

Smith, D. (2010). South African unions suspend public sector strike. Relief for hospitals and schools as staff go back to work, but unions say their demands have still not been met. *The Guardian, Monday 6 September 2010*. Retrieved September 12, 2012, from <http://www.guardian.co.uk/world/2010/sep/06/south-africa-strike-suspended>

Smith, J. A. (1995). Semi-structured interviewing and qualitative analysis. In J. Smith, R. Harre & L. Van Langenhove (Eds.), *Rethinking Methods in Psychology*. London: SAGE.

Smith, J. A. (1996). Beyond the divide between cognition and discourse: using interpretative phenomenological analysis in health psychology. *Psychology and Health, 11*, 61-271.

Smith, J. A. (1999). Towards a relational self: social engagement during pregnancy and psychological preparation for motherhood. *British Journal of Social Psychology, 38*, 409-426.

Smith, J. A. (2004). Reflecting on the development of interpretive phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative Research in Psychology, 1*, 39-54.

Smith, J. A., & Dunworth, F. (2003). Qualitative Methodology. In K. Connolly and J. Valsiner (Eds.), *The handbook of developmental psychology*. London: SAGE.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

- Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: theory, method and research*. Los Angeles: Sage.
- Smith, J. A., Harré, R., & Van Langenhove, L. (Eds.), (1995). *Rethinking psychology*. London: Sage.
- Smith, J. A., Jarman, M., & Osborne, M. (1999). Doing interpretative phenomenological analysis. In M. Murray & K. Chamberlain (Eds.), *Qualitative Health Psychology: Theories and Methods*. SAGE.
- Smith, J. A., & Osborn, M. (2003). Interpretative Phenomenological Analysis. In Smith (Ed.), *Qualitative Psychology, a practical guide to research methods*. London, Sage Publishers.
- Smith, J.A. & Osborn, M. (2004). Interpretative phenomenological analysis. In G. Breakwell (Ed.), *Doing social psychology* (pp.229–254). Oxford: Blackwell.
- Smith, J. A., & Osborn, M. (2008). Interpretative phenomenological analysis. In Smith JA (Ed.), *Qualitative psychology: a practical guide to research methods, 2nd edition*. pp 53-80. London: Sage.
- Smith, M. Y., Redd, W., Peyser, P., & Vogl, J. (1999). Post-Traumatic Stress Disorder in cancer: a review. *Journal of Psycho-Oncology*, 8, 521-537.
- Smith, E. R., & Semin, G. R. (2007). Situated social cognition. *Current Directions in Psychological Science*, 16 (3), 132-135.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

South Africa HIV and AIDS Statistics (n.d.). Retrieved June, 19, 2012, from www.avert.org/south-africa-hiv-aids-statistics.htm

Springer, S. A., Dushaj, A., & Azar, M. M. (2012). The Impact of DSM-IV Mental Disorders on Adherence to Combination Anti-retroviral Therapy Among Adult Persons Living with HIV/AIDS: A Systematic Review. *Journal of AIDS Behaviour, 16* (8), 2119–2143. doi: 10.1007/s10461-012-0212-3

Srivastav, V. P. (2006). *HIV/AIDS and Human Rights*. Delhi: Indian Publishers distributors.

Statistics South Africa. (2011). Retrieved September 15, 2012, from <http://www.statssa.gov.za/publications/P0341/P03412011.pdf>

Stein, D. J., Seedat, S., Herman, A., Moomal, H., Heeringa, S., Kessler, R. C., & Williams, D. R. (2008). Lifetime prevalence of psychiatric disorders in South Africa. *British Journal of Psychiatry, 192* (2), 112-117.

Stein, D. J., Seedat, S., & Emsley, R. A. (2005). HIV/AIDS in Africa – A role for the mental health practitioner? *South African Medical Journal, 95* (3), 166-167.

Steinberg, J. (1999). Crime: Beyond 2000. *Siyaya, Issue 4, Autumn*, 47-49. Idasa: Cape Town.

Strydom, H. (2002). Ethical aspects of research in the social sciences and human services professions. In A. S. de Vos, H. Strydom, C.B Fouche., & C. S. L. Delport. (Eds.), *Research at Grassroots: a primer for the social*

HIV, PTSD AND TRAUMATIC LIFE EVENTS

- sciences and human service professions*, 62-76. Pretoria: Van Schaik Publishers.
- Stutterheim, S. (2011). *Understanding HIV-related Stigma, Social and Psychological processes*. F & N Boekservice: Amsterdam.
- Stutterheim, S. E., Pryor, J. B., Bos, A. E., Hoogendijk, R., Muris, P., & Schaalma, H. P. (2009). HIV-related stigma and psychological distress: The harmful effects of specific stigma manifestations in various social settings. *AIDS*, 23 (17), 2353-2357.
- Suhrcke, M. (2005). Young people and HIV/AIDS: awareness and attitudes. *Common Health*, 11, 53-58.
- Summerfield, D. (1995). Addressing human response to war and atrocity: Major challenges in research and practices and the limitations of Western psychiatric models. *Beyond trauma: Cultural and societal dynamics*, 17-29.
- Summerfield, D. (1999). A critique of seven assumptions behind psychological trauma programmes in war-affected areas. *Social science & medicine* (1982), 48 (10), 1449.
- Summerfield, D. (2001). The invention of post-traumatic stress disorder and the social usefulness of a psychiatric category. *BMJ: British Medical Journal*, 322 (7278), 95.
- Tabacknick, B. G. & Fidell, L. S. (2007). *Using multivariate statistics* (5th edition). Allyn & Bacon.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Tacon (2012). PTSD in the context of malignant disease. Retrieved on

January 26, 2012, from

www.intechopen.com/source/pdfs/26613/InTech_Ptsd_in_the_context_of_malignant_disease.pdf

Talbert, F., Wagner, P., Braswell, L & Husein, S., (1995). Analysis of Long-term Stress Reactions in Emergency Room Patients, An Initial Study.

