Exploring possible influences of HIV/AIDS-related stigma on risky sexual behaviour and childbearing decisions: Cape Town 2002-2009

Takwanisa Machemedze

Dissertation presented for the degree of
Doctor of Philosophy
in the Department of Sociology,
University of Cape Town, South Africa
November 2016

Supervisors

Prof. Nicoli Nattrass
Prof. Rajen Govender

Faculty of Humanities

Declaration

I, Takwanisa Machemedze hereby declare that the work on which this thesis is based is my original work (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. I authorise the University to reproduce for the purpose of research either the whole or any portion of the contents in any manner whatsoever.

Signature: 

Date: ……28/11/2016…….

Signature Removed

Acknowledgements

I acknowledge the support and contribution of several people towards the completion of this dissertation. Firstly, I would like to express my sincere gratitude to my supervisors, Professor Nicoli Nattrass and Professor Rajen Govender, for their support and guidance. I thank Nicoli for encouraging my research and for allowing me to grow as a social science researcher. I also thank Rajen for his expertise and guidance on structural equation modeling techniques. Their motivation and intellectual guidance helped me throughout my research work and writing of this thesis. I could not have imagined having better supervisors and mentors for my Ph. D. study.

I would like to thank the University of Cape Town (UCT), DataFirst and the Centre for Social Science Research (CSSR)/AIDS and Society Research Unit (ASRU) for their financial assistance. Without their financial support, it would not have been possible to conduct this research.

My sincere thanks also go to DataFirst, my employer, who allowed me a flexible time-table for both working and studying. I would also like to thank the entire team at DataFirst for their continuous encouragement and support. A special mention goes to Professor Martin Wittenberg who facilitated part of my funding through DataFirst, Lynn Woolfrey for proofreading and Alison Siljeur for assistance with administrative paperwork.

I also acknowledge assistance from Nondumiso Hlwele and Thobani Ncapi both from the Centre for Social Science Research. Certain times I needed access to some of the field material and Thobani was always there to help. They also both shared their experiences about township life which helped in shaping some ideas about this research.

I would also like to thank my family for the support they provided me through my entire life. My family, to whom this dissertation is dedicated to, has been a constant source of love, support and strength all these years. This is especially to my late father, Nyambipo Machemedze and mother, Loveness Kativu-Machemedze.

This also goes to my friends for being there when I needed you the most, and all others who I have not yet acknowledged.

Finally, I am grateful to my wife, Dorothy, twin sons, Tapiwa and Tawonga, for accepting my studies as part of their life. Dorothy read numerous drafts of this thesis and was always there to cheer me up. I love you all dearly.

Abbreviations

AIDS	Acquired immunodeficiency syndrome
ARV	Antiretroviral
ASRU	AIDS and Society Research Unit
ASSA	Actuarial Society of South Africa
CAPS	Cape Area Panel Study
CSSR	Centre for Social Science Research
DHS	Demographic and Health Survey
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immunodeficiency Virus
HSRC	Human Sciences Research Council
KHPS	Khayelitsha HAART Panel Study
MSF	Médecins Sans Frontières (MSF)
NGO	Non-governmental organization
NYS	National Youth Survey
PGWC	Provincial Government of the Western Cape
PLWHA	People Living With HIV/AIDS
PMTCT	Prevention of Mother to Child Transmission of HIV
RDP	Reconstruction and Development Programme
SEM	Structural Equation Modeling
SSA	sub-Sahara Africa
StatsSA	Statistics South Africa
TAC	Treatment Action Campaign
UCT	University of Cape Town
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
USA	United States of America
WHO	World Health Organization

Table of Contents

Tables

Figures

Abstract

Exploring possible influences of HIV/AIDS-related stigma on risky sexual behaviour and childbearing decisions: Cape Town 2002-2009

This dissertation uses survey data to explore HIV/AIDS-related stigma as it is manifested in the general population of young adults in Cape Town and amongst people living with HIV/AIDS (PLWHA) on highly active antiretroviral treatment (HAART) in Khayelitsha (an African township in Cape Town). For the general population, we assessed how 'symbolic stigma' (negative attitudes and moral assessments of PLWHA) was related to risky sexual behaviour and whether this was mediated by perceived risk of HIV infection. For PLWHA, we assessed whether 'internalized stigma' and perceptions of stigmatizing attitudes in the broader population (mediated through disclosure of HIV sero-status to sexual partners and experiences of depression and anxiety symptoms) were associated with condom use. We also assessed the relationship between experiences of stigma, internalization of stigma, perceptions of stigma and childbearing desires of PLWHA

The study found out that young Black and Coloured women who held symbolic HIV/AIDS-related stigma attitudes were more likely to perceive themselves at a reduced risk of infection with HIV and continue to engage in risky sexual behaviours. There were indications of possible race-gender differences in perceived risk of HIV infection and the practice of risky sexual behaviours.

For PLWHA, there was evidence to suggest that both internalized and perceived stigma deterred women's disclosure of their HIV status to sexual partners. However, disclosure of sero-status to sexual partners did not necessarily translate into initiation of safer sex practices. Results suggest that women in this community were disadvantaged when it came to condom use negotiation. Both internalized stigma and disclosure of HIV status to a sexual partner were associated with higher levels of depression and anxiety symptoms which in turn was associated with inconsistent or no condom use. Results also suggest that there may be pathways connecting internalized stigma and condom use other than experiences of depression/anxiety and disclosure of one's HIV status to a sexual partner.

We found various experiences of stigma among people living with HIV/AIDS in Khayelitsha to be associated with both increased and decreased odds of intending to have children (or more children). Experienced stigma was significantly associated with childbearing intentions. However, women's decisions to bear children appeared to be more influenced by whether they had a live-in sexual partner than experiences of stigma. We could not establish statistically significant relationships between perceived stigma and childbearing intentions both independently and after controlling for other variables. Internalized stigma was independently associated with reduced childbearing intentions but not after controlling for other relevant variables. Reported childbearing intentions among this sample of PLWHA were associated with the occurrence of at least one pregnancy after two years but are not statistically significantly related to condom use practices.

Takwanisa Machemedze

November 2016

1 Introduction

Acquired Immune Deficiency Syndrome (AIDS), caused by the Human Immunodeficiency Virus (HIV), is one of the most stigmatized medical conditions in the world (Phillips, Moneyham and Tavakoli, 2011: 359; Simbayi, Kalichman, Strebel *et al.*, 2007a: 1823). Stigma was classically defined by Goffman as "an attribute that is deeply discrediting" with the bearer of stigma reduced "from a whole and usual person to a tainted, discounted one" (Goffman, 1963: 3). Other theoretical work similarly emphasizes that stigma is socially constructed (Link and Phelan, 2001; Parker and Aggleton, 2003), but processed and experienced at the individual level (Herek, 2002: 595). Goffman (1963: 4-5), identified three aspects of stigma ("blemishes of individual character", "tribal stigma" – also interpreted as stained social identity through group membership, and "physical deformities") that are all characteristic of HIV/AIDS. In relation to HIV/AIDS, aspects of stigma resulting from social factors include attribution of immoral responsibility to those affected (e.g. sexual promiscuity, homosexuality, intravenous drug use), its perceived fatality that evokes exaggerated fear of infection, and its deleterious effects on physical appearance (e.g. skin lesions, persistent opportunistic infections) (Herek, 1999: 1109-1110).

People Living with HIV/AIDS (PLWHA) are stigmatized in most societies where this has been studied. The expression of this stigma varies, as it is socially constructed, and therefore shaped by the unique history of the epidemic in a particular social context (Herek, 1999: 1107). In the case of South Africa, the HIV/AIDS epidemic is seen as primarily driven by heterosexual means (Shisana, Rehle, Simbayi *et al.*, 2009: xv). People in the general population (who assume that they are not infected by HIV) attach a negative social identity to people in particular social groups associated with sexual promiscuity whom they perceive to be responsible for the spread of HIV/AIDS (e.g. Petros, Airhihenbuwa, Simbayi *et al.*, 2006; Cloete, Strebel, Simbayi *et al.*, 2010; Airhihenbuwa, Okoror, Shefer *et al.*, 2009).

Previous analyses of HIV/AIDS-related stigma have usefully distinguished between different dimensions of the problem, notably moral blaming of PLWHA ('symbolic stigma'), exaggerated fear of infection through contact with PLWHA ('instrumental stigma') and reported behaviour that discriminates against those infected with HIV ('behavioural stigma') (Maughan-Brown, 2008; Herek and Capitanio, 1998). PLWHA may experience stigma ('experienced stigma'), perceive and/or anticipate it in the general population ('perceived stigma'), and even internalize the negative designation attached to HIV/AIDS and develop feelings of guilt or shame because of their illness ('internalized stigma') (Berger, Ferrans and Lashley, 2001; Maughan-Brown, 2008).

It is widely accepted that HIV/AIDS-related stigma has negative social and psychological consequences, and can undermine HIV prevention and treatment efforts. For example, a systematic review of the international literature shows that HIV/AIDS-related stigma hinders HIV/AIDS prevention, access to treatment, treatment adherence, and care and support for PLWHA (Mahajan, Sayles, Patel *et al.*, 2008). The impact of stigma on sexual behaviour and child-bearing decisions, however, is less well researched, especially with regard to quantitative analysis and the pathways through which different dimensions of stigma may influence such behaviour and decisions. This study explores the impact of HIV/AIDS-related stigma as it is manifested in the general population of young adults in Cape Town on their risky sexual behaviours (non-condom use and multiple sexual partnerships). This study also explores the impact of stigma on condom use and childbearing decisions amongst PLWHA in Cape Town, in the context of stigmatizing attitudes and behaviours within the general population of Cape Town.

Of particular interest to our study is how different dimensions of HIV/AIDS-related stigma potentially influence the practice of safer sex. For example, a study of the general population in a township in Cape Town found that individuals who hold stigmatizing attitudes towards PLWHA are less likely to get tested for HIV and also less likely to practice safer sex (Kalichman and Simbayi, 2003). The

international literature suggests that HIV/AIDS-related stigma, especially moral blaming of certain social groups (out-groups) for the spread of HIV infection, creates perceptions of being at reduced risk or no risk of HIV infection (on the part of in-groups) and thereby limits motivations to practice safer sex (Riley and Baah-Odoom, 2010; Catania, Coates and Kegeles, 1994). Experiences of HIV/AIDS-related stigma among PLWHA also have the potential to hinder the practice of safer sex. For example, a meta-analytic study of samples of women from developing countries suggests that previous experiences of stigma or perceptions of stigma deter these women from disclosing their HIV status to potential sex partners (Medley, Garcia-Moreno, McGill *et al.*, 2004). Such non-disclosure was found to be associated with unprotected sex among some South African samples of PLWHA (Kiene, Christie, Cornman *et al.*, 2006; Olley, Seedat, Gxamza *et al.*, 2005; Olley, Seedat and Stein, 2004). The practice of unprotected sex, in such cases, has been attributed to difficulties involved in negotiating condom use without disclosing one's HIV status or causing suspicion about one's HIV status due to fear of stigma (Medley, Garcia-Moreno, McGill *et al.*, 2004). HIV/AIDS-related stigma is also associated with negative psychological outcomes (Berger, Ferrans and Lashley, 2001; Mak, Cheung, Law *et al.*, 2007) which in turn are associated with a tendency to engage in risky behaviour, including risky sexual behaviour (Murphy, Durako, Moscicki *et al.*, 2001; Mustanski, Garofalo, Herrick *et al.*, 2007).

According to Goffman (1963: 41-45), recipients of stigma often develop strategies to conceal their stigmatizing condition from others. This is the case in South African samples of PLWHA who employ strategies to pass as "normal", for example, by getting pregnant to comply with social expectations (Oni, Ross and van der Linde, 2013: 4-5; Cooper, Harries, Myer *et al.*, 2007: 28; Van Zyl and Visser, 2015: 438). However, getting pregnant exposes the sexual partner and the child to HIV infection, unless managed appropriately through safe conception methods (Bekker, Black, Myer *et al.*, 2011). This is further compounded, for example, by the fear of stigma which was found to deter some South African women living with HIV/AIDS from discussing their pregnancy desires with health care

professionals (Cooper, Harries, Myer *et al.*, 2007: 280). They thereby miss opportunities to be informed about safer conception methods that minimize risks of HIV transmission.

1.1 Dissertation Objectives

The current study explores some of the potential relationships between HIV/AIDS-related stigma and the practice of risky sexual behaviour, in the general population of Cape Town, and amongst a sample of PLWHA in Khayelitsha (an African township in Cape Town). The objective is to contribute to the broader quantitative literature on stigma and sexual behaviour of PLWHA by providing a case study from a developing country. The study also demonstrates insights to be gained from analysing potential determinants of risky sexual behaviour and childbearing intentions within the social context of stigmatization in the broader population.

1.2 Statement of the problem

Stigma is socially constructed (Link and Phelan, 2001; Parker and Aggleton, 2003) and thus will inevitably vary across social contexts. A key focus for this study is thus to explore how HIV/AIDS-related stigma is expressed by the general population and experienced by PLWHA. The study goes on to explore the correlation between various dimensions of stigma and risky sexual behaviour in the general population of Cape Town and amongst PLWHA in Khayelitsha.

Evidence in the international literature shows inconsistent relationships between HIV/AIDS-related stigma among PLWHA and risky sexual behaviour (particularly unprotected sex). Some studies observed direct (Preston, D'Augelli, Kassab *et al.*, 2004: 299) or indirect (Preston, D'Augelli, Kassab *et al.*, 2007: 227; Clum, Chung, Ellen *et al.*, 2009: 1458) relationships between various experiences of HIV/AIDS-related stigma and risky sexual practices. Other studies, however, found experiences of HIV/AIDS-related stigma to be associated with less risky sexual behaviour (Varni, Miller and

Solomon, 2012: 2335-2336). Some studies could not establish statistically significant relationships between experiences of HIV/AIDS-related stigma and sexual behaviour (Courtenay-Quirk, Wolitski, Parsons *et al.*, 2006: 63; Vanable, Carey, Blair *et al.*, 2006: 7; Wolitski, Pals, Kidder *et al.*, 2009: 1277). Most of these studies were conducted in developed countries, and for varying samples that include men who have sex with men, homeless people, and adolescents, among others.

1.3 Significance of the research

This study is relevant to the ongoing fight against new HIV infections by contributing to our understanding of the factors shaping behaviour risk for HIV infection, and particularly HIV/AIDS-related stigma as a potential impediment to HIV prevention. There are few studies of HIV/AIDS-related stigma and sexual behaviour in South Africa, and these vary by sample and measures. This study uses comprehensive measures of HIV/AIDS-related stigma from longitudinal (panel) data to explore some relationships that are problematic to conceptualize using cross-sectional data. We also use structural equation modelling (SEM) to test simultaneously a number of interconnected relationships which appear to be implied by some studies that test separate relationships.

1.4 Chapter outline

The dissertation is organized in ten chapters. The first four chapters engage with the available literature. Chapter 2 provides an overview of the academic literature to determine possible relationships between HIV/AIDS-related stigma among people in the general population (typically assumed to be HIV-negative and stigmatizers), their self-perceived risk of HIV infection, and risky sexual behaviour for HIV infection. Chapter 3 explores the academic literature on possible relationships between HIV/AIDS-related stigma among PLWHA (the stigmatized), their disclosure of HIV status to sexual partners, psychological distress/anxiety, and their risky sexual behaviour for HIV

infection. Chapter 4 reviews the available literature on possible relationships between HIV/AIDS-related stigma among PLWHA and their fertility desires.

