FACULTY OF HEALTH SCIENCES

UNIVERSITY OF CAPE TOWN

FACTORS ASSOCIATED WITH PSYCHOLOGICAL DISTRESS AMONG YOUTH AND ADULTS LIVING WITH HIV IN SOUTH AFRICA

BY

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DECLARATION

I, Nolusindiso Ncitakalo, present this thesis in fulfilment of the requirements for the degree of Doctor of Philosophy in the Department of Psychiatry and Mental Health, Faculty of Health Sciences, University of Cape Town. I hereby declare that the work on which this thesis is based is my original work both in concept and execution (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university. Ethical approval was obtained from Human Research Ethics Committee of the Faculty of Health Sciences at the University of Cape Town (HREC REF: 349/2017) (see Appendix A).

This thesis includes published and non-published papers. Rules for inclusion of the papers have been adhered to as per general provision 6.7 in the General Rules for the Degree of Doctor of Philosophy (PhD) of the University of Cape Town. I confirm that I have been granted permission by the University of Cape Town's Doctoral Degrees Board to include the four publications listed below in my PhD thesis. Where co-authorships are involved, the co-authors have agreed that I may include the publications.

The following four co-authored papers are formally included as part of the thesis:

1. Ncitakalo, N., Mabaso, M., Joska, J., & Simbayi, L. Prevalence and predictors of common mental disorders among people living with HIV in sub-Saharan Africa: A systematic review of the literature. (Submitted to the Journal of AIDS Research and Therapy).
2. Ncitakalo N, Mabaso M, Maduna V, Joska J, Simbayi L. Prevalence and Correlates of Psychological Distress Among HIV Positive Individuals in South Africa: Findings from the 2012 HIV National Household Survey. Journal of Psychology and Psychotherapy Research; 2019, 6: 30-40.
3. Ncitakalo, N, Mabaso, M., Joska, J., Simbayi, L. (2021). Factors associated with external HIV-related stigma and psychological distress among people living with HIV in South Africa. SSM - Population Health, 14.
4. Ncitakalo N, Sigwadhi LN, Mabaso M, Joska J, Simbayi L. Exploring HIV status as a mediator in the relationship of psychological distress with socio-demographic and health related factors in South Africa: findings from the 2012 nationally representative

population-based household survey. AIDS Res Ther. 2023 Feb 6;20(1):6. doi: 10.1186/s12981-022-00498-5. PMID: 36747255; PMCID: PMC9901137.

Appendix B is my letter of motivation to the Doctoral Degrees Board, which describes my contribution to each of the abovementioned publications. Moreover, Appendix C is the approval letter from the Doctoral Degrees Board to include each of the abovementioned publications in this thesis.

All papers were submitted to different journals in the style required by the different journals. However, for this thesis the referencing has been standardised.

Signature: Signed by candidate

Date: 16 October 2023

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ABSTRACT

Background

Mental disorders represent a growing public health challenge globally. Evidence shows that mental disorders like depression and anxiety are more prevalent in people living with HIV (PLHIV) than in the general population. South Africa carries the world's heaviest burden with 7.9 million people (14% of the population) living with HIV in 2017. However, there is limited literature on mental health disorders among PLHIV in South Africa particularly population-based cross-sectional studies, as most available evidence of mental disorders among PLHIV is from small-scale studies.

Studies have shown the relationship between mental disorders and HIV to be complex and bidirectional. The bidirectional nature of the relationship between mental disorders and HIV implies a complex relationship between factors associated with both health conditions where they co-exist. Improved understanding of the relationship between mental disorders, HIV and associated factors is important for designing interventions to mitigate the impact of both conditions among coinfected individuals.

In epidemiological surveys, the presence of common mental disorders may be measured in terms of caseness or through a set of defined questions known as an instrument or scale. While there is a relationship between psychological distress, depressive and the anxiety symptoms, psychological distress scales are usually slightly broad but capture construct. Studies that are attempting to describe the prevalence of anxiety and depression sometimes use measures of psychological distress as a proxy. In large epidemiological surveys, psychological distress measures are used, as opposed to smaller and clinical studies. Similarly for this study, psychological distress was measured by both depressive and anxiety symptoms.

Aim and objectives

The aim of this study was to explore the extent and effect of psychological distress among youth and adults with HIV in South Africa. The specific objectives were as follows: 1) To conduct a systematic review and meta-analysis of studies on prevalence and correlates of depressive and anxiety symptoms among PLHIV in Southern Africa; 2) To determine the prevalence of depressive and anxiety symptoms and associated risk factors among PLHIV in South Africa; 3) To explore the relationship between HIV-related stigma and psychological

distress among PLHIV in South Africa; 4) To explore the complex pathways linking HIV status as a mediator in the relationship of psychological distress with socio-demographic and health related factors in South Africa.

Methodology

Different sub-samples were used for each paper, depending on the focus or aim of the paper. For the first objective, the systematic review and meta-analysis followed the Preferred Reporting Items for Systematic Review and Meta-analysis (PRISMA) guidelines. To fulfil the second objective, descriptive statistics were used to summarize background characteristics of the study sample and the prevalence of psychological distress. Bivariate logistic regression analysis were used to assess the relationship between psychological distress and each explanatory variable. Additionally, statistically significant variables were entered into a multivariate logistic regression analysis to identify factors independently associated with psychological distress. For the third objective, bivariate and multivariate logistic regression models were used to identify factors associated with stigma among PLHIV with psychological distress. Lastly, generalised structural equation modelling (G-SEM) path analysis was used to explore the direct and indirect relationships of socio-demographic, health and HIV-related factors with psychological distress using HIV status as a mediator.

Findings

The results of this study were published in four papers, which constitute Chapters 2, 3, 4 and 5. Chapter 2, in the systematic review a total of 27 articles met the eligibility criteria out of the 467 articles. The overall pooled prevalence for depression was 23%, and anxiety was 15%. Prevalence of depressive and anxiety symptoms was significantly higher among females, separated or widowed, unemployed and older age. Additionally, depressive and anxiety symptoms were significantly associated with low income, low education, urban residence, low physical activity, violence and/or partner conflict exposure, lack of social support, stigma and alcohol in PLHIV. In Chapter 3, the prevalence of psychological distress was significantly higher among females (38.2%) than males (28.5%). Psychological distress was significantly associated with being female, low socio-economic conditions, low educational attainment, marital status (being divorced/ separated), unemployment, having chronic conditions, hazardous alcohol drinking and low social support. In Chapter 4, the findings showed that psychological distress among HIV positive individuals was 34.4% and of these, 37.9%

experienced high levels of HIV-related stigmatizing attitudes. Stigmatizing attitudes among PLHIV were significantly associated with no schooling/primary level education, incorrect knowledge about HIV and myths about HIV and never testing for HIV. In Chapter 5, the HIV positive status was shown to be a mediating factor. Psychological distress was significantly associated with female gender, not being married, having no education/primary level education, reproductive age group 25–49 years, 50 years and older, residing in urban areas, high risk drinkers, hazardous drinkers, ever testing for HIV and reporting of fair /poor self-rated health.

Conclusion

The systematic review and secondary analysis of the nationally representative population-based household survey confirmed that psychological distress, as measured by depressive and anxiety symptoms was associated with specific socio-demographic, socio-behavioural and HIV-related factors including stigma among PLHIV in South Africa. The findings also suggest that HIV positive status was a mediating factor in the relationship between psychological distress and identified covariates. These findings highlight the importance of integrated screening and management of psychological distress and HIV. Furthermore, the findings underscore the need for highly targeted interventions tailored for identified groups of PLHIV. Lastly, more longitudinal studies are needed to track changes and trends over time on factors associated with mental disorders and HIV and the impact of respective interventions.

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LIST OF ACRONYMS

AIDS	Acquired Immunodeficiency Syndrome
ART	antiretroviral treatment
AUDIT	Alcohol Use Disorder Identification Test
CDC	Centers for Disease Control and Prevention
CMD	Common Mental Disorders
DBS	dried blood spot
DBE	Department of Basic Education
DOH	Department of Health
DSM	Diagnostic and Statistical Manual of Mental Disorders
EA	Enumeration area
HIV	Human Immunodeficiency Virus
HREC	Human Research Ethics Committee
HSRC	Human Sciences Research Council
LAMIC	low- and middle-income country
MDD	major depressive disorder
PEPFAR	President's Emergency Plan for AIDS Relief
PLHIV	People Living with HIV
PTSD	post-traumatic stress disorder
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analysis
SEM	Structural equation model
SES	socio-economic status
SANAC	South African National AIDS Council
SANHANES	South African Health and Nutrition Examination Survey
SSA	Sub-Saharan Africa
STATA	Statistical Analysis Software
TB	Tuberculosis
UCT	University of Cape Town
UNAIDS	The Joint United Nations Programme on HIV/AIDS
UNICEF	United Nations Children's Fund
VP	Visiting Point
WHO	World Health Organisation

CHAPTER 1
INTRODUCTION

1.1 Background

Human immunodeficiency virus (HIV) infection constitutes a global pandemic with approximately 38.4 million people with HIV worldwide [1]. Recently, the global progress against HIV was negatively affected by instabilities such as the COVID-19 pandemic that have disrupted health services in most parts of the world and led some countries to reallocate their limited health resources away from the HIV response [2]. Nevertheless, continue to be a public health challenge in the most affected countries.

Most persons with HIV live in sub-Saharan Africa, and South Africa bears the burden of having the largest number of people living with HIV (PLHIV) in the world. Sub-Saharan Africa is home to only 12% of the global population, yet it accounts for 71% of the global burden of HIV infection [3]. Countries in both southern and eastern Africa account for about 80% of people living with HIV in the continent. South Africa alone accounted for over a quarter of the region's new infections in 2018 [3]. The prevalence of HIV in South Africa is one of the highest in the world, at nearly 18.3% of the adult population [4].

The latest data collected by UNAIDS shows that while new HIV infections fell globally in 2021, the drop was only 3.6% compared to 2020, which was the smallest annual reduction since 2016 [2]. These data showed that global progress against HIV is slowing rather than accelerating as the rate of new infections is not falling as fast as before. Despite advances in HIV prevention and treatment in recent decades, HIV continues to be one of the leading causes of disease burden and imposes a substantial public health challenge in countries in sub-Saharan Africa [4].

Furthermore, women and girls continue to be disproportionately affected by HIV. HIV prevalence among young women is reported to be three times more (9.1%) than that in young men (3.0%) of the same age group in sub-Saharan Africa [5]. This disparity was also observed and prominent among 15- to 49-year-olds, as the prevalence among women in this age group was two times higher (24.5%) than among men (12.1%) [5]. These reported inequalities within gender are stalling progress in the HIV response.

1.1.1 Defining mental disorders and psychological distress

Mental disorders are mental health conditions that are characterised by a clinically significant disturbance in an individual's cognition, perceptions, emotional regulation, or behaviour [6-8]. They are usually associated with distress or impairment in important areas of functioning. Mental disorders may also be referred to as mental health conditions.

Generally, depression and anxiety are referred to as "common mental disorders" that negatively affect how one feels, thinks and acts. They are associated with distress, disability, or a significantly increased risk of suffering death, pain and disability. The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) [9] describes depression as a mental health disorder characterised by persistent feelings of sadness or grief and anxiety as disorders that share features of excessive fear and anxiety and related behavioural disturbances. The International Statistical Classification of Diseases (ICD-10) [10] and DSM-5 highlight the most common symptoms associated with depression as follows: lack of energy, feelings of worthlessness, loss of interest in activities previously enjoyed, prolonged sadness, significant weight gain or loss, sleeping too much or too little, irritable mood, accompanied by somatic and cognitive changes that significantly affect the individual's capacity to function. The criteria symptoms for mental disorders must be present nearly every day to be considered present.

Psychological distress is defined as a state of emotional suffering characterised by a range of symptoms of depression and anxiety, and experiences of a person's internal life that are commonly held to be troubling, confusing or out of the ordinary [11-12]. It describes the unpleasant feelings or emotions that an individual may have when feeling overwhelmed. It covers a wide spectrum, ranging from normal feelings of vulnerability, sadness and fears to problems that can become disabling such as depression, anxiety, extensive worries, negative thoughts, or social isolation [13].

Jackson and Finney [14] further explain that psychological distress can manifest in multiple ways and at different levels of severity. It can be experienced as sadness, anxiety or distraction and in the most extreme cases psychotic symptoms. It can be caused by many things, a severe stressor, everyday stressors, medical illness, or mental illness. High levels of psychological distress indicate impaired mental health and may reflect common mental disorders, like depressive and anxiety disorders [15]. In research, psychological distress is commonly measured with self-report rating scales like the General Health Questionnaire or MHI-5, derived from the RAND-36 questionnaire or The Kessler Psychological Distress Scale (K10)

[16]. Different diagnostic instruments and cut-offs are used to measure depression and anxiety in research. These tools may affect diagnostic sensitivity and specificity. However, studies have examined the validity and reliability of the various diagnostic or screening tools.

1.1.2 Mental disorders among PLHIV

HIV infects the brain early in the course of infection [17]. The central nervous system is a target organ system of HIV [18] as the virus damages nerve cells in the brain, ultimately developing HIV-associated neurocognitive disorders and behavioural and motor functions [19]. In the 1980s and 90s, before effective antiretroviral treatment, as many as half of all PLHIV developed debilitating brain conditions. HIV causes serious neurological conditions including dementia. Psychological distress and psychiatric disorders result from a combination of biological and psychosocial factors, and they significantly affect many health-related outcomes.

The burden of mental disorders continues to grow with a significant impact on health, social and economic factors in all world countries [20]. Like physical health, mental health is influenced by various social, economic, and political factors [21-23]. Certain groups such as women and people living in poverty are disproportionately affected by mental disorders [24]. Moreover, there are extreme inequities which are cross-national with 80% of people affected by mental disorders living in low- and middle-income countries [25].

Research evidence shows that mental health is assigned a low priority in many developing countries, resulting in a large treatment gap [26-27]. The availability of resources for treatment and prevention of mental disorders remains a crucial factor. Morris and colleagues define resources in terms of governance, financing, mental health care delivery, human resources, essential medicines, and information systems [28]. For example, financing is a fundamental mental health system building block. Findings from the World Health Organisation's (WHO's) project Atlas [29] indicate inequalities between countries regarding their public financing of mental health. Moreover, due to limited resources for the treatment and prevention of mental disorders, it is estimated that 35-50% of people globally, with severe mental disorders, receive no treatment [24].

Epidemiological studies show that PLHIV are at a greatly increased risk of developing mental disorders, often suffering from depression and anxiety as they adjust to their diagnosis [30-32]. Similarly, people living with mental disorders can also be at higher risk of HIV. The risks are

aggravated by various factors such as social, cultural, economic, and physical environments in which people live. Depression has been identified as a major mental health problem among PLHIV in South Africa [33]. About one in six South Africans suffers from anxiety, depression, or substance-use problems [34]. Moreover, research evidence indicates that PLHIV are twice as likely to have depression compared to those who are not infected with HIV [35].

Literature on mental disorders and HIV suggests that both conditions are stigmatized worldwide [30]. HIV remains highly stigmatized throughout sub-Saharan Africa [36-37]. The issue of stigma and discrimination among PLHIV remains a major challenge as it has negative implications in their lives. For instance, some people get rejected and receive no support from their families after disclosing their positive HIV status [38]. Consequently, PLHIV choose to be silent about their HIV status as they fear stigmatization and discrimination. This silence has harmful consequences as they sometimes continue engaging in high-risk behaviour [38].

The findings of a study conducted among participants who were on antiretroviral treatment (ART) in the Free State province of South Africa, with correlates of symptoms of both anxiety and depression being investigated using the Hospital Anxiety and Depression Scale (HADS), demonstrated the prevalence of symptoms of anxiety at 30.6% and that of depression at 25.4%. The findings also revealed that perceived stigma was positively correlated with symptoms of both anxiety and depression [39]. Further, it was found that participants who belonged to a support group were less likely to have been depressed, and stigma was associated with an increase in symptoms of both anxiety and depression [39].

While depression is found to be a common mental disorder among PLHIV, anxiety also remains a common emotional reaction seen in PLHIV [40]. This reaction may emerge at diagnosis or later during the progression of HIV illness. Anxiety in PLHIV is regarded as a disabling mental health problem that often impairs adherence to treatment and in turn worsens HIV progression [40]. Both depression and anxiety are identified as common mental disorders that affect the quality of life of PLHIV, and these conditions are likely to adversely affect adherence to antiretroviral therapy among those with reduced quality of life.

Apart from poor treatment adherence among PLHIV, both depression and anxiety increase the likelihood of risky sexual behaviour among this group of people [39,41]. This was evident in a study conducted among patrons of alcohol-serving venues in Cape Town where the findings revealed that substance use and mental health distress interact to increase HIV sexual risk

behaviour [42]. Since people often use alcohol to cope with stressors, it is therefore likely that when they are depressed and vulnerable, they engage in unsafe sexual activities. Furthermore, a cohort study among men and women living with HIV in the Eastern Cape Province found that depressive symptoms were associated with physical or sexual intimate partner violence and risky sexual behaviours that put both men and women at risk of sexually transmitted infections including HIV [43].

Furthermore, stigma is especially problematic for PLHIV and mental disorders as it can create barriers to accessing health care, education, employment, and affordable housing, which in turn may exacerbate the experience of marginalisation [44]. Despite all the work done over the past decades, HIV-related stigma continues to be a driver of the epidemic and a challenge to HIV prevention, treatment, and care efforts [45-46].

Like many other countries in the region, South Africa strives to meet the UNAIDS 95-95-95 goals (diagnosing 95% of all PLHIV, providing ART to 95% of those diagnosed, and achieving viral suppression for 95% of those treated). Mental disorders are often a critical barrier to early and consistent HIV care engagement and long-term viral suppression. A few studies conducted in sub-Saharan Africa have found that people with mental disorders are less likely to be linked to ART or start treatment [35,47]. For example, one study conducted in South Africa found that depressed individuals had a higher odd of waiting at least three months following an HIV diagnosis to initiate ART compared to their non-depressed counterparts [48].

South Africa still has substantial gaps in HIV treatment access between different age groups as well as gender. This is illustrated in the progress towards achieving the 95-95-95 UNAIDS targets among PLHIV in South Africa. Findings from the 2017 and 2019 survey data showed that the third 95 target for viral suppression was not met (64% to 66%), at either national or provincial levels [49]. Even though progress has been observed with the first two targets, more work is needed to achieve and maintain a suppressed viral load.

Mental disorders have been consistently associated with poor adherence to ART. In South Africa in particular, further evidence is needed to characterise the association between mental disorders, HIV care engagement, and achievement of viral suppression. The mechanisms through which mental disorders undermine successful HIV care engagement are not fully clear. Mental disorders and distress may become key drivers of lower rates of viral suppression, especially in youth and women, which are the groups with higher HIV prevalence. More data

is therefore needed to assess trends in viral suppression among persons with HIV and mental disorders.

1.2 Problem statement

Although considerable work has been done on mental health and HIV in South Africa, there is need for further research on the prevalence of mental disorders specifically depressive and anxiety disorders among PLHIV and the associated factors. Mental health studies have been done on a small scale, for example provincially or locally within urban and rural areas in some districts and municipalities [50]. Many of these studies prioritised specific populations such as children and adolescents living with HIV, pregnant and postpartum women living with HIV, and key populations living with HIV [51]. According to Parcesepe et al., knowledge gaps remain in mental health research among PLHIV in sub-Saharan countries, including South Africa. Parcesepe and colleagues propose that epidemiological research is needed to 1) advance the understanding of the prevalence of mental health disorders and associated factors among PLHIV compared to people without HIV and 2) improve understanding of the bidirectional relationship between mental health disorders, including factors mediating or moderating as potential intervention targets to improve mental health and HIV treatment outcomes among PLHIV with mental health disorders, including the prevalence of mental health multimorbidities and their impact on HIV treatment outcomes. With South Africa forming the current epicenter of the epidemic, accurate estimations of the burden of mental disorders in HIV-infected individuals are needed. More research is required to contribute to existing literature and advance interventions and strategies to address co-morbid mental illness among PLHIV. Therefore, the purpose of this study was to assess the prevalence of psychological distress as measured by depressive and anxiety symptoms and associated factors among PLHIV in South Africa using a nationally representative household-based population survey.

1.3 Study aim

The aim of this study was to explore the extent and effect of psychological distress among youth and adults with HIV in South Africa.

1.4 Study objectives

The following were the specific objectives:

a) To conduct a systematic review and meta-analysis of studies on the prevalence and factors associated with depressive and anxiety symptoms among people living with HIV in Southern Africa

b) To determine the prevalence of depressive and anxiety symptoms and associated risk factors among PLHIV in South Africa

c) To explore the relationship between HIV-related stigma and psychological distress among PLHIV in South Africa

d) To explore the complex pathways linking HIV status as a mediator in the relationship of psychological distress with socio-demographic and health-related factors in South Africa.

1.5 Theoretical framework

The study was guided by the theory of fundamental causes developed Link and Phelan [52], with significant elaboration and extension by Lutfey and Freese [53] to conceptualise the linkages between persistent health disparities and multiple risk factors across varied contexts [54-55]. The theory of fundamental causes is rooted in Lieberson's (1985) concept of basic causes, which was first applied to the association between socioeconomic status (SES) and mortality by House and colleagues [56-57]. As a sociological theory, the fundamental causes theory addressed this issue by calling on social stratification, stigma, and racism as they affected medical treatments and health outcomes.

According to Link and Phelan, a fundamental cause theory has four essential features. Firstly, it recognises multiple disease outcomes of a health condition; secondly, it also recognises the influence of multiple risk factors; thirdly, it recognises that access to resources can be used to avoid risks or to minimise the consequences of disease; and fourthly, it recognises that the association between a fundamental cause and health are reproduced over time via the replacement of intervening mechanisms [52]. The fundamental causes theory represents an effort to advance a causal explanation in order to understand how and why associations between risk and protective factors emerge and, when and under what conditions particular risk factors are prominent in the disease risk relationship.

In this study, the fundamental cause theoretical framework was used to guide the analysis of the inter-relationships between HIV and psychological distress. The researcher hypothesised that among individuals who were infected with HIV, background and socio-demographic

factors such as sex, age, education, marital status, employment, socio-economic status, locality type, and social support would be associated with psychological distress. Other fundamental causes include HIV-related stressors such as HIV status and stigma and discrimination, which lead to limited access to resources and increased vulnerability to poor mental health.

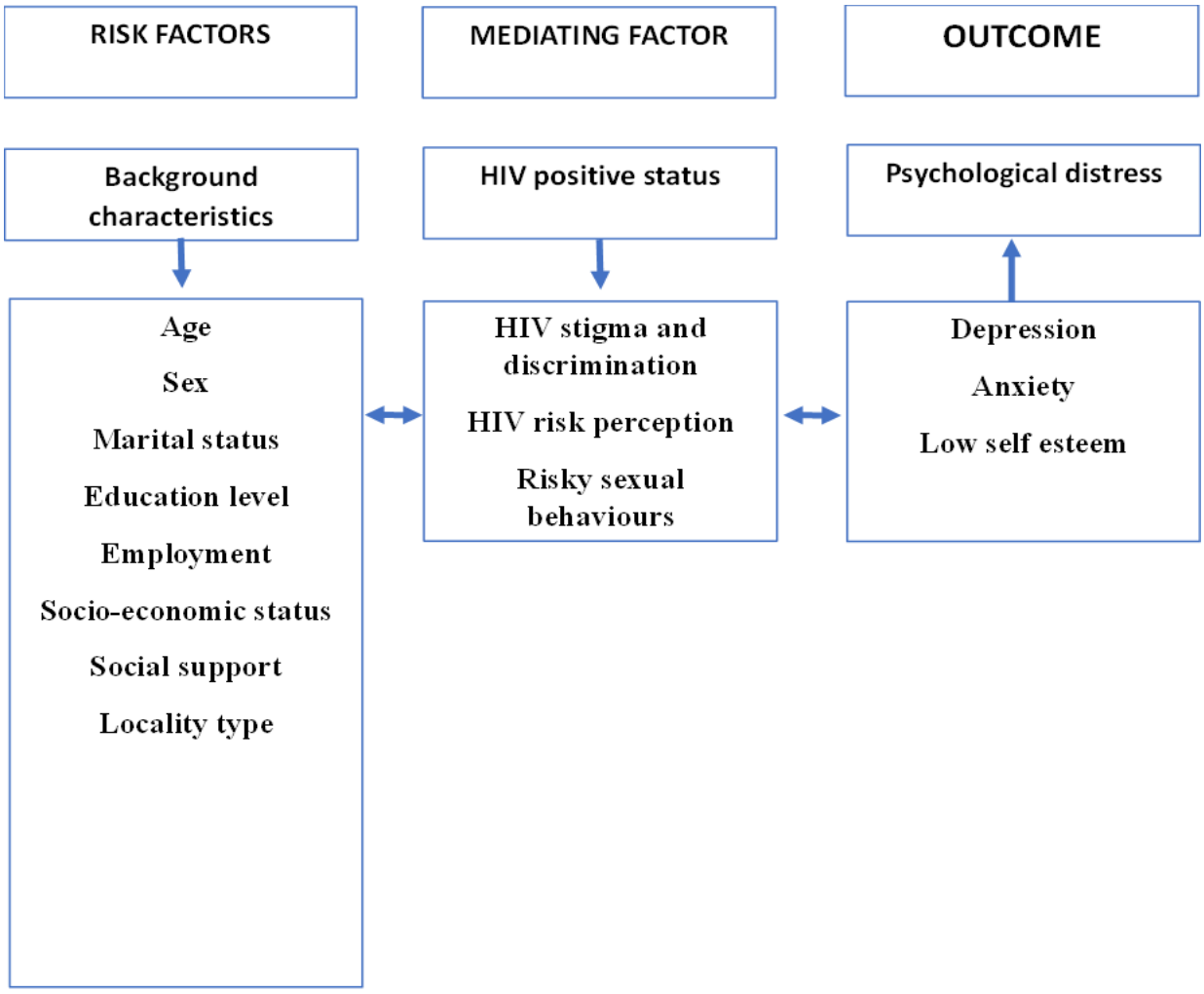

Figure 1: Fundamental cause theory for factors associated with psychological distress among people living with HIV

1.6 Coherence of the thesis

This thesis is based on a large national household survey data. Secondary data analysis was conducted. The work is not presented as a monograph-type thesis but described in unique manuscripts, of which three have been published to date and one is currently under review in an international journal. All these manuscripts were formatted uniformly for the purposes of this thesis, with regards to referencing style and use of terms, but the content will remain

unchanged from that which has been either published or submitted for publication. Below is the layout of the thesis chapters.

Chapter 1: The first chapter of this thesis elucidates the background and context of the current study which focused on the factors associated with common mental disorders among HIV positive people in all nine provinces of South Africa. The chapter also highlights the gap in literature on mental health and HIV research in South Africa. Further, the aims and objectives of the study are presented in the chapter. The chapter also provides an overview of the theoretical framework that guided and underpinned this study. The chapter ends with a layout of the thesis chapters.

Chapter 2 provides a systematic review and meta-analysis of the literature on prevalence and predictors of depressive and anxiety symptoms among PLHIV in Southern Africa. This chapter provides literature on what is known about HIV and mental disorders in Southern Africa. It documents and describes studies reporting on associated factors of mental disorders, mainly depression and anxiety, and that have pooled the available evidence to estimate the prevalence of depressive and anxiety symptoms among PLHIV in Southern Africa.

Chapter 3 is presented as a manuscript which was accepted and published in the Journal of Psychology and Psychotherapy Research as **Ncitakalo, N**., Mabaso, M., Maduna, V., Joska, J. & Simbayi, L. (2019). Prevalence and correlates of psychological distress among HIV positive individuals in South Africa: Findings from the 2012 HIV National Household Survey. Journal of Psychology and Psychotherapy Research, 6, 30-40. DOI: https://doi.org/10.12974/2313-1047.2019.06.6

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Chapter 5 is represented as a manuscript which was accepted and published in the AIDS Research and Therapy journal as **Ncitakalo N,** Sigwadhi LN, Mabaso M, Joska J, Simbayi L. Exploring HIV status as a mediator in the relationship of psychological distress with socio-demographic and health related factors in South Africa: findings from the 2012 nationally

representative population-based household survey. AIDS Res Ther. 2023 Feb 6;20(1):6. doi: 10.1186/s12981-022-00498-5.

Chapter 6 provides a detailed discussion of the key findings of this study. The chapter highlights the meaning, importance, and relevance of the results. Its focus is on explaining and evaluating the key findings of the study, showing how they relate to the literature review and research questions, and making an argument in support of the overall conclusion. It also provides explanations regarding the research questions, as well as the significance of the study and how the questions were addressed. The chapter provides a holistic summary and assessment highlighting the strengths and limitations of the study, followed by the conclusions and recommendations.

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CHAPTER 2

PREVALENCE AND FACTORS ASSOCIATED WITH DEPRESSIVE AND ANXIETY SYMPTOMS AMONG PEOPLE LIVING WITH HIV IN SOUTHERN AFRICA: A SYSTEMATIC REVIEW AND META-ANALYSIS

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ABSTRACT

Background: Depression and anxiety are the most prevalent common mental disorders among people living with HIV (PLHIV). The presence of these disorders is associated with various factors. This systematic review and meta-analysis pooled the available evidence to estimate the prevalence and factors associated with depressive and anxiety symptoms among PLHIV in Southern Africa.