Journal of Clinical Psychology in Medical Settings, 2 (2), 133-148.

The American Heritage Stedman's Medical Dictionary. Retrieved June, 06, 2012, from Dictionary.com website:

<http://dictionary.reference.com/browse/trauma>

Theuninck, A. C., Lake, N., & Gibson, S. (2010). HIV-related post-traumatic stress disorder. Investigating the traumatic events. *AIDS Patient Care and STD's*, 24, 485-491.

Thom, R., (2008). *Depression and Anxiety in HIV Infected Individuals Attending HIV treatment facilities at various sites in South Africa: Occurrence and Related Factors. A Descriptive-Analytic Study.* (Unpublished Thesis). University of Witwatersrand, 2008.

Thorpe, J. (2010). *Victim Empowerment South Africa: Latest statistics, South Africa Remains a Violent Country.* Retrieved September 18, 2012, from <http://victimempowermentsa.wordpress.com/2010/09/14/latest-crime-statistics-south-africa-remains-a-violent-country/>

Thrasher, S., & Dalgleish, T. (1999). *The use of information-processing paradigms to investigate post-traumatic stress disorder: A review of the*

HIV, PTSD AND TRAUMATIC LIFE EVENTS

evidence. Wiley series in clinical psychology. (pp. 176-192). New York, NY, US: John Wiley & Sons Ltd.

Timberg, C. (2005, January 14). In S. Africa, stigma magnifies pain of AIDS. *The Washington Post*. Retrieved July, 21, 2012, from <http://www.washingtonpost.com/wp-dyn/articles/A7822-2005Jan13.html>

Tsao, J., Dobalian, A., Moreau, C., & Dobalian, K. (2004). Stability of Anxiety and Depression in a National Sample of Adults With Human Immunodeficiency Virus. *Journal of Nervous and Mental Disease*, 192 (2), 111-118.

Tull, M. (2013). *Rumination*. Retrieved September 08, 2013, from <http://ptsd.about.com/od/glossary/g/ruminate.htm>

Tull, M., (2012). *PTSD and HIV/AIDS*. Published January 29, 2012. Retrieved June 17, 2012, from <http://ptsd.about.com/od/relatedconditions/a/PTSDandHIV.htm>

Ullrich, P., Lutgendorf, S., & Stapleton, J. (2002). Social constraints and depression in HIV infection: effects of sexual orientation and area of residence. *Journal of Social and Clinical Psychology*, 21 (1), 46 – 66.

UNAIDS. (2000). *Opening up the HIV/AIDS epidemic: guidance on encouraging beneficial disclosure, ethical partner counselling & appropriate use of HIV case-reporting*. Geneva, Joint United Nations Programme on HIV/AIDS. Retrieved October 30, 2010, from http://whqlibdoc.who.int/unhcr/2000/UNAIDS_00.42E.pdf

HIV, PTSD AND TRAUMATIC LIFE EVENTS

UNAIDS. (2006, December). *Aids Epidemic Update*. Retrieved March 29, 2007, from http://www.unaids.org/en/HIV_data/epi2006/default.asp.

UNAIDS. (2007). *Inter-Parliamentary Union, UNDP. Taking Action against HIV*. A handbook for parliamentarians. No 15/2007.

UNAIDS. (2008). *2008 Report on the global AIDS epidemic* (No. 08.25E/JC1510E). Geneva, Switzerland: UNAIDS.

UNAIDS (2009). *AIDS Epidemic Update. Joint United Nations Programme on HIV/AIDS (UNAIDS) and World Health Organization (WHO) 2009*.

Retrieved November 20, 2011, from

http://www.unaids.org/en/media/unaids/contentassets/dataimport/pub/report/2009/jc1700_epi_update_2009_en.pdf

UNAIDS. (2010). *UNAIDS report on the global AIDS epidemic*. Retrieved September 10, 2012, from

http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2010/20101123_globalreport_en%5B1%5D.pdf

UNAIDS. (2011). Press Release: *Nearly 50% of people who are eligible for anti-retroviral therapy now have access to lifesaving treatment*. Retrieved April 16, 2012, from

www.unaids.org/en/media/unaids/contentassets/documents/pressrelease/2011/11/20111121_PR_WAD2011_Report_en.pdf

United Nations (1995). *Report of the World Summit for Social Development: Copenhagen, 6-12 March 1995*. Retrieved March 15th, 2013, from

<http://www.un.org/documents/ga/conf166/aconf166-9.htm>

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Van Den Heuval, L., Chishinga, N., Kinyanda, E., Weiss, H., Patel, V.,

Ayles, H., ... Seedat, S. (2013). Frequency and correlated off anxiety and mood disorders among TB- and HIV-infected Zambians. *Aids Care: Psychological and Social Aspects of AIDS/HIV*.

Psychological and Social Aspects of AIDS/HIV.

Doi:10.1080/09540121.2013.793263

Van Der Kolk, B. A. (1996). The complexity of adaption to trauma. In B. A.