Chapters 5 to 10 report on our empirical analysis of data from two panel studies in Cape Town. Chapter 5 provides the background to our study area and Chapter 6 discusses the survey designs of the data used, and ethical considerations for the respective studies. Chapters 7, 8 and 9 discuss in detail our analysis of the data. Chapter 7 explores the relationships described in Chapter 2 using survey data for young adults living in Metropolitan Cape Town. Chapters 8 and 9 explore the relationships described in Chapters 3 and 4 respectively using survey data for PLWHA in Khayelitsha. Chapter 10 summarizes the conclusions reached and provides suggestions for further research.

2 HIV/AIDS-related stigma, risk perception and risky sexual behaviour in the general population

Heterosexual sex is the major driver of HIV/AIDS infections in South Africa (Shisana, Rehle, Simbayi *et al.*, 2009; Shisana, Rehle, Simbayi *et al.*, 2014). Most research has operationalized risk behaviours related to heterosexual transmission of HIV/AIDS in terms of being sexually active, having multiple sex partners (serial or concurrent) and engaging in risky/unprotected sex (Eaton, Flisher and Aaro, 2003). Several empirical studies based on different samples of South African youths have also found that HIV status is associated with being sexually active for a longer time, being in concurrent relationships, increasing the number of sex partners, and inconsistent condom use (Nattrass, Maughan-Brown, Seekings *et al.*, 2012; Pettifor, Rees, Kleinschmidt *et al.*, 2005; Jewkes, Dunkle, Nduna *et al.*, 2006).

Based on an understanding of the risk behaviours for HIV transmission, intervention measures have been implemented to create awareness and help prevent new HIV infections. For example, the South African government's policy to minimize risks of sexual transmission of HIV included distributing free condoms and promoting information campaigns about safe sex (National Department of Health and National Treasury, 2003). At a regional level, the 'Expert Think Tank' meeting on AIDS prevention in the high HIV prevalence countries of southern Africa (including South Africa) that convened in Lesotho in May 2006 recommended priority interventions that aimed to: (a) "reduce the number of multiple and concurrent partnerships", (b) "increase consistent and correct condom use" and (c) "continue programming around delayed sexual debut in the context of condom programming and reduced partnerships" (SADC, 2006: 3). In South Africa's case, HIV information campaigns probably helped raise awareness in that nationally representative surveys found that more than 90% of people in South Africa across all age groups have at least heard about HIV/AIDS (Department of Health, Medical Research Council and OrcMacro, 2007: 85-86; Department of Health, Medical

Research Council and DHS+. 2002: 76-77). But to what extent these campaigns have encouraged people to engage in safer sex is a much more open question.

On the assumption that people make systematic use of information available to them, various health behaviour models have been developed or adapted in an attempt to understand why people fail to protect themselves better against HIV infection. The models of behaviour change[1] include the Health Belief Model (HBM) (Rosenstock, Strecher and Becker, 1994; Janz and Becker, 1984) and AIDS Risk Reduction Model (ARRM) (Catania, Coates and Kegeles, 1994; Catania, Kegeles and Coates, 1990). The HBM postulates that individuals will only take steps to prevent a disease if they perceive the risks to their health to be serious, if they feel at risk and if they are aware that something could be done to reduce their risk of contracting the disease or moderate its severity. The ARRM model combines constructs from other models including the HBM. The ARRM model assumes that the process of behaviour change occurs in three stages: (1) identification and labelling of one's behaviour as risky, (2) making the commitment to choose low risk behaviour and (3) behaviour change (Catania, Kegeles and Coates, 1990: 54-55).

Catania, *et al.* (1994) applied the ARRM to a sample of adults in the USA, and found that individuals with strong stereotyped beliefs about the kind of people who are likely to contract HIV are less likely to label their own sexual behaviour as risky. A hypothesis emerging around this finding is that stigmatizing attitudes or stereotyping beliefs are associated with reduced perception of being at risk of contracting HIV and, as a result, individuals with these attitudes continue to engage in risky sexual behaviour (Riley and Baah-Odoom, 2010). One of the hypotheses to be tested in this study is the suggested mediation relationship, that is, whether stigmatizing attitudes are associated with reduced

[1] There are other theories of behaviour as opposed to behaviour change

self-perceived risk of infection with HIV, which then results in failure to take HIV/AIDS prevention measures and risky sexual behaviours.

To test these relationships, this study uses data from the Cape Area Panel Study (CAPS)[2], a longitudinal study of young adults (aged between 14 and 22 in 2002 until they were aged 20 to 29 in 2009) in metropolitan Cape Town, South Africa. Respondents in the CAPS sample were asked various questions pertaining to demographic, social, economic, sexual and reproductive health matters. The main variables of interest include stigma attitudes of youth towards HIV infected individuals, their self-perceived risk of infection with HIV, and the related sexual risk behaviours for HIV infection (ever had sex, condom use at last sex, and number of sexual partners in the 12 months preceding the survey).

The following sections provide some background on the main variables of interest which are HIV/AIDS-related stigma attitudes, perceived risk of infection with HIV, and risky sexual behaviour among South African youths.

2.1 HIV/AIDS-related stigma

As noted earlier, stigma is defined as "an attribute that is deeply discrediting" that reduces the bearer "from a whole and usual person to a tainted, discounted one" (Goffman, 1963: 3). Goffman emphasized that stigma refers not directly to an attribute but to a "special kind of relationship between attribute and stereotype" (Goffman, 1963: 4). Evolving definitions have broadened the stigma concept to capture the social structural inequality that contributes to stereotyping (Link and Phelan, 2001; Parker and Aggleton, 2003). Link and Phelan (2001: 366-367) define stigma as the co-occurrence of

[2] More details about CAPS are provided in Chapter 6

its components – distinguishing and labelling differences, associating human differences with negative attributes, separating ‘‘us’’ from ‘‘them’’, and status loss and discrimination – within the context of social, economic and political power. Parker and Aggleton (2003) describe how stigma is used to legitimize social inequalities of power and domination between those stigmatizing others and the stigmatized.

A characteristic that is socially undesirable, for example HIV/AIDS in the case of this study, leads to what Goffman (1963) defined as a ‘spoiled identity’ that can in turn lead to further stigma and discrimination. HIV/AIDS-related stigma is widely acknowledged as a major barrier to effective HIV/AIDS prevention, treatment, care, and support in many countries, including South Africa (UNAIDS, 2013). In the case of HIV/AIDS, most studies have assessed stigma in terms of the beliefs and attitudes of those perceived to be stigmatizing others (Parker and Aggleton, 2003: 15). HIV/AIDS-related stigma on the part of those perceived to stigmatize is sometimes broken down into other dimensions that include symbolic and instrumental stigma (see Herek and Capitanio, 1998; Herek, 2002).

2.1.1 Symbolic stigma

Symbolic stigma arises from moral judgement of the cause of HIV/AIDS or groups of people associated with the disease (Herek, 2002; Herek and Capitanio, 1998). It is “based on the metaphorical social meanings attached to AIDS, the people who get it, and the ways in which it is transmitted” (Herek, 2002: 598). Symbolic stigma attitudes are understood to perform an ‘expressive’ function that arises from a psychological “need to affirm one’s self-concept by expressing personal values” (Herek and Capitanio, 1998: 1).

In the US, for example, HIV/AIDS was originally associated with homosexuality (where homosexuality was judged to be morally wrong by many people) and injecting drug users (Herek,

2002; Herek, 1991). As a result, HIV/AIDS-related symbolic stigma attitudes were directed towards these groups of individuals (Herek, 2002; Herek, 1991). In the case of South Africa, where heterosexual sex is the predominant mode of transmission of HIV (Shisana, Rehle, Simbayi *et al.*, 2009), the blaming and shaming for infection is thought to be directed towards individuals perceived to be promiscuous (e.g. Petros, Airhihenbuwa, Simbayi *et al.*, 2006; Cloete, Strebel, Simbayi *et al.*, 2010; Airhihenbuwa, Okoror, Shefer *et al.*, 2009). Thus, HIV/AIDS-related symbolic stigma is tied to pre-existing forms of stigma towards groups of people identified with socially judged immoral behaviour, which is also associated with being the driver of the HIV epidemic.

2.1.2 Instrumental stigma

Instrumental stigma attitudes are understood to derive from the fear of HIV/AIDS which is perceived as a communicable and lethal illness (Herek, 2002). These attitudes perform an 'evaluative' function that arises from a psychological concern about getting HIV and the desire to protect oneself from infection (Herek and Capitanio, 1998). Beliefs (accurate and inaccurate) about HIV transmission then play a role in how individuals make contact with those infected or perceived to be infected with HIV. For example, those who believe casual social contact can cause HIV infection are less likely to have such contact with an infected individual (Herek, 2002; Herek, Widaman and Capitanio, 2005). Examples of behaviour shaped by instrumental stigma attitudes include avoidance of touching PLWHA or refusing to share a bottle of water with an HIV infected person for fear of becoming infected (Maughan-Brown, 2010: 371).

The distinction between symbolic and instrumental stigma is that the former is based on distancing oneself from HIV by blaming the associated 'out groups' and the latter is based on inflated fear of infection by keeping physically distant from those infected or perceived to be infected (Stein, 2003). Deacon, *et al*. (2005: 47) argue that symbolic and instrumental stigma should not be part of the same analytical category since they originate from different processes, although they are both socially constructed. According to Deacon, *et al.* (2005: 41), measures of instrumental stigma used in previous

research ask respondents about their behavioural intentions (for example, whether they would share a bottle of water with an HIV positive person) while symbolic stigma is measured by questions probing people's beliefs about the blameworthiness of PLWHA. Thus what is termed instrumental stigma is usually operationalised as intended discrimination based on exaggerated fear of contracting HIV through contact with an infected individual. Deacon, *et al*. (2005: 41) further argue that defining instrumental and symbolic stigma together assumes a "direct relationship between stigma, intended discrimination and discrimination", although it can be argued that only some forms of stigma may have a direct relationship with discrimination.

2.2 HIV/AIDS related stigma in South Africa

There is no comprehensive and standard set of measures for each of the various HIV/AIDS-related stigmas (Nyblade, 2006). Several measures have been used in various South African social surveys to assess the general public's stigma attitudes towards PLWHA (for example Maughan-Brown, 2004; Shisana, Rehle, Simbayi *et al.*, 2014; Kalichman, Simbayi, Jooste *et al.*, 2005). Maughan-Brown (2004) conceptualized stigma in terms of its various components, which include projected behavioural intentions towards PLWHA, symbolic and instrumental stigma attitudes. Kalichman, *et al.* (2005) used a survey instrument designed to assess feelings towards PLWHA by asking questions which fall into three categories: Coercive attitudes, blame, and avoidant behaviours. Nationally representative surveys, for example, the South African Demographic and Health Survey (DHS) of 2003 (see Department of Health, Medical Research Council and OrcMacro, 2007) and the South African National HIV Prevalence, Incidence, and Behaviour Survey (2002, 2005, 2008, 2012) conducted by the Human Sciences Research Council (HSRC) (see Shisana, Rehle, Simbayi *et al.*, 2014; Shisana, Rehle, Simbayi *et al.*, 2005; Shisana, Rehle, Simbayi *et al.*, 2009; Shisana and Simbayi, 2002) also included questions on knowledge and stigmatizing attitudes. The DHS 2003 and the South African National HIV Prevalence, Incidence, and Behaviour Surveys (we will refer to the latter as 'HSRC household surveys' for ease of reference) measure stigma by asking respondents about their projected

negative/positive behaviour towards PLWHA, i.e. behavioural intentions. Since the instruments used in these studies are different, results regarding stigma are not strictly comparable. In addition, general conclusions from the studies are mixed. Table 1 presents previous findings on HIV/AIDS-related stigmatizing attitudes, beliefs, and behavioural intentions towards PLWHA in South African studies based on populations of young adults.

Findings presented in Table 1 show that both the DHS and the HSRC household surveys observed low levels of stigma attitudes towards PLWHA among young adults, and that stigma might be falling over time. The instruments used in these studies did not explicitly define stigma but, following Maughan-Brown (2004), we can classify the questions used to probe stigma as falling under 'behavioural intentions to stigmatize'. Maughan-Brown (2004), who conceptualized stigma in terms of its various components (including behavioural intentions, symbolic, and instrumental stigma attitudes), observed that levels of behavioural intentions to stigmatize were generally lower in Cape Town, compared to both instrumental and symbolic stigma attitudes. Maughan-Brown (2010) also used panel data from CAPS to assess changes in stigma over two time periods and observed that there appears to have been a general increase in stigmatizing attitudes (in all components assessed) towards PLWHA between 2003 and 2006. As a result, it appears that while individuals' reported intentions to stigmatize are improving, as indicated from some of the nationally representative surveys, symbolic and instrumental stigma attitudes are not improving – at least as evidenced in the CAPS.

Table 1: Previous findings on HIV/AIDS-related stigma attitudes in South Africa

Reference	Dataset	Age groups	Study design	Definition of stigma	Findings
Kalichman *et al.* (2005)	No particular name	≥15	Cross-sectional	Not specifically defined	10-58% of the overall sample approved various items on stigma attitudes towards PLWHA
Maughan-Brown (2006)	CAPS (2003)	14-25	Cross-sectional	Behavioural intentions	Low levels of behavioural intentions to stigmatize
				Symbolic	Symbolic and instrumental stigma prevalent
				Instrumental	
Maughan-Brown (2010)	CAPS (2003 and 2006)	16-29	Longitudinal	Behavioural intentions	General increase in behavioural intentions to stigmatize between 2003 (2-7%) and 2006 (6-20%)
				Symbolic	General increase in symbolic stigma attitudes between 2003 (29-42%) and 2006 (53-58%)
				Instrumental	General increase in instrumental stigma attitudes between 2003 (20-54%) and 2006 (34-56%)
Department of Health *et al.*(2007)	DHS 2003	15-24	Cross-sectional	Not specifically defined	25.5-86.8% report acceptance towards PLWHA
Shisana *et al*. (2014)	HSRC 2005*	15-24	Cross-sectional	Not specifically defined	74.5-91.0% held positive attitudes towards PLWHA
	HSRC 2008*	15-24	Cross-sectional	Not specifically defined	76.6-92.7% held positive attitudes towards PLWHA
	HSRC 2012*	15-24	Cross-sectional	Not specifically defined	81.9-92.1% held positive attitudes towards PLWHA
					Overall improvement in positive attitudes towards PLWHA

*These are the "South African National HIV Prevalence, Incidence and Behaviour Surveys" conducted by the HSRC in 2005, 2008 and 2012

2.3 HIV/AIDS risk perception

Perceived risk of infection with HIV is a central construct of models of behaviour change, as it is assumed to be a key determinant of sexual behaviour and important in shaping why people might engage in behaviour change from risky sexual behaviour to safer sex (Prohaska, Albrecht, Levy *et al.*, 1990). This is because it is hypothesized in health behaviour theories that individuals who perceive themselves to be at high risk are more likely to adopt protective behaviour (Rosenstock, Strecher and Becker, 1994). Several South African studies that measure perceived risk of infection with HIV/AIDS ask respondents a simple question such as, "In your opinion, how at risk are you of HIV infection?" (e.g. Anderson, Beutel and Maughan-Brown, 2007: 100; Macintyre, Rutenberg, Brown *et al.*, 2004: 242). Measurement of risk perception using such a single item is considered less reliable than using a scale with a number of items (Napper, Fisher and Reynolds, 2012). However, a number of previous South African studies have utilized single item measures of risk perception, rather than scales (e.g. Anderson, Beutel and Maughan-Brown, 2007; Macintyre, Rutenberg, Brown *et al.*, 2004; Tenkorang, Rajulton and Maticka-Tyndale, 2009).