Methods: Using the Preferred Reporting Items for systematic Reviews and Meta-Analyses guidelines, a comprehensive literature search was performed in PubMed, Scopus, PsycINFO, Africa Wide and CINAHL databases from 1981-2022. A meta-analysis of the selected studies was performed using the random effects model. The heterogeneity of studies was investigated using I^2 test statistics. Publication bias was checked with a funnel plot.

Results: A total of 27 articles met the eligibility criteria out of the 467 articles that were initially identified. The overall pooled weighted prevalence for depression was 23% (95% CI: 19%-28%, I^2=98%), and anxiety was 15% (95% CI: 9%-23%, I^2=98%). Factors strongly associated with increased prevalence of depression and anxiety included being female, separated or widowed, unemployed, older age, low income, low education, urban residence, low physical activity, violence and/or partner conflict exposure, lack of social support, stigma and alcohol use in PLHIV.

Conclusion: The findings show that the burden of depression and anxiety is high among PLHIV. There is a need for more screening and treating of depression and anxiety in PLHIV to improve HIV outcomes and achieve the 95-95-95 UNAIDS targets. Integration of mental disorders treatment into HIV care should also be prioritised.

2.1 Background

Eastern and southern Africa remain the regions that are most heavily affected by HIV, with 20.6 million people (54%) of all people living with HIV (PLHIV) in the world [1]. Despite advances in HIV prevention and treatment in recent decades, HIV continues to be one of the leading causes of disease burden and imposes a substantial public health challenge in countries in sub-Saharan Africa [2]. The stress associated with living with HIV can affect a person's mental health [3]. Mental health refers to a person's overall emotional, psychological, and social well-being [3-5].

PLHIV have a higher risk of some mental health disorders than people who do not have HIV. For example, depression and anxiety are two of the most common mental health conditions faced by PLHIV [3-8]. In sub-Saharan Africa, 10 to 20% of people living with HIV are reported to have major depression, and another 20 to 30% have elevated depressive symptoms or minor depression [9]. Other studies show that the prevalence rates of depression in PLHIV varies widely and range between 2.7% and 76.7% [10].

Evidence shows that mental disorders such as depression and anxiety in PLHIV can have a negative impact on their health status, healthcare-seeking behaviours, and quality of life [9,10]. Studies show that these mental health disorders are associated with several unfavourable health outcomes among PLHIV, such as poor social conditions, poor treatment adherence, poor treatment outcomes, poor quality of life, and risky behaviours [11-14]. Therefore, an improved understanding of the drivers of mental health disorders among PLHIV is important in the HIV treatment and care cascade.

Several socio-demographic factors have been found to be associated with mental disorders in PLHIV, and these include older age, female gender, low education, and unemployment [3,15,16]. In addition, comorbidities with opportunistic infections, perceived stigma, stressful life events, food insecurity, older age, low income, and advanced HIV disease have been associated with mental disorders such as depression and anxiety in PLHIV [3,16].

Southern Africa has the highest HIV prevalence globally [17] and PLHIV experience high rates of mental disorders [15,18]. However, no study has extensively summarised data on the burden and contextual determinants of mental health disorders among PLHIV in this sub-region. A comprehensive understanding of factors associated with depressive and anxiety symptoms in this population group is important for providing evidence towards the successful prevention

and treatment of these mental disorders in PLHIV. Therefore, this review aimed to synthesize evidence on the prevalence and factors associated with depressive and anxiety symptoms among PLHIV in Southern Africa.

2.2 Methods

The systematic review and meta-analysis followed the Preferred Reporting Items for Systematic Review and Meta-analysis (PRISMA) guidelines [23]. The study protocol was registered with the International Prospective Register of Systematic Reviews (PROSPERO) under registration number CRD42023405967. In this review, the diagnosis of depressive and anxiety symptoms is defined as psychological distress, which is a state of emotional suffering [20].

2.2.1 Eligibility criteria

The criteria for entering the systematic review included studies assessing the prevalence of anxiety, depression, and associated factors, that is, studies that provide odds ratios (ORs) among PLHIV published between 1981 and 2022. The period going back to 1981 covers the time when the first HIV cases were reported across the globe. Narrative reviews, opinion pieces, and letters, or any other publications lacking primary data and/or explicit descriptions of the method were excluded. A PRISMA flowchart demonstrating the process of literature screening is presented in Figure 1.

2.2.2 Types of studies

Experimental and observational studies were reviewed. Experimental studies included individual randomised control trial, cluster randomised control trial and quasi randomised control trial. Observational studies included cross-sectional, cohort, case-control studies and case reports.

2.2.3 Search strategy and selection criteria

The search strategy was developed in PubMed using Medical subject heading (MeSH) terms. The search terms were amended in other databases to obtain optimal searching. A comprehensive literature search of relevant studies was conducted using five databases, namely PubMed, Scopus, PsycINFO, Africa Wide and CINAHL through EbscoHost and Academic Search Premier. A wide search strategy was used to obtain studies from 1981 to date and with no language restrictions. A varying combination of words and MeSH terms with southern African countries filter were used. The following keywords were used: ‘prevalence’ (MeSH),

‘depression’ (MeSH), ‘depressive disorder’ (MeSH), ‘anxiety disorders’ (MeSH), ‘psychological distress’ (MeSH), ‘HIV’ (MeSH), ‘acquired immunodeficiency syndrome’ (MeSH), and ‘southern African countries’.

2.2.4 Types of participants

This included all age groups of PLHIV in southern African countries diagnosed with depressive and anxiety symptoms.

2.3 Outcome of interest

The primary outcome of interest was the prevalence and associated factors of depressive and anxiety symptoms among PLHIV.

2.4 Study selection

Firstly, duplicate articles from various databases were removed using the eligibility criteria. The selection process was carried out in three stages by two reviewers. First, titles and abstracts were screened. The two independent reviewers compared their results, and when both reviewers agreed to “include” or were “unsure” those records were retained for full-text screening. Second, the available full-text articles were read thoroughly and those suitable for the review were selected. Third, the two independent reviewers compared their selection, and disagreements were resolved through discussion to ensure that all articles met the inclusion criteria.

2.5 Data extraction and analysis

Data from each study was extracted by the two independent reviewers using a data extraction form designed in a Microsoft Excel spreadsheet. Extracted data included first author’s name, year of publication, country, study design, sample size, study population, assessment tools, outcome measures, the prevalence of depression and anxiety, risk factors, and other characteristics of the study sample. Any discrepancies in extracted data were resolved through consultation with a third independent reviewer. Search results were uploaded to EndNote Software, a reference package that facilitates the management of references and bibliographies.

2.5.1 Assessment of risk of bias

Each of the included studies was assessed for risk of bias using the Critical Appraisal Skills Programme (CASP) quality assessment tool [21]. The tool has multiple domains for different

study designs. The quality assessment for risk of bias was reviewed independently and cross-checked by a third reviewer for discrepancies.

2.5.2 Dealing with missing data

For studies having missing data, efforts were made to contact the primary authors to request the missing data.

2.5.3 Assessment of heterogeneity

Heterogeneity among the included studies was assessed using the Chi^2 of homogeneity and quantified using the I^2 test statistic. An I^2 statistic estimate of greater than 50% was used as an indicator of large statistical heterogeneity.

2.5.4 Assessment of reporting biases

Test for asymmetry with a funnel plot was conducted to investigate the risk of publication bias by type of study. The funnel plot was critically examined for asymmetry.

2.5.5 Data synthesis

Data was pooled from studies of similar study designs, similar participants, and similar outcomes in a meta-analysis using the random-effects model if there was no significant statistical heterogeneity, methodological difference, or high risk of bias. Pooled prevalence estimates are expressed as mean estimates and 95% confidence intervals (CIs). Furthermore, moderator analysis was carried out to identify the independent predictors of the prevalence of depression and anxiety among PLHIV. The study findings were interpreted by considering the methodological quality of the studies and the strength of the evidence. Analysis was conducted using standard summary statistics, a meta-analysis was performed, and a Forest plot was drawn using REVMAN software.

2.5.6 Sensitivity analysis

Sensitivity analysis was conducted to check whether the meta-analysis results were influenced by study designs and study settings. The issues suitable for sensitivity analysis were identified during the review process.

2.6 Results

2.76.1 Identification of studies

The electronic search yielded 467 articles. After duplicates had been removed, 329 articles remained. Of these, a further 281 articles were removed after the titles and abstracts were screened. Forty articles remained to review the full text for eligibility. From them, 18 articles were removed, and 22 articles were retained including five articles identified through cross-referencing. A total of 27 articles with full text that met the inclusion criteria were included in our final analysis. An overview of the process of study selection is presented in Figure 2.

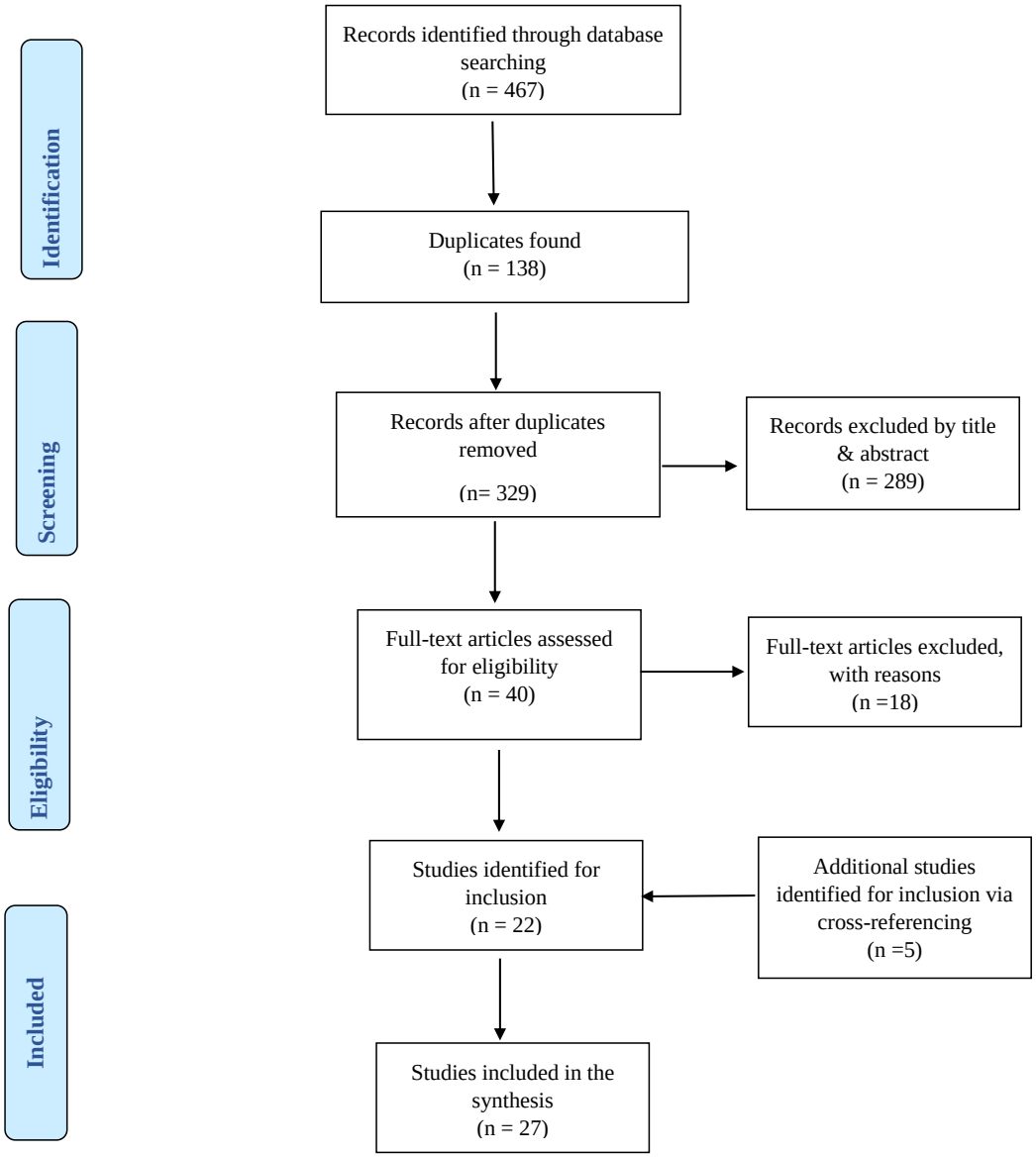


Figure 2: PRISMA flow chart for the systematic review process

2.6.2 Description of included studies

Table 1 provides details and characteristics of included studies. Articles included were published between 2003 and 2022. Among the total of 27 studies included in our analysis, 17 were carried out in South Africa [22-38], whereas three of the studies were conducted in Botswana [39-41], three studies in Zambia [42- 44], and one study in Zimbabwe [45], Lesotho [46], Malawi [47], and Mozambique [48], respectively. The majority (n=20) of the included studies had used a cross-sectional study design, five were cohort studies, one was a randomised controlled trial and the other used a mixed method study design. Many of the studies had been conducted in primary health care clinics and hospitals (n=26), some of these facilities were in urban (n=20) and others in rural (n=7) settings.

2.6.3 Assessment tools used

Various screening tools based on different cut-off scores were used to measure depressive and anxiety symptoms. In the 27 included studies, 15 different scales were used to measure depression and anxiety symptoms. A nine-item Patient Health Questionnaire (PHQ-9) was used in seven studies [22-23,34,36,41,46,48] to measure depression. The Mini International Neuropsychiatric Interview (MINI) was also used in four studies [27,30,42,44] to measure depression. Four studies [25,27,41,43] used the Center for Epidemiologic Studies Depression Scale (CES-D), the Beck Depression Inventory (BDI) was used by three studies [24,28,39], and the Edinburg Postnatal Depression Scale (EPDS) was used by three studies [26,31-32]. Two studies [29,45] used the Composite International Diagnostic Interview (CIDI 3.0) and another two [37-38] used the Child Depression Inventory-Short (CDI:S) to measure both depressive and anxiety symptoms. Kagee and Martin [24] used the Hopkins Symptom Checklist (HSCL-25) to screen both depressive and anxiety symptoms.

The Generalized Anxiety Disorder-7 (GAD-7) was used by three studies [23,34,48] to measure anxiety symptoms, while one other study [28] used the Beck Anxiety Inventory (BAI). In other studies that focused on adolescents [37,40], depressive and anxiety symptoms were measured by the Mini-International Neuropsychiatric Interview for Children and Adolescents (MINI-KID) and the Revised Children's Manifest Anxiety Scale (RCMAS). Sall and colleagues [35] used the 3rd (DSM-III) and 4th (DSM-IV) edition of the Diagnostic and Statistical Manual (DSM) of Mental Disorders to diagnose and describe depressive and anxiety disorders among mine workers.

Table 1: Characteristics of studies included in the systematic review and meta-analysis

Author(s)	Year of publication	Country	Study design	Sample size	Study population	Assessment tool used	Outcome of interest	Prevalence estimates
Besa et al [42]	2015	Zambia	Cross-sectional study	185	HIV positive adults	MINI	Depression	Depression- 7%
Cholera et al [22]	2017	South Africa	Cohort study	340	HIV positive 18 years and older	PHQ-9	Depression	Depression- 30%
Di Gennaro et al [48]	2022	Mozambique	Cross-sectional study	1096	Adolescents and youth living with HIV	GAD-7 PHQ-9 PC-PTSD-5 CAGE-AID	Anxiety, depression, PTSD, and alcohol–drug abuse	Anxiety- 10.3% Depression- 11.4% PTSD- 14.7% Alcohol & drug abuse- 36%
Haas et al [23]	2020	South Africa	Cohort study	1088	Adolescents receiving ART	PHQ-9 GAD-7 PC-PTSD-5 CAGE-AID	Mental disorders and substance use	Anxiety- 2.2% Depression-4.4% PTSD- 3.5% Substance use- 1.7%
Hayes-Larson et al [46]	2017	Lesotho	Cross-sectional study	371	TB-HIV patients	PHQ-9 AUDIT	Depressive symptoms and hazardous/harmful alcohol use	Depression- 30%
Kagee & Martin [24]	2010	South Africa	Cross-sectional study	85	Patients living with HIV	BDI HSCL	Depression and anxiety	Depression- 37.6%
Lawler et al [39]	2011	Botswana	Cross-sectional study	120	HIV positive individuals	BDI-FS (7)	Depression	Depression- 38%
Malava et al [47]	2018	Malawi	Cross-sectional study	206	Patients receiving HIV care	PHQ-9	Depression & suicidal ideation	Depression- 12% Suicidal ideation- 16%
Mokhele et al [25]	2019	South Africa	Cross-sectional study	690	Adult women 18 years and older	CES-D	Postpartum depression	Depression- 25%
Mokwena & Shiba [26]	2014	South Africa	Cross-sectional study	211	HIV positive women in primary health care	EPDS	Postnatal depression	Depression- 49.3%

Author(s)	Year of publication	Country	Study design	Sample size	Study population	Assessment tool used	Outcome of interest	Prevalence estimates
Myer et al [27]	2008	South Africa	Cross-sectional study	465	HIV positive individuals enrolled into HIV care and treatment services	MINI CES-D HTQ	Depression, PTSD & alcohol abuse	Depression- 19%
Nel & Kagee [28]	2013	South Africa	Cross-sectional study	101	Patients receiving antiretroviral treatment	BDI BAI	Depression & anxiety	Depression- 40.4% Anxiety- 28.7%
Nyirenda et al [29]	2013	South Africa	Cross-sectional study	422	HIV-infected and -affected older people in rural areas	CIDI 3.0	Depression	Major depressive episode- 14.8% Brief depressive episode- 24.6% Any depressive episode- 39.4%
Okawa et al [43]	2018	Zambia	Mixed method study	190	Adolescents living with HIV	CES-D	Depression	Depression- 25.3%
Olashore [40]	2022	Botswana	Cross-sectional study	622	Adolescents living with HIV	MINI-KID	Depression & suicidal behaviour	Depression- 23% Suicidal behaviour- 18.9%
Olley et al [30]	2006	South Africa	Cohort study	149	Patients with recently diagnosed HIV	MINI	Depression & PTSD	Depression- 34.9% PTSD- 14.8%
Peltzer & Shikwane [31]	2011	South Africa	Cross-sectional study	607	HIV positive women in primary care	EPDS	Depression	Depression- 45.1%
Peltzer et al [32]	2018	South Africa	Randomized controlled trial	607	HIV-infected women in public primary care in rural area	EPDS	Depression	Prenatal depression- 48.7% Postnatal depression- 35.6%
Ramirez-Avila [33]	2012	South Africa	Cohort study	1545	Newly diagnosed HIV-infected patients	MHI-5	Depression	Depression- 55%
Rane et al [34]	2018	South Africa	Cohort study	1271	HIV infected individuals	PHQ-9 GAD-7	Depression & anxiety	Depression- 33% Anxiety- 9%
Sall et al [35]	2009	South Africa	Cross-sectional study	38	HIV infected mine workers	DSM-III DSM-IV	Psychiatric symptoms	Depression- 13% Anxiety- 21%

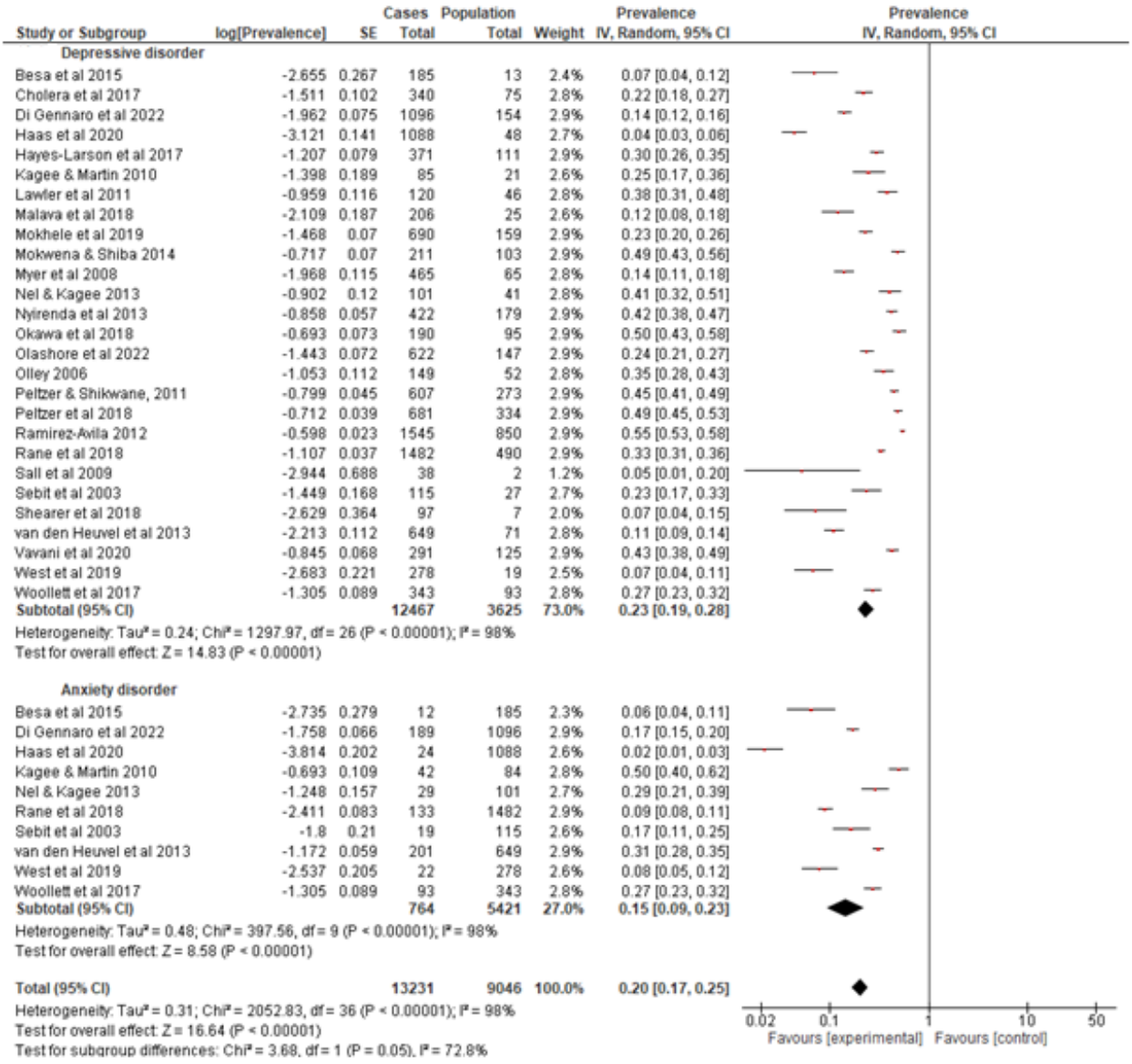
Author(s)	Year of publication	Country	Study design	Sample size	Study population	Assessment tool used	Outcome of interest	Prevalence estimates
Sebit et al [45]	2003	Zimbabwe	Cross-sectional study	194	HIV positive and negative adults	CIDI	Psychiatric disorders	Depression- 27% Anxiety- 19%
Shearer et al [36]	2018	South Africa	Cross-sectional study	97	Patients on antiretroviral therapy	PHQ-9	Depressive symptoms	Depression- 7%
van den Heuvel et al [44]	2013	Zambia	Cross-sectional study	649	Adult patients with HIV & TB	MINI	Anxiety & mood disorders	Anxiety- 30.8% Depression- 11.3%
Vavani et al [41]	2020	Botswana	Cross-sectional study	291	People living with HIV	CES-D	Depression	Depression- 43.4%
West et al [37]	2019	South Africa	Cross-sectional study	278	Adolescents living with HIV	CDI:S RCMAS	Anxiety, depression & PTSD	Depression- 17.8% Anxiety- 8.9% PTSD- 13.4%
Woollett et al [38]	2017	South Africa	Cross-sectional study	343	HIV positive adolescents	CDI:S	Depression, anxiety, suicidality, PTSD	Depression & anxiety-27% Suicidality- 24%

Alcohol Use Disorders Identification Test (AUDIT); Beck Anxiety Inventory (BAI); Beck Depression Inventory (BDI); Beck Depression Inventory-Fast Screen for Medical Patients (BDI-FS) [7]; Center for Epidemiologic Studies Depression Scale (CES-D); Child Depression Inventory-Short (CDI:S); Composite International Diagnostic Interview (CIDI 3.0); Cut down, Annoyed, Guilty, and Eye-opener Adapted to Include Drugs (CAGE-AID); Diagnostic and Statistical Manual of Mental Disorders, 3rd Edition (DSM-III), 4th Edition (DSM-IV); Edinburg Postnatal Depression Scale (EPDS); Generalized Anxiety Disorder-7 (GAD-7); Hopkins Symptom Checklist (HSCL); Mental Health Index-5 (MHI-5); Patient Health Questionnaire- 9 (PHQ-9); Primary Care PTSD Screen (PC-PTSD-5); Revised Children's Manifest Anxiety Scale (RCMAS); The Mini International Neuropsychiatric Interview (MINI); The Mini-International Neuropsychiatric Interview for Children and Adolescents (MINI-KID)

2.6.4 Prevalence of depressive and anxiety symptoms

Figure 3 presents the Forest plot for the estimated prevalence of depressive and anxiety symptoms among PLHIV in selected countries in Southern Africa. The prevalence was assessed in a total of 27 studies. The prevalence of depression was reported in all the included studies. Of these, ten studies [23-24,28,34-35,37-38,44-45,48] reported the prevalence of anxiety or its symptoms. No study investigated the prevalence of anxiety or its symptoms as a stand-alone mental disorder among PLHIV.

The overall pooled weighted prevalence of depressive and anxiety symptoms was 23% (95% CI: 19%-28%, I^2=98%), and for anxiety was 15% (95% CI: 9%-23%, I^2=98%), respectively. The highest prevalence of depression was 55% (95% CI: 53%-58%) and the lowest prevalence was 4% (95% CI: 3%-6%). The highest prevalence of anxiety was 50% (95% CI: 40%-62%) and the lowest prevalence was 6% (95% CI: 4%-11%).



Each red square is the prevalence rate, and the length of the line on which the square is located denotes 95% confidence interval. The black diamond shape represents the overall prevalence rate.

Figure 3: Forest plot for the pooled prevalence of depressive and anxiety symptoms among PLHIV in southern Africa based on random effects model

2.6.5 Associated factors of depressive and anxiety symptoms

Various factors associated with depressive and anxiety symptoms were reported in almost all studies included in this review. Association between social support and depressive and anxiety symptoms was observed in four studies [26,31,37,40]. In the current review, comorbidity [42,46], disability [30], stigma and discrimination [31-32,48], physical activity [27,44], exposure to violence, psychological intimate partner violence and/or household conflicts [27,37,43], linkage to care or antiretroviral treatment [22,24,28,39], alcohol use [32,46-47], financial support from partner [26], loss of a parent [40] were strongly and significantly

associated with depressive and anxiety symptoms among PLHIV in the selected southern African countries.

Furthermore, socio-demographic factors that significantly increased the risk for higher depressive and anxiety symptoms among PLHIV included older age and young age/adolescents [23,32,42], female sex [29,39-40,44], low educational level [25-26,32,46], urban residence [29], socio-economic status/ employment [29,32,42] and marital status (being divorced/ separated) [42]. Having perceived good support from the healthcare providers, family and friends were shown to be a protective factor particularly among young people/adolescents living with HIV.

In this review, four studies examined prevalence of postpartum depression and associated factors among women living with HIV [25-26,31-32]. These studies showed that depressed mood was found to be common among HIV-positive postpartum women. This was significantly associated with the following factors: lack of social support, stigma and discrimination, non-adherence to antiretroviral treatment, level of education, physical and psychological intimate partner violence, lack of male involvement during pregnancy, financial support by the baby's father, whether the baby was planned, baby's health status, partner alcohol use and partner/husband having other sex partners.

2.6.6 Excluded studies

A total of 22 studies were excluded and the reasons were that the studies conducted outside Southern Africa, were not target population, not outcome of interest, and studies with inappropriate methodology (Table 2).

Table 2: Summary of reasons for study exclusion

Author (year)	**Reasons for study exclusion**
Boyes et al (2019)	Depressive and anxiety symptoms were not assessed
Breet et al (2014)	The study focused on social support and PTSD
Dow et al (2014)	The study not in line with our outcome of interest
Gadanya & Sale (2008)	The study was conducted outside Southern Africa
Kagee (2010)	The study not in line with our outcome of interest
Kinyanda et al (2011)	The study was conducted in East Africa
Lwidiko et al (2018)	The study was conducted in East Africa
Mthembu et al (2017)	The study did not focus on PLHIV

Author (year)	Reasons for study exclusion
Mwangala et al (2022)	The study was conducted in East Africa
Olley et al (2004)	Prevalence of depression was not assessed
Olley et al (2004)	The study did not present appropriate methodology
Olley et al (2005)	They study focused on PTSD
Peterson et al (2012)	The study was conducted in West Africa
Roberts et al (2021)	The study was not in line with our outcome of interest
Rodriguez et al (2018)	The study was not in line with our outcome of interest
Tlhajoane et al (2018)	The study population and outcomes were not in line with our
Tuthill et al (2017)	The study was not in line with our outcome of interest
Verhey et al (2018)	The study focused on PTSD and self-experiences life traumas

2.6.7 Risk of bias in included studies

We had 20 cross-sectional studies, five cohort studies, one RCT study, and one mixed method study. All studies had a low risk of bias as most of the domains in the risk of bias assessment had minimal flaws.