Van Der Kolk, A. C. McFarlane, & L. Weisaeth. (Eds.), *Traumatic stress:*

The effects of overwhelming experience on mind, body and society. New

York: Guilford Press.

Van Dyk, A. C. (2001). *HIV/AIDS Care and Counselling: A multidisciplinary*

approach (2nd Ed). Cape Town. Pearson Education.

Van Dyk, A. C., & Van Dyk, P. J. (2003). "What is the point of knowing?"

Psychosocial barriers to HIV/AIDS voluntary counselling and testing

programmes in South Africa. *South African Journal of Psychology*, 33 (2),

118-125.

Van Etten, M. L., & Taylor, S. (1998). Comparative efficacy of treatments

for post-traumatic stress disorder: A meta-analysis. *Clinical Psychology*

and Psychotherapy, 5, 126-144.

Vance, D. E., & Woodley, R. A. (2008). Spiritual Expressions of Coping in

Adults with HIV: Implications for Successful Aging. *Journal of Religion,*

Disability and Health, 12 (1), 37-57.

Vella, V., Govender, T., Dlamini, S., Taylor, M., Moodley, I., David, V., &

Jinabhai, C., (2008). Evaluation of the anti-retroviral therapy in KwaZulu-

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Natal, South Africa. Retrieved June 27, 2012, from

<http://www.sudafrica.cooperazione.esteri.it/utlSudafrica/IT/download/pdf/Italian%20Cooperation%20Economic%20evaluation%20of%20ART%20in%20KZN.pdf>

Vermeer, W., Bos, A. E., Mbwambo, J., Kaaya, S., & Schaalma, H. P. (2009).

Social and cognitive variables predicting voluntary HIV counseling and testing among Tanzanian medical students. *Patient Education and Counselling*, 75 (1), 135-140.

Visser, M. J., & Forsyth, B. W. (2009). Addressing HIV-related stigma.

Visser, M. J., Kershaw, T., Makin, J. D., & Forsyth, B. W. C. (2008).

Development of parallel scales to measure HIV-related stigma. *Journal of AIDS and Behavior*, 12 (5), 759 - 771.

Visser, M. J., Makin, J. D., & Lehobye, K. (2006). Stigmatizing attitudes of

the community towards people living with HIV/AIDS. *Journal of Community & Applied Social Psychology*, 16 (1), 42-58.

Vrana, S., & Lauterbach, D. (1994). Prevalence of traumatic events and post-

traumatic psychological symptoms in a non-clinical sample of college students. *Journal of Traumatic Stress*, 7 (2), 289-302.

Weathers. F. W., & Keane, T. M. (2007). The criterion A problem revisited:

Controversies and challenges in defining and measuring psychological trauma. *Journal of Traumatic Stress*, 20, 107-121.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

- Weaver, R. (2004). *Reaching out? Donor approaches to Faith Based Organisations in response to HIV/AIDS*. Middelsex: Tearfund.
- Weinel, E. (1990). Long-term psychotherapy of HIV-patients: Indications and experiences. Retrieved October 10, 2011, from <http://www.aegis.org/aidsline/1990/dec/m90c1751.html>
- Weiss, D. S., & Marmar, C, D. (1997). The Impact of Event Scale-Revised. In J. P. Wilson & T. Keane (Eds.), *Assessing psychological trauma and PTSD*. New York: Guilford Press.
- Weiss, M. G., Ramakrishna, J., & Somma, D. (2006). Health-related stigma: Rethinking concepts and interventions 1. *Psychology, Health & Medicine, 11* (3), 277-287.
- Wells, A., & Matthews, G. (1994). *Attention and emotion: A clinical perspective*. Lawrence Erlbaum Associates, Inc
- Wengraf, T. (2001). *Qualitative research interviewing*. London: Sage.
- Whetten, K., Reif, S., Whetten, R., & Murphy-McMillan, L. K. (2008). Trauma, mental health, distrust, and stigma among HIV-positive persons: Implications for effective care. *Journal of Psychosomatic Medicine, 70*, 531-538.
- WHO. (2001). *Fact sheet: Women and HIV/AIDS*. Retrieved 10, August 2008, from <http://www.who.int/mip2001/files/2271/242-WomenandHIVAIDSforMIP.pdf>.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

- WHO. (2002). *Integrating Gender into HIV/AIDS Programmes*. Retrieved 15 September, 2012, from http://www.who.int/gender/hiv_aids/hivaids1103.pdf
- WHO. (2009). *AIDS epidemic update*. Retrieved November 8, 2010, from http://data.unaids.org/pub/FactSheet/2009/20091124_FS_global_en.pdf
- Williams, A. B., Burgess, J. D., Danvers, K., Malone, J., Winfield, S. D., & Saunders, L. (2005). Kitchen Table Wisdom: A Frierian Approach to Medication Adherence. *Journal of the Association of Nurses in AIDS Care, 16*, (1), 3-12.
- Williams, D. R., Herman, A., Kessler, R. C., Sonnega, J., Seedat, S., Stein, D. J., ... Wilson, C. M. (2004). The South Africa Stress and Health study: rationale and design. *Metabolic brain disease, 19* (1-2), 135-147.
- Williams, S. L., Williams, D. R., Stein, D. J., Seedat, S., Jackson, P. B., & Moomal, H. (2007). Multiple Traumatic Events and Psychological Distress: The South Africa Stress and Health Study. *Journal of Traumatic Stress, 20* (5), 845–855. doi: 10.1002/jts.20252
- Willig, C. (2001). *Introducing Qualitative Research in Psychology: Adventures in theory and method*. Philadelphia: Open University
- Wingwood, G. M., Reddy, P., Peterson, S. H., Di Clemente, R. J., Moguduka, C., Braxton, N., & Mbewu, A. D. (2008). HIV stigma and mental health status among women living with HIV in the Western Cape, South Africa. *South African Journal of Science, 104*, (5-6).