Several previous studies show that more than 80% of young South Africans perceive themselves at no risk or at low risk (relative to moderate risk or high risk) of infection with the HIV virus (see Macintyre, Rutenberg, Brown *et al.*, 2004; Anderson, Beutel and Maughan-Brown, 2007; Fraser-Hurt, Zuma, Njuho *et al.*, 2011). Some of the studies that analysed demographic information found significant gender differences in perceived risk. Females are more likely to perceive themselves at risk of infection with HIV than males (Pettifor, Rees, Steffenson *et al.*, 2004; Shisana, Rehle, Simbayi *et al.*, 2014). In a nationally representative survey conducted in 2012, for example, 5.7% of South African women believed that they were definitely going to get infected with HIV compared to 3.7% of men, with this difference being statistically significant ($p < 0.001$) (Shisana, Rehle, Simbayi *et al.*, 2014: 87-88). The perception of an increased risk of infection with HIV/AIDS among females is argued to be in line with the ultimate measure of infection, where HIV prevalence in South Africa is observed to be higher among women (14.4%) relative to men (9.9%) (Shisana, Rehle, Simbayi *et al.*,

2014: 36). There are also racial differences: Black people are more likely to perceive themselves at risk of infection with HV/AIDS, relative to other racial groups (Coloured, White, and Indian) (Beutel and Anderson, 2013; Shisana, Rehle, Simbayi *et al.*, 2014). A general conclusion drawn from these studies is that most young adults in South Africa perceive themselves to be at a low risk of infection with the HIV virus.

2.4 Risky sexual behaviour

Sexual debut

Entrance into the sexual risk groups for HIV infection is marked by 'sexual debut', that is, the beginning of sexual activity. Obviously in the context of a generalized heterosexual HIV epidemic, individuals who are sexually active are more likely to be infected with the HIV virus than those who have never had sex.

Typical measures of sexual activity among South African youths include whether an individual ever had sex and their age at sexual debut (Eaton, Flisher and Aaro, 2003). Those who engage in sex at an early age increase the number of years of their lives they are at risk of heterosexual HIV infection. UNAIDS further defines "high-risk sex" as sex with non-marital or non-cohabiting partners (Joint United Nations Programme on HIV/AIDS (UNAIDS), 2000). Most young adults who engage in sex at an early age are more likely to fall under the "high-risk sex" category.

Table 2 presents some findings from previous research on indicators of sexual debut and sexual activity among young adults in South Africa. These findings are from the nationally representative South African National HIV Prevalence, Incidence and Behaviour Surveys (Shisana, Rehle, Simbayi *et al.*, 2009; Shisana, Rehle, Simbayi *et al.*, 2014), the CAPS (Camlin and Snow, 2008) and the National Youth Survey (NYS 2003) (Pettifor, Rees, Kleinschmidt *et al.*, 2005). These studies cover the period between 2002 and 2012, with most in the earlier part of the period.

Table 2: Sexual experience amongst young South African adults - various indicators

	HSRC[a] 2002	CAPS[b] 2002	NYS[c] 2003	HSRC[a] 2005	HSRC[a] 2008	HSRC[d] 2012
Ever had sex (14-22)						
Male		43.4%				
Female		42.7%				
First sex at <15 years						
Male	13.1%		17.5%[e]	11.9%	11.3%	16.7%
Female	5.3%		7.8%	5.1%	5.9%	5.0%

Note: HSRC surveys refers to the "South African National HIV Prevalence, Incidence and Behaviour Surveys" conducted by the HSRC in 2002, 2005, 2008 and 2012 for easy of reference.
[a] see Shisana *et al.* (2009)
[b] see Camlin and Snow (2008)
[c] see Pettifor *et al.* (2005)
[d] see Shisana *et al.* (2014)
[e] First sex at ≤14 years for both males and females

Results presented in Table 2 show that nearly half of the CAPS sample aged 14-22 reported having had sex. According to the HSRC household surveys, a consistent proportion of about 10% of the samples of young adults aged 15-24 (reported in 2002, 2005 and 2008) reported having experienced sex before the age of 15 and this proportion increased to 11% for 2012 (Shisana, Rehle, Simbayi *et al.*, 2014: xxxi). These results support findings from other studies suggesting that sexual debut occurs mostly among teenagers in South Africa (Simbayi, Chauveau and Shisana, 2004; Eaton, Flisher and Aaro, 2003). Generally, young men engage in sex at a younger age than women, as evidenced by the proportion who had ever had sex and those who had sex before age 15 (14 or less for the NYS 2003) in Table 2.

Most youth engage in sex before marriage, as the large South African national surveys show that the median age at marriage is greater than the median age at sexual debut (Marteleto, Lam and Ranchhod, 2008: 353). This is further supported by results from the 2003 DHS (Department of Health, Medical Research Council and OrcMacro, 2007) which uses the UNAIDS definition of 'high-risk sex' - sex with non-marital or non-cohabiting partners (Joint United Nations Programme on HIV/AIDS (UNAIDS), 2000). Results from 2003 DHS show that most young adults engage in such high risk sex

(99.1% and 94.6% of young men in the 15-19 and 20-24 age groups respectively and, 94.8% and 84.6% of young women in the 15-19 and 20-24 age groups respectively). Since most young adults have sex in non-committed (non-marital or non-cohabiting) relationships, they are likely to increase their sexual partners – another indicator commonly used for HIV risk.

Multiple sexual partnerships

Multiple sexual partnerships increase the chances of infection with HIV if these are linked to sexual networks that facilitate the transmission of the virus. Table 3 presents previous findings on the prevalence of multiple partnerships (more than one sexual partner in the 12 months preceding each survey) among young South African adults.

Table 3: Sexual partnerships amongst young South African adults

	HSRC[f] 2002	DHS[g] 2003	HSRC[f] 2005	HSRC[f] 2008	HSRC[h] 2012
More than one sexual partner in the last 12 months – males					
15-19		8.2%			
20-24		24.0%			
15-24	23.0%		27.2%	30.8%	37.5%
More than one sexual partner in the last 12 months – females					
15-19		2.9%			
20-24		3.8%			
15-24	8.8%		6.0%	6.0%	8.2%

Note: HSRC surveys refers to the "South African National HIV Prevalence, Incidence and Behaviour Surveys" conducted by the HSRC in 2002, 2005, 2008 and 2012 for easy of reference.

[f] see Shisana *et al.* (2009)

[g] see Department of Health, Medical Research Council and OrcMacro (2007)

[h] see Shisana *et al.* (2014)

Findings in Table 3 show varying proportions of young adults reporting more than one sexual partner in the 12 months preceding the respective surveys, ranging from 8.2-37.5% for young men and 2.9-8.8% for young women in the various age groups. The HSRC household surveys show an increase in the proportion of young men reporting more than one sexual partner in each year preceding each survey. Other indicators include the mean number of sexual partners in the year preceding a particular

survey. The National Youth Survey of 2003 observed a mean of more than one for both young men (mean of 1.8 sexual partners) and women (mean of 1.1 sexual partners) (Pettifor, Rees, Kleinschmidt *et al.*, 2005: 1527).

Condom use

Consistent and correct condom use reduces the chances of HIV transmission through sexual contact. Table 4 presents previous findings on the prevalence of condom use among young people in South Africa.

Table 4: Condom use amongst young South African adults -various indicators

	HSRC[i] 2002	CAPS[j] 2002	NYS[k] 2003	DHS[l] 2003	HSRC[i] 2005	HSRC[i] 2008	HSRC[m] 2012
Condom use at first sex (14-22)							
Male		49.0%					
Female		40.4%					
Condom use at last sex-male							
15-24	57.1%		56.8%		72.8%	85.2%	67.5%
14-22		64.7%					
Condom use at last sex-female							
15-24	46.1%		48.0%		55.7%	66.5%	49.8%
14-22		40.1%					
Condom use at last higher risk in last 12 months - male							
15-19				25.0%			
20-24				27.7%			
Condom use at last higher risk in last 12 months – female							
15-19				49.2%			
20-24				53.0%			

Note: HSRC surveys refers to the "South African National HIV Prevalence, Incidence and Behaviour Surveys" conducted by the HSRC in 2002, 2005, 2008 and 2012 for easy of reference.
[i] see Shisana *et al.* (2009)
[j] see Camlin and Snow (2008)
[k] see Pettifor *et al.* (2005)
[l] see Department of Health, Medical Research Council and OrcMacro (2007)
[m] see Shisana *et al.* (2014)

Results in Table 4 show that nearly half of the CAPS sample who reported ever having had sex did not use a condom at sexual debut (49.0% for males and 40.4% for females from the CAPS sample).

For the CAPS sample, again, the proportion of young adults reporting condom use at last sex is higher than that reporting condom use at first sex. The proportion reporting condom use at last sex ranges from 56.8-85.2% for males and 40.1-66.5% for females (excluding results for DHS 2003). For the DHS 2003, the proportion reporting condom use at last high-risk sex is even lower, with about a quarter of young man and about half of young women reporting having used a condom.

Results presented in Tables 2-4 demonstrate that significant numbers of young South Africans are probably at risk of infection with HIV/AIDS through engaging in sex at a young age with many partners and not using condoms consistently or at all.

2.5 Theorized relationships between HIV/AIDS-related stigma, HIV/AIDS risk perception, and risky sexual behaviour

2.5.1 HIV/AIDS-related stigma and risk perception

The preceding sections on stigma have discussed how instrumental stigma promotes physical distancing of an individual from those infected or perceived to be infected with HIV. Symbolic stigma will lead individuals to distance themselves psychologically from 'out groups' perceived to be associated with HIV infection. This psychological distancing from risk functions to control fear and anxiety, albeit by providing a false sense of security (Stein, 2003: 98). As a result, individuals who hold negative symbolic attitudes perceive HIV/AIDS as a disease of certain 'out-groups' and are therefore more likely to perceive themselves as being safe and not vulnerable to HIV infection. A further implication is that individuals who hold symbolically stigmatizing attitudes may not practice safe sex with 'in group' members whom they also perceive as safe from HIV infection (Deacon, Stephney and Prosalendis, 2005). This, of course, exposes them to risk of infection.

In the case of instrumental stigma, it is possible for stigmatizing individuals to protect themselves from HIV infection by avoiding contact with PLWHA. Different types of stigma thus have different implications for behaviour and possibly also for perceived and actual risk of HIV infection.

2.5.2 Risk perception and sexual behaviour

The relationship between risk perception and sexual behaviour is difficult to conceptualize. There are two broad theories about the relationship: (a) the behaviour motivation hypothesis (self-perceived risk leads to protective action); and (b) the risk reappraisal hypothesis (current self-perceived risk is a reflection of current or past risk or protective behaviour) (see Brewer, Weinstein, Cuite *et al.*, 2004; Gerrard, Gibbons and Bushman, 1996).

Behaviour motivation hypothesis

The 'behaviour motivation hypothesis' assumes that an increased perception of risk today leads to preventative behaviour in the future (see Gerrard, Gibbons and Bushman, 1996). Risk perception is thus assumed to be the cause of behaviour change. In order to test this hypothesis, one needs to measure risk perception at one point in time and behaviour at a future time (Brewer, Weinstein, Cuite *et al.*, 2004). Using cross-sectional rather than panel data is less than ideal because it amounts to predicting variability in past behaviour based on currently held perceptions. Furthermore, using cross-sectional data to test hypotheses which require temporal precedence of the variables usually leads to overestimation of the relationship between model variables and behaviour outcomes (Bryan, Schmiege and Broaddus, 2007: 368).

Table 5 presents results from previous research, using the CAPS sample, on the relationship between perceived risk of infection with HIV and risky sexual behaviour among youths in Cape Town. The sexual risk behaviour outcomes assessed include: Cross-sectional data analysis of whether an

individual reported having had sex (Anderson, Beutel and Maughan-Brown, 2007), survival analysis of age at first sex using longitudinal data (Tenkorang, Rajulton and Maticka-Tyndale, 2009) and 'sexual risk-taking' (Tenkorang, 2013; Tenkorang, Maticka-Tyndale and Rajulton, 2011). The 'sexual risk-taking' variable used in Tenkorang (2013: 130) and Tenkorang, *et al.* (2011: 527) is derived from CAPS data on youth who reported not having had sex in Wave 1 (in 2002) but could have experienced sex before Wave 3 (2005). An ordinal variable is then derived where the "no-risk" category includes individuals who had still not had sex by Wave 3, and the "low-risk" category includes individuals who have had sex by wave 3, who reported condom use at both first and last sexual intercourse, and had sex with only one sexual partner in the 12 months preceding the wave 3 survey. The "high-risk" category includes all respondents who reported not having used a condom at first and last sexual encounter, plus those who reported having more than one sexual partner in the 12 months preceding wave 3, even though they used a condom at both first and last sexual intercourse (see Tenkorang, 2013; Tenkorang, Maticka-Tyndale and Rajulton, 2011). Generally, it is observed that perceived risk of infection with HIV is associated with delays in sexual debut and reports of consistent condom use (Tenkorang, Rajulton and Maticka-Tyndale, 2009; Anderson, Beutel and Maughan-Brown, 2007; Tenkorang, Maticka-Tyndale and Rajulton, 2011; Tenkorang, 2013).

Risk reappraisal hypothesis

The 'risk reappraisal hypothesis' assumes that taking an action believed to reduce the risk of contracting a disease leads to decreased self-perceived risk for the disease (see Gerrard, Gibbons and Bushman, 1996). Similar to the behaviour motivation hypothesis, testing this hypothesis also ideally requires longitudinal data (Brewer, Weinstein, Cuite *et al.*, 2004). Previous studies that tested the risk reappraisal hypothesis using longitudinal data from the CAPS sample (see Table 5) found that those who have been sexually active or with sexual experience are likely to perceive themselves as at greater risk of contracting HIV/AIDS (Beutel and Anderson, 2013; Anderson, Beutel and Maughan-Brown, 2007). In other words, youth in the CAPS sample who were not sexually active or had no sexual experience perceive their risk of infection with HIV to be low.

Table 5: Previous findings on the relationships between risk perception and various sexual risk behaviour indicators

Reference	Dataset	Methodology	Outcome	Findings
Anderson *et al*. (2007)	CAPS	Longitudinal	sexual debut	Reciprocal relationship:
			risk perception	High perceived risk of infection associated with delay in sexual debut
				Sexual experience associated with higher perceived risk
Tenkorang *et al.* (2009)	CAPS	Longitudinal	sexual debut	Perceived risk of infection associated with delay in sexual debut
Tenkorang *et al.* (2011)	CAPS	Longitudinal	sexual risk-taking	Perception of high risk associated with less sexual risk behaviour
Beutel and Anderson (2013)	CAPS	Longitudinal	risk perception	Those sexually active perceive an increase in their risk of infection
				Condom use at last sex associated with increases in risk perception
Tenkorang (2013)	CAPS	Longitudinal	sexual risk taking	Perception of high risk associated with less risky sexual behaviour

Other variables of interest

Health behaviour theories propose that knowledge about the risk in question is one modifying factor for risk perception and behaviour change. In the particular context of HIV/AIDS, knowledge is considered to create awareness such that the greater the knowledge individuals have about safer sex, the more likely they are to practice safer sex (King, 1999; Noar, 2007: 395). Personal knowledge of someone with HIV/AIDS is also argued to influence risk perception, as individuals witness a person ill with AIDS and thus presumably adopt safer sexual behaviours (Macintyre, Rutenberg, Brown *et al.*, 2004: 239). These variables will therefore be included in the analysis.