2.7 Discussion

This systematic review and meta-analysis revealed that the pooled prevalence for depression and anxiety was high among PLHIV in the selected Southern African countries. Prevalence also varied widely within and between the countries. The overall prevalence estimates were comparable to other sub-regional estimates in western and eastern Africa [10,49]. To the best of our knowledge, this is the first review from southern African countries to comprehensively collate information on prevalence and factors associated with depressive and anxiety symptoms among PLHIV. Key findings from the included studies are discussed in relation to wider literature below.

2.7.1 Demographic factors

This review found some evidence that female gender is a risk factor for depressive and anxiety symptoms. Female gender has been identified as a risk factor for depressive and anxiety symptoms among PLHIV [29,39-40,44]. Females were almost two times more likely to be depressed than their male counterparts. Similar studies have shown that females from sub-Saharan Africa living with HIV could be at a higher risk of depressive symptoms because of

additional experiences of traumatic events such as intimate partner violence and sexual abuse, some of which may have had a role in their acquisition of HIV infection [50-51]. Further work is needed to determine whether these disparities between men and women are related to HIV or social factors.

In agreement with other studies, age was also significantly associated with depressive and anxiety symptoms, reported across three studies [23,32,42]. PLHIV of both younger and older age were more likely to have depressive symptoms. In addition, level of education was significantly associated with depressive and anxiety symptoms among PLHIV [25-26,32,46]. Furthermore, an association was observed between socio-economic status/employment and depressive symptoms [29,32,42].

2.7.2 HIV-specific factors

This review found evidence of an association between ART adherence and depressive and anxiety symptoms. This is in line with other reviews conducted in sub-Saharan Africa that have found similar results [3,6,52]. Linkage to care and/or treatment adherence was found to be significantly associated with depressive and anxiety symptoms [22,24,28,39]. Non-adherence of HIV medication was associated with depressive symptoms, while those in HIV treatment were less likely to show depressive and anxiety symptoms. Adherence to HIV treatment plays a protective role as it results in higher CD4 counts, implying good physical health due to suppressed viral load. Other factors associated with depressive and anxiety symptoms include multiple sexual partners and lack of condom use. Risky sexual behaviours have been shown to increase vulnerability to the development of depressive and anxiety symptoms [53,54].

2.7.3 Psychosocial factors

The findings of this review indicate that good support from a healthcare provider, partner, friends and family provides protection against depressive and anxiety symptoms [26,31,37,40], which is consistent with wider literature about the positive impacts of social support for PLHIV [55-57]. The results of this review also showed that stigma and discrimination significantly increased the risk for depressive and anxiety symptoms among PLHIV [31-32,48] and are significant barriers to HIV treatment, often leading to negative consequences and poor health outcomes. Consistent with previous research, depression has also been linked with intimate partner violence/abuse. Other factors associated with depressive and anxiety symptoms among PLHIV included grief/loss of a parent and suicidality.

Overall, fewer studies, ten of the 29, in this review focused on anxiety compared to depression. This under-investigation of anxiety disorders is of concern because these studies reported high rates of anxiety. The under-investigation of anxiety disorders can be partly attributed to the paucity of adequately validated measurement tools of anxiety [58]. Therefore, there is a need for adequate validation of measurement tools for anxiety, taking into consideration contextual and cultural differences within the region.

2.8 Limitations

The data from a variety of sources was pooled in this study, so caution should be taken when interpreting the findings. Comparability of the included studies was complicated by the diversity of assessment tools, analytic strategies, and reporting standards. Data from some countries was under-represented in our dataset. This can lead to overestimation or underestimation bias. In addition, the limited number of studies in some countries made it difficult to provide conclusive evidence with results pooled from fewer studies. Therefore, that variation in studies should be taken into consideration if any attempts are made to generalise our findings across the different countries. Despite these limitations, this review provides useful information for improving mental health services among PLHIV in the selected southern African countries.

2.9 Conclusion

This review showed that the prevalence of depressive and anxiety symptoms is relatively high among PLHIV in Southern Africans. The prevalence depressive and anxiety symptoms were associated with demographic characteristics, HIV specific drivers and psychosocial factors. Given the diversity and number of assessment tools identified, there is a need for standardisation and validation of the different scales of the commonly reported measures of depression and anxiety. In addition, more studies are needed in the region especially in the most affected countries. Even though there are mental health interventions that have been tested in some African sub-regions, there is an urgent need to prioritise mental health treatment among PLHIV, especially mental health treatment integrated into HIV care, with appropriate resources to address the current screening and treatment gap in Southern Africa.

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Contributions of authors

NN developed the study protocol with the help of LA. NN conceptualized the study and developed the methodology under the supervision of LS and JJ. NN performed the search, screening, and data extraction under the guidance of LA. MM reviewed data extraction and assessed the quality. NN wrote the first draft of the manuscript, and all authors provided feedback. LA, LS, and JJ provided content expertise for this review. All authors read and approved the final manuscript.

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Availability of data and materials

All data generated and analysed during this study are included in this review.

Ethical approval and consent to participate

Not applicable.

Declarations of interest

The authors declare that they have no competing interests.

Consent for publications

Not applicable.

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CHAPTER 3

PREVALENCE AND CORRELATES OF PSYCHOLOGCIAL DISTRESS AMONG HIV POSITIVE INDIVIDUALS IN SOUTH AFRICA: FINDINGS FROM THE 2012 HIV NATIONAL HOUEHOLD SURVEY

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ABSTRACT

Psychological distress symptoms like depression and anxiety are potentially dangerous conditions in HIV positive individuals influencing health-seeking behaviour, care and treatment leading to poor health outcomes. This study sought to determine the prevalence of psychological distress symptoms and associated socio-demographic and health related factors amongst HIV positive individuals. The study used the 2012 data from a nationwide cross-sectional population-based household survey that was conducted using a multi-stage stratified cluster sampling design. Bivariate and multivariate logistic regression analysis were used to identify factors associated with psychological distress among HIV positive individuals. Of 2 536 HIV infected individuals found in the study, 34.5% reported psychological distress symptoms. The prevalence of reported psychological distress symptoms was significantly higher among females (38.2%) than males (28.5%). Increased likelihood of psychological distress among HIV positive males was significantly associated with residing in urban informal areas than urban formal areas [OR=2.5(95% CI: 1.2-5.6), p=0.021], not engaging in vigorous intensity sport [OR=2.1 (95% CI: 1.2-3.8), p=0.009]. The decreased likelihood was significantly associated with being employed [OR=0.6 (95% CI: 0.4-1.0), p=0.066], not having any chronic condition [OR=0.5(95% CI: (0.3-1.0), p=0.037], and low risk drinkers than hazardous drinkers [OR=0.3(95% CI: 0.1-0.9), p=0.036]. Among HIV positive females, increased likelihood of psychological distress was significantly associated with never seeing a health personnel [OR=2.8 (95% CI: 1.2-6.7), p=0.022]. The decreased likelihood was significantly associated with seeing a health personnel more than one year ago than in the past 6 months [OR=0.7 (95% CI: 0.4-1.0), p=0.051], and not having any chronic conditions [OR=0.6 (95% CI: 0.5-0.9), p=0.017]. The findings suggest a need for integrated interventions including those addressing mental health issues which target HIV positive individuals in urban informal areas, the unemployed, hazardous risk drinkers, and those with chronic medical conditions.

Keywords: Psychological distress, HIV positive individuals, HIV Prevalence, Correlates, Household survey, South Africa.

3.1 Introduction

HIV and mental health continue to be major public health issues globally [1]. South Africa carries the world's heaviest HIV burden with 7.9 million people (14.0 % of the population) living with HIV [2]. HIV can result in considerable psychological distress that manifest in depression and anxiety burden [3, 4]. Psychological distress symptoms of depression and anxiety are often common among HIV positive individuals [5, 6].

In the context of HIV, psychological distress symptoms like depression and anxiety can influence health-seeking behaviour or uptake of diagnosis and treatment for HIV/AIDS, creating non-adherence to treatment, adding to the burden of HIV disease and increasing the risk of mortality and morbidity due to HIV [7-9]. However, psychological distress symptoms often remain undetected and untreated in HIV health-care settings [9, 10]. Therefore, improved understanding of the prevalence of psychological distress symptoms (i.e., depression and anxiety) and associated factors is important in the fight against HIV.

Research evidence shows that the prevalence of psychological distress varies according to socio-demographic factors such as younger or older age, abuse, and poor health status [8, 11, 12]. In South Africa, while the rise in psychological distress symptoms (depression and anxiety) among HIV positive individuals has been observed [4, 13, 14], the prevalence of psychological distress and factors associated among HIV positive individuals nationally is poorly understood.

This paper investigates the prevalence of psychological distress symptoms and associated socio-demographic and health-related factors amongst HIV positive individuals in South Africa using the 2012 nationally representative population-based household survey. Previous studies have been small scale both in terms of national representativeness and also sample sizes [15-17].

3.2 Methods

3.2.1 Study Design and Sample

This analysis is based on data from the 2012 South African National HIV Prevalence, Incidence, and Behaviour Survey, a cross-sectional population-based survey described in detail elsewhere [18]. The survey used a multi-stage stratified cluster sampling design to draw a systematic probability sample of 15 households from a total of 1,000 enumeration areas (EAs)

selected randomly from a database of 86,000 EAs developed Statistics South Africa (Stats SA). The selection of EAs were stratified by both province and locality type and race group. The selected EAs formed the primary sampling units, and the visiting points (VPs) or households within the EAs were used as secondary sampling units. A systematic random sample of 15 VPs was selected from each of the 1,000 EAs, yielding a total sample size of 15,000 VPs [18].

Three detailed age-appropriate questionnaires (i.e., one for parent/guardian of children aged 0 to 11 years, one for children aged 12 to 14 years, and one for persons aged 15 years and older) were used to solicit information related to demographic characteristics, HIV-related knowledge, attitudes, and behaviours as well as health-related issues. In particular, the questionnaire for those 15 years and older also included a module with questions that assessed the participants' levels of psychological distress symptoms (presence or absence of depression and anxiety disorders) to all consenting individual using the Kessler 10 scale [19, 20].

Dried blood spots (DBS) specimens were also collected from participants who consented for HIV testing. Samples were tested for HIV using an enzyme immunoassay (EIA) (Vironostika HIV Uni-Form II plus O, Biomeriux, Boxtel, The Netherlands), and samples which tested positive were retested using a second EIA (Advia Centaur XP, Siemens Medical Solutions Diagnostics, Tarrytown, New York, USA). Any samples with discordant results on the first two EIAs were tested with a third EIA (Roche Elecys 2010 HIV Combi, Roche Diagnostics, Mannheim, Germany).

3.2.2 Measures

The primary outcome is based on respondent's experience of anxiety and depressive disorders based on how they felt during the previous 30 days. This was measured using the Kessler 10 scale [19, 20] which consists of 10 items. This scale has been validated among low- and middle-income countries including South Africa [21, 22]. This scale measures these symptoms by asking: 'In the past 30 days, how often did you feel: tired out for no good reason; so nervous that nothing could calm you down, hopeless; hopeless; restless or fidgety, so restless that you could not sit still; depressed; that everything was an effort; so sad that nothing could cheer you up; worthless?' The frequency with which each of these items was experienced was recorded using a 5-point Likert scale (1 = never, 2 = rarely, 3 = some of the time, 4 = most of the time, 5 = all of the time). Row scores were then summed to calculate a total score indicating whether the respondents were likely to be well (score below 20), experiencing mild (score 20–24), moderate (score 25– 29) or severe (score 30 and above) psychological distress [21]. The scores

were then dichotomized into those who scored <19 absence of psychological distress = 0) and those who scored ≤ 20 (presence of psychological distress =1). The internal reliability coefficient for the K-10 in this study was Cronbach alpha = 0.90.

Explanatory variables included socio-demographic factors such as sex (male and female), age (15-24, 25 to 34 years, 35 to 49 years, and 50 years and older), race (Black African and other races), marital status (not married and married), education level (no education/primary, secondary and tertiary), employment status (employed, not employed), locality type (urban formal, urban informal, rural informal, and rural formal), and asset-based socio-economic status (SES) based on the availability/ownership and utility of a broad range of household assets such as water, electricity, television, computer, refrigerator, and washing machine [23]. Multiple correspondence analyses (MCA) was used to calculate a composite indicator score computed by adding up all weighted responses [24]. The predicted score for each household was used to compute five quintiles (1st lowest, 2nd lower, 3rd middle, 4th higher and 5th highest) representing a continuum of household SES from the most poor to the least poor.

Other explanatory variables included health-related variables such as the last time one saw a health personnel (within the past6 months/more than 6 months but not more than a year ago/more than one year ago/never), hospitalization within the past year (yes/no), physical activity (not active/moderate activity/vigorous activity), presence of a chronic condition (yes/no), HIV status (positive/negative), ever test for HIV (yes/no), and awareness of HIV status (yes/no), and alcohol use risk score (nonexcessive/excessive) based on a questionnaire for Alcohol Use Disorder Identification Test (AUDIT) scale [25], The AUDIT is a10-item self-report instrument that includes quantity and frequency of alcohol use and was designed to identify individuals for whom alcohol use is a risk factor either for developing alcohol problems or who already experience alcohol-related problems [26]. AUDIT scores range from 0 to 40, and in South Africa scores of 8 or greater are used to identify individuals who may be at risk or who are experiencing alcohol problems (also referred to as hazardous or harmful drinking). Hazardous drinking is defined as a quantity or pattern of alcohol consumption that places patients at risk for adverse health events, while harmful drinking is defined as alcohol consumption that results in adverse events (e.g., physical or psychological harm to themselves or others) [27].

3.2.3 Data Analysis

Data was analysed using STATA 12 software (Stata Corporation, College Station, Texas, USA). Descriptive statistics were used to summarize background characteristics of the study sample and the prevalence of psychological distress symptoms by sex. Bivariate logistic regression analysis were used to assess the relationship between psychological distress symptoms and each explanatory variable. Statistically significant variables were entered into a multivariate logistic regression analysis to identify factors independently associated psychological distress symptoms among HIV infected individuals. Crude Odds ratios (OR) and adjusted a OR for the bivariate and multivariate models respectively with 95% confidence intervals (CI) were used as a measure the effect of each variable on psychological distress. All statistical analysis was significant at a p-value ≤ 0.05. Weighting procedures were carried out before data analysis to account for the multi-level complex design of the survey. Sample weights were introduced to correct for potential bias at the EA, household, and individual levels and also to adjust for non-response. The analyses took into account the complex, multi-level, stratified design of the survey using the svy command to adjust for unequal sampling.

3.3 RESULTS

3.3.1 Characteristics of the Study Sample

A sub-sample of 2 536 HIV positive participants aged 15 years and older was used in the analysis, 38.6% (789) males and 61.4% (1747) females. Table 3 shows that the majority of the participants were females (61.4%), and 40.1% were aged 25 to 34 years (40.1%). The majority were Black African (97.2%), not married (81.0%), had secondary level education (74.5%), were unemployed (62.9%), and were from low SES households (56.1%) and about 40.5 % were from urban formal areas and 41.6% from urban formal areas.

Table 3: Socio-Demographic Characteristics of the Study Sample, South Africa 2012

Variables	Total*	%
Sex		
Males	789	38.6
Females	1747	61.4
Age groups (years)		
15-24	387	11.9
25 to 34	896	40.1

Variables	Total*	%
35 to 49	884	38.6
50+	369	9.4
Race Group		
Black African	2307	97.2
Other Race Groups	229	2.8
Marital status		
Not married	2041	81.0
Married	458	19.0
Education Level		
No education/Primary	557	21.2
Secondary	1502	74.5
Tertiary	81	4.3
Employment status		
Unemployed	1521	62.9
Employed	889	37.1
Asset based SES**		
Low SES	1433	56.1
Middle SES	885	38.4
High SES	192	5.5
Locality type		
Urban formal	874	40.5
Urban informal	503	13.4
Rural informal	826	41.6
Rural formal	333	4.6

3.3.2 Prevalence of Psychological Distress

Of the 2 536 HIV positive participants that responded to the questions on psychological distress, 34.5% (95% CI: 30.7-38.6) reported psychological distress symptoms. The prevalence of reported psychological distress symptoms was significantly higher among HIV positive females than males (38.3%; vs 28.5%, $p<0.001$). Table 4 shows that the proportion of reported

psychological distress among HIV positive males was only significantly higher among the unemployed when compared to those who were employed (36.7 vs 22.6%, p=0.008) and those residing in urban informal areas compared to other locality types (40.7%; p=0.046).

Table 4: Prevalence of psychological distress and socio-demographic characteristics among HIV infected individuals by sex, South Africa 2012

Variables	Males				Females			
	n	%	95% CI	p-value	n	%	95% CI	p-value
Age groups (years)								
15-24	91	22.1	11.5-38.2	0.128	296	31.5	24.7-39.1	0.072
25 to 34	274	25.8	19.4-33.4		622	35.6	29.9-41.6	
35 to 49	280	34.0	25.7-43.4		604	42.8	36.2-49.8	
50+	144	23.2	14.4-35.3		225	42.3	32.3-53.0	
Race Group								
Black African	689	28.7	23.8-34.2	0.394	1618	38.4	34.3-42.6	0.442
Other Race Groups	100	22.6	12.5-37.3		129	31.7	17.8-49.9	
Marital status								
Not married	592	29.6	23.9-36.0	0.198	1449	38.9	34.5-43.5	0.141
Married	186	21.7	13.7-32.6		272	32.3	25.1-40.5	
Education Level								
No education/Primary	190	31.4	21.8-43.0	0.707	367	40.4	31.9-49.5	0.107
Secondary	434	26.5	20.9-32.9		1068	39.1	34.5-43.8	
Tertiary	27	28.8	10.5-58.1		54	20.8	10.0-38.4	
Employment status								
Unemployed	340	36.7	28.7-45.4	0.008	1181	38	33.5-42.8	0.959
Employed	410	22.6	17.0-29.3		479	37.8	30.5-45.7	
Asset based SES								
Low SES	444	30.1	23.6-37.5	0.502	989	37.8	32.2-43.8	0.767
Middle SES	269	24.4	17.3-33.3		616	37.3	32.1-42.9	
High SES	68	31.9	16.0-53.7		124	43.1	30.0-57.3	
Locality type								
Urban formal	304	22.6	16.2-30.5	0.046	570	39.9	33.5-46.7	0.856
Urban informal	147	40.7	30.1-52.1		356	37.3	29.4-45.9	
Rural informal	196	31.5	23.0-41.4		630	37.2	30.8-44.1	
Rural formal	142	24.9	17.5-34.1		191	37.8	28.9-47.6	

Subtotals do not add up to the overall total due to non-response and / or missing data, CI-Confidence Intervals. SES-Socio-Economic Status.

Table 5 shows that with health-related variables the proportion of reported psychological distress among HIV positive males was significantly higher among individuals that reported fair/poor than excellent/good self-rated health (SRH) (47.8%; 95% CI: 38.1-57.7), p<0.001), those that did not engage in vigorous intensity sport than those who did (33.4% vs. 19.0%, p=0.004), had been hospitalised for any illness in the past 12 months than those who were not (48.6% vs 25.8%, p= 0.009) and chronic medical condition than those who did not (44.0% vs 23.3%, p<0.001). Similarly, the proportion of reported psychological distress among HIV positive females among individuals that reported fair/poor than excellent/good SRH (54.1% vs 32.2%, p<0.001), those that did not engage in vigorous intensity than did (39.8% vs. 7.7%, p=0.008) and moderate intensity sport than did (40.5% vs. 29.2%, p=0.006), never saw health personnel in the past 12 months than did do so more than one year ago, more than 6 months but not more than a year ago and within the past 6 months (56.7% vs. 28.8% vs. 43.6% vs. 39.2%, p=0.011), and had chronic medical condition than did not (47.4% vs. 34.7%, =0.001).

Table 5: Prevalence of Psychological Distress and Health-Related Variables among HIV-Infected Individuals by Sex, South Africa 2012

Variables	**Males**				**Females**			
Self-rated health	**n**	**%**	**95% CI**	**p-value**	**n**	**%**	**95% CI**	**p-value**
Fair/poor	217	47.8	38.1-57.7	<0.001	486	54.1	46.8-61.2	<0.001
Excellent/good	570	20.6	16.1-26.0		1253	32.2	27.9-36.7	
Do you do vigorous intensity sport?								
Yes	264	19.0	13.2-26.6	0.004	222	27.7	20.7-35.8	0.008
No	521	33.4	27.2-40.2		1519	39.8	35.4-44.4	
Do you do moderate intensity sport?								
Yes	283	24.8	17.6-33.7	0.272	332	29.2	22.8-36.6	0.006
No	501	30.5	24.7-37.1		1410	40.5	36.0-45.2	
When was last time you saw a health personnel?								
Within the past six months	407	32.8	26.1-40.3	0.520	1025	39.2	34.4-44.3	0.011
More than six months but not more than a year	123	34.3	23.3-47.4		273	43.6	34.3-53.3	
More than one year ago	212	18.0	11.0-28.0		373	28.8	22.3-36.2	
Never	43	26.7	13.0-47.1		64	56.7	36.8-74.6	
Have you been hospitalised in the past 12 months?								
Yes	79	48.6	30.9-66.7	0.009	170	35.2	25.9-45.8	0.521

Variables	Males				Females			
No	709	25.8	21.4-30.9		1571	38.7	34.4-43.1	
Do you have any chronic medical condition?								
Yes	196	44.0	33.5-55.1	<0.001	530	47.4	39.9-55.0	0.001
No	589	23.3	18.7-28.8		1209	34.7	30.4-39.2	
Alcohol use AUDIT score*								
Hazardous drinkers (20+)	321	32.1	24.4-40.9	0.104	1293	38.0	33.5-42.7	0.107
Abstainers	221	20.0	13.9-28.0		219	37.0	25.4-50.4	
Low drinkers (1-7)	124	29.1	17.7-44.0		62	41.9	27.7-57.5	
High risk drinkers (8-19)	25	45.0	22.9-69.2		9	100.0		

Subtotals do not add up to the overall total due to non-response and / or missing data, CI-Confidence Intervals, *Alcohol risk score based on a questionnaire for Alcohol Use Disorder Identification Test (AUDIT).

3.3.3 Factors Associated with Psychological Distress

Bivariate Models

Table 6 shows that in the bivariate logistic regression analysis with socio-demographic factors among HIV positive males, the increased likelihood of psychological distress was significantly associated with living in urban informal areas [OR=2.4 (95% CI: 1.2-4.5), p=0.010]. While the decreased likelihood was significantly associated with being employed than unemployed [OR=0.5 (95% CI: 0.3-0.8), p=0.005). Among HIV positive females, the increased likelihood of psychological distress was significantly associated with age among those aged 35 to 49 years [OR=1.6 (95% CI: 1.1-2.5), p=0. 0.023] than among those of other ages. While the decreased likelihood was significantly associated with having tertiary level education than having no education or primary level education [OR=0.4 (95% CI: 0.2-0.9), p=0.037].

Table 6: Bivariate Logistic Regression Models of Socio-Demographic Factors Associated with Psychological Distress among HIV Infected Individuals by Sex

	Male Model				Female Model			
Age group (in) years	**OR**	**95% CI**		**p-value**	**OR**	**95% CI**		**p-value**
15-24	1				1			
25 to 34	1.2	0.6	2.7	0.614	1.2	0.8	1.8	0.407
35 to 49	1.8	0.8	4.0	0.136	1.6	1.1	2.5	0.023
50+	1.1	0.5	2.5	0.881	1.6	1.0	2.7	0.073
Race Group								
Black African	1				1			

	Male Model				Female Model			
Age group (in) years	**OR**	**95% CI**		**p-value**	**OR**	**95% CI**		**p-value**
Other Race Groups	0.7	0.3	1.6	0.407	0.7	0.4	1.5	0.426
Marital status								
Not married	1.0				1			
Married	0.7	0.4	1.2	0.174	0.8	0.5	1.1	0.143
Education Level								
No education/Primary	1				1			
Secondary	0.8	0.4	1.4	0.418	0.9	0.7	1.3	0.765
Tertiary	0.9	0.2	3.3	0.852	0.4	0.2	0.9	0.037
Employment status								
Unemployed	1				1			
Employed	0.5	0.3	0.8	0.005	1.0	0.7	1.4	0.957
Asset based SES								
Low SES	1				1			
Middle SES	0.8	0.4	1.3	0.287	1.0	0.7	1.3	0.883
High SES	1.1	0.4	2.7	0.849	1.2	0.7	2.3	0.467
Locality type								
Urban formal	1				1			
Urban informal	2.4	1.2		0.010	0.9	0.6	1.4	0.609
Rural informal	1.6	0.9		0.110	0.9	0.6	1.3	0.521
Rural formal	1.1	0.6	4.5 2.8 2.1	0.690	0.9	0.6	1.5	0.716

SES-Socio-economic status, unadjusted OR-Odds ratio, CI-Confidence intervals, SES-socio-economic status, p-value ≤ 0.05 considered significant.

Table 7 shows that in the bivariate logistic regression analysis with health-related factors among HIV positive males, the increased likelihood of psychological distress was significantly associated with not doing vigorous intensity sport [OR=1.3 (95% CI:1.3-3.6), p=0.005]. While the decreased likelihood of psychological distress was significantly associated with reported excellent/good SRH than fair/poor SRH [OR=0.3 (95% CI: 0.2-0.5), p<0.001], visiting health personnel more than a year ago than in the past 6 months [OR=0.4 (95% CI: 0.2-0.9), p=0.015], not being hospitalized in the past 12 months [OR=0.4 (95% CI: 0.2-0.8), p=0.006], and not having any chronic medical condition [OR=0.4 (95% CI: 0.2-0.7), p<0.001].

Similarly, among HIV positive females, the increased likelihood of psychological distress was significantly associated with not doing vigorous intensity sport [OR=1.7 (95% CI: 11.2-2.6),

p=0.008] and moderate intensity sport [OR=1.7 (95% CI: 1.1-2.4), p=0.007]. While the decreased likelihood was significantly associated with reported excellent/good SRH than fair/poor SRH [OR=0.4 (95% CI: 0.3-0.6), p<0.001], visiting health personnel more than a year ago than in the past six months [OR=0.6 (95% CI: 0.4-0.9), p=0.014], and not having any chronic medical condition [OR=0.6 (95% CI: 0.4-0.8), p=0.001].

Table 7: Bivariate Logistic Regression Analysis of Health-Related Factors Associated with Psychological Distress among HIV Infected Individuals by Sex

	Male Model				**Female Model**			
	OR	**95% CI**		**p-value**	**OR**	**95% CI**		**p-value**
Self-rated health (SRH)								
Fair/poor	1				1			
Excellent/good	0.3	0.2	0.5	<0.001	0.4	0.3	0.6	<0.001
Do you do vigorous intensity sport?								
Yes	1				1			
No	2.1	1.3	3.6	0.005	1.7	1.2	2.6	0.008
Do you do moderate intensity sport?								
Yes	1				1			
No	1.3	0.8	2.2	0.273	1.7	1.1	2.4	0.007
When was last time you saw a health personnel?								
Within the past six months	1				1			
More than six months but not more than a year	1.1	0.6	2.0	0.83	1.2	0.8	1.8	0.372
More than one year ago	0.4	0.2	0.9	0.015	0.6	0.4	0.9	0.014
Never	0.7	0.3	1.9	0.544	2.0	0.9	4.7	0.097
Have you been hospitalised for any illness in the past 12 months?								
Yes	1				1			
No	0.4	0.2	0.8	0.006	1.2	0.7	1.8	0.528
Do you have any chronic medical condition?								
Yes	1.0				1.0			
No	0.4	0.2	0.7	<0.001	0.6	0.4	0.8	0.001
Alcohol use AUDIT score*								
Hazardous drinkers (20+)	1				**	**	**	**
Abstainers	0.6	0.2	1.9	0.374	**	**	**	**
Low drinkers (1-7)	0.3	0.1	1.1	0.062	**	**	**	**
High risk drinkers (8-19)	0.5	0.1	1.9	0.308	**	**	**	**

Unadjusted OR-Odds ratio, CI-Confidence intervals, *Alcohol risk score based on a questionnaire for Alcohol Use Disorder Identification Test (AUDIT), **The variable was omitted by the model, p-value ≤ 0.05 considered significant.

Multivariate Model

Figure 4 shows final multivariate model for factors associated with reported psychological distress symptoms among HIV positive males and females. In the male model the increased likelihood of psychological distress was significantly associated with residing in urban informal areas than urban formal areas [aOR=2.5(95% CI: 1.2-5.6), p=0.021], and not engaging in vigorous intensity sport [aOR=2.1 (95% CI: 1.2-3.8), p=0.009]. The decreased likelihood of psychological distress was significantly associated with being employed [aOR=0.6 (95% CI: 0.4-1.0), p=0.066], not having any chronic condition [aOR=0.5 (95% CI: (0.3-1.0), p=0.037], and low risk drinkers than hazardous drinkers [aOR=0.3 (95% CI: 0.1-0.9), p=0.036].

In the female model, the increased likelihood of psychological distress was significantly associated with never seeing a health personnel [aOR=2.8 (95% CI: 1.2-6.7), p=0.022]. The decreased likelihood of psychological distress was significantly associated with seeing a health personnel more than one year ago than in the past 6 months [aOR=0.7 (95% CI: 0.4-1.0), p=0.051], and not having any chronic conditions [aOR=0.6 (95% CI: 0.5-0.9), p=0.017].