HIV, PTSD AND TRAUMATIC LIFE EVENTS

- Withell, B. (2000). A study of the experiences of women living with HIV/AIDS in Uganda. *International Journal of Palliative Nursing*, 6 (5), 234-244.
- Wong, L. H., Van Rooyen, H., Modiba, P., Richter, L., Gray, G., McIntyre, J. A., ... Coates, T. (2009). Test and tell: correlates and consequences of testing and disclosure of HIV status in South Africa (HPTN 043 Project Accept). *Journal of acquired immune deficiency syndromes (1999)*, 50 (2), 215.
- World Health Organization. (1992). International Classification of Mental and Behavioural Disorders: ICD-10. *Geneva, Ill: WHO*.
- World Health Organisation. (1997). *Composite international diagnostic interview, version 2.1*. Geneva: WHO.
- Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and Health*, 15, 215-228.
- Yehuda, R. (1999). Biological factors associated with susceptibility to post-traumatic stress disorder. *Canadian Journal of Psychiatry*, 44 (1), 21-32.
- Young, C. (2011). Understanding HIV-related post-traumatic stress disorder in South Africa: a review and conceptual framework. *African Journal of AIDS Research*, 10 (2), 139-148.
- Young, J. E., Klosko, J. S., & Weishaar, M. E. (2003). *Schema therapy: A practitioner's guide*. Guilford Press.

APPENDIX A**RESEARCH TITLE: HIV, Traumatic Life Events and Symptoms of PTSD****PARTICIPANT LEAFLET AND CONSENT FORM**

You have been asked to participate in this study due to your HIV-positive status and your attendance to the G J Crookes VCT clinic. Your participation is voluntary and you are free to decline to participate at any time. You are free to withdraw from the study at any time.

Aims: The purpose of the study is to examine the psychological consequences of living with HIV as well as explore the possible traumatic life events which you may have had in your lifetime. I hope that the information gained in this research will help people to better understand the symptoms of people who have been diagnosed and are living with HIV, this will hopefully contribute to a more holistic treatment approach in the future.

The study will be conducted at G J Crookes Hospital using voluntary participants from the VCT clinic. The study will be run over one month and hopes to recruit 150-200 participants.

Procedure: As a participant you will be asked to participate in an interview which will enquire about any traumatic or shocking life events which may have happened in the past and how they have impacted on your life. I will also be asking questions about your experiences of living with HIV and the effects that this has on your life now.

Risks: The questions are of a personal nature and may remind you of some upsetting events. However, the interview will be conducted by myself, a Clinical Psychologist, and you are free and encouraged to discuss and speak about any discomfort or problems which may arise. Should you feel the need to discuss this more after the interview a formal session will be scheduled with either myself or an alternative Clinical Psychologist. If at any time you would like to stop participating in this research you are free to do so.

Costs: There are no financial costs directly associated with participation in this study

Benefit: Individuals who suffer from PTSD will receive intervention and appointments will be booked with one of two hospital psychologists. In addition you will be benefiting researchers, doctors, psychologists and other medical professionals in allowing us to see what symptoms manifest. If you wish, you will be informed of the results of this study when it has been completed.

Confidentiality: No personal details such as your name, where you live or who you are will be divulged. All material will be kept strictly confidential by the Clinical Psychologist conducting this study.

Disclaimer/Withdrawal: You agree that your participation in this study is completely voluntary and that you may withdraw from the study at any time during the interview. If you have any questions you are free to ask the Clinical Psychologist (Melissa Boulind) conducting the study by calling 039 978 7098, or by coming to G J Crookes Hospital and setting up an appointment. You acknowledge that you have been given an opportunity to ask questions and they have been answered to your satisfaction.

Conclusion: The research has been explained to me. I agree to participate in the research study.

Signature of Participant

Date

HIV, PTSD AND TRAUMATIC LIFE EVENTS

APPENDIX B**INTAKE QUESTIONNAIRE****DEMOGRAPHIC DATA:**

Name

Age.....Ethnicity.....

Home LanguageMarital status

Last grade completed at schoolOccupation

Family structure and circumstances

MEDICAL DATA:

CD 4 count

Symptoms noted by doctor

PERSONAL:

When did you find out you were HIV positive?

How did you find out you were HIV positive?

Have you told your family and friends about diagnosis? Explain...

Are you willing to meet for a follow up discussion?

If yes, please provide contact details

HIV, PTSD AND TRAUMATIC LIFE EVENTS

APPENDIX C

PTSD MODULE OF THE COMPOSITE INTERNATIONAL DIAGNOSTIC INTERVIEW

INSTRUCTIONS: I would like to ask you about some extremely stressful of upsetting events that sometimes occur to people.