2.6 Background summary

The preceding review demonstrates a general picture of stigmatizing attitudes of South African youths towards PLWHA, self-perceived risk of infection with HIV, and HIV-related sexual risk behaviours. Some of the studies indicated that South African youths are becoming more accepting of PLWHA by reporting lower levels of stigma, measured in terms of behavioural intentions, while other studies found an increase in other aspects of stigma, such as moral blaming of those infected (symbolic stigma) and avoiding contact with PLWHA for fear of infection (instrumental stigma).

The review above also demonstrates that South African youths perceive themselves being at low risk of infection with HIV. Some of the studies found that young women are more likely to perceive themselves at risk of infection with HIV than young men, and this is in line with the higher HIV prevalence observed among women.

Findings for risky sexual behaviour show that some South African youths are putting themselves at risk of infection with HIV/AIDS through engagement in sex at a young age, with many partners, and not using condoms consistently, or not using them at all. There are also gender differences in the risky

sexual behaviours: A higher proportion of young men are engaging in sex at a young age with many partners, relative to their female counterparts. In addition, a larger proportion of young men are reporting condom use relative to young women.

3 HIV/AIDS-related stigma, disclosure, psychological distress, and risky sexual behaviour among PLWHA

AIDS policy in South Africa during the 2000s was infamous for the AIDS denialism of President Mbeki and resistance on the part of his health minister to providing HAART in the public health sector (Nattrass, 2007). The only places where PLWHA could access HAART were in the private sector or in demonstration projects run by non-governmental organizations, such as Médecins Sans Frontières (MSF) in Khayelitsha. However, after a successful campaign by civil society activists, HAART became more widely available after 2004 (Nattrass, 2007). Between then and 2008 the number of people on HAART rose dramatically (see Adam and Johnson, 2009: 663). HIV-testing programmes also increased, suggesting that the number of PLWHA who were aware of their seropositive status also increased. The *South African National HIV Prevalence, Incidence and Behaviour Surveys* (2002, 2005, 2008, 2012) indicates that the proportion of people testing for HIV continued to increase because the proportion of people who tested for HIV in the 12 months preceding the survey in 2012 was significantly higher than that reported in the 2008 survey (Shisana, Rehle, Simbayi *et al.*, 2014: 85).

The increasing HAART uptake probably contributed to increased opportunities for HIV prevention. Not only does HAART help reduce new HIV infections by lowering the viral load of patients, but a HAART rollout might also contribute to greater AIDS awareness and condom use. Some studies have observed higher condom use among PLWHA attending clinics than in the wider South African population (Lurie, Pronyk, de Moor *et al.*, 2008: 490). However, others point to continued risky sexual behavior by PLWHA who are aware of their seropositive status (Kalichman, Simbayi and Cain, 2010; Shuper, Kiene, Mahlase *et al.*, 2014).

The *South African National HIV Prevalence, Incidence and Behaviour Survey* that was conducted in 2012 estimated that 12.2% of South Africans (about 6.4 million people) were HIV-positive (Shisana,

Rehle, Simbayi *et al.*, 2014: 108). Given that South Africa's HIV epidemic is driven primarily by heterosexual contact, it is of grave concern that only an estimated 37.8% of HIV-positive males and 55.0% of HIV-positive women in South Africa at the time knew their seropositive status (Shisana, Rehle, Simbayi *et al.*, 2014: 86). Furthermore, some studies found that most PLWHA remained sexually active after learning about their HIV status, and many engaged in unprotected sex (Kiene, Christie, Cornman *et al.*, 2006; Olley, Seedat, Gxamza *et al.*, 2005). In addition to infecting others, unsafe sexual practices are potentially harmful also for PLWHA, who are at risk of re-infection with a new strain of the virus.

Due to the effectiveness of HAART, PLWHA who start antiretroviral treatment early and who adhere to treatment drugs are now living longer lives (see Bor, Herbst, Newell *et al.*, 2013; Lima, Harrigan, Bangsberg *et al.*, 2009; Johnson, Mossong, Dorrington *et al.*, 2013; Nakagawa, Lodwick, Smith *et al.*, 2012). The improved longevity of PLWHA, together with new HIV infections, has given rise to an increasing number of PLWHA (Zaidi, Grapsa, Tanser *et al.*, 2012). Understanding the sexual behaviour of PLWHA is thus an increasingly important research area, especially with regard to understanding the factors contributing to unsafe sexual practices by HIV-positive people who are aware of their HIV status. Such information is important for the design of HIV prevention programmes.

HIV/AIDS-related stigma is often assumed to be one of the factors contributing to risky sexual behaviour on the part of PLWHA. For example, a number of South African studies observed that fear of HIV/AIDS-related stigma among PLWHA is associated with non-disclosure of HIV-status to sexual partners (e.g. Cloete, Strebel, Simbayi *et al.*, 2010). Non-disclosure of HIV status, in turn, is associated with unprotected sex, a risk behaviour for HIV transmission (e.g. Simbayi, Kalichman, Strebel *et al.*, 2007b; Eisele, Mathews, Chopra *et al.*, 2008). Such studies support the hypothesis that some HIV-seropositive persons may not disclose their sero-status to a sexual partner in order to avoid potentially negative consequences, such as being stigmatized. They might also not initiate condom use

for fear of causing suspicion about their HIV status. In this reasoning, disclosure of one's seropositive status is assumed to give the other partner options to take precautionary measures like negotiating condom use or abstinence to avoid HIV infection. Hence disclosure is assumed to be important in encouraging behaviour leading to lower risk of HIV infection.

Some international studies hypothesize that stigma among PLWHA is associated with negative psychological outcomes (for example, depression) which in turn is associated with the general tendency to engage in risk behaviour, that includes sexual risk (Clum, Chung, Ellen *et al.*, 2009). This is hypothesized to occur, for example, when PLWHA try to escape from negative self-awareness thoughts (that are characteristic of internalized stigma) that lead to psychological distress/depression, by engaging in risk behaviour such as unprotected sex (Clum, Chung, Ellen *et al.*, 2009). Increased levels of negative psychological outcomes among PLWHA may also be a result of this group receiving less social support than they need. In such cases, PLWHA may be getting limited social support for a number of reasons, including the experience of symbolic or instrumental stigma following their disclosure, and lack of support as a result of not disclosing their status, because people are not aware of the additional psychological and/or physical assistance they might need (Stutterheim, Bos, Pryor *et al.*, 2011). This is one example of the complex relationship between stigma, disclosure, psychological distress, and risky sexual behaviour among PLWHA.

To add to the complexity, constructs of stigma and disclosure are social processes occurring within specific contexts, and are continuously redefined by changing understandings of HIV/AIDS and treatment options. In addition, even if PLWHA overcome barriers of disclosure (mainly due to fear of stigma) to sex partners, they may continue to have unprotected sex because of a number of factors as will be discussed in sections to follow.

Quantitative studies that explore the connection between HIV/AIDS-related stigma and unprotected sex are based mainly on studies from developed countries. Some studies investigate this relationship

for both men and women (e.g. Vanable, Carey, Blair *et al.*, 2006) and others examine samples of men who have sex with men (Hatzenbuehler, O'Cleirigh, Mayer *et al.*, 2011; Courtenay-Quirk, Wolitski, Parsons *et al.*, 2006). In addition, where this relationship has been tested, results have been generally mixed. Some of the studies found HIV/AIDS-related stigma on the part of PLWHA to be associated with risky sexual behaviour (e.g. Hatzenbuehler, O'Cleirigh, Mayer *et al.*, 2011) and other studies found no association (e.g. Vanable, Carey, Blair *et al.*, 2006; Courtenay-Quirk, Wolitski, Parsons *et al.*, 2006). A recent study in South Africa found HIV/AIDS-related stigma to be associated with greater chances of unprotected sex (Earnshaw, Smith, Shuper *et al.*, 2014).

Our study tests some of the mechanisms by which HIV/AIDS-related stigma may influence risky sexual behaviour among PLWHA. To test these relationships, data were used from the Khayelitsha HAART Panel Study (KHPS)[3], a longitudinal study that collected data from people on HAART living in Khayelitsha (a township in Cape Town, South Africa). The data were collected in three waves, from 2004 to 2007, and comprise information about work, living arrangements, health, and sexual relationships. The main variables of interest include: Experience of stigma, perceptions of stigma, symptoms of depression and anxiety, disclosure of HIV status to a sexual partner, and the related risky sexual behaviours for HIV infection (being sexually active, and non-condom use). The following sections discuss these variables and develop a set of hypotheses as to how they may relate to each other.

3.1 HIV/AIDS-related stigma in the context of PLWHA

Chapter 2, together with the preceding section, provides a review of the stigma concept in general and how it is operationalised and researched in the general population. This section focuses on experiences of stigma on the part of PLWHA themselves. The literature usually distinguishes between:

[3] More details about this study are provided in Chapter 6

Experienced stigma (i.e. arising out from 'enacted stigma' on the part of stigmatizers), internalized stigma, and perceived stigma (see Nyblade, 2006; Maughan-Brown, 2008). Before we discuss each of these stigma dimensions, we first look at some distinctions between stigma bearers in relation to any social interaction, as suggested by Goffman (1963), and this helps us understand some of the contexts in which each of the stigma dimensions is constructed.

3.1.1 Discreditable and discredited

Goffman (1963: 41-42) distinguishes between people who are *discredited* - whose stigmatizing condition is apparent to others - and people who are *discreditable* - whose stigmatizing condition is not readily apparent or known to others beforehand. Discredited individuals must work to draw attention away from the stigmatizing conditions and as a result, management of tension in their social encounters is critical (Goffman, 1963: 41-42). The tension reducing techniques that are employed include deflection, for example, through humour or being cheerful in trying to normalize the interaction (Berger, Ferrans and Lashley, 2001: 520).

As opposed to the *discredited* person, the *discreditable* person has the opportunity and responsibility to manage the undisclosed discrediting information by judging how, to whom and where to disclose. Since people with a discreditable condition are wary of their condition being discovered, they may employ strategies by which they present themselves as "normal" (Goffman, 1963: 41-45). In the case of HIV, where the symptoms are not apparent to others, particularly during the early stages of the disease, or because of improved health due to HAART, PLWHA who are aware of their serostatus have the opportunity to choose whether to disclose or not. Individuals who have *discreditable* HIV/AIDS may employ strategies that include non-disclosure (concealment) or partial disclosure (controlling which people get to know about their HIV status) and avoidance or withdrawing from potentially awkward social interactions (Berger, Ferrans and Lashley, 2001: 520). However, when information is not handled tactfully and confidentially by the stigma bearers or their trusted

colleagues, a *discreditable* person can become *discredited* if their stigmatized condition becomes known to others.

3.1.2 Experienced stigma from enacted stigma

Scambler and Hopkins (1986) introduced a distinction between 'enacted' and 'felt' stigma in their work on stigma associated with epilepsy. Felt stigma has been referred to as the fear of being discriminated against, or the acceptance of shame associated with the potentially stigmatizing condition (see following sections on internalized and perceived stigma). This section reviews experienced stigma, which refers to actual experiences of discrimination because of possession of a devalued attribute (Scambler and Hopkins, 1986; Scambler, 1998). The stigmatized individual's status in society is reduced, and they face reduced life chances and opportunities, through discrimination, as they are considered inferior and are considered by discriminators to represent a danger to society (Goffman, 1963; Link and Phelan, 2001).

In the case of HIV/AIDS, stigmatizers 'enact' their attitudes through discrimination and other overt expressions of prejudice. These include refusal to touch PLWHA, negative comments and expressed attitudes, and through subtle cues that discredit and marginalize PLWHA in social settings. As discussed previously, international research has distinguished between different categories of stigma on the part of stigmatizers, notably instrumental stigma (born out of fear of infection) and symbolic stigma arising out of more damning attitudes towards certain groups of people (see Chapter 2). But whatever the motivation, PLWHA experience the stigma as psychologically and socially harmful. For the stigmatized, experienced stigma is the real experience of prejudice, stereotyping, and discrimination from others in the society (Scambler and Hopkins, 1986; Scambler, 1998).

South African research into experienced stigma and discrimination of PLWHA highlights social isolation (Cloete, Simbayi, Kalichman *et al.*, 2008), losing a job, or a place to stay (Cloete, Simbayi, Kalichman *et al.*, 2008; Simbayi, Kalichman, Strebel *et al.*, 2007b; Kohi, Makoae, Chirwa *et al.*, 2006), and exclusion from schooling and the military, physical and verbal abuse, rape, and murder (see Skinner and Mfecane, 2004). These experiences of stigma and discrimination occur in various contexts of social interaction between individuals. These include the family, the community, or institutions such as the workplace, religious groupings, school, or health care settings.

3.1.2.1 *Some contexts of stigma and discrimination in South Africa*

Family setting

A study based on three South African communities in Khayelitsha, Gugulethu, and Mitchell's Plain observed forms of discrimination experienced by PLWHA from family members. These include: Family members refusing to eat food prepared by PLWHA, or preventing them from preparing food and refusal to share or separate eating utensils (Okoror, Airhihenbuwa, Zungu *et al.*, 2007: 6-7). In another community, in Thulamela Municipality in the Vhembe District of Limpopo Province, family members did not want to touch the baby of a family member living with HIV/AIDS, some HIV positive family members have even been denied food and expelled from their home (Ndou, Risenga and Maputle, 2013: 126) though this appears to be the exception rather than the rule. In some cases, partners have been divorced because of their HIV status (Ndou, Risenga and Maputle, 2013: 126) and, in worst cases, murdered by their partners who learned of their HIV status. For example, Mpho Motloung, a young female teacher from Soweto, was shot dead by her husband (also a teacher from Soweto), who then killed himself. On her body was the note: "HIV positive Aids" (Treatment Action Campaign, 2000) and the shooting is suspected to be related to Mpho's HIV status.

Community setting

South Africa has witnessed some of the worst cases of discrimination in which PLWHA are murdered by members of their community because of their HIV status. Examples include the murders of Gugu Dlamini (see Baleta, 1999) and Lorna Mlofana (see Skinner and Mfecane, 2004) by members of their respective communities, after disclosing their HIV status. Gugu Dlamini, an activist, was beaten, stabbed and stoned to death by a group of men from her home township of KwaMancinza (in eastern KwaZulu-Natal province) for disclosing her HIV status to the public on radio and national television (Baleta, 1999). Lorna Mlofana was a female member of the Treatment Action Campaign (TAC) from Khayelitsha, South Africa. She was raped, and then murdered after she told the men who raped her that she was HIV positive (Skinner and Mfecane, 2004: 160).

PLWHA are also isolated by their communities, as reported in another South African study. This study revealed that HIV positive women were not allowed to cut vegetables for cooking at gatherings, and members of the community refused to buy from a spaza shop owned by an HIV positive person (Ndou, Risenga and Maputle, 2013: 128).