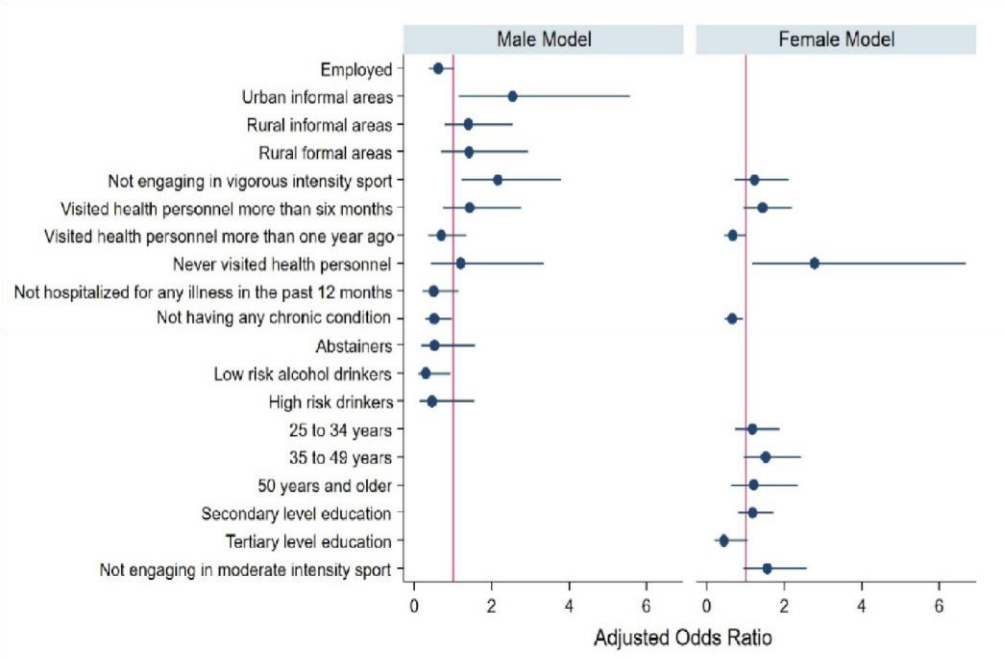

Figure 4: Coefficient plots of the multivariate logistic regression models of factors associated with psychological distress among HIV positive individual stratified by sex

3.4 Discussion

This study sought to determine the prevalence of psychological distress symptoms and associated socio-demographic and health-related factors among HIV positive individuals in

South Africa. The following results were found. Firstly, the prevalence of psychological distress symptoms among HIV positive individuals was 34.5%. Secondly, the prevalence of reported psychological distress symptoms was significantly higher among females (38.2%) than males (28.5%). Thirdly, increased likelihood of psychological distress among HIV positive males was significantly associated with residing in urban informal areas than urban formal areas, and not engaging in vigorous intensity sport while decreased likelihood was significantly associated with being employed, not having any chronic condition, and low risk drinkers than hazardous drinkers. Fourthly, among females, increased likelihood of psychological distress was significantly associated with never seeing a health personnel while decreased likelihood was significantly associated with seeing a health personnel more than one year ago than in the past 6 months, and not having any chronic conditions.

In this study, the prevalence of psychological distress was significantly higher among females compared to males. Similar findings were reported by the South African National Health and Nutrition Examination Survey (SANHANES) [28]. These findings are also in line with other studies that found high prevalence of psychological distress among females due to factors such as pregnancy, poverty, sexual harassment and abuse [29]. It's been argued that females are at a distinct disadvantage in most South African communities such as economic and gender inequality including sex roles, and such disparities make females more susceptible to psychological distress.

The findings of this study showed that contextual factors such as type of residence and employment contribute to the risk of psychological distress. Prevalence of psychological distress was found higher among males who resided in urban informal areas and those who were unemployed than their female counterparts. In support of these findings, evidence showed that contextual factors such as poor socioeconomic status, are related to both HIV/AIDS and psychological distress symptoms such as depression and anxiety [30, 31]. In line with current findings, psychological distress symptoms such as depression were also found in males who resided in informal settlements and were associated with stealing because of hunger, being more controlling in relationships, and being more ashamed about lack of work [31]. Furthermore, consistent with current findings, research demonstrates that conditions such as poverty, poor housing and amenities, unemployment, and gender inequality may be additional stressors to one's wellbeing [7].

Among females, the findings showed that factors such as poor health, never seen a health personnel and presence of chronic medical conditions were found to be associated with psychological distress. In agreement with current findings, poor self-rated health and diagnoses with other chronic medical illnesses have been associated with psychological distress among HIV positive individuals [32]. Poor emotional and physical health often co-occur among HIV positive individuals, and it is therefore important to intervene in an integrated manner that address all of their health needs [33]. In addition, studies show that physical activity can change an individual's mental state and therefore help prevent and manage mental health problems [34, 35].

This study is not without limitations. The study relied on self-report for obtaining data on depression and anxiety diagnosis to assess psychological distress symptoms. The K10 scale used to measure psychological distress is also not a diagnostic tool but rather a screening tool. This study does not examine the aetiology of the psychological distress but only correlates thereof; we therefore could not determine the causes of psychological distress but instead made associations with mediating factors. The study may also be limited by other unmeasured important predictors of psychological distress that were not accounted for in the analysis. Nevertheless, this nationally representative population-based study adds to the growing literature on the prevalence of psychological distress and associated factors among HIV positive individuals both globally and in South Africa due to the large number of HIV positive individuals involved.

3.5 Conclusion

In conclusion, the reported co-occurrence of psychological distress symptoms and HIV suggest a need for integrated intervention strategies (prevention, treatment, and health promotion) for HIV and psychological distress especially among females. The findings also suggest a need for a targeted focus on HIV positive individuals in urban informal areas, the unemployed, hazardous risk drinkers, and those with chronic medical conditions. As there is big shortage of professional mental health practitioners in most countries in sub-Saharan Africa including South Africa, there is need to consider expanding the role played by lay (non-specialist) health providers in local communities who have been successfully used to provide both pre-and post-counselling during testing for HIV infections to also provide for follow-up counselling [36, 37]. However, there is also a need for more studies that track changes and trends overtime on

factors that underlie linkages between psychological distress symptoms and HIV in South Africa.

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CHAPTER 4

FACTORS ASSOCIATED WITH EXTERNAL HIV-RELATED STIGMA AND PSYCHOLOGICAL DISTRESS AMONG PEOPLE LIVNG WITH HIV IN SOUTH AFRICA

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ABSTRACT

Background: HIV-related stigma and psychological distress among people living with HIV (PLHIV) pose a public health challenge in most African countries. This study aims to investigate the association between HIV-related stigmatizing attitudes and psychological distress amongst PLHIV in South Africa using the 2012 nationally representative population-based household survey. Methods: The data used in the analysis were collected using a multi-stage stratified cluster sampling design. Bivariate and multivariate logistic regression models were used to identify factors associated with stigma among PLHIV with psychological distress. A total of 2521 HIV positive individuals that responded to the question on psychological distress, 34.3% had psychological distress and 37.9% experienced high levels of HIV related stigmatizing attitudes. Stigmatizing attitudes among PLHIV with psychological distress were significantly less likely among those with secondary level education [aOR = 0.67 (95% CI: 0.44–1.01), p = 0.050], those with correct knowledge about HIV and rejection of myths about HIV [aOR = 0.58 (95% CI: 0.38–0.89), p = 0.013], and those who ever tested for HIV [aOR = 0.65 (95% CI: 0.42–1.01), p = 0.054]. Conclusion: The findings suggest a need to reinvigorate stigma-reduction interventions in the national HIV response with emphasis on HIV awareness and education campaigns. In addition, HIV testing services should be reinforced through communication strategies targeted against HIV stigmatization, discrimination and fear. There is also a need to continuously engage PLHIV in programs through counselling and support interventions for acceptance of HIV positive status and to help them cope with HIV-related stigma.

Keywords: People living with HIV Stigma Psychological distress South Africa

4.1 Background

HIV-related stigma is one of the biggest challenges facing people living with HIV (PLHIV) and has been associated with poor mental health [1]. Stigma has been shown to have a negative impact on quality of life for people living with HIV [2;3]. Evidence suggests that psychosocial distress and general substance use increase amongst stigmatized PLHIV [4]. In addition, individuals with substance use disorders may engage in reckless behaviours or be exposed to heightened risks and likelihood of victimization [4]. PLHIV are more likely to be the victims of abuse, assault, and other violent crimes relative to seronegative individuals [5].

Stigma has also been linked with health-related risk factors including poor seeking healthcare and non-adherence to antiretroviral therapy [6-8]. Furthermore, experiences of social rejection, disapproval, and discrimination related to HIV may heighten a person's sense of shame regarding their illness and serve to lessen their motivation to maintain optimal health [9]. Evidence shows that stigma is associated with concealment of HIV status and avoidance of health care for fear of being identified and stigmatized [10. Therefore, HIV-related stigma poses as a significant obstacle to the treatment and prevention of HIV/AIDS [11]. In addition, HIV-related stigma can result in negative self-image that may in turn exert subtle negative influences on social interactions and affect behavioural outcomes such as engagement in risk behaviour [9]. Consequently, PLHIV experiencing higher levels of HIV-related stigma are at increased risk of transmitting the infection to others [8].

HIV-related stigma has been consistently associated with poor mental health outcomes [1;12]. Evidence shows that PLHIV are two to three times likely to develop mental disorders than HIV negative people [13-15]. Psychological problems such as depression and anxiety are among the most common comorbidities among PLHIV across the world [16-18]. Research studies in different countries across the sub-Saharan Africa have reported high prevalence rates of mental disorders among PLHIV [19-21]. The presence of mental disorders among PLHIV is also associated with numerous health and healthcare seeking behaviours such as poor adherence to medications and low rates of retention in HIV care [22-24].

While HIV-related stigma and psychological distress are each independent barriers to health seeking behaviour, HIV prevention and ART initiation, the interrelationship between these two remains poorly understood. Several studies have examined constructs of stigma and psychological distress, however, the role of HIV-related stigma mechanisms on the effect of psychological mechanisms on health outcomes remains complex due to a number of mediating

pathways [25-27]. The mediating pathways involved are important in designing interventions aimed at reducing the effects of HIV-related stigma and induced psychological distress [28].

Since HIV-positive serostatus is often not evident, managing social relationships and serostatus disclosure to avoid stigma and discrimination has been suggested as an added source of stigma induced stress among PLHIV [29]. Different intervention strategies have been proposed, one that targets stigma (both externalized and internalized) and another that treats depression and addresses other mediating psychosocial factors [28]. However, these are complex constructs that cannot be seen as a simple single notion. Programs with adequate resources may even target all these mechanisms in a comprehensive intervention strategy to maximize the probability of success in reducing the effects of HIV-related stigma on the well-being of PLHIV [28]. However, more nuanced and deeper understanding of how different mechanisms affect health outcomes among PLHIV is important in designing interventions aimed at reducing the effects of HIV-related stigma.

Evidence shows that the mechanisms of how stigma affects psychological distress among PLHIV may be explained by several biological, environmental, social, economic and demographic factors [30]. Therefore, the understanding of mechanisms between HIV-related stigma and psychological distress may be influenced by mediating contextual factors. Characterizing contexts of the populations of interest is important and should be incorporated in designing interventions to reduce stigma [30]. This paper examines factors associated with HIV related stigmatizing attitudes among HIV-positive people in South Africa who are psychologically distressed using the 2012 nationally representative population-based HIV household survey.

4.2 Methods

4.2.1 Data source

This study used data from the 2012 South African National HIV Prevalence, Incidence and Behaviour Survey, a nationally representative population-based household survey, described in detail elsewhere [31]. Briefly, participants were selected using multi-stage cluster sampling design. A systematic probability sample of 15 households was drawn from each of 1000 enumeration areas (EAs) selected randomly from strata defined by locality type and province from the updated 2007 master sample of census EAs. All members belonging to selected household were asked to participate in the survey.

4.2.2 Study procedure

The survey administered age-appropriate questionnaires to consenting participants, soliciting information on demographic factors, and HIV-related knowledge, attitudes, practice, sexual history and behaviours including questions on HIV-related stigma [31]. Dried blood spots (DBS) specimens were also collected from participants who consented for HIV testing. Samples were tested for HIV antibodies using a testing algorithm with three different immunoassays (Vironostika HIV Uni-Form II plus O, Biomeriux, Boxtel, The Netherlands; Advia Centaur XP, Siemens Medical Solutions Diagnostics, Tarrytown, NJ, USA; (Roche Elecys 2010 HIV Combi, Roche Diagnostics, Mannheim, Germany).

The current study is based on a sub-sample of youth and adult individuals 15 years and older who tested positive for HIV who responded to questions which measured both HIV-related stigma and psychological distress during the interviews.

4.2.3 Measures

Primary outcome

The primary outcome measure of the HIV stigma scale was based on a question relating to attitudes and beliefs against PLHIV with 7 items measuring various aspects of HIV-related stigma [32]: (1) Would you buy food if you knew that a shopkeeper or food seller had HIV? (2) Would you be willing to care for a family member with AIDS? (3) If a teacher has HIV but is not sick, he or she should be allowed to continue teaching? (4) Is it a waste of money to train or give a promotion to someone with HIV/AIDS? (5) Would you want to keep the HIV positive status of a family member a secret? (6) Are you comfortable talking to at least one member of your family about HIV/AIDS? (7) A person would be foolish to marry a person who is living with HIV/AIDS?

Exploratory factors analysis was used to analyse responses to these questions (yes = 1, no = 2, not sure = 3). A varimax orthogonal rotation was used to assess the underlying domains of stigma and reduce the number of items needed [33]. Eigenvalues were used to identify factors that account for most variance within the items, and Cronbach's Alpha was used to assess the reliability of factor loadings. Variables with a factor loading of at least 0.4 and factors with an eigenvalue of at least 1 were retained for the final analysis [34]. A simple HIV stigma index score was then calculated by summing the scores across all the items. Scores below the mean were classified as low levels of stigma and those above as high levels of stigma. The index

variable was dichotomized into a binary outcome measure of low stigma = 0 and high stigma = 1. A Cronbach's Alpha of 0.60 or greater was considered sufficient to determine reliability.

The HIV stigma index scale was stratified by the presence and absence of psychological distress using respondent's experience of anxiety and depressive disorders measured using the Kessler 10 scale [35], which consists of 10 items that describe how they felt during the previous 30 days. How often did you feel: Tired out for no good reason? So nervous that nothing could calm you down? Hopeless; Restless or fidgety: So restless that you could not sit still; Depressed? That everything was an effort? So sad that nothing could cheer you up? Worthless?' Responses to these items were recorded using a 5-point Likert scale (1 = never, 2 = rarely, 3 = some of the time, 4 = most of the time, 5 = all of the time). This scale has been validated among low-and middle-income countries including South Africa [36;37]. The scores from these responses were then summed to calculate a total score indicating whether the respondents were likely to experience psychological distress. Raw scores were then summed to calculate a total score indicating whether the respondents were likely to be well (score below 20), experiencing mild (score 20–24), moderate (score 25–29) or severe (score 30 and above) psychological distress (Andrews & Slade, 2001). The scores were then dichotomized into those who scored <19 absence of psychological distress = 1) and those who scored ≥20 (presence of psychological distress = 2).

Explanatory variables

Explanatory variables included socio-demographic factors such as age in years (15–24, 25–34, 35–49, 50 years and older), sex (male and female), race groups (black African and other races), educational level (primary/no education, secondary, tertiary), employment status (unemployed and employed), asset-based SES (low and high) and locality type (urban formal, urban informal, rural informal/tribal areas, rural formal/farm areas). This also included HIV-related knowledge and awareness factors such as correct knowledge and rejection of myths about HIV (no and yes), ever test for HIV (no and yes), know HIV results (no and yes), self-perceived risk of HIV infection (no and yes), exposure to ARVs (no and yes), self-rated health (fair/poor and good/excellent).

4.2.4 Statistical analysis

Descriptive statistics were used to summarize characteristics of the study sample. Bivariate logistic regression was used to assess the factors associated with high levels of stigmatizing attitudes among HIV positive individuals with psychological distress. Statistically significant

variables were entered into multivariate logistic regression analysis. All models accounted for the complex survey design. Crude and adjusted odds ratios (aOR) with 95% confidence intervals (CI) and a p-value ≤ 0.05 were considered statistically significant. All statistical analyses were conducted using the Stata software package All statistical analysis was done in Stata version 15.0 software using "svy" commands to introduce command to take into account complex survey design (Stata Corp, College Station, Texas, USA).

4.3 Results

4.3.1 Sample characteristics and HIV-related stigma

Table 8 presents sample characteristics of the study sample and the prevalence of high levels of stigmatizing attitudes among HIV positive individuals with psychological distress. The sample consisted mainly of those 25–34 years, was predominantly female and Black African. The majority were married, had secondary level education, unemployed, were from low SES households and resided in urban and rural informal areas. Most respondents did not have correct knowledge and rejection of myths about HIV, never tested for HIV, and did not know their HIV status. About half perceived themselves as being at risk of HIV infection. The majority were not on ARVs and reported excellent/good self-rated health.

The sample comprised 2521 HIV positive individuals that responded to the question on psychological distress, and 34.3% (95%CI: 30.5–38.3) had psychological distress. Of these, 37.9% (95% CI: 32.7–43.4) had high levels of stigmatizing attitudes for HIV. Table 1 shows that the prevalence of HIV related stigmatizing attitudes among HIV positive individuals with psychological distress was higher among those 50 years and older, other race groups, the married, those with no education or with primary level education, the unemployed, those from low SES households and those residing rural informal areas. The stigma levels were also higher among those who had no correct knowledge and rejection of myths about HIV, those who never tested for HIV, those who perceived themselves as being at risk of HIV, those not on ARTs and those who reported fair/poor self-rated health.

Table 8: Socio-demographic characteristics and prevalence of high levels of stigmatizing attitudes among HIV positive individuals with psychological distress

Variables	**Study sample**		**Presence of psychological distress**		
	Total	**%**	**n**	**%**	**CI**
Age in years					
15 to 24	384	11.9	101	27.5	17.2-40.8
25 to 34	890	40.3	274	37.5	28.7-47.2
35 to 49	879	38.4	320	40.2	32.0-49.0
50 years and older	368	9.4	126	41.8	30.3-54.3
Sex					
Male	784	38.4	209	45.1	34.9-55.8
Female	1737	61.6	612	34.7	28.8-41.1
Race groups					
Black African	2293	97.3	758	38.1	32.8-43.6
Other races	228	2.7	63	31.6	15.8-53.2
Marital status					
Not married	2029	80.9	676	37.9	32.3-43.8
Married	456	19.1	123	38.4	24.7-54.3
Educational level					
Primary/no education	555	21.3	194	56.1	45.4-66.3
Secondary	1493	74.4	473	31.9	25.4-39.2
Tertiary	81	4.3	19	32.8	11.7-64.4
Employment status					
Unemployed	1510	63	534	35.5	29.6-41.7
Employed	885	37	248	40.9	30.6-52.0
Asset based SES					
Low	2016	80.3	648	40.2	34.5-46.2
High	479	19.7	159	29.2	17.9-43.6
Locality type					
Urban formal	871	40.4	279	35.7	26.1-46.5
Urban informal	500	13.4	164	17.5	11.3-26.3
Rural informal / tribal areas	818	41.5	283	45.6	38.4-53.0
Rural formal / farm areas	332	4.6	95	56.5	43.7-68.4
Correct knowledge and myth rejection about HIV					
No	2013	81.3	666	39	33.1-45.3

Variables	Study sample		Presence of psychological distress		
	Total	**%**	**n**	**%**	**CI**
Yes	508	18.7	155	32.5	23.1-43.6
Ever test for HIV					
No	474	19.4	128	42.6	29.6-56.6
Yes	2041	80.6	693	36.9	31.3-42.9
Know HIV results					
No	1895	94.7	647	36.4	30.5-42.7
Yes	97	5.3	29	37.6	19.0-60.8
Self-perceived risk of HIV					
No	1239	48.6	454	38.2	31.0-45.9
Yes	1221	51.4	340	38.3	30.7-46.5
Exposure to ARVs					
No	1738	69.7	529	39.7	32.9-46.9
Yes	781	30.3	291	34.3	27.1-42.3
Self-rated health					
Fair/poor	700	28.4	356	36.6	29.0-44.9
Good/excellent	1811	71.6	465	38.9	32.0-46.3

CI-confidence interval, SES = socio-economic status.

4.3.2 Factors associated with HIV related stigmatizing attitudes

Bivariate models

Table 9 presents results of the bivariate logistic regression models of the association between high levels stigmatizing attitudes among PLHIV with psychological distress. Increase in levels stigmatizing attitudes for HIV was significantly associated with other race groups, those residing in rural informal/tribal areas and rural formal/farm areas, and those who perceived themselves as being at risk of HIV infection. Decrease in levels stigmatizing attitudes for HIV was significantly associated with secondary and tertiary level education, high SES households, correct knowledge and rejection of myths about HIV, ever tested for HIV, and exposure to ARTs.

Table 9: Bivariate regression models of factors associated with HIV related stigmatizing attitudes among PLHIV with psychological distress.

Variables	**High levels of stigmatizing attitudes**			
Age in years	**OR**	**95% CI**		**p-value**
15 to 24	1			
25 to 34	1.26	0.82	1.93	0.29
35 to 49	1.51	0.98	2.35	0.06
50 years and older	1.62	0.95	2.75	0.08
Sex				
Male	1			
Female	0.73	0.53	1.00	0.05
Race groups				
Black African	1			
Other races	1.69	1.00	2.88	0.05
Marital status				
Not married	1			
Married	0.88	0.59	1.32	0.543
Educational level				
Primary/no education	1			
Secondary	0.60	0.41	0.88	0.01
Tertiary	0.43	0.14	1.30	0.14
Employment status				
Unemployed	1			
Employed	1.17	0.85	1.61	0.35
Asset based SES				
Low	1			
High	0.69	0.50	0.96	0.03
Locality type				
Urban formal	1			
Urban informal	0.67	0.42	1.06	0.09
Rural informal / tribal areas	1.22	0.83	1.79	0.30
Rural formal / farm areas	2.07	1.25	3.41	0.00
Correct knowledge and myth rejection about HIV				
No	1			
Yes	0.54	0.37	0.80	0.00
Ever test for HIV				

Variables	High levels of stigmatizing attitudes			
No	1			
Yes	0.56	0.38	0.82	0.00
Know HIV results				
No	1			
Yes	0.68	0.33	1.43	0.31
Self-perceived risk of HIV				
No	1			
Yes	1.36	1.03	1.78	0.03
Exposure to ARVs				
No	1			
Yes	0.75	0.56	1.00	0.05
Self-rated health				
Fair/poor	1			
Good/excellent	0.95	0.74	1.21	0.66

CI-confidence interval, SES = socio-economic status.

Multivariate model

Fig. 5 multivariate logistic regression model of factors associated with high levels stigmatizing attitudes among PLHIV with psychological distress. HIV related stigmatizing attitudes among PLHIV with psychological distress was significantly less likely among those with secondary level education [aOR = 0.67 (95% CI: 0.44–1.01), p = 0.050] compared to no education/primary level education, those with correct knowledge and rejection of myths about HIV [aOR = 0.58 (95% CI: 0.38–0.89), p = 0.013] compared to their counterparts, and those who ever tested for HIV [aOR = 0.65 (95% CI: 0.42–1.01), p = 0.054].

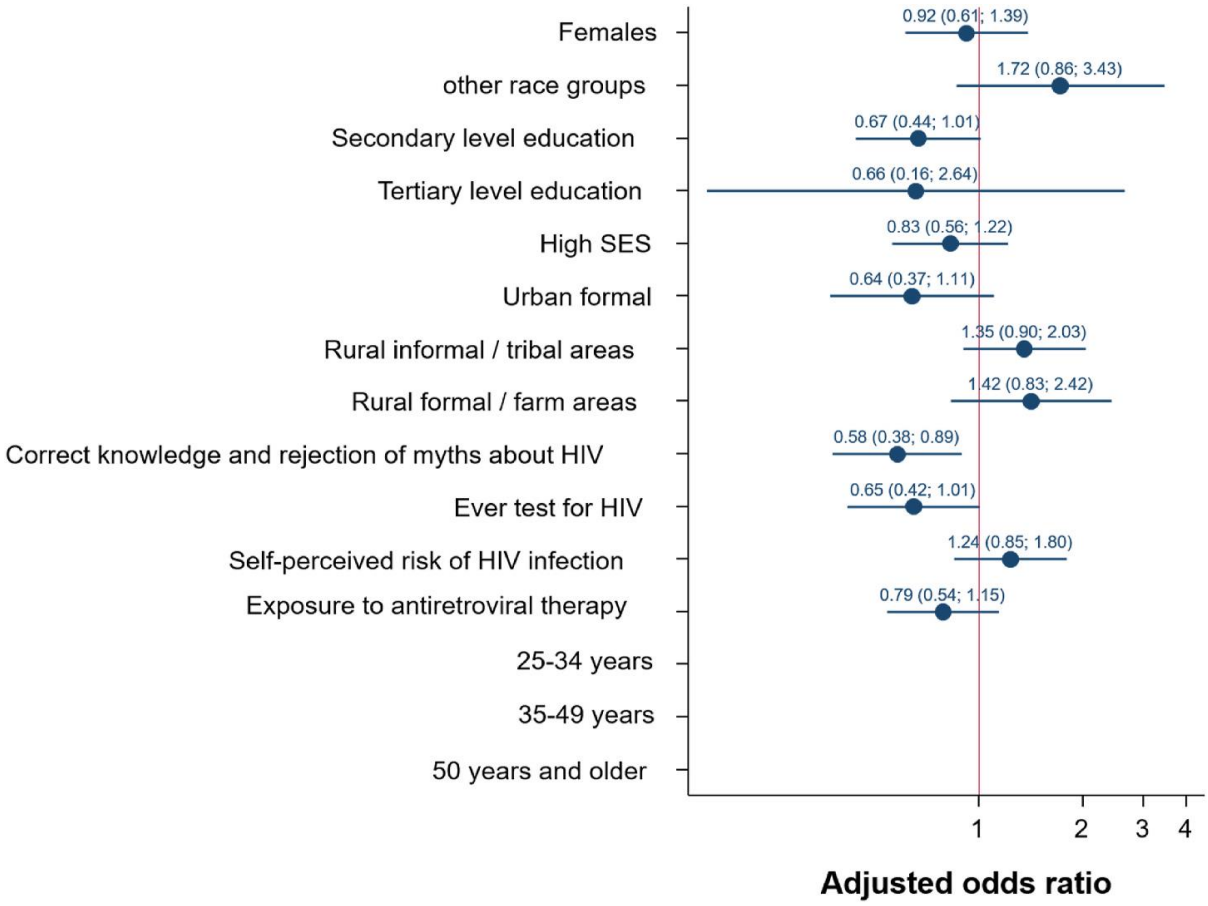

Figure 5: Multivariate regression models of factors associated with HIV related stigmatizing attitudes among PLHIV with psychological distress

4.4 Discussion

This study used a nationally representative sample and shows that the prevalence of high levels of HIV related stigmatizing attitudes was higher among people with psychological distress compared to their counterparts. Despite many millions of rands spent on HIV education in South Africa, the results of the 2012 national survey indicated poor HIV knowledge [31]. In this sub-sample of HIV positive individuals, three quarters of the study sample had secondary level education but only 18.7% of the total sample knew the correct answers to the questions about HIV. Furthermore, although the majority of respondents indicated that they had tested for HIV, most did not know their HIV status, and about half perceived themselves at risk of HIV, and a third reported exposure to ARVs. These findings suggest a need for the involvement of the Department of Basic Education (DBE) in the response to the HIV epidemic through a life skills programme to improve HIV knowledge levels, especially because the majority of respondents reported secondary level education. This has been the case since year 2000 with little or success, and in 2017 DBE developed a new national policy which mandated it to

provide curriculum-based Sexuality Education and access to Sexual Reproductive Health Services. The current observations suggest that the implementation of the new policy need to be monitored and regularly evaluated to improve HIV education, teach learners skills to reduce their risk of infection and reduce the associated stigma.

The findings revealed that HIV related stigmatizing attitudes were higher among those with psychological distress and varied by socio-demographic variables. HIV related stigmatizing attitudes were higher among older age group, males, those with lower education, those from low SES household, and those residing in urban and rural informal areas. The prevalence of HIV related stigmatizing attitudes was also higher among those who had no correct knowledge and rejection of myths about HIV, those who never tested for HIV, and those not on ART among PLHIV experiencing psychological distress.

Other studies also found that the prevalence of HIV related stigmatizing attitudes varies with socio-demographic and health-related factors and context [38-40]. This probably reflects the complex nature of HIV-related stigma and the social process that interacts with socio-demographic factors, HIV-knowledge, HIV testing and exposure to ART to reinforce stigma and discrimination [41;42]. In this study the results of the final model revealed that the odds of HIV related stigmatizing attitudes among PLHIV with psychological distress were low among those with higher levels of education. Evidence shows that people with low or no educational attainment are likely to have misconceptions about HIV and may not have appropriate information regarding HIV mode of transmission and treatment [43-46]. Furthermore, the findings showed that HIV related stigmatizing attitudes among PLHIV with psychological distress was less likely among those with correct knowledge and rejection of myths about HIV. HIV-related stigma has been associated with a lack of proper information regarding the spread of the disease and fear [47]. It has been demonstrated that increased education reduced stigma [48;49]. Hence, the need to have more HIV education and skill building strategies.