Ask Questions 1 -11 and code the answers in column 1

		Column 1		Column 2	
		No	Yes	No	Yes
1	Did you ever have direct combat experience in war?	1	5	1	5
2	Were you ever involved in a life threatening accident?	1	5	1	5
3	Were you ever involved in a fire, flood or other natural disaster?	1	5	1	5
4	Did you ever witness someone being badly injured or killed?	1	5	1	5
5	Were you ever raped, that is someone had sexual intercourse with you when you did not want to, by threatening you or using some degree of force?	1	5	1	5
6	Were you ever sexually molested, that is someone touched or felt your genitals when you did not want them to?	1	5	1	5
7	Were you ever seriously physically attacked or assaulted?	1	5	1	5
8	Have you ever been threatened with a weapon, held captive or kidnapped?	1	5	1	5
9	Have you ever been tortured or the victim of terrorists?	1	5	1	5
10	Have you ever experienced any other extremely stressful or upsetting event? Description:	1	5	1	5
If the other events in 10 are bereavement, chronic illness, business loss, marital or family conflict, book, movie or television, code 1. Others code 5.					
11	Have you ever suffered a great shock because one of the events on the list happened to someone close to you? If yes, ask briefly what was the event that you found most stressful or upsetting when it happened to someone close to you? Description:	1	5	1	5
If the other events in 11 are bereavement, chronic illness, business loss, marital or family conflict, book, movie or television, code 1. Others code 5.					

If there are no 5's in column 1 you can end the questionnaire.

If there is only one 5 in column 1, code 5 for that event in column 2 and skip the next question and ask **Question 12**. If there are others skip to **Question 13**.

HIV, PTSD AND TRAUMATIC LIFE EVENTS

12a: You mentioned that you have experienced (event coded 5 in column 1). Did this happen only once in your lifetime or more than once? If once, skip to **Question 13**. If there are others ask: of these times was one of them more stressful and upsetting than the others?

12b: You said that you have experienced (events coded 5 in column 1). Of those events, which was the most stressful or upsetting? Code 5 for that event in Column 2.

13 For the event coded 5 in column 2 ask: How old were you when (event) happened?

Age: _____

14 For the event coded 5 in column 2 ask: When it happened, did you feel terrified?

NO.....1

YES.....5

15 For the event coded 5 in column 2 ask: When (event) happened, did you feel helpless?

NO.....1

YES.....5

Now I would like to ask you about the time after the stressful or upsetting experience happened to you.

Ask 16 to 25 for the event coded 5 in column 2.

16 Did you keep remembering (event) when you didn't want to?

NO.....1

YES.....5

17 After it, did you keep having bad dreams or nightmares about it?

NO.....1

YES.....5

18 Did you suddenly act or feel as though (the event) was happening again even though it wasn't?

NO.....1

YES..... 5

19 Did you get very upset when you were reminded of it?

NO.....1

YES.....5

20 Did you sweat or did your heart beat fast or did you tremble when you were reminded of (the event)?

NO.....1

YES.....5

HIV, PTSD AND TRAUMATIC LIFE EVENTS

21 After (the event) did you have trouble sleeping?

NO.....1 **YES.....5**

22 After it, did you feel unusually irritable or lose your temper a lot more than is usual for you?

NO.....1 **YES.....5**

23 After it, did you have trouble concentrating?

NO.....1 **YES.....5**

24 After (the event) did you become very much more concerned about danger or very much more careful?

NO.....1 **YES.....5**

25 After (the event) did you become jumpy or easily startled by ordinary noises or movements?

NO.....1 **YES.....5**

If 16 to 25 all coded a 1 then discontinue the questionnaire

26 Did you deliberately try not to think or talk about (the event)?

NO.....1 **YES.....5**

27 Did you avoid places or people or activities that might have reminded you of it?

NO.....1 **YES.....5**

28 After (the event) was your memory blank for all or part of (the event)?

NO.....1 (skip to Question 29) **YES.....5**

If the event coded 5 in column 2 is the witness of an accident (Question 4) or events happened to relatives or friends (Question 11), skip to Question 29

Otherwise ask:

Did you suffer a head injury as a result of (the event)?

NO.....1 **YES.....5**

Were you unconscious for more than ten minutes?

NO.....1 **YES.....5**

HIV, PTSD AND TRAUMATIC LIFE EVENTS

29 After (the event) did you lose interest in doing things that were once important or enjoyable for you?

NO.....1

YES.....5

30 After (the event) did you feel more isolated or distant from other people?

NO.....1

YES.....5

31 After (the event) did you find that you had more difficulty experiencing normal feelings such as love or affection towards other people?

NO.....1

YES.....5

32 After (the event) did you begin to feel that there was no point in thinking about the future anymore?

NO.....1

YES.....5

If Questions 26 to 32 all coded 1 discontinue the questionnaire.

33 You said that you had problems after (the event) like (symptoms which coded 5 in questions 16-22). How soon after (the event) did you start to have any of these problems?

Code the lowest number

SAME DAY1

THAT WEEK2

THAT MONTH3

WITHIN 6 MONTHS4

WITHIN 1 YEAR5

MORE THAN 1 YEAR6

If more than 1 year ask: how old were you?

Age_____

34 How long did you continue to have any of these problems because of (the event)?

Code the lowest number

SAME DAY1

THAT WEEK2

THAT MONTH3

WITHIN 6 MONTHS4

WITHIN 1 YEAR5

MORE THAN 1 YEAR6

HIV, PTSD AND TRAUMATIC LIFE EVENTS

35 When was the last time you had any of these problems as a result of (the event)?

Code the lowest number

SAME DAY	1
THAT WEEK	2
THAT MONTH	3
WITHIN 6 MONTHS	4
WITHIN 1 YEAR	5
MORE THAN 1 YEAR	6

Age _____

36 Did you tell a doctor about the problems that occurred as a result of (the event)?

NO.....**1** **YES**.....**5** **(skip to 2)**

Did you tell any other professional?