Other settings

Other contexts of HIV/AIDS-related stigma and discrimination reported in South African studies include health care settings, workplaces, religious groupings, and school settings. It is reported that, in Kwazulu-Natal senior healthcare practitioners divert patients diagnosed as HIV positive to less experienced health care workers (Famoroti, Fernandes and Chima, 2013: 6). There are also instances of PLWHA who lost their jobs because of their HIV status, as reported in a Cape Town study (see Cloete, Simbayi, Kalichman *et al.*, 2008). Acts of HIV/AIDS-related stigma can also happen within religious groupings, for example, church members avoiding shaking hands with PLWHA after church services, as reported in a sample of PLWHA in Khayelitsha, Cape Town (see Rohleder and Gibson, 2006: 32). Children in schools can also be subject to stigma and discrimination. It has been reported

that some HIV positive children in the East Rand, Gauteng, were expelled from school or excluded from sporting activities (see Kheswa, 2014: 536).

3.1.2.2 *The discredited and enacted stigma*

In order for PLWHA to experience enacted stigma from the general population, the stigmatizers have to know the bearer's stigmatized HIV status. Therefore, it is the discredited individuals who are likely to experience enacted stigma and discrimination as they are more easily identified (Chaudoir, Earnshaw and Andel, 2013). A number of previous studies looked at how people experience stigma when they disclose their HIV status to a few selected individuals (limited disclosure), individuals who could conceal but chose to be open about their HIV status (full disclosure) and individuals who have visible symptoms of HIV/AIDS (visibly stigmatized). A study based on a sample of PLWHA living in the developed world observed that those who chose to be open and those with visible symptoms of HIV/AIDS report experiencing more stigma than the limited disclosers (Stutterheim, Bos, Pryor *et al.*, 2011).

An important South African study that looks at different levels of disclosure is that of Almeleh (2006; 2012), and we discuss this in greater length later. Both quantitative and qualitative studies based on samples of PLWHA living in Khayelitsha, Cape Town observe that experienced stigma is mostly a consequence of visibly poor health, or assumed HIV/AIDS symptoms (Maughan-Brown, 2007: 28; Okoror, BeLue, Zungu *et al.*, 2014: 39; Almeleh, 2012: 84). Therefore, the real or perceived health status of PLWHA plays an important role in how they experience stigma. The visible symptoms of AIDS motivate discrimination, based on exaggerated fear of infection through contact. However, stigma as it affects PLWHA is not only linked to visible symptoms of HIV/AIDS or a result of disclosure of one's HIV status. There are other forms of stigma that affect individuals with both visible and concealable HIV/AIDS.

3.1.3 Internalized stigma

People living with HIV/AIDS may also feel guilty and ashamed of their HIV status, thereby accepting the negative social judgements encapsulated in AIDS stigma. Acceptance of negative designations and negative attitudes by PLWHA is known as the internalization of stigma (Fife and Wright, 2000; Berger, Ferrans and Lashley, 2001; Lee, Kochman and Sikkema, 2002). PLWHA may internalize stigma after experiences of enacted stigma, or if their social environment denigrates or discriminates against people like them. Internalized stigma then occurs when an individual assumes the "spoiled identity" of their condition, believed in by their society. Even individuals who are not exposed to overt acts of discrimination may internalize stigma. This occurs when these individuals internalize stigmatizing attitudes they used to hold for others with the condition before they became ill themselves. Rohleder and Gibson (2006: 33) found that some women from Cape Town who were living with HIV had incorporated the 'deviant' identity they previously attached to PWHLA as part of their self-identity.

Some scholars have conceptualized internalized stigma as the "product of internalization of shame, blame, hopelessness, guilt, and fear of discrimination associated with being HIV-positive" (Brouard and Wills, 2006: 1). As a result, some quantitative studies have attempted to measure internalized stigma by asking questions that probe some of the related topics of shame and self-blameworthiness for being HIV positive (e.g. Berger, Ferrans and Lashley, 2001; Fife and Wright, 2000; Lee, Kochman and Sikkema, 2002). In a study based on a sample of PLWHA in Cape Town (South Africa), more than a third of the sample reported feeling dirty, ashamed, or guilty, because of their HIV status (Simbayi, Kalichman, Strebel *et al.*, 2007a: 1826). Another study of PLWHA living in Khayelitsha, using data that will be utilised also in our study, observed varying degrees of internalized stigma, with shame being the most frequent (expressed by about 50% of respondents) dimension of internalized stigma (Maughan-Brown, 2008: 216). Cloete, *et al.*(2008: 1106) also observed internalized stigma among a sample of PLWHA in Cape Town, where respondents did not disclose their HIV status to

others (57% of the sample) , felt guilty (47% of the sample) and felt ashamed (43% of the sample) of being HIV-positive. Evidence of HIV/AIDS–related internalized stigma reported in broader South African studies include PLWHA isolating themselves from friends and family, or from social gatherings (dos Santos, Kruger, Mellors *et al.*, 2014: 6). Other studies argue that PLWHA internalize the negative markers of HIV/AIDS (such as guilt, shame, self-blaming) even more than may be exhibited towards them by society (Simbayi, Kalichman, Strebel *et al.*, 2007a: 1829).

Internalized stigma is psychologically damaging and is linked to a number of negative mental health factors that includes increased distress (often measured as depression symptoms), anxiety, and feelings of hopelessness (Clum, Chung, Ellen *et al.*, 2009; Lee, Kochman and Sikkema, 2002; Simbayi, Kalichman, Strebel *et al.*, 2007a; Mak, Cheung, Law *et al.*, 2007). Herek, *et al.* (2013: 48) argue that the poor self-image that characterises internalized stigma has a deleterious effect on self-esteem and that leads to negative psychological outcomes, such as depression and anxiety. Simbayi, *et al.*(2007a), for example, found that internalized stigma, assessed in a sample of PLWHA in Cape Town, was associated with signs of cognitive–affective depression (measured using items from the Centers for Epidemiological Studies Depression Scale (CES-D) (Radloff and Locke, 1986)). Internalized stigma is also associated with low levels of social support and destructive coping strategies (e.g. drug use). For example, internalized stigma is found to be associated with self-isolation (e.g. dos Santos, Kruger, Mellors *et al.*, 2014: 9) and isolation is argued to undermine social support for PLWHA possibly as a result of decreased social integration (Earnshaw and Kalichman, 2013). A study based on a sample of homeless/unstably housed PLWHA in the US found internalized stigma to be associated with drug use (Wolitski, Pals, Kidder *et al.*, 2009). It is argued from the same study that the drug use may be used as a coping strategy to overcome feelings of shame and guilt associated with being HIV positive.

Also highlighted in the preceding sections is that internalized stigma discourages disclosure of the stigmatizing condition (see also Wolitski, Pals, Kidder *et al.*, 2009). Studies of US samples of lesbian, gay and bisexual respondents (discreditable or concealable stigma) and African-American respondents (discredited or visible stigma) found that *discreditable* individuals in general demonstrate greater internalized stigma than *discredited* individuals (Chaudoir, Earnshaw and Andel, 2013; Cook, Arrow and Malle, 2011; Hatzenbuehler, Nolen-Hoeksema and Dovidio, 2009). This suggests that discreditable individuals who internalize stigma are less likely to disclose their HIV status because they fear discrimination. Internalized stigma is argued to reinforce and legitimize society's prejudiced beliefs about stigmatized conditions (see Brouard and Wills, 2006; Morrison, 2006). In short, failure to disclose appears to be the result of a complex and dynamic relationship between internalized stigma and perceptions of stigma in the broader society.

3.1.4 Perceived stigma or anticipated stigma

Perceived stigma among PLWHA refers to the individual's perception of being stigmatized, and the likelihood of being stigmatized, by society (Fife and Wright, 2000; Berger, Ferrans and Lashley, 2001). Two factors are relevant: Their perception of general social attitudes and behaviours that devalue and discriminate against PLWHA in society, and their fears and expectations about how they personally will be treated by people who find out about their HIV status (Berger, Ferrans and Lashley, 2001; Nyblade, 2006). With regard to the first factor, a person living with HIV/AIDS may not have personally experienced stigma but still believe that the social context of PLWHA is stigmatizing, based on other people's experiences of stigma (Maughan-Brown, 2008: 213). Perceptions of stigma are also likely to be influenced by how individuals accept a stigmatized role. This is based on the argument that individuals who have internalized stigma are also likely to have perceptions of being stigmatized by society (Earnshaw and Kalichman, 2013: 33).

International literature suggests that levels of stigma perceived by PLWHA are generally higher than levels of experienced stigma or discrimination (Bogart, Cowgill, Kennedy *et al.*, 2008; Clark, Lindner, Armistead *et al.*, 2004; Green, 1995). This is because in addition to experiencing stigma, perceptions of stigmatization are influenced by both the experience of stigma, and coverage of the stigmatized states in the media (Deacon, Stephney and Prosalendis, 2005). For example, one study in the US examined the interconnectedness of stigma experiences within the family where the parents are HIV positive. This study observed that fears of discrimination (among HIV positive mothers (96%), HIV positive fathers (89%) and their families (97%)) were out of proportion to actual experiences of discrimination (HIV positive mothers (79%), fathers (67%) and families (79%)) (Bogart, Cowgill, Kennedy *et al.*, 2008: 248). Another study, based on a sample of people living in Scotland (Glasgow and Edinburgh), examined attitudes of both the general public and PLWHA. The study observed that PLWHA perceived less liberal attitudes towards PLWHA by the general public than were reported by the general public (Green, 1995). It can be argued that such differences may also be attributed to covert acts of stigma and discrimination that are not covered in typical surveys. This may result in an underestimate of the levels of enacted stigma, especially if asked from the perspective of stigmatizers (Maughan-Brown, 2008: 160). Another example is that of PLWHA who perceived that they were being stigmatized and treated differently at some health care centres in Gugulethu and Khayelitsha because their clinic files had a different colour coding or they had different waiting rooms (see Okoror, BeLue, Zungu *et al.*, 2014: 38). In this example, the colour coding might be a common practice that serves as an efficient filing process even for non-stigmatized conditions, but presents a problem for stigmatized conditions. As a result, the color coding used in the filing process can possibly lead to perceptions of being stigmatized among PLWHA. When such PLWHA are interviewed in a survey, their reported experiences of being stigmatized could possibly be greater than their actual experiences of stigma and discrimination.

Chaudoir, *et al.* (2013: 77) argue that there is no difference in the way perceived stigma affects *discredited* and the *discreditable* individuals. This is possibly a result of the generalized stigmatization beliefs and vulnerability of PLWHA, regardless of whether their status is apparent to others or not.

The international literature suggests that expectation of possible prejudice and discrimination from others discourages PLWHA from disclosing their HIV sero-status to others (e.g. Clark, Lindner, Armistead *et al.*, 2004; Derlega, Winstead, Greene *et al.*, 2004). For example, Clark, *et al.* (2004) found that increased perceptions of stigma in HIV-positive African-American women in the US was associated with not disclosing their HIV status to family and friends. This non-disclosure of HIV status is argued to have a number of consequences in the life of PLWHA. These include missing out on opportunities for social support, increased isolation and anxiety, and not taking measures to introduce safe sex practices (Chesney and Smith, 1999). Participants in some qualitative studies based on South African samples also reported that fear of negative reactions, such as rejection or violence, deter them from disclosing their HIV status to certain audiences (Almeleh, 2006; Almeleh, 2012; Mills and Maughan-Brown, 2009).

Perceived stigma is also associated with poor psychological well-being of stigmatized people. This has been attributed to difficulties PLWHA experience in coping with their discredited identity, which can lead to poor psychological health, for example, increased distress, depression, and generalized anxiety disorders (Clark, Lindner, Armistead *et al.*, 2004; Earnshaw and Chaudoir, 2009; Emlet, 2007; Varni, Miller, McCuin *et al.*, 2012). Clark, *et al.*(2004) find that increased perceptions of stigma in HIV-positive African-American women in the US are associated with poorer psychological functioning. Another study of US adults aged fifty-plus living with HIV/AIDS found that individuals who perceived negative public attitudes towards PLWHA reported more depressed moods than those who did not (Emlet, 2007). This relationship is also found in a sample of young adults (aged 16-25) in the US living with HIV/AIDS (Wright, Naar-King, Lam *et al.*, 2007). The study found that perceived

negative reactions of others to their HIV status are associated with symptoms of depression and anxiety in PLWHA.

Perceived stigma is also associated with delayed seeking of HIV treatment and non-adherence to HIV treatment (Chesney and Smith, 1999; Wasti, Simkhada, Randall *et al.*, 2012; Wolitski, Pals, Kidder *et al.*, 2009). For example, a study based on a sample of homeless/unstably housed PLWHA in the US found that those who had higher perceptions of being stigmatized were more likely to miss taking their pills for HIV treatment (Wolitski, Pals, Kidder *et al.*, 2009). Another study of a sample of people in Nepal on HAART also identified fear of stigma from the wider community as hindering the adherence of this sample to treatment (Wasti, Simkhada, Randall *et al.*, 2012).

Experienced stigma, internalized stigma and perceived stigma, while analytically distinct, are nevertheless related. For example, Maughan-Brown (2007) found that internalized stigma and perception of stigma amongst PLWHA in Cape Town are both positively related to experiences of stigma. A similar argument is also proposed for internalized stigma in that individuals who view themselves negatively because of their HIV status might also perceive others to view them in stigmatizing ways (Earnshaw and Kalichman, 2013: 33).

3.2 The stigmatized: Psychological distress, HIV status disclosure and risky sexual behaviour

Previous research indicates that disclosure of one's HIV positive status to potential sex partners has important implications for reducing the spread of HIV (Pinkerton and Galletly, 2007). This is because potential sex partners may decline to have sex with a known HIV positive person or disclosure may create opportunities for both partners to negotiate and make informed decisions related to their sexual interaction. For example, sex partners can agree to adopt condom use after one has disclosed their

HIV status, thereby reducing risk of HIV infection (Pinkerton and Galletly, 2007: 698). However, PLWHA may not disclose their HIV sero-status to sexual partners for a number of reasons. These include: Fear of discrimination (e.g. rejection, abandonment, or even physical violence), breaches of confidentiality or loss of privacy, loss of social support, and missed sexual opportunities (Benotsch, Rodrı´guez, Hood *et al.*, 2012). Even if people overcome barriers to disclosure, meta-analytic studies found inconsistent relationships between HIV status disclosure to sexual partners and adoption of safer sexual practices (Simoni and Pantalone, 2004). Other studies found that non-disclosure is not necessarily associated with risky sexual behaviour. For example, a sample of HIV positive men in the US who had not disclosed their HIV positive status to sexual partners revealed that these men did practice safer sex (Crepaz and Marks, 2003: 384-385). This is argued to be a result of their own sense of responsibility to protect themselves and their sex partners from HIV infection. The focus on disclosure in our study is important, as it is key to the relationship between stigma and risky sexual behaviour.