Furthermore, HIV related stigmatizing attitudes among PLHIV with psychological distress was low among people who ever tested for HIV. There is considerable evidence showing an inverse relationship between HIV-related stigma and HIV testing [50;51;8]. Studies show that voluntary counselling contributes to reducing HIV-related stigma because it provides information that may reduce misconceptions about HIV and minimise mental stress [52;53]. These findings highlight the fact that one's initial prognosis, access to accurate information

regarding HIV, and access to care and supportive services are important in dealing with HIV stigma and psychological induced distress.

This study has some limitations. It is based on a cross-sectional design, which is appropriate for identifying associations, and not suitable for exploring causal pathways. Although item nonresponse can never be totally prevented, gaps in the data matrix or missingness can pose serious problems in the analysis, because restricting the analysis to complete cases results in loss of information, and therefore estimates may be less efficient [54]. The data on both psychological distress and HIV-related stigma were collected through a self-reported questionnaire, therefore recall bias and social desirability bias may exist. In addition, others have also suggested that self-reports of stigma and discrimination are not reliable for measuring discrimination at the structural or social level [55]. There is a need for more evidence that the construct of HIV stigma scale and the Kessler psychological distress scale are relatively consistent across different settings or cross-cultural populations. Nonetheless, given the widespread stigma experienced by people with HIV and its fairly consistent manifestations, we hypothesize that the validated HIV Stigma 7-item scale will have relevance in a variety of settings in South Africa. Furthermore, the K10 scale has been validated and can be used to detect HIV related mood and anxiety disorders among HIV positive individuals [37]. Another limitation is that the focus of this study was on stigmatizing attitudes but the many studies that have explored stigma, including a multi-country African study, have noted that the stigma associated with people living with HIV, is both internal and external, and it is this combination that has such disastrous effects [12]. However, this study was unable to investigate internal stigma since it was not measured in the national survey. Nevertheless, the major strength of this study is the fact that it utilised data from a large nationally representative survey, which can be generalised to other PLHIV in the country.

4.5 Conclusion

The findings identified little or no education, insufficient HIV knowledge and myth rejection, and never testing for HIV, as factors associated with HIV-related stigmatizing attitudes among PLHIV experiencing psychological distress. The findings suggest a need to reinvigorate stigma-reduction interventions in the national HIV response with emphasis on HIV awareness and education campaigns. In addition, HIV testing services should be reinforced through communication strategies targeted against HIV stigmatization, discrimination and fear. These interventions should be targeted at multiple levels including the interpersonal institutions such

as schools, and workplaces. There is also a need to continuously engage PLHIV in programs through counselling, social support, appropriate coping strategies (resilience and self-efficacy) for acceptance of HIV positive status and to help them adapt to any encountered difficulties due to HIV-related stigma and psychological distress.

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CHAPTER 5

EXPLORING HIV STATUS AS A MEDIATOR IN THE RELATIONSHIP OF PSYCHOLOGICAL DISTRESS WITH SOCIO-DEMOGRAPHIC AND HEALTH RELATED FACTORS IN SOUTH AFRICA: FINDINGS FROM THE 2012 NATIONALLY REPRESENTATIVE POPULATION-BASED HOUSEHOLD SURVEY

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ABSTRACT

Background

Psychological distress as measured by mental disorders like depression and anxiety is more prevalent in people living with HIV (PLHIV) than in the general population. However, the relationship between mental disorders and HIV is complex and bidirectional. Improved understanding of the relationship between mental disorders and HIV is important for designing interventions for this group. This paper explores the interrelationships of psychological distress with HIV and associated socio-demographic and health-related factors.

Methods

This secondary data analysis used the 2012 South African population-based household survey on HIV collected using a cross-sectional multi-stage stratified cluster sampling design. Generalized structural equation modelling (G-SEM) path analysis was used to explore the direct and indirect relationships of socio-demographic, health and HIV-related factors with psychological distress as measured by Kessler 10 scale using HIV status as a moderator variable.

Results

A total of 20,083 participants were included in the study, 21.7% reported psychological distress, of whom (32.6%) were HIV positive. In the final path model with HIV status as a moderator, psychological distress was significantly more likely among age group 25–49 years (AOR: 1.4 [95% CI 1.3–1.6]), age 50 years and older, (AOR: 1.4 [95% CI 1.2–1.6]), females (AOR: 1.6 [95% CI 1.4–1.8]), high risk drinkers (AOR: 1.9 [1.6–2.2]) hazardous drinkers (AOR: 4.4 [95% CI 3.1–6.3]), ever tested for HIV (AOR: 1.2 [95% CI 1.1–1.3]). Psychological distress was significantly less likely among the married [AOR: 0.8 (0.7–0.9)], other race groups [AOR: 0.5 (0.5–0.6)], those with secondary level education (AOR: 0.9 [95% CI 0.8–0.9]), and tertiary level education (AOR: 0.7 [95% CI 0.6–0.9]), those from rural informal [AOR: 0.8 (0.7–0.9)], and rural formal [AOR: 0.8 (0.7–0.9)] areas and those who rated their health as excellent/good [AOR: 0.4 (0.4–0.5)].

Conclusion

The findings highlight the importance of designing tailored interventions targeted at psychological distress among PLHIV especially the elderly, females, those with no education and / or low education attainment and those residing in informal urban areas.

Keywords: Psychological distress, HIV status, South Africa, Structural Equation Model

5.1 Introduction

The comorbidity of HIV and mental disorders has become an increasing major public health challenge and is a substantial burden to society [1]. Common mental disorders are recognized as frequent psychiatric comorbid conditions among PLHIV [2]. Depression is found to be more common in people living with HIV compared with prevalence estimates in the general population [3], directly impacting their quality of life and impeding their enrolment and retention in treatment [4]. Research studies have shown that the causes of mental disorders are multi factorial and include among others biological, social, and economic factors [5].

There is considerable evidence that common mental disorders are distributed according to economic gradient across society and that the poor and disadvantaged suffer disproportionately from common mental disorders and their adverse consequences [5]. Moreover, Knifton and Inglis argue that the mental health of individuals is shaped by the social, environmental and economic conditions in which they are born, grow, work and age [6]. In addition, there is consistent evidence that experience of socioeconomic disadvantage, including unemployment, low income, poverty, debt and poor housing, is associated with poorer mental health [7, 8]. Evidence show that socio-economic conditions and lifestyle factors have a direct influence on the prevalence and severity of mental disorders in both men and women especially among those living with HIV [9].

HIV infection and mental illness are linked in many ways, for example, acquiring HIV can be a serious psychological trauma and can predispose a person to different mental disorders [9]. PLHIV are additionally affected due to lack of social support, poor self-esteem, stigma, and discrimination [10, 11]. This, in turn, predisposes them to psychological problems like depression and anxiety at greater rates than the general population [12, 13]. In addition, HIV-related stigma has been recognised as a fundamental cause of health inequalities [14]. HIV-related stigma has been observed as a contributing factor to mental health and substance use problems among people living with HIV [15]. In addition, HIV testing, and awareness of HIV positive status affects mental capacity to cope especially because of social stigma associated with living with HIV [16]. Since HIV stigma and discrimination affect the emotional well-being and mental health, these feelings can keep people from getting tested and treated for HIV [16, 17].

Reducing the burden of comorbid mental disorders is key to achieving the UNAIDS care cascade goals of 95–95–95 [18]. Mental disorders have been recognized as a risk factor for

HIV transmission, through their effects on various aspects of sexual and health seeking behaviour [19–21]. Evidence shows that mental disorders can increase risk of HIV acquisition through both direct and indirect pathways [22]. Regarding direct pathways, several studies have shown that sexually active people with mental disorders have higher risk sexual behaviour, including inconsistent condom use, having multiple sexual partners, trading sex, and drinking alcohol before sex [23–25]. Indirect pathways include multiple co-occurring conditions such as mental disorders, substance use disorder, and posttraumatic stress emanating from physical, sexual and / or emotional abuse [20, 21]. Both mental disorders and substance use disorders are known predictors of poor HIV disease management including suboptimal adherence to antiretroviral therapy (ART) and faster disease progression [20, 21]. Other studies suggest that the relationship between mental disorders and HIV/AIDS is complex and bidirectional [26].

Many factors contribute to the high comorbidity of HIV and mental health conditions. However, the underlying factors remain poorly understood. Elsewhere, studies have used structural equation model (SEM) to understand this complex relationship by investigating a conceptual model of the pathways linking wellbeing including mental health, social support, self-rated health and HIV-related stigma [26]. SEM has been utilized to develop psychological model to predict antiretroviral therapy medication adherence behaviour [27]. Others have used SEM to investigate factors associated with HIV risk behaviours and mental health and examine the role of intersecting stigmas [28]. However, in sub-Saharan African countries including South Africa there is paucity of large population-based studies of complex interactions between psychological distress, HIV status and predisposing factors.

This paper therefore explores the relationship of psychological distress with HIV status and associated socio-demographic, health related factors in South Africa using the 2012 nationally representative household-based population survey on HIV.

5.2 Methodology

5.2.1 Data source

This secondary data analysis used the 2012 South African population-based household survey on HIV [29]. The data was collected using a multi-stage stratified cluster sampling design. A total of 1000 census enumeration areas (EAs) from the 2001 population census in South Africa were randomly selected using probability proportional to size and stratified by province, locality type and race in urban areas from a database of 86,000 EAs. In each sampled EA a

total of 15 visiting points (VPs) or households were used as secondary sampling units. Persons of all ages living in South African households and hostels were eligible to participate and formed the ultimate sampling unit.

Four questionnaires including a household questionnaire and three age-appropriate individual questionnaires were used for data collection. These questionnaires were translated into main languages spoken in the nine provinces across the country and administered by trained fieldworkers. Fieldworkers were trained on community entry, obtaining informed consent/assent, conducting interviews, maintaining confidentiality, ethical procedures, collection of dried blood spot (DBS) specimen for laboratory testing and quality control procedures. The questionnaires solicited among others information about socio-demographic characteristics, sexual behaviours, knowledge, beliefs, and practices related to HIV including HIV related stigma and discrimination against PLHIV.

In addition, blood specimens were collected from consenting individuals for HIV testing using DBS. Blood samples were tested for HIV using an enzyme immunoassay (EIA) (Vironostika HIV Uni-Form II plus O, Biomeriux, Boxtel, The Netherlands), and samples which tested positive were retested using a second EIA (Advia Centaur XP, Siemens Medical Solutions Diagnostics, Tarrytown, New York, USA). Any samples with discordant results on the first two EIAs were tested with a third EIA (Roche Elecys 2010 HIV Combi, Roche Diagnostics, Mannheim, Germany). The current study is based on a sub-sample of youth and adult individuals 15 years and older who responded to the questions on psychological distress.

5.2.2 Ethical consideration

Ethical approval for the study was obtained from the Research Ethics Committee of the Human Sciences Research Council, South Africa (REC: 5/17/11/10) as well as by the Associate Director of Science of the National Center for HIV and AIDS, Viral Hepatitis, STD and TB Prevention at the USA's Centers for Disease Control and Prevention (CDC) in Atlanta, Georgia, USA. All persons who agreed to participate in the survey were required to provide either written or verbal consent for both the interview and specimen collection. Parents and guardians of children under 18 years of age were asked to give informed consent for inclusion of their children in the survey. Children under 18 years were required to confirm their assent by placing a tick or cross in a demarcated box in addition to providing written consent by means of a signature (where possible).

5.2.3 Measures

5.2.3.1 Endogenous variables

Psychological distress was the observed endogenous variable based on the respondent's experience of depressive and anxiety disorders measured using The Kessler Psychological Distress Scale (K10) [30]. This scale has been validated among low- and middle-income countries including South Africa [31, 32]. This scale consists of the following 10 items that describe how they felt during the previous 30 days: How often did you feel: Tired out for no good reason? So nervous that nothing could calm you down? Hopeless; Restless or fidgety: So restless that you could not sit still; Depressed? That everything was an effort? So sad that nothing could cheer you up? Worthless?' Responses to these items were recorded using a 5-point Likert scale (1 = never, 2 = rarely, 3 = some of the time, 4 = most of the time, 5 = all of the time). The raw scores were summed, and a total score grouped into four categories that indicated that respondents were likely to be well (score below 20), experiencing mild (score 20–24), moderate (score 25–29) or severe (score 30 and above) psychological distress [33]. The scores were then dichotomized into a binary outcome those who scored < 19 (absence of psychological distress = 0) and those who scored ≥ 20 (presence of psychological distress = 1). The internal reliability coefficient for the K-10 in this study was Cronbach alpha = 0.90.

5.2.3.2 Exogenous variables

The selected exogenous variables included a set of demographic variables such as age (15–24, 25–34, 35–49, 50 years and older), sex (male and female), race (Black African and other races), educational level (primary/no education, secondary, tertiary), employment status (unemployed and employed), locality type (urban formal, urban informal, rural informal/ tribal areas, rural formal/farm areas) [34] and asset based socio-economic status constructed using multiple correspondence analyses (MCA) based on questions on availability/ownership of broad range of household assets ownership and access to utilities. MCA calculated a composite indicator score computed by adding up all weighted responses [35]. The predicted score for each household was used to compute five quintiles (1st lowest, 2nd lower, 3rd middle, 4th higher and 5th highest) representing a continuum of household SES from the poorest to the least poor. These were then dichotomised into low SES (lowest 3 quintiles) and high SES (highest 2 quintiles).

This also included HIV-related variables such as self-perceived risk of contracting HIV infection (no and yes), HIV knowledge and myth rejection (no and yes), ever tested for HIV (no and yes), correct HIV knowledge and myth rejection based on responses from the following questions: (Can AIDS be cured? Can a person reduce the risk of HIV by having fewer sexual partners? Can a healthy-looking person have HIV? Can a person get HIV by sharing food with someone who is infected? Can a person reduce the risk of getting HIV by using a condom every time he/she has sex? (no and yes), awareness of HIV status based on the question "Have you been told/informed of the result of your most recent test? (no and yes), external HIV-related stigma (yes and no), self-rated health (fair/poor and good/excellent), based on the Alcohol Use Disorder Identification Test (AUDIT) score (0 = abstainers; 1–7 = low-risk drinkers; 8–19 = high-risk drinkers; 20+ = hazardous drinking) [36].

5.2.3.3 Mediator variable

HIV status was included as a mediator in the relationship between the endogenous and exogenous variables. It is hypothesized that HIV status mediates the effects of demographic, health and HIV-related variables on psychological distress.

5.2.4 Conceptual model and analysis

Generalized structural equation modelling (G-SEM)- path analysis was used to explore the direct and indirect relationships of key variables with psychological distress using HIV status as a mediator variable (see Fig. 6). The conceptual model follows the Fundamental Causes Theory which suggests that individuals' health condition is influenced by contextual factors [31] such as demographics (age, gender, race, locality), socio-economic status (educational level, employment), social contexts (social support), and persistent health disparities (self-rated health, HIV related stigma). This model also includes health and HIV-related factors such alcohol use AUDIT score, self-rated health, HIV testing history (ever had an HIV test), awareness of HIV status, self-perceived risk of HIV, and experiences of externalised HIV-related stigma. G-SEM was used to measure linear and non-linear causal relationships among selected variables, while simultaneously accounting for measurement error. G-SEM is a combination of three statistical techniques: multiple regression, path analysis, and factor analysis. Its purpose was to determine the extent to which a proposed theoretical model, expressed by a set of relations among different constructs, is supported by the collected data. Parameters from a G-SEM model are constants and indicate the nature and size of the relationship between two variables being assessed. Mediation analysis for each variable was

performed and a final path analysis including the goodness of fit was conducted. Goodness-of-fit chi square test, root mean square error of approximation (RMSEA), Tucker–Lewis's index (TLI), and comparative fit index (CFI) were used to assess the model fit. All variables with $p < 0.05$ were considered statistically significant and statistical analyses were performed using Stata (V.16, Stata Corp, College Station, Texas, USA) statistical software.

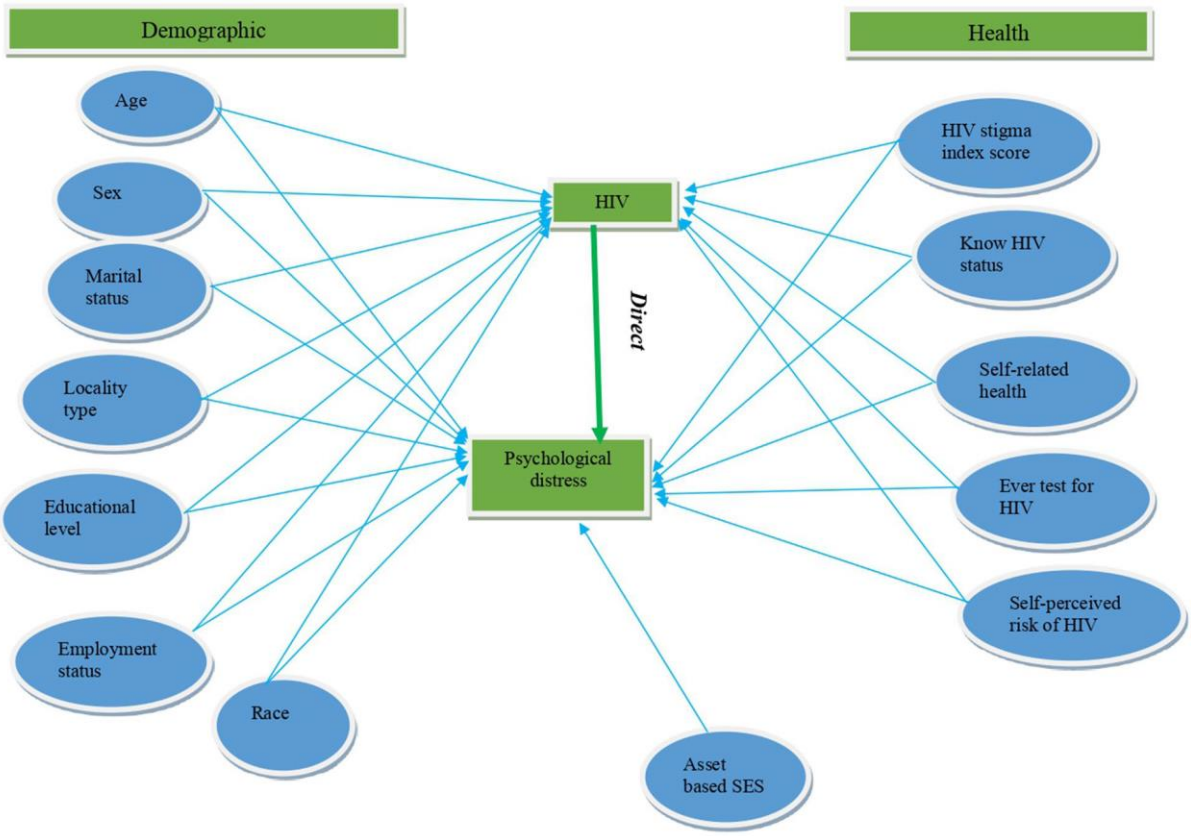

Figure 6: Conceptual model of the relationship between psychological distress, mediator variable HIV status, socio-demographic, health and HIV-related variables

5.3 Results

Characteristics of the study sample Table 10 shows that most participants were aged 25 to 49 years, female, not married, Black African, had secondary level education, unemployed, from low SES households, resided in urban areas, abstained from alcohol, rated their health as good/excellent, reported ever testing for HIV, not aware of their HIV status, perceived themselves as being at risk of HIV, and about half reported experiences of externalised HIV related stigma.

Table 10: Socio-demographic, health and HIV-related characteristics of the study sample (n = 20,083)

Variables	**Study sample**	
Age group (years)	**Total**	**%)**
15 to 24	5 716	28.5
25 to 49	8 573	42.7
50+	5 789	28.8
Sex		
Male	8 503	42.3
Female	11 580	57.7
Race group		
African	12 097	60.3
Other	7 970	39.7
Marital status		
Not Married	13 235	66.8
Married	6 568	33.2
Education level		
No education/Primary	3 663	21.4
Secondary	12 104	70.7
Tertiary	1 348	7.9
Employment status		
No	11 455	62.6
Yes	6 849	37.4
Asset based SES		
Low SES	10 856	54.7
High SES	9 003	45.3
Locality type		
Urban formal	11 080	55.2
Urban informal	2 159	10.8
Rural informal	4 696	23.4
Rural formal	2 148	10.7
Alcohol use AUDIT score		
Abstainers	11 466	64.0
Low risk drinkers (1-7)	4 759	26.6
High risk drinkers (8-19)	1 498	8.4
Hazardous drinkers 20+)	198	1.1
Self-rated health		

Variables	Study sample	
Fair/poor	4 149	20.7
Good/excellent	15 872	79.3
Ever had HIV test		
No	7 372	36.8
Yes	12 637	63.2%)
Awareness of HIV status		
No	12 045	60.8%)
Yes	7 769	39.2%)
Self-perceived Risk of HIV Infection		
No	3 995	20.1%)
Yes	15 896	79.9%)
Externalised HIV related stigma		
No	9 606	48.2%)
Yes	10 312	51.8%)

SES Socio economic status, AUDIT Alcohol risk score based on a questionnaire for Alcohol Use Disorder Identification Test and scores used for categorisation within parentheses. Subtotals do not total (n) due to non-response and/or missing data

5.3.1 Psychological distress and sample characteristics

Table 11 shows that out of the 20 083 participants (22.7%) had psychological distress, of whom (32.6%) were HIV positive. Psychological distress was significantly higher among those aged 50+ years (26%), among females (26.3%), those not married (23.8%), Black African (26.8%), those with no education (27.4%), those from informal urban areas (28.6%), those who abstained from alcohol (66.6%), those who reported bad/poor self-rated health (39.3%), those who ever tested for HIV (23.9%), those aware of their HIV status (24.3%) and those who perceived themselves as being not at risk of HIV (28.9%).

Table 11: Psychological distress by socio-demographic, health and HIV-related characteristics, South Africa 2012

Sample characteristic	Total (n = 20083)	Psychological distress		p-value
		No (n = 15527)	Yes (n = 4556)	
Age group (years)				<0.001
15 to 24	5 716	4 696 (82.2%)	1 020 (17.8%)	
25 to 49	8 573	6 544 (76.3%)	2 029 (23.7%)	
50+	5 789	4. 84 (74.0%)	1 505 (26.0%)	
Sex				<0.001
Male	8 503	692 (82.2%)	1 511 (17.8%)	
Female	11 580	8 535 (73.7%)	3 045 (26.3%)	

Sample characteristic	Total (n = 20083)	Psychological distress		p-value
		No (n = 15527)	Yes (n = 4556)	
Race group				
African	12 097	8 853 (73.2%)	3 244 (26.8%)	
Other	7 970	6 661 (83.6%)	1 309 (16.4%)	
Marital status				<0.001
Not married	13 235	10 086 (76.2%)	3 149 (23.8%)	
Married	6 568	5 236 (79.7%)	1 332 (20.3%)	
Education level				<0.001
No education/Primary	3 663	2 659 (72.6%)	1 004 (27.4%)	
Secondary	12 104	9 583 (79.2%)	2 521 (20.8%)	
Tertiary	1 348	1 138 (84.4%)	210 (15.6%)	
Employment status				<0.001
No	11 455	8 565 (74.8%)	2 890 (25.2%)	
Yes	6 849	5 623 (82.1%)	1 226 (17.9%)	
HIV stigma index score				0.650
No	9 606	7 413 (77.2%)	2 193 (22.8%)	
Yes	10 312	7 986 (77.4%)	2 326 (22.6%)	
Asset-based SES				<0.001
Low SES	10 856	8 059 (74.2%)	2 797 (25.8%)	
High SES	9 003	7 295 (81.0%)	1 708 (19.0%)	
Self-perceived risk of HIV infection				<0.001
No	3 995	2 842 (71.1%)	1 153 (28.9%)	
Yes	15 896	12 555 (79.0%)	3 341 (21.0%)	
Awareness of HIV status				<0.001
No	12 045	9 431 (78.3%)	2 614 (21.7%)	
Yes	7 769	5 884 (75.7%)	1 885 (24.3%)	
Alcohol use AUDIT score				<0.001
Abstainers	11 466	8 739 (76.2%)	2 727 (23.8%)	
Low risk drinkers (1-7)	4 759	3 947 (82.9%)	812 (17.1%)	
High risk drinkers (8-19)	1 498	1 047 (69.9%)	451 (30.1%)	
Hazardous drinkers 20+)	198	91 (46.0%)	107 (54.0%)	
Self-rated health				<0.001
No	4 149	2 518 (60.7%)	1 631 (39.3%)	
Yes	15 872	12.966 (81.7%)	2 906 (18.3%)	
Ever had HIV test				<0.001

Sample characteristic	Total (n = 20083)	Psychological distress		p-value
		No (n = 15527)	Yes (n = 4556)	
No	7 372	5 857 (79.4%)	1 515 (20.6%)	
Yes	12 637	9 614 (76.1%)	3 023 (23.9%)	
Locality type				<0.001
Urban formal	11 080	8 734 (78.8%)	2 346 (21.2%)	
Urban informal	2 159	1 541 (71.4%)	618 (28.6%)	
Rural informal	4 696	3 512 (74.8%)	1.184 (25.2%)	
Rural formal	2 148	1 740 (81.0%)	408 (19.0%)	
HIV status				<0.001
Negative	17 546	13 816 (78.7%)	3 730 (21.3%)	
Positive	2 537	1 711 (67.4%)	826 (32.6%)	

SES Socio economic status, AUDIT Alcohol risk score based on a questionnaire for Alcohol Use Disorder Identification Test and scores used for categorisation within parentheses. Subtotals do not total (n) due to non-response and/or missing data

5.3.2 HIV status, psychological distress and sample characteristics

Table 12 shows that 4556 participants were psychologically distressed and 18.1% of them were HIV positive. The proportion of HIV positive and psychological distressed patients was higher in females than males (20.2% vs 14%). Lack of education showed that those without education/primary had highest proportion of HIV positive (19.4%), followed by those with secondary education with a decline of only 0.5%. However, participants with tertiary education were twice less likely to be HIV positive (9%). Married participants had lower proportion than the not married group (21.6% vs 9.2%). High proportion of HIV positive patients was among those experiencing HIV stigma (21.6% vs 14.5%) and higher among those who had never had an HIV test (23.1% vs 8.5%).

Table 12: HIV status among participants with psychological distress by socio-demographic, health and HIV-related characteristics, South Africa 2012

Sample characteristic	Total (n = 4556)	HIV status		p-value
		Negative (n = 3730)	Positive ((n = 826)	
Age group (years)				<0.001
15 to 24	1020 (22.4)	919 (90.1)	101 (9.9)	
25 to 49	2029 (44.6)	1430 (70.5)	599 (29.5)	
50+	1505 (33.0)	1379 (91.6)	126 (8.4)	
Sex				<0.001
Male	1511 (33.2)	1299 (86.0)	212 (14.0)	

Sample characteristic	Total (n = 4556)	HIV status		p-value
		Negative (n = 3730)	Positive ((n = 826)	
Female	3045 (66.8)	2431 (79.8)	614 (20.2)	
Education level				0.001
No education/Primary	1004 (26.9)	809 (80.6)	195 (19.4)	
Secondary	2521 (67.5)	2044 (81.1)	477 (18.9)	
Tertiary	210 (5.6)	191 (91.0)	19 (9.0)	
Race group				<0.001
African	3244 (71.2)	2482 (76.5)	762 (23.5)	
Other	1309 (28.8)	1245 (95.1)	64 (4.9)	
Self-perceived risk of HIV Infection				<0.001
No	1153 (25.7)	695 (60.3)	458 (39.7)	
Yes	3341 (74.3)	3001 (89.8)	340 (10.2)	
Awareness of HIV status				<0.001
No	2614 (58.1)	2224 (85.1)	390 (14.9)	
Yes	1885 (41.9)	1463 (77.6)	422 (22.4)	
Alcohol use AUDIT score				0.001
Abstainers	2727 (66.6)	2182 (80.0)	545 (20.0)	
Low risk drinkers (1-7)	812 (19.8)	693 (85.3)	119 (14.7)	
High risk drinkers (8-19)	451 (11.0)	383 (84.9)	68 (15.1)	
Hazardous drinkers 20+)	107 (2.6)	87 (81.3)	20 (18.7)	
Marital status				<0.001
Not Married	3149 (70.3)	2469 (78.4)	680 (21.6)	
Married	1332 (29.7)	1209 (90.8)	123 (9.2)	
Employment status				<0.001
No	2890 (70.2)	2353 (81.4)	537 (18.6)	
Yes	1226 (29.8)	976 (79.6)	250 (20.4)	
Externalised HIV-related stigma				<0.001
No	2193 (48.5)	1874 (85.5)	319 (14.5)	
Yes	2326 (51.5)	1824 (78.4)	502 (21.6)	
Self-rated health				<0.001
No	1631 (35.9)	1273 (78.1)	358 (21.9)	
Yes	2906 (64.1)	2438 (83.9)	468 (16.1)	
Asset-based SES				<0.001

Sample characteristic	Total (n = 4556)	HIV status		p-value
		Negative (n = 3730)	Positive ((n = 826)	
Low SES	2797 (62.1)	2145 (76.7)	652 (23.3)	
High SES	1708 (37.9)	1548 (90.6)	160 (9.4)	
Ever had HIV test				<0.001
No	3023 (66.6)	2326 (76.9)	697 (23.1)	
Yes	1515 (33.4)	1386 (91.5)	129 (8.5)	
Locality type				<0.001
Urban formal	2346 (51.5)	2065 (88.0)	281 (12.0)	
Urban informal	618 (13.6)	454 (73.5)	164 (26.5)	
Rural informal	1184 (26.0)	899 (75.9)	285 (24.1)	
Rural formal	408 (9.0)	312 (76.5)	96 (23.5)	

SES Socio economic status, AUDIT Alcohol risk score based on a questionnaire for Alcohol Use Disorder Identification Test and scores used for categorisation within parentheses. Subtotals do not total (n) due to non-response and/or missing data

5.3.3 Factors associated with psychological distress

Table 13 shows how the exogenous variables influence psychological distress (Step 1 in establishing mediation). Most independent variables significantly influenced psychological distress. Those aged 25 to 45 years, 50 years and older, females and those residing in rural formal and rural informal areas were significantly more likely to develop psychological distress compared to urban formal areas. Those who drink alcohol (low risk drinker, high risk drinker and hazardous drinkers), and those who ever tested for HIV, were also significantly more likely to develop psychological distress compared to their counterparts. In addition, those married were less likely to develop psychological distress compared to the unmarried. Participants with secondary and tertiary level education were significantly less likely to develop psychological distress compared to those with no education.