NO.....**1** **YES**.....**5**

Did you take medication, or use drugs or alcohol more than once for the problems which occurred as a result of it?

NO.....**1** **YES**.....**5**

Did the problems which occurred as a result of (the event) interfere with your life activities a lot?

NO.....**1** **YES**.....**5**

37 Have you ever been very upset with yourself for having the problems which occurred as a result of (the event)?

NO.....**1** **YES**.....**5**

38 Have the problems which have occurred as a result of (the event) ever kept you from going to a party, social event or meeting?

NO.....**1** **YES**.....**5**

HIV, PTSD AND TRAUMATIC LIFE EVENTS

APPENDIX D

AMMENDED PTSD MODULE OF THE COMPOSITE INTERNATIONAL DIAGNOSTIC INTERVIEW FOR HIV (HIV-PTSD)

INSTRUCTIONS: I am now going to ask you some questions around your reactions to hearing that you were HIV-positive and to being HIV-positive.

-
1. After hearing that you were HIV-positive did you keep remembering that you were positive even when you didn't want to?

NO.....1

YES.....5

2. After hearing that you were HIV-positive did you keep having bad dreams or nightmares about it?

NO.....1

YES.....5

3. Did you get very upset when you were reminded being positive?

NO.....1

YES.....5

4. Did you sweat or did your heart beat fast or did you tremble when you were reminded of being HIV-positive ?

NO.....1

YES.....5

5. After hearing that you were HIV-positive did you have trouble sleeping?

NO.....1

YES.....5

6. After hearing that you were HIV-positive, did you feel unusually irritable or lose your temper a lot more than is usual for you?

NO.....1

YES.....5

7. After hearing that you were HIV-positive, did you have trouble concentrating?

NO.....1

YES.....5

8. After hearing that you were HIV-positive did you become very much more concerned about danger or very much more careful?

NO.....1

YES.....5

HIV, PTSD AND TRAUMATIC LIFE EVENTS

9. After hearing that you were HIV-positive did you become jumpy or easily startled by ordinary noises or movements?

NO.....1

YES.....5

10. After hearing that you were HIV-positive Did you deliberately try not to think or talk about this fact?

NO.....1

YES.....5

11. Did you avoid places or people or activities that might have reminded you that you were HIV-positive?

NO.....1

YES.....5

12. After the consultation where you were told you were HIV-positive was your memory blank about this consultation?

NO.....1

YES.....5

13. After hearing that you were HIV-positive did you lose interest in doing things that were once important or enjoyable for you?

NO.....1

YES.....5

14. After hearing that you were HIV-positive did you feel more isolated or distant from other people?

NO.....1

YES.....5

15. After hearing that you were HIV-positive did you find that you had more difficulty experiencing normal feelings such as love or affection towards other people?

NO.....1

YES.....5

16. After hearing that you were HIV-positive did you begin to feel that there was no point in thinking about the future anymore?

NO.....1

YES.....5

HIV, PTSD AND TRAUMATIC LIFE EVENTS

17. You said that you had problems after hearing that you were HIV-positive like (symptoms which coded 5 in questions 1-16). How soon after hearing that you were HIV-positive did you start to have any of these problems?

Code the lowest number

SAME DAY	1
THAT WEEK	2
THAT MONTH	3
WITHIN 6 MONTHS	4
WITHIN 1 YEAR	5
MORE THAN 1 YEAR	6

If more than 1 year ask: how old were you?

Age _____

18. How long did you continue to have any of these problems?

Code the lowest number

SAME DAY	1
THAT WEEK	2
THAT MONTH	3
WITHIN 6 MONTHS	4
WITHIN 1 YEAR	5
MORE THAN 1 YEAR	6

19. When was the last time you had any of these problems ?

Code the lowest number

SAME DAY	1
THAT WEEK	2
THAT MONTH	3
WITHIN 6 MONTHS	4
WITHIN 1 YEAR	5
MORE THAN 1 YEAR	6

20. Did you tell a doctor about the problems like the ones you have been telling me about being related to being HIV-positive?

NO.....1 **YES.....5**

1. Did you tell any other professional?

NO.....1 **YES.....5**

2. Did you take medication, or use drugs or alcohol more than once for the problems you have been telling me about?

NO.....1 **YES.....5**

3. Did the problems which you have just been telling me about interfere with your life or activities a lot?

NO.....1 **YES.....5**

HIV, PTSD AND TRAUMATIC LIFE EVENTS

21. Have you ever been very upset with yourself for having the problems which occurred as a result of being HIV-positive?

NO.....1

YES.....5

22. Have the problems which we have talked about ever kept you from going to a party, social event or meeting?

NO.....1

YES.....5

23. After hearing that you were HIV-positive did you feel terrified or fearful?

NO.....1

YES.....5

24. After hearing that you were HIV-positive did you feel helpless?

NO.....1

YES.....5

APPENDIX E**IMPACT OF EVENT SCALE – REVISED**

INSTRUCTIONS: Below is a list of difficulties people sometimes have after stressful life events. Please read each item and then indicate how distressing each difficulty has been for you **DURING THE PAST SEVEN DAYS** with respect to _____.

How much were you distressed or bothered by these difficulties?