3.2.1 Definition of disclosure

Previous studies identify different forms of disclosure, which include: 'voluntary disclosure' – disclosure without coercion and 'involuntary disclosure' – disclosure without an individual's approval or intent (Sandelowski, Lambe and Barroso, 2004; Varga, Sherman and Jones, 2006; Chandra, Deepthivarma and Manjula, 2003). From these studies, voluntary disclosure is 'managed disclosure', where individuals have control over decisions to disclose (Sandelowski, Lambe and Barroso, 2004; Varga, Sherman and Jones, 2006). Individuals who voluntarily disclose have choices to make that include: 'full disclosure' – naming and giving more details about HIV status, for example, and revealing how one might have got infected with HIV, 'partial disclosure' – giving some information about one's illness, for example, without naming "HIV" in the disclosure process and 'concealment' – involves passing as normal, lying, keeping silent, or finding a way not to disclose (Sandelowski, Lambe and Barroso, 2004: 126-127). In the disclosure process, information is also expressed in

various forms, which include: 'direct' – straightforward disclosure and 'proxy' – stage setting or suggestive disclosure (Varga, Sherman and Jones, 2006: 953).

'Involuntary disclosure' is 'mismanaged disclosure' where individuals lose control of disclosure decisions (Sandelowski, Lambe and Barroso, 2004; Varga, Sherman and Jones, 2006). In involuntary disclosure, one individual may disclose another individual's status without their consent or disclosure may occur through visible symptoms of HIV/AIDS (e.g. skin lesions) (Sandelowski, Lambe and Barroso, 2004: 127).

Our study is interested in voluntary disclosure, which involves an individual making a decision to disclose their HIV status to a sexual partner, and we will loosely refer to this as disclosure. This disclosure of HIV status to others is both an act and a complex selective process that occurs over the course of HIV/AIDS progression (Kalichman, DiMarco, Austin *et al.*, 2003; Almeleh, 2012). It involves an HIV positive person telling someone personally about their HIV positive status. The disclosure process may be difficult in social contexts where an HIV diagnosis is viewed as a death sentence, and therefore highly stigmatized. Depending on many factors, including social context, gender, and type of relationship, disclosure can lead to negative consequences (such as stigma) or it can lead to a supportive response (e.g. Almeleh, 2006) – discussed in more detail below. As a result, the process to disclose one's HIV positive status is carefully negotiated by judging to whom, when and how to disclose. For example, Sandelowski, *et al*. (2004: 126) found that individuals make decisions to disclose within a framework that includes "potential agents, targets, timing, and contents of disclosure, and reasons and rules for disclosure".

HIV status disclosure is found to be motivated either by an individual's self-interest or their concern for other people. A self-interested motivation is when individuals disclose their status to others for their benefit, for example, to relieve the stress of concealing their HIV-status, or to access social

support or support from key individuals (Kalichman, DiMarco, Austin *et al.*, 2003; Simoni, Mason, Marks *et al.*, 1995). An individual can also disclose their HIV status to sex partners or injection drug using partners with the intention of protecting them from possible exposure to HIV (Kalichman, DiMarco, Austin *et al.*, 2003). Therefore, it appears that disclosure of HIV status is negotiated within specific relationships, depending on particular concerns and needs. Chandra, *et al.* (2003: 211) provide another form of voluntary disclosure, in which individuals disclose because of limited choices. For, example, the same study found that a sample of PLWHA from Bangalore, India, included some individuals who felt morally obliged to disclose to people they were staying with who were providing support systems. Some studies based on samples of PLWHA in Cape Town also observed that some women who never experienced serious illness disclose to challenge views of society and educate people about HIV (Almeleh, 2006: 158; Almeleh, 2012: 138-139). This was likely to be the case in Khayelitsha because of the MSF HAART clinic and associated AIDS activism. We pick up on these themes in more detail below.

3.2.2 The stigmatized and HIV status disclosure to sexual partners

It is important to understand contexts that regulate disclosure within sexual relationships where heterosexual transmission of HIV occurs. Our study is interested in disclosure of HIV status to a sexual partner because of its potential to promote safer sex and thereby reduce heterosexual transmission of HIV. Previous studies based on samples from the sub-Sahara region found that disclosure is gendered. This is probably because some factors associated with disclosure are also gendered (e.g. Anglewicz and Chintsanya, 2011: 1001; Mills, de Paoli and Grønningsæter, 2009). The gender power imbalance common in this region is argued to be one of the key issues engendering HIV status disclosure (Bott and Obermeyer, 2013; Maman and Medley, 2003). We therefore review this topic separately for men and women in the quantitative analysis that follows.

3.2.2.1 *Disclosure of HIV status to sexual partners among women*

Research observes that disclosure, in general, and to sexual partners in particular, is complicated for women in patriarchal African societies. In such societies women are often blamed for their HIV status, even when they were infected by their husband (Mbonu, van den Borne and De Vries, 2009; Muyinda, Seeley, Pickering *et al.*, 1997; Petros, Airhihenbuwa, Simbayi *et al.*, 2006; Rankin, Brennan, Schell *et al.*, 2005). This is compounded by the fact that women often have better knowledge of their HIV status than men, perhaps because of their more frequent use of health care services for reproductive needs (Mills, de Paoli and Grønningsæter, 2009: 8). For example, women who attend antenatal clinics are tested for HIV, which means women who have been pregnant are more likely to know their HIV status. There is also higher HIV testing prevalence among women, as observed in a South African national survey, which showed that significantly more women (28.7% of women aged 15-49) had been tested for HIV in the 12 months prior to the survey in 2008, and knew their test results, relative to their male counterparts (19.8%) (Shisana, Rehle, Simbayi *et al.*, 2009: 49). The high awareness of HIV status by women leaves them with more responsibility to disclose, as they are more likely to be the first person in the relationship to discover that they are HIV positive. It is found that in some social contexts, men interpret this high awareness as an indicator that women are getting infected and bringing HIV into the relationship. It could also be that men deliberately interpret women's disclosure in this way to deflect attention from their culpability (Mills, de Paoli and Grønningsæter, 2009: 23). In a qualitative study in Cape Town, South Africa, Mills, *et al.* (2009: 8) found that men are reluctant to be tested for HIV, or they experience fewer situations which compel them to be tested,. As a result, women, in our particular context of Khayelitsha (South Africa), are more likely to find themselves in a situation where they know their HIV status first and have the responsibility to disclose to sexual partners.

Some South African studies found that not all women disclose their HIV status, and fear of stigma is often identified as the primary barrier to disclosure (e.g. Brandt, 2007; Maughan-Brown, 2008; Skhosana, Struthers, Gray *et al.*, 2006; Almeleh, 2006; Almeleh, 2012). This point to the importance

of understanding the specific contexts within which stigma and discrimination intersect with disclosure decisions. For example, Link and Phelan (2001) highlight that stigma exists within context of social, economic and political power. Disclosure by women is therefore negotiated within these social contexts of gender power imbalance and vulnerability. Even within the same context, the understanding of HIV/AIDS is changing over time, from being viewed as a fatal illness to being seen as a manageable chronic disease. The perceived potential stigmatizing response of the spouse or partner after disclosure is likely to be shaped by the changing dynamics of HIV.

In a meta-analysis, Medley, Garcia-Moreno, McGill, *et al.* (2004) found that the feared consequences of HIV status disclosure reported by women in samples from developing countries include: Fear of abandonment, rejection and discrimination, accusations of infidelity, and violence. This has been attributed to women's subordinate status to men: Women in developing countries may have limited access to social and economic resources, independent of their partners (Maman and Medley, 2003; Bott and Obermeyer, 2013). As a result, fear of being abandoned and losing economic or financial support discourages women from disclosing their HIV status to long-term sexual partners. The fear may be legitimate and arise from these women witnessing these consequences in society. For example, Mathews, Kuhn, Fransman, *et al.* (1999) found that 9% of a sample of HIV positive women in Cape Town who disclosed their HIV status reported that their partner abandoned them after disclosure.

Some women living with HIV/AIDS experience violence after their partner learns of their status. The example of the murder of Mpho Motloung (cited previously) can potentially deter other women living with HIV from disclosing their HIV status to their partners. In a sample of Cape Town women living with HIV/AIDS, 13% reported experience of violence from a sex partner after disclosure (Mathews, Kuhn, Fransman *et al.*, 1999).

African women are also often accused of infidelity and blamed for spreading HIV. In a meta-analysis of focus group research and analysis of an email forum on experiences of stigma in Africa, France (as cited in Maughan-Brown, 2008) noted:

> In almost all interviews, women were cited as suffering more from stigma – *"they are blamed for the spread of HIV by their partners and families which is related to notions of promiscuity. Women suffer because they come out whereas men hide their status and blame women". "If a women is HIV+, she is blamed for infecting the man. If the man is sick it is seen as an unfortunate stroke of luck – he is given sympathy and not blamed"* (p.27).

The blaming of women for HIV infection reinforces notions of women's reduced power within relationships and society. This intolerance of women living with HIV/AIDS relative to men may make it difficult for women to disclose their HIV status to sexual partners.

In addition to fear of stigma, other correlates of HIV status disclosure found in some studies based on South African samples include: Being married, prior discussion with their sexual partner about HIV testing, less experience of violence, a partner with tertiary education (Makin, Forsyth, Visser *et al.*, 2008), older age, more socio-economic assets, length of time since diagnosis (Wong, Van Rooyen, Modiba *et al.*, 2009), having a steady sexual partner, a partner with known HIV status, perception of stigma not being too much of a problem, and being on HAART (Vu, Andrinopoulos, Mathews *et al.*, 2012). Since fear of stigma is often the primary reason for non-disclosure of HIV status, some of these correlates also intersect with perceptions of stigma, to influence disclosure of one's HIV status to a sexual partner.

For example, scholars argue that fear of losing a steady relationship deters women in steady partnerships from disclosing their positive status (Vu, Andrinopoulos, Mathews *et al.*, 2012: 136). In addition, PLWHA may take time between diagnosis and disclosure, depending on the type of relationship. For example, Antelman, Fawzi, Kaaya, *et al.* (2001: 1868) found that prevalence of

disclosure to a sex partner among women attending an antenatal clinic in Tanzania ranged from 22% within two months after diagnosis to 40% after nearly four years. It is observed that individuals who fail to disclose soon after diagnosis may find it difficult to disclose as the relationship progresses because they fear losing the building intimacy and closeness (Vu, Andrinopoulos, Mathews *et al.*, 2012). However, other studies found that women in long term relationships where there is trust and love are more likely to disclose than those in relationships of shorter duration (Sigxashe, Baggaley and Mathews, 2001: 908). In such cases, the trust and love in the relationship may overcome the fear of losing the relationship, in favour of protecting the partner from exposure to HIV by disclosing to them. These are some of the dynamics of HIV status disclosure within sexual relationships. These confirm that the relationship between stigma and disclosure is contextual, and shaped by many factors.

Being on HAART treatment is another factor that intersects with stigma to influence HIV status disclosure. One of the reasons is that, in societies where HIV/AIDS is less understood, people may believe that a person living with HIV/AIDS can be identified by stereotyped HIV/AIDS symptoms (such as extreme weight loss, skin lesions). HAART improves the health status of PLWHA and removes some of the symptoms that are understood as stereotypical of PLWHA. As a result, the improved health status reduces perceptions of negative consequences and creates a better environment for disclosure (Vu, Andrinopoulos, Mathews *et al.*, 2012: 136). Almeleh (2006: 157-158) presents an example of a woman who disclosed to her ex-boyfriend who used to stereotype PLWHA. Her reason was to challenge views held by her boyfriend by showing him that he was in love with a person living with HIV, who was looking healthy, contrary to what he believed. This is an example of how incentives to disclose can differ and are shaped by context. In the case of this woman, the fact that she was able to access a HAART program and was involved in HIV activism was crucial to her disclosure.

Another important aspect in the stigma-disclosure relationship is timing of disclosure. Disclosure is an act as well as a process negotiated over time. Negotiation of the disclosure process likely begins when

an individual gets an HIV diagnosis. People are diagnosed at different stages of HIV/AIDS disease progression. For example, people diagnosed in later stages of the disease might be in urgent need of support systems and likely to disclose early, relative to the diagnosis (Almeleh, 2006: 148). In such a case, fears of stigma and discrimination are overridden by the urgent need for social support. Such a scenario, however, is less likely, the more widespread HIV treatment services become.

HIV positive people may also wait to disclose until they have 'accepted' their status and prepared themselves to disclose based on evaluations of potential risks and benefits (Almeleh, 2006: 150). In the process, the stigmatized individual gauges who to disclose to, and how to disclose, when to disclose and where to disclose (Goffman, 1963: 42). The choice of who to disclose to is a product of the evaluation of potential risks and benefits. Almeleh (2006: 149), for example, found that a sample of women in Cape Town disclosed most often to their mothers, followed by brothers, sisters, boyfriends, cousins, and friends, in that order. This may partly be because seven of the eleven women (63.6%) in the sample were single, two were married and two had boyfriends. Therefore, mothers might be the closest person to offer the needed support for those not in committed relationships. The fact that three of the seven single women were pregnant and one had an HIV positive baby and these women still tended to disclose more to mothers than sex partners suggests less disclosure in non-committed sexual relationships. In this particular sample, high disclosure to mothers and sisters may also have been a result of female respondents being more likely to disclose to female relatives. It is also suggested that this could be because females more often provide the much-needed health-related social support (Almeleh, 2006: 160).

Almeleh (2012: 178) also found high disclosure rates among a sample of women living with HIV/AIDS in Khayelitsha. About 90% of the women in this sample had disclosed to sexual partners and all of them had disclosed to at least one person. The high disclosure rates have been attributed to the fact that most of the women were part of an HIV/AIDS advocacy campaign group, TAC, where disclosure was integral and inevitable.

Preceding discussions suggest that PLWHA, and particularly women, may not disclose their status out of fear of stigma (perceived or anticipated stigma) where this can help to avoid experiencing stigmatizing behaviour on the part of others. However, non-disclosure of the stigmatizing condition does little to address internalized stigma, or the fear of encountering enacted stigma with its related psychological distress, as discussed elsewhere on health-related stigma (Scambler, 2009).

3.2.2.2 *Disclosure of HIV status to sexual partners among men*

The preceding section highlighted the fact that men are reluctant to test for HIV unless circumstances compel them to do so. As a result, a lower proportion of South African men know their HIV status (Shisana, Rehle, Simbayi *et al.*, 2009: 49; Shisana, Rehle, Simbayi *et al.*, 2014: 86) and they are therefore less likely than women to have to confront how, when and to whom they disclose.

Unlike women, men in male-dominated societies are less likely to face and perceive negative consequences when they disclose to sex partners in longstanding relationships. As a result, perceptions of such stigmatizing acts are less likely to feature in their disclosure decisions. However, men are still affected by some aspects of anticipated or perceived stigma. They are likely to fear rejection and loss of sexual opportunities after disclosure (Tshweneagae, Oss and Mgutshini, 2015: 4).

Previous studies observed that men's non-disclosure of HIV status to sex partners is associated with internalized stigma. For example, samples of men in rural Malawi and Ethiopia report that they do not disclose their status, as this would reveal that they had extramarital partners (Anglewicz and Chintsanya, 2011: 1003; Deribe, Woldemichael, Njau *et al.*, 2010: 35). Internalized stigma in the form of self-blame and shame in these cases, possibly hinders men from disclosing their status. This is in agreement with findings based on a sample of PLWHA in Cape Town. This study found that men are more likely to never have discussed AIDS with friends. They also report experiencing more

internalized stigma than women (Simbayi, Kalichman, Strebel *et al.*, 2007a: 1827). Cases in a study from Swaziland show that men report that it is easier to disclose to their wives, as they also want them to get tested for HIV and to change their lifestyle (Zamberia, 2009: 75). These studies we identified suggest that men's non-disclosure is less influenced by fear of stigma (especially violent manifestations) dictated by gender power imbalances.