Table 13: Model of the relationship of psychological distress with socio-demographic, health and HIV-related variables

Psychological distress	OR	95% CI		p-value
Age categories				
15-24	Ref			
25 to 49	1.49	1.33	1.67	<0.001
50+	1.42	1.23	1.63	<0.001
Sex				
Male	Ref			
Female	1.63	1.48	1.80	<0.001

Psychological distress	**OR**	**95% CI**		**p-value**
Marital status	Ref			
Not married				
Married	0.80	0.72	0.89	<0.001
Race				
African	Ref			
Other	0.53	0.47	0.60	<0.001
Educational level				
Primary	Ref			
Secondary	0.88	0.79	0.98	0.004
Tertiary	0.70	0.57	0.87	<0.001
Employment status				
No				
Yes	0.78	0.70	0.86	<0.001
Asset based SES				
Low	ref			
high	1.01	0.90	1.14	0.884
Locality type				
Urban formal	Ref			
Urban informal	0.97	0.84	1.13	0.686
Rural informal	0.78	0.68	0.89	<0.001
Rural formal	0.79	0.66	0.92	0.002
Alcohol use AUDIT score				
Abstainers	Ref			
Low risk drinkers (1-7)	0.90	0.81	1.01	0.071
High risk drinkers (8-19)	1.88	1.61	2.20	<0.001
Hazardous drinkers 20+)	4.43	3.12	6.27	<0.001
Self-rated health				
Fair/poor	Ref			
Good/excellent	0.40	0.37	0.45	<0.001
Ever test for HIV				
No				
Yes	1.16	1.04	1.29	0.008
Awareness of HIV status				
No	Ref			
Yes	1.02	0.91	1.13	0.786

Psychological distress	OR	95% CI		p-value
Self-perceived risk of HIV				
No	Ref			
Yes	0.92	0.82	1.02	0.111
Externalised HIV related stigma				
No	Ref			
Yes	0.93	0.85	1.02	0.111

SES Socio economic status, AUDIT Alcohol risk score based on a questionnaire for Alcohol Use Disorder Identification Test and scores used for categorisation within parentheses. Subtotals do not total (n) due to non-response and / or missing data. OE: Odds ratio; CI: confidence intervals

Table 14 shows how the exogeneous variables influence the mediator variable HIV status (Step 2 in establishing mediation). Those aged 25 to 45 years, 50 years and older were significantly more likely to be HIV positive compared to 15 to 24 years. Similarly, participants residing in informal and formal rural areas were likely to be HIV positive than formal urban participants. Those who ever tested for HIV were more likely to be HIV positive than those who had never tested. Furthermore, those married, were significantly less likely to develop psychological distress compared to the unmarried group. Those who rated their health as excellent/good were also significantly less likely to develop psychological distress compared to poor self-rated health.

Table 14: Model of the relationship of the mediator variable HIV status with socio-demographic, health and HIV related variables

HIV status	OR	95%CI		p-value
Age categories				
15-24	Ref			
25 to 49	3.84	3.29	4.47	<0.001
50+	1.50	1.21	1.87	<0.001
Sex				
Male	Ref			
Female	1.57	1.37	1.80	<0.001
Marital status				
Not married	Ref			
Married	0.41	0.36	0.48	<0.001
Race				
African	Ref			
Other	0.19	0.15	0.23	<0.001
Education status				
Primary	Ref			

HIV status	OR	95%CI		p-value
Secondary	0.94	0.82	1.09	0.416
Tertiary	0.44	0.32	0.59	<0.001
Employment status				
No	Ref			
Yes	0.94	0.82	1.09	0.416
Asset based SES				
Low				
High				
Locality type				
Urban formal	Ref			
Urban informal	1.48	1.25	1.75	<0.001
Rural informal	1.22	1.05	1.42	0.009
Rural formal	1.60	1.31	1.94	<0.001
Alcohol use AUDIT score				
Abstainers	Ref			
Low risk drinkers (1-7)	0.93	0.81	1.08	0.358
High risk drinkers (8-19)	1.00	0.80	1.25	0.967
Hazardous drinkers 20+)	1.50	0.92	2.44	0.102
Self-related Health				
No	Ref			
Yes	0.68	0.59	0.78	<0.001
Ever test for HIV				
No	Ref			
Yes	2.15	1.83	2.54	<0.001
Awareness of HIV status				
No	Ref			
Yes	0.75	0.66	0.86	<0.001
Self-perceived risk of HIV				
No	Ref			
Yes	0.41	0.36	0.46	<0.001
Externalised HIV related stigma				
No	Ref			
Yes	1.24	1.10	1.39	<0.001

SES Socio economic status, AUDIT Alcohol risk score based on a questionnaire for Alcohol Use Disorder Identification Test and scores used for categorisation within parentheses. Subtotals do not total (n) due to non-response and/or missing data. OE: Odds ratio; CI: confidence intervals

Figure 7 shows how the mediator variable influences psychological distress (Step 3 in establishing mediation). The final model shows that HIV significantly influenced psychological distress levels in the third equation. A strong association between most of the

exogenous variables and psychological distress was observed, thus second condition satisfied. HIV status was a strong predictor of psychological distress therefore third condition satisfied.

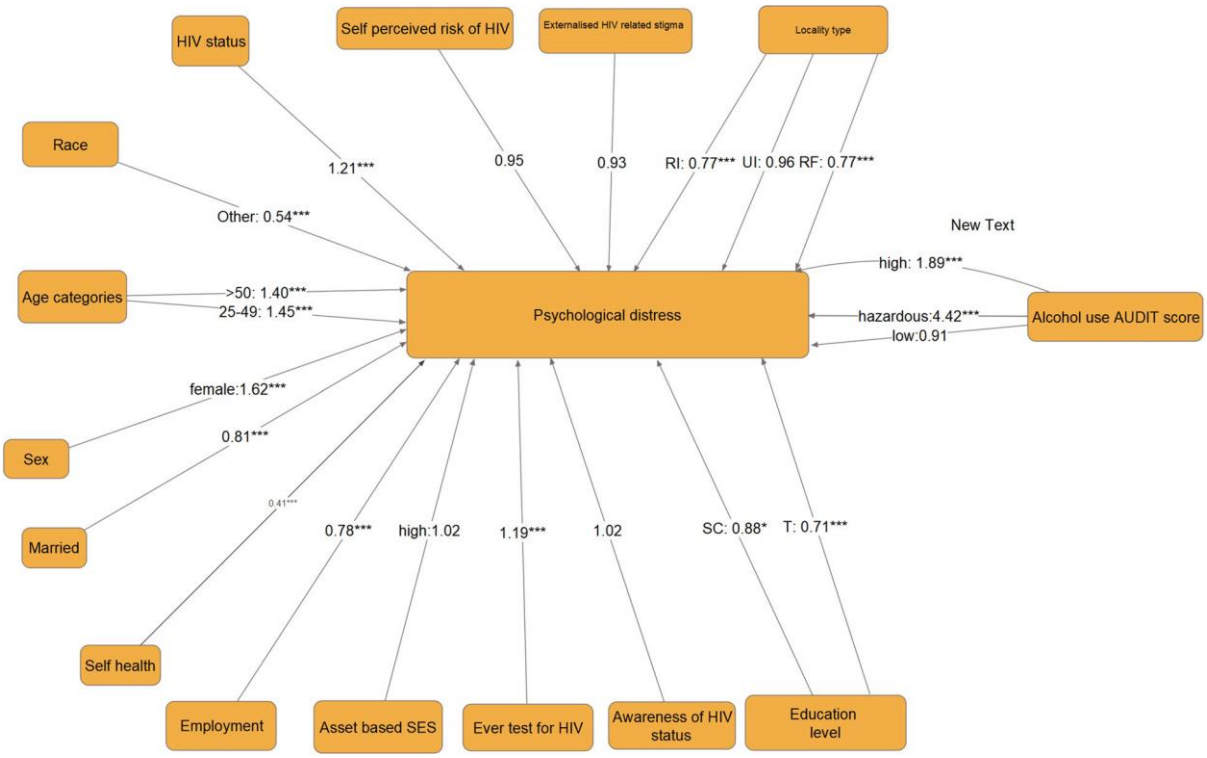

Figure 7: Final path model of the relationship between psychological distress, mediator variable, socio-demographic, health and HIV related variables

In the final model (Table 15), those aged 25 to 49 years and 50 years and older were more likely to develop psychological distress compared to those aged 15–24 years. Females were more likely to develop psychological distress compared to males. Those residing in rural areas were significantly more likely to develop psychological distress compared to those residing in urban formal areas. Those who ever tested for HIV were more likely to develop psychological distress compared to those who had never tested. Furthermore, high risk and hazardous alcohol drinkers were more likely to develop psychological distress. Psychological distress was significantly less likely among married participants compared to unmarried participant, those with secondary and tertiary educational level compared to no education, the employed compared to the unemployed and those who rated their health as good/excellent compared to those who rated their health as fair/poor.

Table 15: Model of the relationship of psychological distress with socio-demographic, health, HIV-related variables and HIV status as a mediator

Psychological distress	AOR	95% CI		p-value
HIV status				
Negative	Ref			
Positive	1.21	1.07	1.38	0.003
Age group (years)				
15-24	Ref			
25 to 49	1.45	1.29	1.63	<0.001
50+	1.40	1.21	1.61	<0.001
Sex				
Male	Ref			
Female	1.62	1.47	1.79	<0.001
Race group				
African	Ref			
Other	0.54	0.48	0.61	<0.001
Marital status				
Not married	Ref			
Married	0.81	0.73	0.91	<0.001
Educational level				
Primary	Ref			
Secondary	0.88	0.79	0.98	0.025
Tertiary	0.71	0.58	0.88	0.001
Employment status				
Unemployed	Ref			
Employment	0.78	0.70	0.86	<0.001
Asset Based SES				
Low	Ref			
High	1.02	0.90	1.14	0.805
Locality type				
Urban formal	Ref			
Urban informal	0.96	0.83	1.12	0.596
Rural informal	0.77	0.68	0.88	<0.001
Rural formal	0.77	0.66	0.91	0.002
Alcohol use AUDIT score				
Abstainers	Ref			

Psychological distress	AOR	95% CI		p-value
Hazardous drinkers (20+)	4.42	3.12	6.27	<0.001
Low risk drinkers (1-7)	0.91	0.81	1.01	0.079
High risk drinkers (8-19)	1.89	1.61	2.20	<0.001
Self-related health				
Fair/Poor	Ref			
Good/Excellent	0.41	0.37	0.46	<0.001
Ever had HIV test				
No	Ref			
Yes	1.19	1.05	1.34	0.005
Awareness of HIV status				
No	Ref			
Yes	1.02	0.92	1.14	0.676
Self-perceived risk of HIV				
No	Ref			
Yes	0.95	0.85	1.05	0.302
Externalised HIV related stigma				
No				
Yes	0.93	0.85	1.01	0.087

SES –Socio-economic status; AUDIT - Alcohol risk score based on a questionnaire for Alcohol Use Disorder Identification Test and scores used for categorisation within parentheses; Subtotals do not total (n) due to non-response and / or missing data. OR –Odds Ratios, CI – confidence intervals

Table 16 shows that the introduction of HIV status into the model did not weaken the effect of any independent variables. Slight changes on alcohol use AUDIT score among the hazardous drinkers reduced by almost 2%, those aged 50+ were reduced by 2%, sex by 0.05% reduction. A one percent reduction on rural informal locality type was observed. However, the relationship between educational levels, race, self-perceived risk, knowledge of HIV results, marital status, HIV stigma index score, asset-based SES, self-related health, and ever test for HIV did not differ after the introduction of HIV status. This supported the last condition by Baron and Kenny confirming that HIV status mediates the effect of independent variables towards psychological distress. The likelihood ratio test shows that the p-value is less than 0.05 suggesting that model 2 is better than the previous model, and that our model is a good fit. RMSEA assessed the population error, and it was very small close to zero suggesting a good fit of our model. The same idea was supported by the p-close of 1. TLI value greater than 0.95 provide evidence of the acceptance of model fit.

Table 16: The performance of the three fit statistics (Likelihood ratio, RMSEA, TLI, CFI.)

Fit statistic	Value	Description
Likelihood ratio		
chi2_ms (2)	3161.428	Model 1 vs. Model 2
p > chi2	<0.001	
chi2_bs (11)	3049.923	baseline vs. saturated
p > chi2	<0.001	
Population error		
RMSEA	0.000	Root mean squared error of approximation
90 CI, lower bound	<0.001	
upper bound	0.000	
p-close	1.000	Probability RMSEA <= 0.05
Baseline comparison		
CFI	1.000	Comparative fit index
TLI	1.000	Tucker-Lewis index

5.4 Discussion

In this study, we examined the interrelationships between psychological distress, HIV status and associated factors among youth and adults 15 years and older using data from a nationally representative cross-sectional survey. This is the first study that explored the complex and bidirectional relationship between psychological distress and HIV status and associated predisposing factors to both conditions. The prevalence of psychological distress among the study population was 21.7%, and of these 12.6% were HIV positive.

The final model with HIV status as a mediator variable showed that other than HIV infection, psychological distress was significantly associated with older age group than youth (15–24 years and female. There is lack of consistent results about how age affects depression and anxiety [37]. Contrary to current findings, other studies found lower level of distress in older age groups [38]. In South Africa, HIV is a major problem among the youth especially among females [34]. Other studies have also found a higher prevalence of psychological distress among women living with HIV compared to men. It is likely therefore that high levels of HIV infection among the youth and females predispose these population groups to psychological distress. These observations emphasize the need for differentiated care and targeted interventions to support these vulnerable groups.

Furthermore, the model showed that heavy alcohol intake was associated with psychological distress. Other studies have also found that harmful lifestyle factors such as excessive drinking in PLHIV increased risk for anxiety and depressive symptoms [36]. This suggests that interventions should mitigate the effects of adverse lifestyle factors such as alcohol abuse in preventing psychological distress especially among PLHIV. The current findings therefore highlight the importance of screening for alcohol abuse in this group.

In agreement with current findings, other studies found that HIV-infected individuals with psychological distress were more likely to have had an HIV test, partly due to worry arising from the knowledge of potentially being infected [39]. Evidence shows that the impact of being diagnosed with HIV infection, associated stigma, social isolation, and discrimination may all lead to depressive disorders among PLHIV. However, others argue that symptoms of depression and distress are common among persons seeking HIV testing and are therefore not a consequence of an HIV-positive test result [40]. Nevertheless, the findings of this study support proposals for greater integration of mental health services with HIV testing services especially in populations suffering from high levels of psychological distress.

The finding that marriage is protective of psychological distress is consistent with other studies indicating a benefit of marriage for mental health partly due to family/social support since marriage protects against feelings of loneliness [41]. Other studies also found that those in marriage suffer less psychological distress and have higher levels of emotional and psychological well-being than those who are single, divorced, or cohabiting [42]. The observed positive influence of marriage on psychological distress highlights the importance of improving marital quality to promote mental health.

The observed differences in psychological distress between Black Africans and other race groups in the context of HIV can be attributed to the racial disparities rooted in structural and contextual inequalities that sustain the HIV epidemic among Black Africans [43]. Other studies also observed that socio-economic status help explain differences between Black Africans and other race groups [44]. This suggest that addressing social and resource inequality such as access to basic services, education, and employment will in a way address social stressors and mitigate psychological distress especially among PLHIV.

The finding of protective effects of socio-economic status indicators such as education attainment and employment against psychological distress is partly because educational

achievement has a positive effect on outlook in life and increase self-efficacy, which in turn helps people cope with life's problems and stresses [45]. On the other hand, employment promotes positive emotions due to social security since jobs provide resources that can mitigate stress, support healthy lifestyles and thereby promote mental health [46]. Therefore, policies promoting access to education and reducing unemployment may be important for mitigating the impact of psychological distress especially among PLHIV.

The findings also suggest that the relationship between HIV and psychological distress differs across urban and rural settings. The currents results suggest that residing in rural areas is protective of psychological distress while other studies have observed that people in rural areas present with higher levels of symptoms of psychological distress than their urban counterparts [39, 47]. In South Africa, the high levels of psychological distress may be linked to the persistently high level of HIV prevalence in urban settings [29]. This highlights the importance of integrating mental health care in HIV-related care in areas where most of the population live with HIV.

5.5 Limitations

While SEM remains a powerful tool for exploratory analysis and for the hypothesis-generating process, the analysis may be limited by the difficulty to describe the relationship between HIV and co-occurring mental disorders that may be present prior to HIV diagnosis. The analysis may also be limited by the possibility that other unmeasured variables may have affected the observed relationship between endogenous and exogenous variables and between endogenous variables. In addition, social desirability response bias due to self-report may have influenced some of the results. The cross-sectional nature of the study prevents causal inference limiting our understandings of the exact nature of the relationship between HIV status and psychological distress. Causal pathways could be better clarified with a longitudinal study design.

5.6 Conclusion

HIV status was found to have a direct effect on psychological distress. We therefore conclude that HIV status mediates the relationship between psychological distress and the exogenous factors such as age, sex, race, education and employment. It is important to buffer the impact of these interrelations through effective psychological distress interventions to improve the health and wellbeing of PLHIV in South Africa. These interventions may include provision of social support, self-esteem enhancement, and improving coping skills. The format and content

of such interventions should be context specific. Finally, integration of mental health and HIV services is needed.

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CHAPTER 6
GENERAL DISCUSSION, RECOMMENDATIONS AND CONCLUSIONS

This chapter provides an overview of the thesis and discusses the key findings presented in each of the chapters. I will further emphasise their implications in relation to policy, research, and practice. Further, I will detail key strengths and limitations of the thesis, and then offer concluding remarks and recommendations.

6.1 Overview of the study

In South Africa, there are relatively few large-scale studies that have investigated the relationship between HIV and mental disorders. Prior to 2010 there was a lack of national surveys on prevalence of mental disorders among PLHIV in South Africa [1], except for clinic- or hospital-based small scale studies. Exploring the prevalence and associations of mental disorders among PLHIV may guide relevant mental health interventions. For example, discovering the key associations will help for more focus to be put on the mostly affected groups. This may also help policymakers to provide appropriate resources to address the current screening and treatment gap of mental health among PLHIV.

HIV-related stigma is known to be a key driver of both HIV care continuum disruption, as well as psychological distress. In addition to key demographic and clinical variables, the finding that stigma is mediating psychological distress may provide additional weight to developing and strengthening stigma-reduction interventions. Measuring and addressing stigma across the entire care continuum should remain priority.

Psychological distress likely arise from a range of psycho-social and biological factors. In PLHIV, an additional set of variables is probably also contributing. The extent to which all of these factors contribute may lead to improved general interventions, but possibly may also facilitate more person-centred approaches. It is therefore vital to examine these associated factors in PLHIV to eventually get a comprehensive understanding of the complex relationship between psychological distress and HIV for future successful interventions.

This study used secondary data from the HSRC's fourth South African National HIV Prevalence, Incidence, Behaviour and Communication Survey [2] which is available online on http://dx.doi.org/doi:10.14749/1485430466). Research was based on a sub-sample of youth and adult individuals 15 years and older who tested positive for HIV – they were invited to respond to questions which measured both HIV-related stigma and psychological distress during the interviews.

The aim was to explore the extent and effect of psychological distress among youth and adults with HIV in South Africa. This aim was achieved through the fulfilment of the following objectives:

1. Systematically review existing literature of studies focusing on prevalence and associations of depressive and anxiety disorders in PLHIV in Southern Africa.
2. Determine prevalence and correlates of psychological distress among PLHIV in South Africa.
3. Determine factors associated with external HIV-related stigma and psychological distress among PLHIV in South Africa.
4. Develop a structural equation model to describe the relationship between depression and anxiety disorders with psychosocial factors, HIV status, and HIV-related stigma

6.2 Discussion of key findings

6.2.1 The pooled prevalence of depression and anxiety symptoms in PLHIV in Southern Africa is high

In the systematic review and meta-analysis we found an overall pooled weighted prevalence of depressive and anxiety symptoms among PLHIV in Southern Africa of 23%. The confidence interval was (95% CI: 19%-28%), which most likely resulted from the use of a variety of scales or assessment tools used in the different studies. This prevalence is significantly higher than the 12-month prevalence of 8.1% and 4.9% reported in the SASH study [3]. In our own analysis, we found a prevalence of psychological distress of 34.5%. Reasons for this higher rate include the increase in HIV prevalence over the years, women who continue to be disproportionately affected by HIV and other socio-economic factors such as the exponential rise in South African employment rate over the years.

6.2.2 Female gender appears to be a significant contributor to depression and anxiety, and gender in general provides some guidance on contextual influences

Female gender has been identified as a risk factor for depression in the general population, including in Southern Africa [4-6], as well as persons with HIV [7-10]. Disparities in rates of psychological distress between males and females may be due to gender inequality, which increases the likelihood of females to be psychologically distressed [11]. Initiatives such as advocacy and empowerment for women in communities could play a vital role in a form of social support to help reduce vulnerability to psychological distress. Salk et al.'s [6] meta-analysis found that gender differences in depression started emerging around adolescence. This was also the case in the current review with prevalence of depression and anxiety in studies including younger participants ranging from 2.2% to 27%.

In the HSRC data-set, the prevalence of psychological distress symptoms was significantly higher among females (38.2%) than males (28.5%). Among women with HIV, an increased likelihood of psychological distress was significantly associated with never seeing health personnel, while decreased likelihood was significantly associated with seeing health personnel more than once, not being hospitalised in the past 12 months and not having any chronic conditions. Care contacts are therefore a critical point of intervention for women.

Among males, increased likelihood of psychological distress was significantly associated with residing in urban informal areas as opposed to urban formal areas. These findings are consistent with previous findings from Nyirenda and colleagues who showed that living in an urban area was significantly associated with increased chances of having a depressive episode [12]. Furthermore, increased likelihood of psychological distress was also associated with not engaging in vigorous intensity sport while decreased likelihood was significantly associated with being employed, not having any a chronic condition and low risk drinkers more than hazardous drinkers. These data among men suggest that factors related to hegemonic masculinity may be important: being active, strong and working. Alcohol use behaviour remains a perennial challenge.

6.2.3 Poverty and psycho-social factors remain drivers of psychological distress

We found that social factors such as locality type or poor housing, and employment status contribute to the risk of psychological distress. This is congruent with a review on social determinants of mental disorders, which revealed that poverty and lower income status are consistently associated with increased prevalence of common mental disorders [13]. Social

service interventions become a critical focus point to improve these risk factors. For example, society approaches such as better housing, vocational skills development for the unemployed and poverty alleviation programs can help vulnerable individuals and deliver social benefits to communities. Being employed and receiving social support is protective. These findings agree with those of other reviews conducted in sub-Saharan Africa [14-16].

Excessive alcohol consumption has been linked to HIV risk and psychological distress [9,17-18]. Alcohol screening and treatment is therefore important and should be considered as other chronic medical conditions in health care facilities. Furthermore, effective behavioural risk-reduction interventions to address alcohol abuse should be prioritised.

6.2.4 Effective HIV care engagement is a must

Persons adhering to ART are less likely to be distressed. On the other hand, the high rates of depressive and anxiety disorders among PLHIV were also associated with delayed HIV diagnosis, late ART initiation and lack of viral suppression. Even though substantial progress has been observed in South Africa, the treatment gap remains a challenge, which affects achievement of the last UNAIDS goal of viral suppression.

It is also important to create robust indicators to track the social determinants of mental disorders among PLHIV. In addition, population-based and longitudinal studies are needed to better characterise these associations and describe how they lead to the development and persistence of mental disorders, and to monitor the outcomes of any interventions.

We found that over a third (37.9%) of PLHIV experienced high levels of HIV-related stigmatizing attitudes and this was associated with various demographic and HIV-related factors. Similar to current findings, other studies have shown that the prevalence of HIV-related stigmatizing attitudes varies with socio-demographic and health-related factors and context [19-21]. These observations highlight the need for customised interventions targeted at the identified population groups as well as the importance of investigating and addressing stigma across the entire HIV care continuum.

Existing stigma-reduction interventions appear to be inadequate and need to be strengthened. Stigma reduction interventions need to be provided across the spectrum of health care providers, patients and communities. It would be valuable to have commitment from the Department of Basic Education in response to the HIV epidemic through their programmes in schools to improve HIV knowledge levels. In addition, HIV testing services should be

reinforced through communication strategies targeted against HIV stigmatization and discrimination. For example, clinic-based and community-based programmes to educate people on HIV stigma, taking into account elements such as gender, race, educational level and socio-economic status should be prioritised.

6.2.5 Psychological distress is the result of several related demographic and clinical variables

In the final SEM model with HIV status as a mediator variable, psychological distress was significantly more likely among females, adults older than 25 years, at least heavy drinkers and those who ever tested for HIV. Marriage and higher levels of education appear to be protective. These factors are difficult to modify but highlighting the role the education plays as an upstream driver is important to communicate to policy makers. Living in a rural area appeared to also confer protection. This could be due to the fact that people who reside in rural areas engage in vigorous physical activity more than those in urban residents and have less prevalence of alcohol use than those residing in urban areas [22].

6.3 Overall conclusions

This thesis has been able to confirm, by using results from different manuscripts, that mental disorders are indeed prevalent in persons with HIV. While this finding is in line with international studies, our high rates of psychological distress suggest that PLHIV might be developing depressive and anxiety symptoms much earlier. With the large number of individuals with psychological distress, particularly youth and women, it is vital that clinicians screen for mental disorders when they do for HIV, so treatment initiation is introduced early. We would argue that with more active screening of mental disorders, individuals who display symptoms should also be treated when initiated onto ART. Validated screening tools may be used for this purpose, for early identification of depressive and anxiety symptoms among PLHIV.

This study provides evidence that can be used to guide health care service provision in South Africa and elsewhere. It is evident that HIV infection is epidemic in southern Africa, with the highest number of infected people in the world living in South Africa. In this study, HIV status was found to have a direct effect on psychological distress. Furthermore, HIV-related stigma was also found to be significantly associated with psychological distress which eventually manifests poor ART adherence. This confirms the study's hypotheses that mental disorders are key drivers of the treatment gap and poor quality of life among PLHIV. Likewise, local 95-95-

95 data suggests that the last column of viral suppression is challenging, especially among youth. While the prevalence of psychological distress is quite high in PLHIV, our findings suggest a treatment gap particularly among women and young people. These vulnerable groups should be targeted for any intervention in the form of psychosocial and financial support. Social support may lower the risk for mental disorders among PLHIV.

The theory of fundamental causes was introduced in Chapter 1 as a suggested framework to guide the study. The theory was used to guide the selection of potential covariats and the analysis of psychological distress and associated factros among PLHIV. The hypothesis was that some socio-demographic factors such as sex, age, education, marital status, employment and socio-economic status predisposes PLHIV to psychological distress. The framework posits that there is a bidirectional relationship between HIV and psychological distress. Furthermore, psychological distress is associated with HIV-related factors such as stigma and psychological distress. This allowed for the investigation of the complex pathways linking HIV status as a mediator in the relationship of psychological distress with socio-demographic and health-related factors.

While fundamental cause theory helped in identifying potential covariates that informed the analysis and the identified socio-structural factors associated with psychological distress among PLHIV. The framework has important limitations since it assumes that social stratification is static while it varies between populations [23]. Social inequality is the most important cause of health inequality which was not captured in framing this study. There is a need to reframe fundamental cause theory to produce research that illuminates dynamics in the influence of social stratification on health and also to reveal the potential for context to modify social gradients in health [23].

6.4 Strengths and limitations of the study

Several strengths and limitations have been highlighted.

6.4.1 Strengths

- The study used secondary data from the 2012 South African National HIV Prevalence, Incidence and Behaviour Survey, a nationally representative population-based household survey. One major strength is the use of data from a large national representative survey, which provides prevalence estimates of both HIV and depressive and anxiety disorders that can be generalised among youth and adults 15 years and older in South Africa.

- The prevalence estimates of HIV and depressive and anxiety symptoms add to the scarce literature on nationally representative studies in South Africa, and these findings can inform policy and practice in the country.
- The observed relationship between psychological distress, HIV status, HIV-related stigma and associated factors can be generalised to the study population in the country.
- SEM pathways utilised in the final model improved the understanding of complex interaction linking psychological distress, HIV status and predisposing factors.