Item response

0 = not at all; 1 = a little bit; 2 = moderately; 3 = quite a bit; 4 = extremely

	Item	0	1	2	3	4
1	Any reminder brought back feelings about it					
2	I had trouble staying asleep					
3	Other things kept making me think about it					
4	I felt irritable and angry					
5	I avoided letting myself get upset when I thought about it or was reminded of it					
6	I thought about it when I didn't mean to					
7	I felt as if it hadn't happened or wasn't real					
8	I stayed away from reminders of it					
9	Pictures about it popped into my head					
10	I was jumpy and easily startled					
11	I tried not to think about it					
12	I was aware that I still had a lot of feelings about it, but I didn't deal with them					
13	My feelings about it were kind of numb					
14	I found myself acting or feeling like I was back at that time					
15	I had trouble falling asleep					
16	I had waves of strong feelings about it					
17	I tried to remove it from my memory					
18	I had trouble concentrating					
19	Reminders of it caused me to have physical reactions, such as sweating, trouble breathing, nausea or a pounding heart					
20	I had dreams about it					
21	I felt watchful and on-guard					
22	I tried not to talk about it					

APPENDIX F

SAMPLE of IPA Transcript: Participant B

Theme	Transcript	Personal Thoughts
Death	<p><i>Clinician:</i> And in your life – what...what stressful things have happened to you?</p> <p><i>Participant B:</i> Stressful things that I have had before. The hardest thing my child that passed away. This year on March.</p> <p><i>Clinician:</i> This year</p> <p><i>Participant B:</i> Mmmm I found out that he was HIV positive</p> <p><i>Clinician:</i> Okay</p> <p><i>Participant B:</i> Because he was infected by me at birth</p> <p><i>Clinician:</i> Mmmm he got infected at birth?</p>	<p>Child dying – traumatic</p> <p>Fresh trauma – still grieving</p> <p>Volunteers story of how found out was HIV positive. Mother-child transmission. Traumatic, possibly feelings of guilt that she passed it on unknowingly.</p> <p>Anger at father</p> <p>Disappointment at him and herself</p>
Transmission	<p><i>Participant B:</i> Because I got it from his father – and he...he never told me. Then when I found out that what he gave us, I asked the father of the child that he knows about that and then he says he knows.</p> <p>And I asked him... you... he never told me</p> <p><i>Clinician:</i> Yeah</p>	<p>“questions – deliberate’ –why didn’t he tell her, frustration and exasperation.</p>
Feelings about HIV	<p><i>Participant B:</i> He said that he was afraid and very embarrassed</p> <p><i>Clinician:</i> Shoo, so you...</p>	<p>Feelings about HIV</p>
Religion	<p><i>Participant B:</i> I was angry with him – really angry, sometimes I cry a lot, and sometimes I pray to God that maybe it was supposed to happen.</p>	<p>Anger and forgiveness</p> <p>death</p> <p>Religion</p>
Mortality	<p>It was gonna going to happen anyway. Everybody dies when your time comes.</p> <p>You not die because you are HIV positive.</p> <p>You die when you come ...</p> <p><i>Clinician:</i> When your time has come. When your time has come...</p>	<p>Going to happen anyway – denial, trying to convince herself and me that it isn’t a big deal.</p> <p>Mortality – dying when time comes</p> <p>Acceptance - trying to convince me perhaps that</p>

HIV, PTSD AND TRAUMATIC LIFE EVENTS

<p>Acceptance</p> <p>Treatment</p> <p>Medication</p>	<p><i>Participant B:</i> I accept it, I... I accept it who I am. I am positive; it is a part of my life that I'm positive.</p> <p>I'm a normal person, I can be angry, I can be happy, just like a normal person. The... the thing is I have to take my treatment as it is prescribed by the doctor – every day</p> <p><i>Clinician:</i> It changes your life, hey?</p>	<p>she is normal. Idea that she can be happy. Fits with concept aspired to by interventions – stay happy and positive. Defending against her feelings</p> <p>Medication</p>
<p>Feelings</p>	<p><i>Participant B:</i> Yeah, but not so much. You have to accept that I, you... who you are, now this is who I am.</p> <p><i>Clinician:</i> What was your life like before you found out about the HIV?</p> <p><i>Participant B:</i> Most of it is still there, before it, um....I was dreaming to be a lawyer. Even now I'm studying.</p> <p><i>Clinician:</i> To be a lawyer?</p>	<p>Acceptance</p> <p>Who I am, no choice. Feeling of finality and fatality in her statement</p> <p>Studying – the future. Making plans and looking forward.</p>
<p>Medication</p>	<p><i>Participant B:</i> Yes, I'm in UNISA. So not much, it's just that now I have to take a lot of pills</p> <p><i>Clinician:</i> Yes</p> <p><i>Participant B:</i> That I'm not taking....</p> <p><i>Clinician:</i> That you weren't taking before?</p> <p><i>Participant B:</i> Yes, sometimes now I do get worried, but before, like with this thing. Because I didn't know that I was positive.</p> <p><i>Clinician:</i> Do you think about it a lot?</p>	<p>Change in routine/medication</p> <p>Thoughts, worries about it. Worries now as she knows that she is HIV positive. Before it didn't worry her as she didn't know.</p>
<p>Rumination</p>	<p><i>Participant B:</i> Sometimes yes – but not everyday</p> <p><i>Clinician:</i> Not everyday, why did you go to get tested?</p>	
<p>Sickness</p>	<p><i>Participant B:</i> I go get tested because my child was was terribly sick, so he was going to get tested. So I was... I had to get tested to, I am his mother. That's how I found out...</p> <p><i>Clinician:</i> Okay, so you went with your child to get tested...</p>	<p>Child ill resulting in both being tested – not voluntary test so to speak – tested by default as referred by doctor (obviously wasn't tested when she was pregnant).</p>