3.2.3 HIV status disclosure to sexual partners and sexual behaviour

Studies based on South African samples found that PLWHA typically remain sexually active after learning about their HIV status, and significant numbers engage in unprotected sex without disclosing their HIV status to HIV negative partners, or partners of unknown status (e.g. Kiene, Christie, Cornman *et al.*, 2006; Olley, Seedat, Gxamza *et al.*, 2005). As noted earlier, unsafe sex in the context of a generalized HIV epidemic is a risky sexual practice that exposes either the HIV negative partner, or both partners, to HIV infection. As a result, HIV/AIDS prevention interventions have focused on promoting condom use, together with other sexual behaviour modification strategies, to control the spread of HIV (National Department of Health, 2007). The assumption is that disclosure creates the opportunity to negotiate and adopt safer sex practices, thereby reducing exposure to HIV transmission. HIV status disclosure may also encourage the other partner to test for HIV and this could further contribute to the reduction of HIV transmission through initiating their informed decision making regarding safer sex practices.

However, even when individuals overcome the barriers of HIV status disclosure to sexual partners (e.g. fear of stigma), the relationship between HIV status disclosure and sexual behaviour is complex. There are no guarantees that disclosure will eventually lead to safer sex behaviour, as this also depends on other factors, that include gender norms, partner characteristics, and tradition (Simoni and Pantalone, 2004).

In patriarchal societies common in the sub-Sahara Africa (SSA) region, married women have limited control over their sexual lives (Rankin, Brennan, Schell *et al.*, 2005; Maticka-Tyndale, 2012). This makes it difficult for women in these societies to initiate condom use with their sexual partners, particularly in married relationships where sexual decision-making is dictated by men. Initiation of condom use by women is seen as a sign of distrust, and condom use is associated with sex in casual sexual relationships. As a result, some HIV positive women in married relationships have unprotected sex to prove commitment to the relationship (Maticka-Tyndale, 2012: 64). There are also indications that men in these societies are reluctant to use condoms due to traditional cultural beliefs about real men not using condoms (e.g. Strebel, Crawford, Shefer *et al.*, 2006: 521). In some cases, it appears that men assume that they are not vulnerable to HIV infection, and therefore reject condom use (Mills, de Paoli and Grønningsæter, 2009: 19). Therefore, even in cases where women overcome barriers of HIV status disclosure to a sexual partner, the sexual partner may still refuse to use condoms, as observed in a sample from Swaziland (e.g. Zamberia, 2009: 74). Some studies also find a decline in condom use over time within longstanding relationships (Harrison and O'Sullivan, 2010: 994-996). This also occurs among HAART patients who abandon condom use, sometimes on the assumption that they are less infectious due to their improved health (e.g. Zamberia, 2009: 70).

It is also important to note that there might be individual differences, such that some people who do not disclose their HIV status to sexual partners may not necessarily engage in unprotected sex. For example, Mills (2009: 9) found that even though some women in a Cape Town sample did not disclose their status to potential sexual partners out of fear of being blamed, they asked the partner to go and get tested, sometimes suggesting that they go together for an HIV test before they have sexual intercourse. Going with the potential partner to be tested, and knowing their status, is a way of facilitating collective decision making regarding their sexual lives.

3.2.4 Psychological distress and risky sexual behaviour

Psychological distress and depression among PLWHA has been found in a few early studies to be positively related to engaging in risky sexual behaviour (Murphy, Durako, Moscicki *et al.*, 2001; Mustanski, Garofalo, Herrick *et al.*, 2007). This is thought to occur when PLWHA try to escape from negative self-awareness thoughts and depression by engaging in risky behaviour, such as unprotected sex (Clum, Chung, Ellen *et al.*, 2009). Murphey, *et al.* (2001: 61) found that HIV infected adolescents in the US who reported higher levels of depression were more likely to report unprotected sex at last sexual intercourse than those who were less depressed. Similar results were also found in a sample of young men who have sex with men in the US, where psychological health problems are associated with unprotected anal sex (Mustanski, Garofalo, Herrick *et al.*, 2007: 41).

3.2.5 Background Summary

The primary goal of the preceding literature review is to understand why PLWHA who are aware of their HIV status may engage in unsafe sexual practices that could result in re-infection (becoming infected with another strain of the virus) or infection of their sexual partner. We explored this topic in the context of stigma attached to HIV and its possible contribution to risky sexual behaviour (unprotected sex).

In the analysis below, we test the hypothesis that PLWHA engage in unprotected sex without disclosing their HIV status to sexual partners because of fear of stigma. If this is so, it would indicate that promoting safer sexual practices requires a better understanding of the dynamics underpinning disclosure, in which fear of stigma is likely to be important. It is also hypothesized that stigma among PLWHA has negative psychological outcomes that are associated with the tendency to engage in risky behaviour that includes risky sexual behaviour. We also examine if this is the case in the particular social context of Cape Town and in the Khayelitsha-based sample of people living on HAART that form the empirical basis of this study.

As highlighted in this literature review, the constructs of stigma and disclosure are complex processes occurring within specific social contexts, and probably continuously redefined by changing understandings of HIV/AIDS and treatment. Thus, it is important to understand the social context regulating stigma, psychological distress, and disclosure of HIV status within sexual relationships. This might help us understand the limitations faced by intervention programmes, particularly those emphasising disclosure as a means of encouraging condom use. At the same time, disclosure exposes PLWHA, and particularly women, to stigma. Access to HAART is also an important aspect of the social context within which stigma is experienced and disclosure decisions are made. As will be discussed in Chapter 6, the Khayelitsha survey data analysed in this study focusses on the first cohort of HAART patients in South Africa.

4 Stigma, childbearing intentions and childbearing

Given that HIV is sexually transmitted, it is hardly surprising that most women in South Africa infected with the HIV virus are of childbearing age. Despite the risk of infecting their sexual partners (or becoming re-infected themselves with a different strain of the virus), studies around the world observed that many PLWHA intend to bear children (e.g. Homsy, Bunnell, Moore *et al.*, 2009; Kanniappan, Jeyapaul and Kalyanwala, 2008; Cooper, Harries, Myer *et al.*, 2007; Cooper, Moodley, Zweigenthal *et al.*, 2009; Kaida, Laher, Strathdee *et al.*, 2011; Myer, Morroni and Rebe, 2007). Such reproductive intentions have medical and public health implications because they increase the risk of new HIV infections of adults, and through mother to child transmission of HIV (Mantell, Smit and Stein, 2009; Thornton, Romanelli and Collins, 2004).

HAART lowers the HIV viral load and as a result reduces the risk of HIV transmission. Its emergence has facilitated a more flexible approach to questions around sexual and reproductive health and rights of PLWHA (London, Orner and Myer, 2008).

The following sections discuss how childbearing among PLWHA can be a risk for HIV transmission if the process is not carefully managed. We also build a set of hypotheses about likely factors that might influence childbearing among PLWHA, with a particular emphasis on how experiences of various HIV/AIDS-related stigma may influence childbearing decisions.

4.1 Reproductive guidelines for HIV affected individuals

During the early stages of the HIV epidemic, reproductive guidelines for PLWHA encouraged women to defer pregnancy because of the poor prognosis associated with HIV infection, and the risk of perinatal transmission (Centers for Disease Control, 1985: 725). However, advances in HIV treatment

and prevention methods over the course of the epidemic provided a more flexible approach to the question of reproduction by PLWHA. HAART, which emerged in the late-1990s, can lower the HIV plasma viral load, thereby reducing both mother-to-child and sexual transmission of HIV/AIDS, as observed in various settings (e.g. Quinn, Wawer, Sewankambo *et al.*, 2000; Castilla, Del Romero, Hernando *et al.*, 2005; Cohen, Chen, McCauley *et al.*, 2011; Attia, Egger, Müller *et al.*, 2009). Reproductive guidelines for PLWHA were adjusted in light of these developments. In 2001, for example, the Centers for Disease Control (CDC) revised its earlier reproductive guidelines to encourage information and support regarding all reproductive options (Rogers, Fowler and Lindegren, 2001). There are now several recommended risk reduction methods for safer conception, where the critical component is that the HIV-infected partner should be on antiretroviral treatment in order to suppress viral replication (e.g. Bekker, Black, Myer *et al.*, 2011; World Health Organization, 2012; US Public Health Service Task Force).

In 2011, for example, the South African HIV Clinicians Society published recommended safer conception methods that fall into two categories: Natural and assisted conception. Recommended natural conception methods include conception through unprotected sex when there is viral load suppression in the HIV-positive partner(s), and timed unprotected intercourse during the peri-ovulatory period in order to increase chances of conception with fewer acts of unprotected sex. Natural methods may also be coupled together with pre-exposure prophylaxis (PrEP) for the HIV negative partner prior to attempted conception or post-exposure prophylaxis (PEP) for the HIV-negative partner after exposure through sexual intercourse. Recommended assisted reproduction techniques include insemination methods that do not require sexual intercourse, that is, intra-uterine insemination, intravaginal insemination and sperm washing, surrogate sperm donation coupled together with insemination (Bekker, Black, Myer *et al.*, 2011).

The conception method best suited to any particular situation depends on a number of factors that include whether partners are sero-discordant or concordant, and the sex of the infected partner, in the

case of sero-discordant partners (e.g. Bekker, Black, Myer *et al.*, 2011; World Health Organization, 2012). The method chosen may also be limited by availability of resources, as technology-intensive methods such as intrauterine insemination are unaffordable in the resource limited settings of most developing countries.

4.2 Natural conception and risk of heterosexual HIV transmission

Several studies utilizing samples of PLWHA from various settings find that the risk of heterosexual HIV transmission between discordant partners is very low under certain conditions. These include cases of low HIV plasma viral load in the infected partner, absence of sexually transmitted infections, and reduced length and frequency of exposure (e.g. Castilla, Del Romero, Hernando *et al.*, 2005; Donnell, Baeten, Kiarie *et al.*, 2010; Gray, Wawer, Brookmeyer *et al.*, 2001). For example, a meta-analytic review of 11 cohorts involving 5021 heterosexual sero-discordant couples finds a zero transmission rate to the uninfected partner in cases where the infected partner was receiving antiretroviral therapy and had a viral load below 400 copies/mL (Attia, Egger, Müller *et al.*, 2009). The same meta-analytic study concludes that data were compatible with one transmission per 79 person-years. Another randomized placebo-controlled trial in 7 African countries observed a 92% reduction in HIV transmission among couples when the infected partner was on HAART (Donnell, Baeten, Kiarie *et al.*, 2010).

While the risk of HIV transmission is greatly reduced by antiretroviral treatment, scholars argue that natural conception methods involving unprotected sex may not be 100% risk free, even with suppressed plasma viral load (Bekker, Black, Myer *et al.*, 2011: 35; Barreiro, Duerr, Beckerman *et al.*, 2006: 160). This cautionary approach is a result of findings of detectable HIV in sexual fluids of both men and women who have undetectable HIV plasma viral load in their blood (Coombs, Reichelderfer and Landay, 2003: 467). As a result, it is difficult to guarantee zero risk of HIV transmission through natural conception even under conditions of an undetectable plasma viral load in the bloodstream.

Furthermore, some couples affected by HIV do not consider recommended guidelines for safer conception. For example, health care providers at some hospitals in eThekwini District (KwaZulu-Natal, South Africa) reported that some PLWHA do not seek preconception counselling and only seek advice when they are already pregnant (Mindry, Crankshaw, Maharaj *et al.*, 2015: 28). Such couples who attempt pregnancy outside recommended safer conception guidelines risk increased chances of HIV transmission.

Over the course of the epidemic, guidelines for antiretroviral treatment initiation for HIV-patients continue to be adjusted to accommodate more PLWHA before they become severely ill (World Health Organization, 2010). The World Health Organization (WHO) starting from 2015, recommends antiretroviral treatment at any CD4 cell count (World Health Organization, 2015). Thus the risks of HIV-transmission will be greatly reduced if all PLWHA initiate and adhere to treatment.

4.3 Fertility and fertility intentions

Studies based on general populations suggest that childbearing intentions or desires among individuals are strong determinants of eventual childbearing (Schoen, Astone, Kim *et al.*, 1999; Pritchett, 1994). There is a small but growing body of literature exploring the link between childbearing intentions and eventual childbearing amongst PLWHA (e.g. Cooper, Harries, Myer *et al.*, 2007; Cooper, Moodley, Zweigenthal *et al.*, 2009; Aka-Dago-Akribi, Du Lou, Dossou *et al.*, 1999; Kaida, Laher, Strathdee *et al.*, 2011). Such studies help health authorities to plan for the reproductive health needs of PLWHA, and perhaps also provide some indication of the potential public health consequences of such fertility desires.

4.4 Factors influencing childbearing decisions of PLWHA

Previous studies found a complex interplay of factors that influence childbearing decisions among PLWHA. These factors include personal characteristics (age, sex, ethnicity, relationship status, number of biological children), and an individual's attitudes and experiences (attitudes towards prospective parenthood, subjective perceptions of health, experience of death of a child due to HIV/AIDS, concerns about orphanhood for their children, health-related concerns, and feelings of internal stigma). Other influencing factors are interpersonal (spousal, family and health workers influences), community (community expressions of stigma and cultural norms and expectations) and structural (availability of and access to prevention of mother to child transmission (PMTCT) programmes, and HAART programmes) (Nattabi, Li, Thompson *et al.*, 2009: 1; Cooper, Harries, Myer *et al.*, 2007).

In a systematic review of the international literature, Nattabi, *et al.* (2009) found younger age, being male, having smaller numbers of living children, positive attitudes towards prospective parenthood, being on PMTCT or HAART, subjective good health, partner's (usually husbands) desire for children and desire to conceal one's stigmatizing condition of being HIV positive, to be some of the factors that generally promote childbearing intentions among PLWHA. The same study also found health-related concerns, negative health worker attitudes, community disapproval, fear of stigma, experience with child mortality due to HIV/AIDS, and concern for possible orphanhood of the born child to be some of the factors that negatively influence childbearing decisions among PLWHA (Nattabi, Li, Thompson *et al.*, 2009).

4.5 HIV/AIDS-related stigma among PLWHA and childbearing decisions

There appears to be no simple relationship between HIV stigma and childbearing desires, in part because the impact appears to vary by the type of stigma experienced by the individual (Craft,

Delaney, Bautista *et al.*, 2007). We briefly review the different measures and understandings of HIV stigma below before we explore how some of these influence childbearing decisions among PLWHA.

4.5.1 Brief on HIV/AIDS-related stigma

Since the HIV/AIDS epidemic in most countries is primarily driven by heterosexual transmission, people who are HIV positive often get morally judged by the general population for getting infected. This is discussed in Chapter 2 as a form of 'symbolic stigma'. Chapter 2 also discusses how some members of the general population exaggerate their fear of infection with the HIV virus by unreasonably avoiding contact with PLWHA, thereby subjecting them to a form of 'instrumental stigma'. However, regardless of the motivation, when PLWHA experience HIV stigma, it is likely to harm their social and psychological wellbeing. Chapter 3 discusses HIV/AIDS-related stigma as it is experienced (real experience of stigma and discrimination), perceived (perceptions about the way PLWHA are stigmatized by society) and internalized (accepting the negative social judgments associated with being HIV positive) by PLWHA.