6.4.2 Limitations

- One of the limitations was the use of self-report for obtaining data on depression and anxiety diagnosis to assess psychological distress symptoms, and this is prone to both social desirability and recall bias.
- Data used for this study was collected 10 years ago. The study's findings may not reflect the current situation of mental disorders among PLHIV due to progress made on HIV over the years in South Africa.
- There may be other unobserved or unmeasured potential covariats that may determine mental health status (e.g., HIV progression status, access to HIV services, peer and other social support, etc.) were not collected in the survey.
- Moreover, the K10 scale that was used to measure psychological distress is not a diagnostic tool but rather a screening tool.
- Since the study made use of survey data, it was not possible to determine a causal relationship between psychological distress and HIV but was rather limited to assessing the associations. The cross-sectional design made it difficult to draw any causal inference.
- Another limitation to note is that the focus was on stigmatizing attitudes rather than internal and external stigma, which are often associated with PLHIV. It was not possible to investigate internal stigma since it had not been measured in the national survey.
- One last limitation is that we only explored the effect of HIV in the bidirectional relationship. However, we did not look at the complete bidirectional pathway. Future studies should explore the direct, indirect and total effect.

6.5 Recommendations

In light of the findings and limitations that are highlighted above, the following recommendations for (1) future research, (2) practice, and (3) policies and programmes are presented below.

6.5.1 Recommendations for future research

Based on the outcomes of this study, the following need to be considered for future research on mental health and HIV in South Africa:

- To validate the most accurate tools such as the Kessler Psychological Distress Scale (K10), for measuring mental disorders in PLHIV.
- To explore different models to improve understanding of the complex relationship between mental disorders and HIV.
- Longitudinal research to ascertain the long-term impact of mental disorders among PLHIV.
- Qualitative studies for in-depth analysis of the concept of HIV and mental disorders to give substance to findings of quantitative surveys.
- Research studies conducted at community and cultural level that focus on mental health awareness, emphasise HIV-related stigma, and provide social support for PLHIV.

6.5.2 Recommendations for practice

The conceptual model in Chapter 5 indicates that HIV status negatively affects the mental well-being of an individual. It is therefore essential for communities of practice, including practitioners, clinicians, psychologists, and social workers, to remain cognisant of HIV-related stigma, discrimination, and issues surrounding non-disclosure when working with PLHIV. It is imperative that professionals be provided with knowledge and information to improve their understanding of the origin, root causes, and manifestations of mental disorders among PLHIV through various information dissemination platforms such as professional training programmes, workshops, seminars, and conferences. This would ultimately allow professionals to develop and effectively implement tailored interventions to support and care for PLHIV with mental disorders.

Regarding psychosocial distress and experiences of HIV-related stigma, it is vital for psychosocial interventions to be integrated with health services especially the HIV programme. This also suggests a need for interventions for appraisal and improving the quality of social support networks.

6.5.3 Recommendations for policymaking and programmes

The findings highlight the continuing need for mental health awareness campaigns and stigma reduction efforts in South Africa. Despite HIV being classified as a manageable illness, HIV-related stigma continues to remain prevalent within our communities. Awareness campaigns and programmes need to be sustained and implemented in areas severely affected by HIV, for example urban informal areas, to bring about a reduction in stigma towards PLHIV.

There is need for practical guidelines for administration of common mental disorder tests such as depressive and anxiety symptoms in most at-risk populations among PLHIV. The findings of this study support proposals for greater integration of mental health services with HIV prevention and treatment services. This suggests inclusion of screening and counselling for psychological distress within the HIV programme.

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APPENDICES

Appendix A:
Methodology of the Primary Study

Background

Below is a general description of the methodology of the primary study. Additional detailed methodologies of the secondary analysis are discussed in each of the manuscripts in chapters 3, 4 and 5. For this PhD study, I used an archived database from a cross-sectional population-based household survey that was conducted in all nine provinces in South Africa. The survey was done by the Human Sciences Research Council (HSRC) in 2012. Included in this appendix is the study design, study population, sampling, data collection, measures, data management and analysis, and ethical considerations.

Study design

For this study, a multi-stage stratified cluster sampling design was applied, where samples were taken in stages using smaller sampling units at each stage. Unlike the previous surveys where at most three or four people in a sampled household were randomly selected to participate based on pre-determined age categories, in the 2012 study, a more robust and representative approach was followed whereby all household members were included (see Shisana et al., 2014). This approach enabled analyses linking HIV results obtained from the participants.

Study population

The survey sample was inclusive of persons of all ages living in South African households and hostels. In selected households/hostels, all household members were invited to participate in the survey. The survey excluded persons living in educational institutions, old-age homes, hospitals, correctional facilities and uniformed-service barracks, as well as homeless persons.

The population for the PhD study included all participants who were eligible to answer the ‘Adult questionnaire’. These participants were fifteen years and older and had responded to the Mental Health questions in the questionnaire. Additionally, the participants were to have tested positive for HIV.

Sampling

A multi-stage disproportionate, stratified cluster sampling approach was used. A total of 1000 census enumeration areas (EAs) from the 2001 population census were selected from a database of 86 000 EAs and mapped in 2007 using aerial photography to create a new updated master sample as a basis for sampling visiting points. In each of these selected 1000 EAs are visiting points or households, which were used as secondary sampling units. A total of 15 randomly selected households in each EA were visited. In essence, a total of 15 000 households were visited. Within each household visited, all individuals were eligible to participate in the survey.

Weighting of the sample

"Owing to the sampling design of the survey, some individuals have a greater or lesser probability of selection than others. Sample weights were introduced at the EA, household and individual levels to correct this potential bias due to unequal sampling probabilities, and also to adjust for non-response. The final sampling weight was thus equal to the final EA weight multiplied by the final VP sampling weight and adjusted for individual nonresponse. The final individual weights were benchmarked to the 2012 mid-year population estimates by age, race, sex and province (Stats SA 2013). This process produced a final sample representative of the population in South Africa for sex, age, race, locality type and province" (Shisana, et al., 2014: page xxv).

Measures

The questionnaire which was used to collect the original data for this study measured the following variables:

Demographics

Background demographic data on participants was collected which included sex, race, age, marriage status, education and employment status.

Psychological distress screening

The 15 years and older questionnaire included a section with questions that assessed the participants' psychological distress levels using the Kessler 10 scale. The Kessler Psychological Distress Scale (K10) is a scale developed in 1992 by Kessler for use in population surveys (Kessler et al, 2003). The K10 is widely recommended as a screening instrument to identify levels of psychological distress. This scale was therefore used with

participants to identify their levels of psychological distress. The following are the 10 questions that are included in the K10, which were asked to the participants.

The Kessler 10 (K10) scale:

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
1. During the last 30 days, about how often did you feel tired out for no good reason?	1	2	3	4	5
2. During the last 30 days, about how often did you feel nervous?	1	2	3	4	5
3. About how often did you feel so nervous that nothing could calm you down?	1	2	3	4	5
4. About how often did you feel hopeless?	1	2	3	4	5
5. During the last 30 days, about how often did you feel restless or fidgety?	1	2	3	4	5
6. About how often did you feel so restless you could not sit still?	1	2	3	4	5
7. About how often did you feel depressed?	1	2	3	4	5
8. During the last 30 days, about how often did you feel that everything was an effort?	1	2	3	4	5
9. About how often did you feel so sad that nothing could cheer you up?	1	2	3	4	5
10. About how often did you feel worthless?	1	2	3	4	5

HIV-related stigma scale

Six individual items were asked in order to elicit attitudes towards people living with HIV based on an 8-item scale that was originally developed by Kalichman et al. (2005). The six items were as follow:

1. People who have AIDS are dirty
2. People who have AIDS are cursed

3. People who have AIDS should be ashamed
4. It is safe for people who have AIDS to work with children
5. People with AIDS must expect some restrictions on their freedom
6. A person with AIDS must have done something wrong and deserves to be punished

Risky behaviours

Risky behaviours were measured by looking at the following items:

1. Sexual activity in the last 12 months
2. How many sexual partners did you have last 12 month?
3. Condom use the last time you had sex

Self-perception of risk of HIV infection

On a scale of 1-4 participants were asked if they think they are at risk of contracting HIV. The response scale was as follow:

1. I will definitely not get infected with HIV
2. I probably won't get infected
3. I am probably going to get infected
4. I am definitely going to get infected with HIV

HIV testing

Dried blood spots (DBS) specimens were collected by finger-prick from participants and were tested for HIV antibodies using a testing algorithm with three different enzyme immunoassays. The HIV-incidence testing algorithm used the newly developed Limiting Antigen-Avidity Assay (LAg-Avidity EIA) in combination with additional information on antiretroviral treatment exposure and HIV viral load. The presence of antiretroviral drugs (ARVs) in HIV-positive DBS samples was confirmed by means of high performance liquid chromatography (HPLC) coupled to tandem mass spectrometry.

Data collection

Data for this PhD study was obtained from the archived database of the HSRC survey. As described above, the survey used a questionnaire to collect data that aimed at obtaining

information related to psychological distress as measured by the K10 scale as well as HIV knowledge, attitudes and behaviours related to HIV/AIDS including HIV/AIDS-related stigma. Specific data related to variables for this study were extracted from the main population-based household survey database.

Data management and analysis

Data management

The dataset for this PhD study was extracted from the HSRC data archives. A process of data cleaning was undertaken using Stata statistical software (STATA). A new dataset was formed from STATA, where selected variables relevant to the PhD study were kept, while all the other variables used for the original survey were dropped. This dataset was designed with range restrictions to ensure that out-of-range data was not captured.

Data analysis

Overall, secondary data analysis was performed using the STATA 15 software. However, detailed methodologies are reported in each of the chapters (4, 5 & 6) covering the objectives of this PhD study. These detailed methodologies include the data analysis procedures undertaken for each study objective. Taking into account the complex multi-level sampling design, weighted data was assessed using STATA 15 software. Descriptive statistics analysis was performed, and regression analysis was conducted to indicate relationships among variables.

Ethical considerations

The survey protocol was approved by the HSRC's Research Ethics Committee (REC: 5/17/11/10) as well as by the Associate Director of Science of the National Center for HIV and AIDS, Viral Hepatitis, STD and TB Prevention at the Centers for Disease Control and Prevention (CDC) in Atlanta, USA. The HSRC's REC has Federal Wide Assurance (FWA) for the Protection of Human Subjects accreditation with the USA's Department of Health and Human Services (DHHS).

The PhD study protocol was approved by the UCT's Faculty of Health Sciences Human Research Ethics Committee (HREC REF: 349/ 2017).

Appendix B:

Ethics Approval

HUMAN RESEARCH ETHICS COMMITTEE
13 MAY 2021
HEALTH SCIENCES FACULTY
UNIVERSITY OF CAPE TOWN

UNIVERSITY OF CAPE TOWN

FACULTY OF HEALTH SCIENCES
Human Research Ethics Committee

FHS016: Annual Progress Report / Renewal

HREC office use only (FWA00001637; IRB00001938)			
This serves as notification of annual approval, including any documentation described below.			
☑ Approved	Annual progress report	Approved until/next renewal date	30.5.22
☐ Not approved	See attached comments		
Signature Chairperson of the HREC/ Designee		Date Signed	13/5/2021

Note: Please note that incomplete submissions will not be reviewed.
Please email this form and supporting documents (if applicable) in a combined pdf-file to hrec-enquiries@uct.ac.za.
Please clarify your plan for research-related activities during COVID-19 lockdown

Comments to PI from the HREC

Principal Investigator to complete the following:

1. Protocol information

Date (when submitting this form)	May 2021		
HREC REF Number	349/2017	Current Ethics Approval was granted until	30 Oct 2019
Protocol title	The associations among HIV status, HIV risk, HIV-related stigma and common mental disorders in South Africa.		
Protocol number (if applicable)			
Are there any sub-studies linked to this study?	☐ Yes ☑ No		
If yes, could you please provide the HREC Ref's for all sub-studies? **Note:** A separate FHS016 must be submitted for each sub-study.			
Principal Investigator	Miss Nolusindiso Ncitakalo		

(Note: Please complete the Closure form (FHS010) if the study is completed within the approval period)

Department / Office Internal Mail Address	Department of Psychiatry & Mental Health

1.1 Does this protocol receive US Federal funding?	☐ Yes	☑ No
1.2 If the study receives US Federal Funding, does the annual report require full committee approval? **Note:** Any annual approvals for **Full Committee** review MUST be submitted on the monthly HREC submission dates. (Please send electronic copy for full committee review to hrec-enquiries@uct.ac.za)	☐ Yes	☐ No
If yes in 1.2 please complete section 1.3 below for invoicing purposes		
1.3 Annual Approval for **full committee** review	- R 3450 (inclusive of vat)	

For invoicing purposes, please provide:	
Sponsor's name	
Contact person	
Address	
Telephone number	
Email Address	

2. List of documentation for approval

3. Protocol status (tick ✓)

☐	Open to enrolment
☐	Closed to enrolment (tick ✓)
☐	Research-related activities are ongoing
☐	Research-related activities are complete, long-term follow-up only
☐	Research-related activities are complete, data analysis only
☐	Main study is complete but sub-study research-related activities are ongoing
☐	Study is closed → Please submit a Study Closure Form (FHS010)

4. Enrolment

(Note: Please complete the Closure form (FHS010) if the study is completed within the approval period)

Number of participants enrolled to date	
Number of participants enrolled, since last HREC Progress report (continuing review)	
Additional number of participants still required	

5. Refusals

Total number of refusals (participants invited to join the study, but refused to take part)	

6. Cumulative summary of participants

Total number of participants who provided consent	
Number of participants determined to be ineligible (i.e. after screening)	
Number of participants currently active on the study	
Number of participants completed study (without events leading to withdrawal)	
Number of participants withdrawn at participants' request (i.e. changed their mind)	
Number of participants withdrawn by PI due to toxicity or adverse events	
Number of participants withdrawn by PI for other reasons (e.g. pregnancy, poor compliance)	
Number of participants lost to follow-up. Please comment below on reasons for loss of follow-up.	
Number of participants no longer taking part for reasons not listed above. Please provide reasons below:	

7. Progress of study

Please provide a brief summary of the research to date including the overall progress and the progress since the last annual report as well as any relevant comments/issues you would like to report to the HREC:

For this PhD, I am using data from a national population-based survey that was conducted in 2012; therefore, field work and data collection have been done. I am doing secondary data analysis.

I am expected to have four papers. Thus far, I have written and submitted three papers:

- One paper was published in December 2019 with the Journal of Psychology and Psychotherapy Research.
- Another paper has been accepted for publication with the SSM- Population Health Journal.
- Another paper has been submitted with the AIDS Research & Therapy Journal, currently awaiting reviewers' feedback.
- I am currently writing the last paper.

8. Protocol violations and exceptions (tick ✓ all that apply)

☑	No prior violations or exceptions have occurred since the original approval
☐	Prior violations or exceptions have been reported since the last review and have already been acknowledged or approved
☐	Unreported minor violations that have occurred since the last review, as well as significant deviations not yet reported, are attached for review

9. Amendments (tick ✓ all that apply)

☑	No prior amendments have been made since the original approval
☐	Prior amendments have been reported since the last review and have already been approved
☐	New protocol changes/ amendments are requested as part of this continuing review (See note below)

Note: If new protocol changes are being requested in this review, please complete an amendment form (FHS006).
Specific changes in the amended protocol and consent/assent forms must be **bolded**, *italicised* or tracked and all changes must include a rationale.

10. Adverse events

10.1 Please provide below or attach a narrative summary of serious adverse events and/ or unanticipated problems since the last progress report. Please indicate changes made to the protocol and informed consent document(s) as a result (if not already reported to the HREC). Please comment on whether causality to any study procedure or intervention could be established
There were no changes made to the protocol.

10.2 Have participants received appropriate treatment/ follow-up/ referral when indicated (e.g. in the case of abnormal or incidental clinical findings, distress or anxiety)?		
☐ Yes	☐ No	☑ Not applicable
If yes, please describe:		

11. Summary of Monitoring and Audit Activities (tick ✓)

11.1 Was this study monitored or audited by an external agency (e.g. SAHPRA, FDA)?		
☐ Yes	☐ No	☑ Not applicable

11.2 Did a Data and Safety Monitoring Board publish a report?		
☐ Yes	☐ No	☑ Not applicable

11.3 If yes, please identify the agency and attach a summary of the findings.

(Note: Please complete the Closure form (FHS010) if the study is completed within the approval period)

Agency Name		Report attached	☐ Yes	☐ No	☑ Not applicable
		DSMB report attached	☐ Yes	☐ No	☑ Not applicable

11.4 Has there been any agency, institutional or other inquiry into non-compliance in this study, or any finding of non-compliance concerning a member of the research team?	
☐ Yes	☑ No
If yes, please explain:	

12. Level of risk (tick ✓)

12.1 In light of your experience of this research, please indicate whether the level of risk to participants has:	
☐	Increased
☐	Decreased
☐	Shown no change
If there has been a change, please explain:	
N/A (data was collected already)	

12.2 Please provide a narrative summary of recent relevant literature that may have a bearing on the level of risk.
None

13. Statement of conflict of interest

Has there been any change in the conflict of interest status of this protocol since the original approval? (tick ✓)	
☐ Yes	☑ No
If yes, please explain and if necessary, attach a revised conflict of interest statement (Section #7 in the New Protocol Application Form FHS013):	

14. Signature

My signature certifies that the above is complete and correct.			
Signature of PI	Natalia	Date	12 May 2021

(Note: Please complete the Closure form (FHS010) if the study is completed within the approval period)

Form FHS011: Study deviation

HREC office use only (FWA00001637; IRB00001938)			
This serves as acknowledgement of a protocol deviation as described below.			
Chairperson of the HREC signature/ Designee		Date	

Note: Please note that incomplete submissions will not be reviewed.
Please email this form and supporting documents (if applicable) in a combined pdf-file to hrec-enquiries@uct.ac.za.

Please clarify your plan for research-related activities during COVID-19 lockdown

Principal Investigator to complete the following:

1. Protocol information

Date (when submitting this form)	12 May 2021
HREC REF Number	349/2017
Project Title	The associations among HIV status, HIV risk, HIV-related stigma and common mental disorders in South Africa
Protocol number (if applicable)	
Principal Investigator	Miss Nolusindiso Ncitakalo
Department / Office Internal Mail Address	Department of Psychiatry & Mental Health

2. Protocol deviation description

Please describe the deviation below, including the reason why the deviation occurred.

Year 2019:

This year was an extremely challenging one for me. I endured multiple deaths of family members very close to me. I could barely cope with the loss and was often not in a good state psychologically. Moreover, I went through employment retrenchment. Unfortunately, the PhD was badly affected as I could not make much progress as we had anticipated and agreed on at the beginning of the year.

Year 2020:

2020 was a progressive year, where I managed to submit two papers. One paper has recently been accepted for publication.

Challenges encountered:

- The publication process, which included back and forth of reviews and corrections of the papers took long.
- Progress was not as speedy due to the national lockdown.

3. Follow-up actions

3.1 Please describe any follow-up action(s) taken or planned as a result of this deviation e.g. DSMB reporting, report to sponsor, informing participants.
Together with my academic supervisors, we agreed on a workplan with timeframes. The two important resolutions were: • To take some time off work so I could focus on the PhD (study leave was taken in March 2021, and others will be scheduled during the year). • To work towards submitting the PhD thesis for external examination before the end of the year.
3.2 Please describe what action(s) have or will be taken to prevent similar deviations in future.
As agreed with the employer, additional time dedicated to PhD will be scheduled.

4. Principal Investigator's acknowledgement of responsibility

This signature indicates the PI has reviewed the deviation, taken appropriate follow-up action and implemented or plans to implement preventative steps where possible.			
Signature of PI	Natalia	Date	12 May 2021

Appendix C:

Motivation to the Doctoral Degrees Board for PhD Thesis by Publication

STUDENT NAME:	**MISS NOLUSINDISO NCITAKALO**
STUDENT NUMBER:	**NCTNOL001**
DEPARTMENT:	**PSYCHIATRY & MENTAL HEALTH**
SUPERVISOR:	**PROF LEICKNESS SIMBAYI**
CO-SUPERVISOR:	**PROF JOHN JOSKA**

MOTIVATION FOR INCLUSION OF PUBLICATIONS IN MY PHD THESIS

Thesis title: The associations among HIV status, HIV risk, HIV-related stigma and common mental disorders in South Africa

Introduction

The burden of mental disorders continues to grow with significant impact on health, social and economic consequences in all countries of the world (WHO, 2019). Like physical health, mental health is influenced by a wide range of social, political and economic factors (Patel, 2014; Silva et al., 2016; WHO, 2014). Certain groups such as women and people living in poverty, are disproportionately affected by mental disorders (Roberts, 2018). Extreme inequalities are cross-national with an estimated 80% of people affected by mental disorders living in low- and middle-income countries (Jacob & Patel, 2014).

Across the globe, a close relationship has been observed between mental disorders and HIV/AIDS. Epidemiological studies show that people living with HIV (PLHIV) are at a greatly increased risk of developing mental disorders, often suffering from depression and anxiety as they adjust to their diagnosis (Chibanda et al., 2016; Choi et al., 2016; Yi et al., 2015). Similarly, people living with mental disorders can also be at a higher risk of HIV infection. The risks are aggravated by various factors such as social, cultural, economic and physical environments in which PLHIV live.

Several other research studies that have been conducted in local areas to investigate the relationship between mental disorders and HIV/AIDS have found it to be a complex one. As the effect of HIV on mental disorders on a national scale is unclear, the understanding and unfolding of both risk and protective factors and predictors is essential for researchers. Moreover, a better understanding of

prevalence estimates of depression and anxiety among PLHIV in the South African population at large is needed, as mental health in general has been given low priority in the country due to high prevalence rates of communicable illnesses such as HIV/AIDS and TB (Mayosi, 2012).

It is important to investigate the behaviours associated with the presence of common mental disorders and explore whether they are risk factors for HIV infection. In this PhD study, the researcher adds to the published literature the prevalence of depression and anxiety disorders among HIV-infected people found in all nine provinces of South Africa, linking them to HIV risk as well as HIV-related stigma. This thesis provides prevalence estimates of common mental disorders from a large national population-based household survey of HIV, which gives us a greater statistical power and ensures a more accurate sample in which to draw conclusions.

Overall description of the project

This PhD makes use of a national household survey data. In 2012, the Human Sciences Research Council (HSRC) conducted the South African National HIV Prevalence, Incidence and Behaviour Survey. The 2012 population-based survey of HIV prevalence was the fourth in the series of national HIV-prevalence surveys that have investigated HIV prevalence and behaviour. Since 2002, the HSRC and its partners have conducted five national surveys that have contributed to the country's understanding of the HIV epidemic over time (see Shisana & Simbayi, 2002; Shisana et al., 2005, 2009, 2014; Simbayi et al., 2019).

In 2012 I was working as a Researcher at the HSRC, and I was one of the Co-Investigators of the survey. My role in the survey was that of a Provincial Coordinator, where I assisted with quality control of the survey throughout the province during fieldwork/data collection. At the end of data collection, I was part of the HRSC teams who worked on data analysis and management, as well as writing up the survey report (see Shisana et al, 2014).

Research Aim & Objectives

Research evidence shows that the relationship between common mental disorders and HIV is complex and bi-directional. It is important to understand these issues in

our context in terms of risk behaviours and/or risk factors. The overall aim of this PhD is to explore the relationship between HIV status, HIV risk and common mental disorders among HIV positive people in all nine provinces of South Africa.

The objectives of this PhD are as follows:

a) To conduct a systematic review of studies on correlates of depression and anxiety disorders in PLHIV
b) To determine the prevalence of depression and anxiety disorders and associated risk factors among PLHIV in a large nationally representative survey of the South African population
c) To explore the associations between stigma, risk behaviour, alcohol use, and socio-demographic variables in PLHIV with and without a depression and anxiety disorders
d) To develop and test the structural equation model (SEM) that describes the relationship between HIV status, depression and anxiety disorders and HIV risk

Coherence of the thesis

This PhD thesis is based on a large national survey data. Secondary data analysis was conducted for all the manuscripts that will be published in peer-reviewed journals. The thesis will be based on four journal articles, two of which have already been published, one is under review in an international journal and the last one is currently being written. All these manuscripts will be formatted uniformly for the purposes of this thesis, with regards to referencing style and use of terms, but the content will remain unchanged from that which has been either published or submitted for publication. The manuscripts included are listed below, with a description of my contribution to each, as well as the co-authors'.

The first objective of this PhD is addressed by a systematic review. In this systematic review, I developed a search methodology with input from my supervisors. With assistance from the UCT Health Sciences Librarian, I then conducted the database and journal search. I reviewed all papers for potential inclusion in the review. The Librarian and I then extracted data into a spreadsheet. I then analysed and summarised all the data myself. Using Endnote software, I transferred and stored references from the databases and library catalogues. I wrote the full first draft of the review. My co-authors reviewed the draft, made comprehensive intellectual contributions before I submitted to the journal. After the first submission, the

review came back with feedback for improving. With guidance from my supervisors, I managed the revisions of the review and resubmitted. I am currently waiting for the journal to give feedback after their second review.

The second manuscript investigated the prevalence of psychological distress symptoms and associated sociodemographic and health-related factors amongst HIV positive individuals in South Africa. I reviewed all the relevant literature for this manuscript. One of the co-authors, Dr Musawenkosi Mabaso did the statistical analysis. I wrote the first draft of the manuscript and then shared it with my supervisors for their perusal. They made intellectual contributions to the first draft. After receiving feedback from all co-authors, I revised the entire manuscript and submitted the final draft for publication. Upon receipt of external reviewers' feedback from the journal, I managed all revisions. All co-authors read and approved the manuscript after revisions were made. This manuscript was resubmitted to the journal, and it was published.

The third manuscript examined the factors associated with HIV related stigmatizing attitudes among HIV-positive people in South Africa who are psychologically distressed. This manuscript speaks to the third objective of the PhD. Again, Dr Mabaso assisted with statistical analysis in this manuscript. I collated and reviewed all the relevant literature for this manuscript. As soon as Dr Mabaso was done with data analysis, I wrote a full draft of this manuscript, and then sent it to my co-authors for comments and input. I then collated all co-authors' contribution and revised the manuscript for submission to a journal. After peer review with the journal, the manuscript was returned with corrections to be done. I managed all revisions myself. I then shared the improved manuscript with the co-authors, and they approved it. I resubmitted the manuscript to the journal. The manuscript was recently published.

The last manuscript required assistance from a Biostatistician with expertise in structural modelling. This manuscript comprises a structural equation model (SEM) of the relationship between HIV status, mental disorders and HIV risk. The model connects all the above-mentioned manuscripts. It helps in explaining how all the variables are related to each other, as well as understanding the determinants of common mental disorders among PLHIV. I am currently conceptualising this manuscript. I have extracted all variables from the national dataset so that the Biostatistician develops the model.

Overview of the thesis

The first chapter of this thesis elucidates the background and context of the study which focuses on relationship between HIV status, HIV risk and common mental disorders among HIV positive people in all nine provinces of South Africa. The chapter also highlights the gap in literature on mental health and HIV/AIDS research in South Africa. The aims and objectives of the study are also included in the chapter, and layout of the forthcoming chapters. The second chapter provides a systematic review of the literature on prevalence and predictors of common mental disorders, depression and anxiety among people living with HIV in sub-Saharan Africa. The third chapter includes the theoretical framework of the study. Following this is chapter four, which provides a detailed narrative of the methodology of the study. Chapter five is presented as a manuscript titled, Prevalence and correlates of psychological distress among HIV positive individuals in South Africa: Findings from the 2012 HIV National Household Survey. Chapter six is presented as a manuscript titled, Factors associated with external HIV-related stigma and psychological distress among people living with HIV in South Africa. Chapter seven includes the structural equation model of factors associated with HIV status, psychological distress and HIV risk behaviours among people living with HIV in South Africa. Chapter eight is the last chapter of the thesis. This last chapter provides a detailed discussion of the key findings of the study. The chapter also highlights the limitations of the study as well as recommendations.

The following are the manuscripts that I intend to include in my PhD:

1. Ncitakalo N, Mabaso M, Maduna V, Joska J, Simbayi L. Prevalence and Correlates of Psychological Distress Among HIV Positive Individuals in South Africa: Findings from the 2012 HIV National Household Survey. Journal of Psychology and Psychotherapy Research; 2019, 6: 30-40.
2. Ncitakalo, N., Mabaso, M., Joska, J., Simbayi, L. (2021). Factors associated with external HIV-related stigma and psychological distress among people living with HIV in South Africa. *SSM - Population Health, 14*. https://doi.org/10.1016/j.ssmph.2021.100809
3. Ncitakalo, N., Mabaso, M., Joska, J., Simbayi, L. Prevalence and predictors of depressive and anxiety disorders among people living with HIV in sub-Saharan Africa: A systematic review of the literature. (manuscript submitted to AIDS Research and Therapy Journal).

Co-authors' declaration:

This serves to declare that none of the co-authors of these manuscripts are students. These manuscripts will only be included in this PhD thesis and not anywhere else.

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Shisana. O., Simbayi, L.C., Rehle, T., Zungu, N.P., Zuma, K., Ngogo, N., Jooste, S., Pillay-van-Wyk, V., Parker, W., Pezi, S., Davids, A., Nwanyanwu, O., Dinh, T.H. and SABSSM III Implementation Team (2009). *South African National HIV Prevalence, Incidence, Behaviour and Communication Survey, 2008: The health of our children* Cape Town: HSRC Press.

Shisana, O., Rehle, T., Simbayi, L.C., Zuma, K., Jooste, S., Zungu, N., Labadarios, D., Onoya, D. et al. (2014) *South African National HIV Prevalence, Incidence and Behaviour Survey, 2012.* Cape Town: HSRC Press.