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Death	<p><i>Participant B:</i> He got cancer – that’s why he passed away.</p> <p><i>Clinician:</i> Ooooooh, okay.</p> <p><i>Participant B:</i> They can’t control the cancer, it was too hard to control because it was too long before they found it.</p> <p><i>Clinician:</i> How old was he when he died?</p> <p><i>Participant B:</i> 7 years, and he was in Grade 2</p>	<p>Child died of cancer?? Unclear if this was the real diagnosis or secondary to HIV. Cancer is a sociably acceptable death or disease.</p> <p>Death and loss, died so young</p> <p>To watch a child die and nothing you can do - traumatic</p>
Religion	<p><i>Clinician:</i> Shoo, very little hey,</p> <p><i>Participant B:</i> Yes, I was so very angry with God, trust me. The way that I don’t understand. He knows everything that I don’t know about. He knows me, the way that I don’t know myself, but He knows.....</p>	<p>Anger</p> <p>Religion, someone to blame and ask why. Why her... why her child. But accepts it</p>
Stigma	<p><i>Clinician:</i> He knows...</p> <p><i>Participant B:</i> So I must accept that he... he called him and then he answered him - go away. So, I have to accept it, I have to live. I have to pray, I have to concentrate for him, not for myself. Maybe he passed away, maybe for my sins. Maybe for the time has come when I passed away I will see him someday. I don’t know, but I’m accepting it.</p>	<p>Existential questions and explanations</p> <p>Feels responsible for his death but excuses it saying that god called him.</p> <p>Looking forward to seeing him when she dies.</p>
Death	<p><i>Clinician:</i> I see, that’s good. But after you found out about your status, how did your life change?</p> <p><i>Participant B:</i> Mmmm I was, I was stressed and, I was depressed. I lost a lot of weight because I was...</p>	<p>Stress, depression, physical changes-lost weight</p>
Mortality	<p><i>Clinician:</i> Really?</p> <p><i>Participant B:</i> Thinking about it, day and night.</p> <p><i>Clinician:</i> Really?</p> <p><i>Participant B:</i> I used to cry, I said: why did I get this disease? I never slept with anybody, I only had the one boyfriend. Why did God do this to me?</p>	<p>Recurrent thoughts, intrusive</p> <p>Symptoms of PTSD</p>
Religion	<p><i>Clinician:</i> Okay...</p>	<p>Emotional, questioning , Existential questions</p> <p>Why??</p>

HIV, PTSD AND TRAUMATIC LIFE EVENTS

Religion	<p><i>Participant B:</i> You know [pause] but, as the time comes I think that everybody got it. Not because it's a bad thing. Maybe God gave it, give it to me. I never went to church until that month but now I know that I have to go to church and pray to God.</p> <p><i>Clinician:</i> So now you are really looking after yourself?</p> <p><i>Participant B:</i> Yes.</p> <p><i>Clinician:</i> Does it make, does it make you feel any different. Does your body feel different... does your mind feel different. Do you feel any different because of the HIV?</p> <p><i>Participant B:</i> Yes, I feel a... lots... lots of things are different in my mind, because now... I know what if somebody says they I have AIDS, the HIV. I don't have to laugh about that. Before – before somebody said that I'm have the HIV I would say oh, oh, How? But now we do understand how does it feel.</p>	Religion
Social support	<p>It's important to know your status so that you can get a treatment so early...</p>	<p>Sees it as a punishment or saving/ potential calling – never went to church</p> <p>More compassionate towards other HIV-positive individuals and she feels she can understand them.</p> <p>She feels less stigma towards HIV now as she has it. Before when she found out about the HIV-status she would say oh, or laugh (probably being glad that it wasn't her)</p>
Stigma	<p><i>Clinician:</i> Mmmm...</p>	<p>Important to know your status and realises that her son dying due to not having access to</p>
Advice	<p><i>Participant B:</i> I understand lots of things. People they don't understand because they...they say that you have HIV because you have had many partners. No it's not about that ... Mmmm ummm.</p> <p>You have got to use condom when you go to... to... to go to become sexually ... maybe... maybe – what am I going to say... maybe it's like, I...I'm not married I can take the partner anytime. So I must be sure I'm using condoms ...</p>	<p>treatment allowed her to live as she gained access in time.</p> <p>Discussion re stigma and assumptions about sex and multiple partners.</p> <p>Advice re safe sex - condoms</p> <p>One partner, remaining faithful</p> <p>Importance of cd4 and monitoring prior to conception> practical concerns. Making something that should happen naturally into a scientific exercise.</p>



HEALTH
KwaZulu-Natal
UGU Health District

G J Crookes Hospital
DEPARTMENT OF
PSYCHIATRY/PSYCHOLOGY

P/Bag X5501 Scottburgh 4180
Tel: 039 978 7094

To Whom it May Concern

RE: Research into traumatic life events and PTSD by Melissa Jane Boulind

This letter serves to confirm that the Department of Psychiatry and Psychology support the research proposed by Ms Boulind.

For any additional queries please feel free to contact me on 082 905 1006 (Dr Lennart Eriksson).

Thank you

Dr L Eriksson
Psychiatrist

0399787094
0829051006