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Silva, M., Loureiro, A., Cardoso, G. (2016). Social determinants of mental health: A review of the evidence. *European Journal of Psychiatry*. 30(4), 259-292.

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Zimbra **blanco@worldonline.co.za**

Fwd: Fw: Consent for inclusion of published papers in a PhD thesis

From : Sindi Ncitakalo <nncitakalo@gmail.com> Thu, Jun 24, 2021 11:37 AM
Subject : Fwd: Fw: Consent for inclusion of published papers in a PhD thesis
To : Prof Blanco <blanco@worldonline.co.za>
Reply To : nncitakalo@gmail.com

From: Musawenkosi M. Mabaso <MMabaso@hsrc.ac.za>
Sent: Wednesday, 23 June 2021 16:48
To: Nolusindiso Ncitakalo <NCTNOL001@myuct.ac.za>
Cc: Leickness L C. Simbayi <LSimbayi@hsrc.ac.za>; John Joska <john.joska@uct.ac.za>
Subject: RE: Consent for inclusion of published papers in a PhD thesis

CAUTION: This email originated outside the UCT network. Do not click any links or open attachments unless you know and trust the source.

Hi Sindi
I also do give my consent for you to include the relevant papers in your PhD. I do also acknowledge your contribution as first author on these papers.

Cheers
Musa Mabaso

From: Leickness L C. Simbayi <LSimbayi@hsrc.ac.za>
Sent: Friday, 18 June 2021 14:53
To: John Joska <john.joska@uct.ac.za>; Nolusindiso Ncitakalo <NCTNOL001@myuct.ac.za>; Musawenkosi M. Mabaso <MMabaso@hsrc.ac.za>
Subject: RE: Consent for inclusion of published papers in a PhD thesis

CAUTION: This email originated outside the UCT network. Do not click any links or open attachments unless you know and trust the source.

Hi Sindi

I also do give my consent for you to include the relevant papers in your PhD. I do also acknowledge your contribution as first author on these papers.

Cheers

Leickness Simbayi

From: John Joska <john.joska@uct.ac.za>
Sent: Friday, 18 June 2021 13:38

Gmail NKOSITHEMBILE PHUNGUZA <nphunguza1@gmail.com>

Fw: Consent for inclusion of published papers in a PhD thesis

Nolusindiso Ncitakalo <NCTNOL001@myuct.ac.za> Thu, Jun 24, 2021 at 10:25 AM
To: "nphunguza1@gmail.com" <nphunguza1@gmail.com>

From: Vincent Maduna <MadunaV@tut.ac.za>
Sent: Thursday, 24 June 2021 10:20
To: Nolusindiso Ncitakalo <NCTNOL001@myuct.ac.za>
Subject: FW: Consent for inclusion of published papers in a PhD thesis

CAUTION: This email originated outside the UCT network. Do not click any links or open attachments unless you know and trust the source.

From: Vincent Maduna
Sent: 23 June 2021 10:20 AM
To: 'Nolusindiso Ncitakalo' <NCTNOL001@myuct.ac.za>
Subject: RE: Consent for inclusion of published papers in a PhD thesis

Dear Sindi

I acknowledge that I am a co-author in a publication and acknowledge and confirm your contribution you as first author. I consent that you can include the publication in your PhD thesis.

Regards,
Mr Vincent Maduna
Tshwane University of Technology
[Quoted text hidden]

To: Nolusindiso Ncitakalo <NCTNOL001@myuct.ac.za>; Leickness L C. Simbayi <LSimbayi@hsrc.ac.za>; Musawenkosi M. Mabaso <MMabaso@hsrc.ac.za>
Subject: Re: Consent for inclusion of published papers in a PhD thesis

Dear Sindi,

I hereby give my consent for you to include the relevant papers in your PhD. I also acknowledge your contribution as first author on these papers.

Regards,
John Joska

From: Nolusindiso Ncitakalo <NCTNOL001@myuct.ac.za>
Date: Friday, 18 June 2021 at 13:31
To: "lsimbayi@hsrc.ac.za" <lsimbayi@hsrc.ac.za>, John Joska <john.joska@uct.ac.za>, Musawenkosi Mabaso <mmabaso@hsrc.ac.za>
Subject: Consent for inclusion of published papers in a PhD thesis

Dear Prof Simbayi, Prof Joska & Dr Mabaso,

Hope this email finds you well.

The Doctoral Degrees Board application requires me to obtain a written consent/ permission from all co-authors of the papers, to include the publications in my thesis. As co-authors, you also need to acknowledge my contribution to each paper.

Will you please reply to this email with your consent? I have to merge all responses into my motivation letter and submit one PDF document.

Thank you in advance.

Kind regards,
Sindi

Appendix D:

Approval by the Doctoral Degrees Board for PhD Thesis by Publication

Permission to include publications in your PhD thesis | Nolusindiso Ncitakalo NCTNOL001

DOCTORAL DEGREES BOARD <ddb@uct.ac.za>

Mon 2021/07/26 11:31

To: Nolusindiso Ncitakalo <NCTNOL001@myuct.ac.za>

Cc: Adri Winckler <adri.winckler@uct.ac.za>; FHS PG ADMIN <fhs-pg@uct.ac.za>; Leickness Simbayi <leickness.simbayi@uct.ac.za>

Dear Nolusindiso Ncitakalo

I hereby confirm that the Deputy Chair of the Doctoral Degrees Board has **approved** your request to include the specified publications in your PhD thesis.

In your thesis (after your declaration that it is your own work) please include the following separate signed statement listing the publications that you were given permission to include:
"I confirm that I have been granted permission by the University of Cape Town's Doctoral Degrees Board to include the following publication(s) in my PhD thesis, and where co-authorships are involved, my co-authors have agreed that I may include the publication(s): "

This declaration serves to notify examiners that the Doctoral Degrees Board has granted you permission to include publications in your thesis.

DDB Permission to include publications in your PhD thesis | Nolusindiso Ncitakalo NCTNOL001

DOCTORAL DEGREES BOARD <ddb@uct.ac.za>
Mon 2022/01/31 16:10
To: Nolusindiso Ncitakalo <NCTNOL001@myuct.ac.za>
Cc: Adri Winckler <adri.winckler@uct.ac.za>; FHS PG ADMIN <fhs-pg@uct.ac.za>; Jodi Carr <jodi.carr@uct.ac.za>; Leickness Simbayi <leickness.simbayi@uct.ac.za>

1 attachments (26 KB)
Declaration_InclusionPublications.docx;

Dear Nolusindiso Ncitakalo

I hereby confirm that the Deputy Chair of the Doctoral Degrees Board has **approved** your request to include the specified publications in your PhD thesis.

In your thesis (after your declaration that it is your own work) please include the following separate signed statement listing the publications that you were given permission to include:

> **"I confirm that I have been granted permission by the University of Cape Town's Doctoral Degrees Board to include the following publication(s) in my PhD thesis, and where co-authorships are involved, my co-authors have agreed that I may include the publication(s): "**
>
> This declaration serves to notify examiners that the Doctoral Degrees Board has granted you permission to include publications in your thesis.

Kind Regards

JANINE ISAACS
Doctoral Degrees Board Administrative Assistant

UNIVERSITY OF CAPE TOWN
Room 5.06 | Masingene Building | Cross Campus Road | | Middle Campus | Rondebosch | South Africa | 7700
Doctoral Candidates Webpage
+27 (0) 21 650 2202

Appendix E:

Turnitin Plagiarism Declaration

UNIVERSITY OF CAPE TOWN
IYUNIVESITHI YASEKAPA • UNIVERSITEIT VAN KAAPSTAD

DOCTORAL DEGREES BOARD

DDB13 - Turnitin plagiarism declaration

Note: This form is completed by **PhD students** and their **supervisors. PhD students must** submit this form with their thesis for examination.

Section A: Student and thesis details	
PhD Candidate Full Name	Nolusindiso Ncitakalo
Student Number	NCTNOL001
Faculty	Faculty of Health Sciences
Department	Mental Health & Psychiatry
Supervisor/s	Professor Leickness Simbayi
Co-Supervisor	Professor John Joska
Thesis Title	Factors associated with psychological distress among youth and adults living with HIV in South Africa

Note: Please complete and sign the applicable declaration.

Section B: Declaration by student				
I,	Nolusindiso Ncitakalo			(Student's name)
hereby declare that this thesis/dissertation has been submitted to the Turnitin module (or equivalent similarity and originality checking software). Plagiarism is to use another's work and pretend that it is one's own and I know that plagiarism is wrong. I confirm that I have discussed and resolved any concerns emanating from the Turnitin report with my supervisor.				
Signed (signature image | text)			**Date**	07/07/2023

Section C: Declaration by supervisor				
I,	Prof Leickness C Simbayi			(Supervisor's name)
hereby declare that this thesis/dissertation has been submitted to the Turnitin module (or equivalent similarity and originality checking software). Plagiarism is to use another's work and pretend that it is one's own. I confirm that I have discussed and resolved any concerns emanating from the Turnitin report with my student.				
Signed (signature image | text)	 Digitally signed by Leickness Simbayi DN: cn=Leickness Simbayi, o=HSRC, ou, email=lsimbayi@hsrc.ac.za, c=US Date: 2023.07.07 12:00:51 +0200'		**Date**	7 July 2023

Appendix F:

Proof of Editing Certificate

JEANNE ENSLIN
FREELANCE LANGUAGE PRACTITIONER

Editing certificate
TO WHOM IT MAY CONCERN

Language editing

I, Jeanne Enslin, acknowledge that I did the language editing of Chapters 1, 2 and 6 of **Nolusindiso Ncitakalo's** thesis to be submitted in fulfilment of the requirements for the degree Doctor of Philosophy in Department of Psychiatry and Mental Health, University of Cape Town.

The title of the thesis is:

FACTORS ASSOCIATED WITH PSYCHOLOGICAL DISTRESS AMONG YOUTH AND ADULTS LIVING WITH HIV IN SOUTH AFRICA

All corrections or changes are evident in the version of the thesis in track changes and with several comments for the student's attention.
The quality of the final document, in terms of language, formatting and references remains the student's responsibility.

Jeanne Enslin
Language editor
+264 812917040

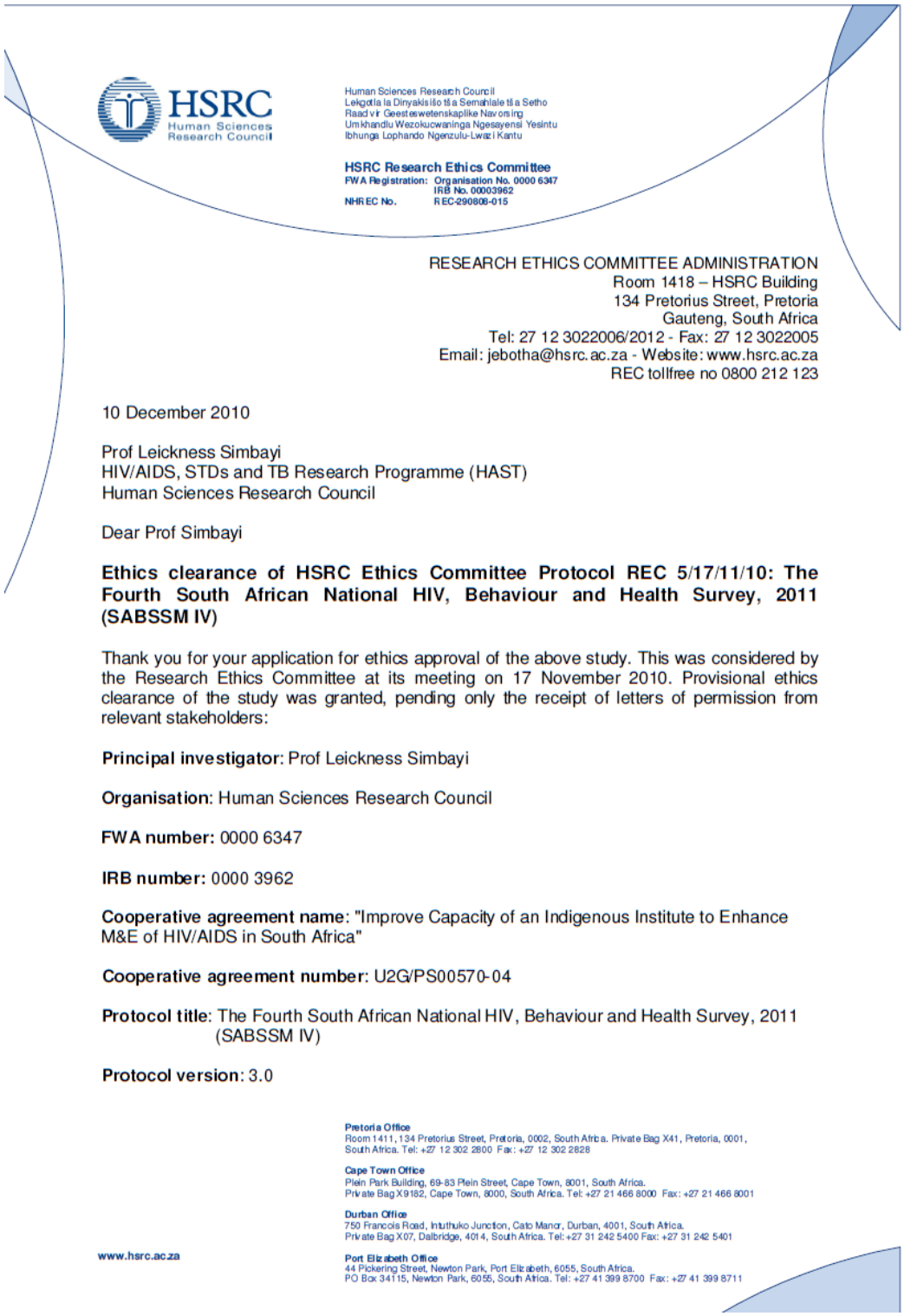
Technical editing

I, Ronel Gallie, acknowledge that checked/corrected layout aspects (whole document), and checked and corrected the reference lists of Chapters 1 and 6 of **Nolusindiso Ncitakalo's** thesis to be submitted in fulfilment of the requirements for the degree Doctor of Philosophy in Department of Psychiatry and Mental Health, University of Cape Town. Detailed feedback has been provided.

Ronèl Gallie
Technical editor
+2784 7780 292

Appendix G:

Ethical Clearance for the Primary Study



HSRC Human Sciences Research Council

Human Sciences Research Council
Lekgotla la Dinyakisišo tša Semahlale tša Setho
Raad vir Geesteswetenskaplike Navorsing
Umkhandlu Wezokucwaninga Ngesayensi Yesintu
Ibhunga Lophando Ngenzulu-Lwazi Kantu

HSRC Research Ethics Committee
FWA Registration: Organisation No. 0000 6347
IRB No. 00003962
NHREC No. REC-290808-015

RESEARCH ETHICS COMMITTEE ADMINISTRATION
Room 1418 – HSRC Building
134 Pretorius Street, Pretoria
Gauteng, South Africa
Tel: 27 12 3022006/2012 - Fax: 27 12 3022005
Email: jebotha@hsrc.ac.za - Website: www.hsrc.ac.za
REC tollfree no 0800 212 123

10 December 2010

Prof Leickness Simbayi
HIV/AIDS, STDs and TB Research Programme (HAST)
Human Sciences Research Council

Dear Prof Simbayi

Ethics clearance of HSRC Ethics Committee Protocol REC 5/17/11/10: The Fourth South African National HIV, Behaviour and Health Survey, 2011 (SABSSM IV)

Thank you for your application for ethics approval of the above study. This was considered by the Research Ethics Committee at its meeting on 17 November 2010. Provisional ethics clearance of the study was granted, pending only the receipt of letters of permission from relevant stakeholders:

Principal investigator: Prof Leickness Simbayi

Organisation: Human Sciences Research Council

FWA number: 0000 6347

IRB number: 0000 3962

Cooperative agreement name: "Improve Capacity of an Indigenous Institute to Enhance M&E of HIV/AIDS in South Africa"

Cooperative agreement number: U2G/PS00570-04

Protocol title: The Fourth South African National HIV, Behaviour and Health Survey, 2011 (SABSSM IV)

Protocol version: 3.0

Pretoria Office
Room 1411, 134 Pretorius Street, Pretoria, 0002, South Africa. Private Bag X41, Pretoria, 0001, South Africa. Tel: +27 12 302 2800 Fax: +27 12 302 2828

Cape Town Office
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PO Box 34115, Newton Park, 6055, South Africa. Tel: +27 41 399 8700 Fax: +27 41 399 8711

www.hsrc.ac.za

Additional materials reviewed and approved by the REC:

Consent forms:

a. Head of Household

b. 18 years and older

c. Parent/guardian of children 17 years and younger

Assent forms:

a. Children aged 12 to 17 years of age

b. Children aged 7 to 11 years of age

Questionnaires:

a. Household questionnaire

b. 18 years and older

c. 12 to 14 year olds

d. Parents/guardians of children aged 11 years and younger

Protocol approval date: 10 December 2010

Date of expiry of protocol approval: 31 December 2011

The Committee wishes you success in your research.

Yours sincerely,

Prof. D R Wassenaar PhD
Chairperson: HSRC REC

Appendix H:

Information Sheet and Consent Form for Participants 18 years & older


THE SOUTH AFRICAN NATIONAL HIV, BEHAVIOUR AND HEALTH SURVEY, 2011

Information sheet and Consent form
Participants aged 18 years and older

Dear Household member

Hello. My name is ..... I would like to inform you of a study, which is being conducted by a group of research organisations led by the Human Sciences Research Council (HSRC).

We are asking all the people aged 18 years and older in the household to respond to some questions. We hope that after combining all people's answers we will learn more about the health status of people living in South Africa.

Please understand that you are not being forced to take part in this study and the choice to participate or not is yours alone. However, we would really appreciate it if you do share your thoughts with us. If you choose not take part in answering the questions, you will not be affected in any way. If you agree to participate, you may stop me and tell me that you don't want to go on with the interview at any time without any consequences to you or your household.

The information you provide will remain confidential and there will be no "come-backs" from the answers you give. Your name will not be written down or recorded in any way.

Although your head of household/parent has given us permission to collect information from all members of this household, we also need your own permission for you to take part in the study. Your interview by our fieldworker will take between 45 and 90 minutes to complete.

I will be asking you questions and I ask that you are as open as possible in answering the questions. Some questions may be of a personal and/or sensitive nature and you are free not to answer them if you do not wish to do so. We know that you cannot be absolutely certain about the answers to some of the questions. When it comes to answering questions there are no right and wrong answers.

If I ask you a question which makes you feel sad or upset, we can stop and talk about it. There are also people from …….(*this will be adapted based on organizations operating in the area.*) who have said they are happy to talk with you about those things that upset you, if you need any assistance later.

After the interview you will be asked by a nurse to allow her to take a few drops of blood from a finger prick on a special filter paper. Collecting the samples will take about 10 minutes. You will experience some minor discomfort but the test can in no way endanger you. Only disposable sterile instruments are used that are clean and completely safe. The interviewers for the survey have been trained in the proper techniques to obtain a sample. The drops of blood will be dried on the filter paper which will be then be sent to a laboratory to test for HIV antibodies. If you are interested in knowing the result of your HIV test, we will provide you with a HIV Specimen Result Request Voucher referring you to a nearby HIV Counselling and Testing site. This voucher will have a unique participant questionnaire number that will assist clinic staff to correctly link your HIV laboratory result to the voucher. Additional information captured on the voucher will include your sex and age, date of result collection, and the name and address of selected clinic. The clinic staff is aware of the study and will gladly assist you. All that you need to do is present the voucher at the clinic. When deciding to participate, you will need to give permission to use the blood sample for the current and ongoing research.

Who to contact if you have been harmed or have any concerns

This research has been approved by the HSRC Research Ethics Committee (REC). If you any complaints about ethical aspects of the research or feel that you have been harmed in any way by participating in this study, please call the HSRC's tollfree ethics hotline 0800 212 123 or the REC Administrator, Jurina Botha on 012 302 2006. Alternatively you may send an e-mail to c@tip-offs.com or to jbotha@hsrc.ac.za. Please note that you do not have to give your name if you do not want to.

If you have concerns or questions about the research you may call the project leaders Mr Sean Jooste at 021 466 7942 or Ms Nompumelelo Zungu at 012 302 2030.

Your contribution to this important study is highly valued.

Thank you for your time.

Yours sincerely

Dr. Olive Shisana
Overall Principal Investigator
CEO
HSRC
Cape Town
Tel: (021) 466 8000
Fax: (021) 461 0299

CONSENT

I hereby agree to participate in the South African National HIV, Behaviour and Health survey. I understand that I am participating freely and without being forced in any way to do so. I also understand that I do not have to provide a blood specimen if I do not want to and that I can stop this interview at any point should I not want to continue and that this decision will not in any way affect me negatively.

I understand that this is a research project whose purpose is not necessarily to benefit me personally.

I have received the telephone number of a person to contact should I need to speak about any issues which may arise in this interview.

I understand that this consent form will not be linked to the questionnaire, and that my answers will remain confidential.

……..

Signature of participant **Date**:……..

The extra copy of the consent form is for you to keep.

Appendix I:

Information Sheet and Assent Form for Participants 12–17 years


THE SOUTH AFRICAN NATIONAL HIV, BEHAVIOUR AND HEALTH SURVEY, 2011

Information sheet and Assent form
Participants aged 12 years to 17 years

Dear Participant

Hello. My name is ..... I work for the Human Sciences Research Council.

We are asking all children aged 12 to 17 years old to respond to some questions. We hope that after combining all children's answers to learn more about the health status of children living in South Africa.

Please understand that your participation is voluntary. You have the right to withdraw your assent to participate at any time without any consequences to you or your or the household.

The information you provide will remain confidential and there will be no "come-backs" from the answers you give. Your name will not be written down or recorded in any way.

Select only one scenario which is appropriate for your age group from below.
Although your parent/guardian has given us permission to collect information from all members of this household, we also need your own permission for you to take part in the study.

If you are 15 years and older:
Your interview by our fieldworker will take between 45 and 90 minutes to complete.

If you are aged 12-14 years:
Your interview by our fieldworker will take about 30 minutes to complete.

When it comes to answering questions there are no right and wrong answers and you are free not to answer any question if you do not wish to do so. If I ask you a question which makes you feel sad or upset, we can stop and talk about it a little. There are also people from …….(*this will be adapted based on organizations operating in the area.*) who have said they are happy to talk with you about those things that upset you, if you need any assistance later.

We would also like to take a finger prick test. The test is anonymous and your name cannot be linked to it. Your participation will help us identify the best ways to protect children. The test does not hurt much at all and involves a finger prick using a sharp pin that will enable us to get a few drops of blood. The drops of blood will be dried on the filter paper which will be then be sent to a laboratory

to test for HIV antibodies. If you are interested in knowing the result of your HIV test, we will provide you with a HIV Specimen Result Request Voucher referring you to a nearby HIV Counselling and Testing site. This voucher will have a unique participant questionnaire number that will assist clinic staff to correctly link your HIV laboratory result. Additional information captured on the voucher will include your sex and age, date of result collection, and the name and address of selected clinic. The clinic staff is aware of the study and will gladly assist you. All that you need to do is present the voucher at the clinic. When deciding to participate, we also will need your permission to use the blood sample for the current and ongoing research.

Who to contact if you have been harmed or have any concerns

This research has been approved by the HSRC Research Ethics Committee (REC). If you any complaints about ethical aspects of the research or feel that you have been harmed in any way by participating in this study, please call the HSRC's tollfree ethics hotline 0800 212 123 or the REC Administrator, Jurina Botha on 012 302 2006. Alternatively you may send an e-mail to c@tip-offs.com or to jbotha@hsrc.ac.za. Please note that you do not have to give your name if you do not want to.

If you have concerns or questions about the research you may call the project leaders Mr Sean Jooste at 021 466 7942 or Ms Nompumelelo Zungu at 012 302 2030.

Your contribution to this important study is highly valued.

Thank you for your time.

Yours sincerely

Dr. Olive Shisana
Overall Principal Investigator
CEO
HSRC
Cape Town
Tel: (021) 466 8000
Fax: (021) 461 0299

CONSENT

I hereby agree to participate in the South African National HIV, Behaviour and Health survey. I understand that I am participating freely and without being forced in any way to do so. I also understand that I do not have to provide a blood specimen if I do not want to and that I can stop this interview at any point should I not want to continue and that this decision will not in any way affect me negatively.

I understand that this is a research project whose purpose is not necessarily to benefit me personally.

I have received the telephone number of a person to contact should I need to speak about any issues which may arise in this interview.

I understand that this consent form will not be linked to the questionnaire, and that my answers will remain confidential.

……..
Signature of participant **Date**:……..

The extra copy of the consent form is for you to keep.

Appendix J:

Information Sheet and Consent Form for Parent/ Guardians of Children 0-17 years

THE SOUTH AFRICAN NATIONAL HIV, BEHAVIOUR AND HEALTH SURVEY, 2011

Information sheet and Consent form
Parent/Guardians of children aged 0 to 17 years

Dear Parent/Guardian

Hello. My name is ..... I would like to inform you of a very important scientific study, which is being conducted by a group of research organisations led by the Human Sciences Research Council (HSRC).

We are asking all parents and children aged 12 years and older in the household to respond to some questions. We hope that after combining all people's answers to learn more about the health status of children living in South Africa, which will help us make useful recommendations to the relevant authorities and organisations.

Please understand that you or your child are not being forced to take part in this study and the choice whether to participate or not is yours alone. However, we would really appreciate it if you or child does share your thoughts with us. If either you choose not take part in answering these questions, you will not be affected in any way.

If either of you agree to participate, you may stop me and tell me that you don't want to go on with the interview at any time without any consequences to you or your or the household.

I will not be recording your name or your child's anywhere on the questionnaire and no one will be able to link you or child to the answers you give. Only the researchers will have access to the unlinked information. The information will remain confidential and there will be no "come-backs" from the answers you give.

Select only one scenario which is appropriate for your age group from below.
Although your head of household has given us permission to collect information from all members of this household, we also need your own permission for you to take part in the study.

If you are a parent/guardian or caregiver of older children (15-17 years):
Your child's interview by our fieldworker will take between 45 and 90 minutes to complete.

If you are a parent/guardian or caregiver of younger children (12-14 years):
Your child's interview by our fieldworker will take about 30 minutes to complete.

If you are a parent/guardian or caregiver of younger children (i.e., under 12 years of age):
Your interview by our fieldworker will take about 30 minutes to complete.

[*Paragraph for use children 12 -17 years*] I will be asking your child questions about his or her own health including HIV/AIDS, their use of health services, their communication about HIV/AIDS, and their home environment. Some questions may be of a personal and/or sensitive nature and your child is free not to answer them if he/she does not wish to do so. I will also be asking some questions that he/she may not have thought about before, and which also involve thinking about the past or the future. When it comes to answering questions there are no right and wrong answers.

[*Paragraph for use children 0-11 years*] I will be asking you questions and ask that you are as open as possible in answering these questions. Some questions may be of a personal and/or sensitive nature and you are free not to answer them if you do not wish to do so. We know that you cannot be absolutely certain about the answers to these questions. When it comes to answering questions there are no right and wrong answers.

If I ask you a question which makes you feel sad or upset, we can stop and talk about it a little. There are also people from ……. (*this will be adapted based on organizations operating in the area.*) who have said they are happy to talk with you about those things that upset you, if you need any assistance later.

If you agree to take part, we would also like your permission to prick your child's finger to take a few drops of his/her blood. Collecting the samples will take about 10 minutes. Your child will experience some minor discomfort but the test can in no way endanger him/her. Blood will be collected using a small sharp instrument called a lancet to prick the tip of your child's finger. Infants under 2 years of age will provide a few drops of blood from a heel prick. Only disposable sterile instruments are used that are clean and completely safe. The interviewers for the survey have been trained in the proper techniques to obtain a sample. Samples will be sent to a laboratory for HIV testing. We will only collect samples from your child if both you and your child give permission. When deciding to participate, you will need to give permission to use the blood sample for the current and ongoing research.

If you are interested in knowing the result of your HIV test, we will provide you or your child with a HIV Specimen Result Request Voucher referring you to a nearby HIV Counselling and Testing site. This voucher will have a unique participant questionnaire number that will assist clinic staff to correctly link your child's HIV laboratory result to the voucher. Additional information captured on the voucher will include your child's sex and age, date of result collection, and the name and address of selected clinic. The clinic staff is aware of the study and will gladly assist. All that you or your child need to be do is present the voucher at the clinic.

Who to contact if you have been harmed or have any concerns

This research has been approved by the HSRC Research Ethics Committee (REC). If you any complaints about ethical aspects of the research or feel that you have been harmed in any way by participating in this study, please call the HSRC's tollfree ethics hotline 0800 212 123 or the REC Administrator, Jurina Botha on 012 302 2006. Alternatively you may send an e-mail to c@tip-offs.com or to jbotha@hsrc.ac.za. Please note that you do not have to give your name if you do not want to.

If you have concerns or questions about the research you may call the project leaders Mr Sean Jooste at 021 466 7942 or Ms Nompumelelo Zungu at 012 302 2030.

Your contribution to this important study is highly valued.

Thank you for your time.

Yours sincerely

Dr. Olive Shisana
Overall Principal Investigator
CEO
HSRC
Cape Town
Tel: (021) 466 8000
Fax: (021) 461 0299

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I understand that this consent form will not be linked to the questionnaire, and that my answers will remain confidential.

……..
Signature of the parent/guardian **Date**:……..