4.6 How stigma discourages childbearing among PLWHA

Evidence in the international literature suggests that experiences of HIV/AIDS-related stigma can deter childbearing among PLWHA. For example, a study of PLWHA in the United States (US) from the mid-2000s found that women who experienced stigma after disclosing their HIV status, or who perceived that prejudice towards PLWHA exists in their society were less likely to intend to have children (Craft, Delaney, Bautista *et al.*, 2007: 932). The study shows that potential parents were fearful of being judged harshly for risking the transmission of HIV to the child, and for bringing children into the world when their health status is compromised (Craft, Delaney, Bautista *et al.*, 2007: 931). Similar fears were also expressed by a South African sample of PLWHA who were discouraged from having children because of criticism from the community for taking the unacceptable risk of transmitting HIV (Cooper, Harries, Myer *et al.*, 2007: 278).

A qualitative analysis of women in South Africa newly diagnosed with HIV observed a lack of interest in child bearing or sex because of fear of HIV transmission to either partner or child. These women blamed sex for their HIV positive status,and were put off by the difficulties of negotiating safe sex. They had feelings of guilt about burdening the community if they die early and someone else has to raise the child. (Cooper and Harries, 2009). The same study suggested that some of the deterrents to childbearing among the women were a function of their understanding about stigma towards PLWHA in their social environment. This hypothesis appears to be reinforced by other findings based on samples of people in the general population. For example, some South African communities do not approve of childbearing among PLWHA (Myer, Morroni and Cooper, 2006). In a study of PLWHA in Uganda, Nattabi, *et al.* (2012: 9) found that individuals who experienced overt acts of stigma and discrimination, together with feelings of worthlessness, had reduced desires to have children.

The perception that HIV stigma can also be directed at the born child can be a concern for the prospective parent, and also reduce child bearing desires. For example, in a qualitative study in India, lack of family support, and experiences of stigma from the family, reduced desires for pregnancy (Kanniappan, Jeyapaul and Kalyanwala, 2008: 628-629). One of the reported reasons for the reduced desires was insecurity about the future prospects of the child in the event of parental death, especially without family support. In a study of PLWHA in Uganda, childbearing and pregnancy invited further stigmatization, in the form of community hostility (Nattabi, Li, Thompson *et al.*, 2012: 5-7). Experienced stigma reduced the desire for more children as PLWHA did not want to expose their children to similar stigmatization. It appears from these studies that experiences of stigma, perception of stigma, and internalization of stigma all deter childbearing among PLWHA, although the social context and availability of appropriate treatment also probably matter.

4.7 How stigma promotes childbearing among PLWHA

In contrast to arguments in the preceding section, experience of HIV/AIDS-related stigma might also promote childbearing among PLWHA. A study based on a US sample of PLWHA found that women who reported higher levels of personalized stigma (personal experiences of stigma) and negative self-image (internalized stigma) had increased desires to bear children (Craft, Delaney, Bautista *et al.*, 2007). For these relationships, it was hypothesized that individuals may bear children in order to conceal their HIV status and pass as 'normal', thereby avoiding the related stigma (Craft, Delaney, Bautista *et al.*, 2007: 933). Fear of stigma can also be a powerful incentive to have children, especially in African societies where there are strong social pressures to have children. In a qualitative study based on a South African sample (in Cape Town), Cooper, *et al.* (2007: 278) provide a case of a woman who intended to have children, both in order to conform to societal expectations of childbearing within a marriage, and to conceal her HIV status from the community:

> *"When I am married I will have to have a baby because...only I and my boyfriend…are aware that I am HIV positive and…people will ask why am I not becoming pregnant in marriage. (HIV-positive woman)" (Cooper, Harries, Myer et al., 2007: 278).*

Another study conducted in South Africa (Tshwane) observed some women living with HIV/AIDS who continue to bear children in order to be accepted by their partners and relatives and thereby avoid the related stigma, as they narrate:

> *"I am very scared of rejection because of my status. I do not want them to know, they will turn away from me." (Female pregnant participant)* (Van Zyl and Visser, 2015: 5).

> *"My partner wanted the baby . . . I did not disclose my status. . . I am very scared to disclose, I fear rejection because I am living with his people." (Female pregnant participant)* (Van Zyl and Visser, 2015: 5).

Thus, fear of HIV/AIDS – related stigma can play a role to encourage childbearing. Another possible hypothesis as to why PLWHA may want to bear children is to have someone to love who loves them back irrespective of their HIV status (Craft, Delaney, Bautista *et al.*, 2007: 933).

4.8 Cultural norms and expectations about childbearing

A qualitative study based on Cape Town women seeking treatment for involuntary childlessness observed that childlessness is stigmatized, especially among Xhosa people (Dyer, Abrahams, Hoffman *et al.*, 2002: 1665). It was reported that childless women are ridiculed and victimized by the community and especially by her partner's family. Childlessness may result in relationship instability, and abandonment of women. People who are childless are also generally found to suffer discrimination, stigma and ostracism in other sub-Saharan African countries (Dyer, 2007). The preceding discussion on how HIV/AIDS-related stigma may influence childbearing decisions, linked with childlessness-related stigma shows the complexity of the social aspects of stigma in the life of PLWHA. A study based on a US sample of women living with HIV summarized this complicated situation in the finding that "our society expects women to be mothers, yet at the same time, it negatively judges HIV positive women who choose to become pregnant, or refuse to abort an existing pregnancy" (Ingram and Hutchinson, 2000: 122).

The HIV positive individual's decisions to bear children may depend on finding a balance between the related health risks (for the child, themselves, and their partners), societal and cultural expectations, personal desires, and concerns about HIV stigma.

4.9 Other determinants of childbearing

This section describes previously observed determinants of childbearing among PLWHA that will be controlled for in our data analyses.

Income

Several South African studies on PLWHA found that having sufficient financial means is an important factor in decisions to bear children (Cooper, Moodley, Zweigenthal *et al.*, 2009; MacGregor and

Mills, 2011). For example, Macgregor and Mills (2011: 6) observed that most of the women living with HIV/AIDS in their study reported that difficulties in providing for a child is one of the challenges of bearing children. Sufficient financial means was also reported as an important factor in decision making about childbearing in another Cape Town sample of PLWHA (Cooper, Moodley, Zweigenthal *et al.*, 2009). We therefore hypothesize that PLWHA from poorer households, and those with less personal income, are less likely to intend to have children. We therefore control for both household and personal income in future regression models.

Education

Education is also considered to influence childbearing decisions in various ways. A prominent theory is that highly educated women have higher opportunity costs that conflict with repeated childbearing, and this may lead to the desire for fewer children (Becker, 1981; Hotz, Klerman and Willis, 1997). It is also argued that less educated women, especially in patriarchal societies, have their livelihood tied to their childbearing ability, and are more likely to desire and have children (Nattabi, Li, Thompson *et al.*, 2012: 9). The suggested inverse relationship between attained education and fertility appears to be supported by evidence from samples of women living with HIV/AIDS in seven African countries, including South Africa (Myer, Carter, Katyal *et al.*, 2010). On the basis of these and other related arguments, we control for education in future regression analyses for fertility intentions.

Living with a partner

In a sample of women from Khayelitsha living with HIV/AIDS, some of the respondents reported that they would consider childbearing in the future if they could find a partner (MacGregor and Mills, 2011: 6) and we control for whether a respondent is living with a partner or not.

Number of living children

Several South African studies found that PLWHA value parenthood in their lives, and that this is a common sentiment in most African societies (MacGregor and Mills, 2011; Cooper and Harries, 2009). Therefore, we control for number of children, on the assumption that those with few children are more likely to intend to have more children (e.g. Myer, Morroni and Rebe, 2007; Kaida, Laher, Strathdee *et al.*, 2011).

5 Background setting

In this section we provide a historical background to HIV/AIDS in South Africa, and establish the context of our study area in Khayelitsha, Cape Town.

5.1 Brief background on HIV/AIDS in South Africa

The first cases of AIDS in South Africa were recorded in 1983 (Ras, Simson, Anderson *et al.*, 1983). Since then, South Africa has witnessed a dramatic increase in the number of people infected with HIV and AIDS. Table 6 shows the estimated HIV prevalence and number of people living with HIV in South Africa over the period 2002-2014, based on figures published by Statistics South Africa (the national statistics office), a demographic projection model (ASSA2008) produced by the Actuarial Society of South Africa (Actuarial Society of South Africa, 2011) and the *South African National HIV Prevalence, Incidence and Behaviour Surveys* (conducted by the HSRC, a national research institute).

Table 6: Estimated HIV prevalence for South Africa by year– various sources

Year	Prevalence			HIV pop (millions)		
	StatsSA	ASSA	HSRC	StatsSA	ASSA	HSRC
2002	9.0	8.4	11.4*	4.1	3.9	
2003	9.1	9.1		4.2	4.3	
2004	9.2	9.6		4.3	4.6	
2005	9.3	10.0	10.8*	4.4	4.8	
2006	9.4	10.3		4.5	5.0	
2007	9.5	10.5		4.6	5.1	
2008	9.7	10.6	10.6	4.8	5.2	5.2
2009	9.8	10.7		4.9	5.4	
2010	9.9	10.9		5.0	5.5	
2011	10.0	11.0		5.1	5.6	
2012	10.1	11.1	12.2	5.3	5.7	6.4
2013	10.1	11.2		5.4	5.8	
2014	10.2	11.3		5.5	5.9	

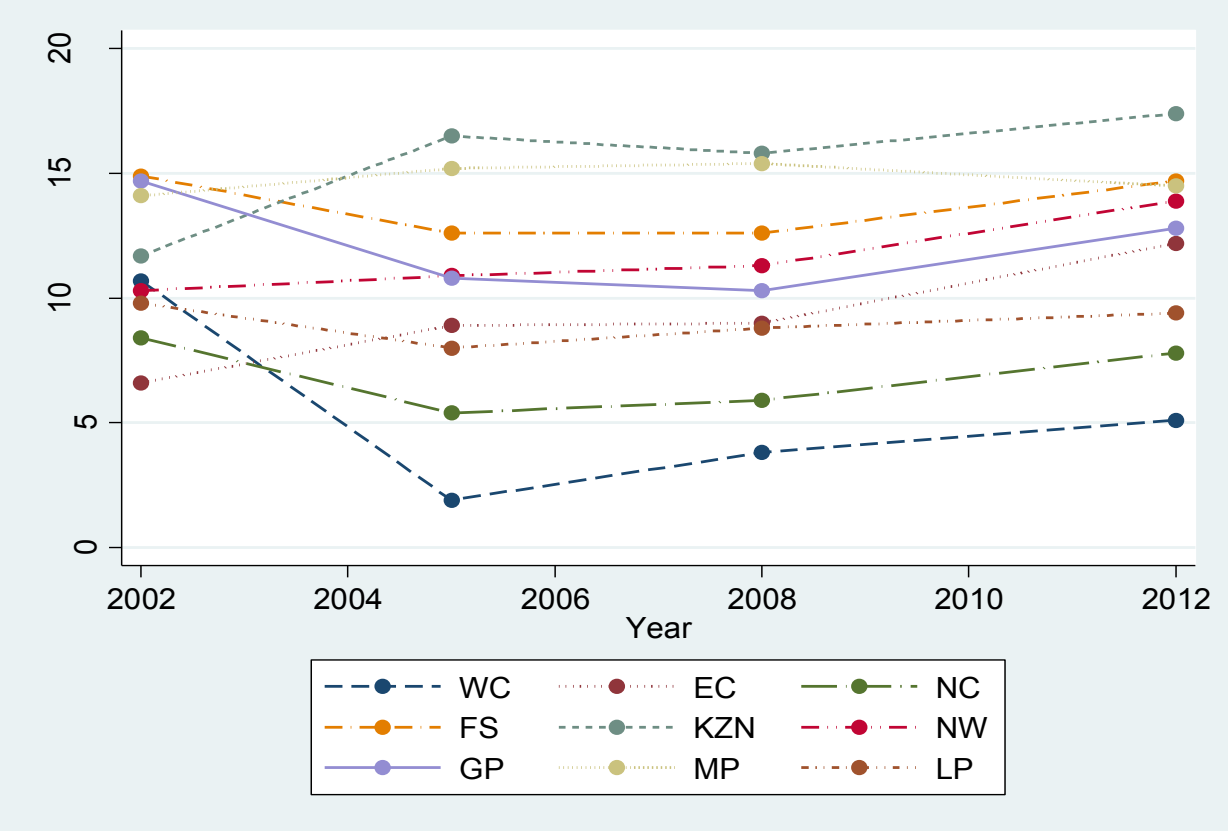
source: Statistics South Africa (2014); Shisana *et al.*(2014); ASSA2008
*prevalence for 2 years old and above

The difference in the estimated prevalence of Statistics South Africa (StatsSA), ASSA and the HSRC survey is a result of different methodologies employed. StatsSA and ASSA estimates are based on the HIV prevalence of women attending public ante-natal clinics (ANC), adjusted for various factors (see Statistics South Africa, 2014; Actuarial Society of South Africa, 2011). The HSRC estimates are based on HIV tests of participants in a series of national surveys (Shisana, Rehle, Simbayi *et al.*, 2014).

Regardless of the estimates used, South Africa has the highest number of PLWHA in the world (WHO, UNAIDS and Unicef, 2011). In 2010, for example, 34 million people were estimated to be infected with HIV globally (WHO, UNAIDS and Unicef, 2011: 19). In the same year, slightly more than two thirds (68%) of all people living with HIV lived in sub-Saharan Africa, a region with only 12% of the global population (*ibid*: 24). South Africa had an estimated 5.6 million PLWHA, based on the WHO/UNAIDS Spectrum and EPP Models (National Department of Health, 2010). South Africa therefore contributed about a quarter of all PLWHA in the sub-Saharan region, and 16% of the global epidemic, in 2010. South Africa is divided into nine provinces, as shown in Figure 1, and HIV prevalence varies significantly by province, with the distribution shown in Figure 2.

Figure 1: **Map of South African Provinces**

Figure 2: South African HIV prevalence by province (2 years and older): 2002-2012



source: Shisana *et al.*(2014: 39)
WC –Western Cape, EC – Eastern Cape, NC – Northern Cape, FS – Free State, KZN – KwaZulu-Natal, NW – North West, GP – Gauteng, MP – Mpumalanga, LP – Limpopo

The Western Cape Province has the lowest prevalence. In addition, HIV prevalence is observed to vary significantly by type of living area. For example, a national survey conducted in 2012 observed HIV prevalence to be high in both "urban informal" (19.9%) and "rural informal" (13.4%) areas, compared to "urban formal" (10.1%) and "rural formal" (10.4%) areas, for South Africans in all age groups (Shisana, Rehle, Simbayi *et al.*, 2014: 36). Our area of study is Khayelitsha, a partially informal urban township in the Cape Town metropolitan municipality (in the Western Cape Province). As of the early 2000s, it had higher levels of HIV prevalence than the other Cape Town sub-districts (Médecins Sans Frontières, University of Cape Town and Western Cape Provincial Department of Health, 2003; Shaikh, Smit and Cloete, 2006). Table 7 shows the variation in the estimated HIV prevalence by areas in the Cape Town Metropolitan area.

Table 7: HIV Prevalence Trends by Area: Cape Town Metropolitan 2000 – 2005

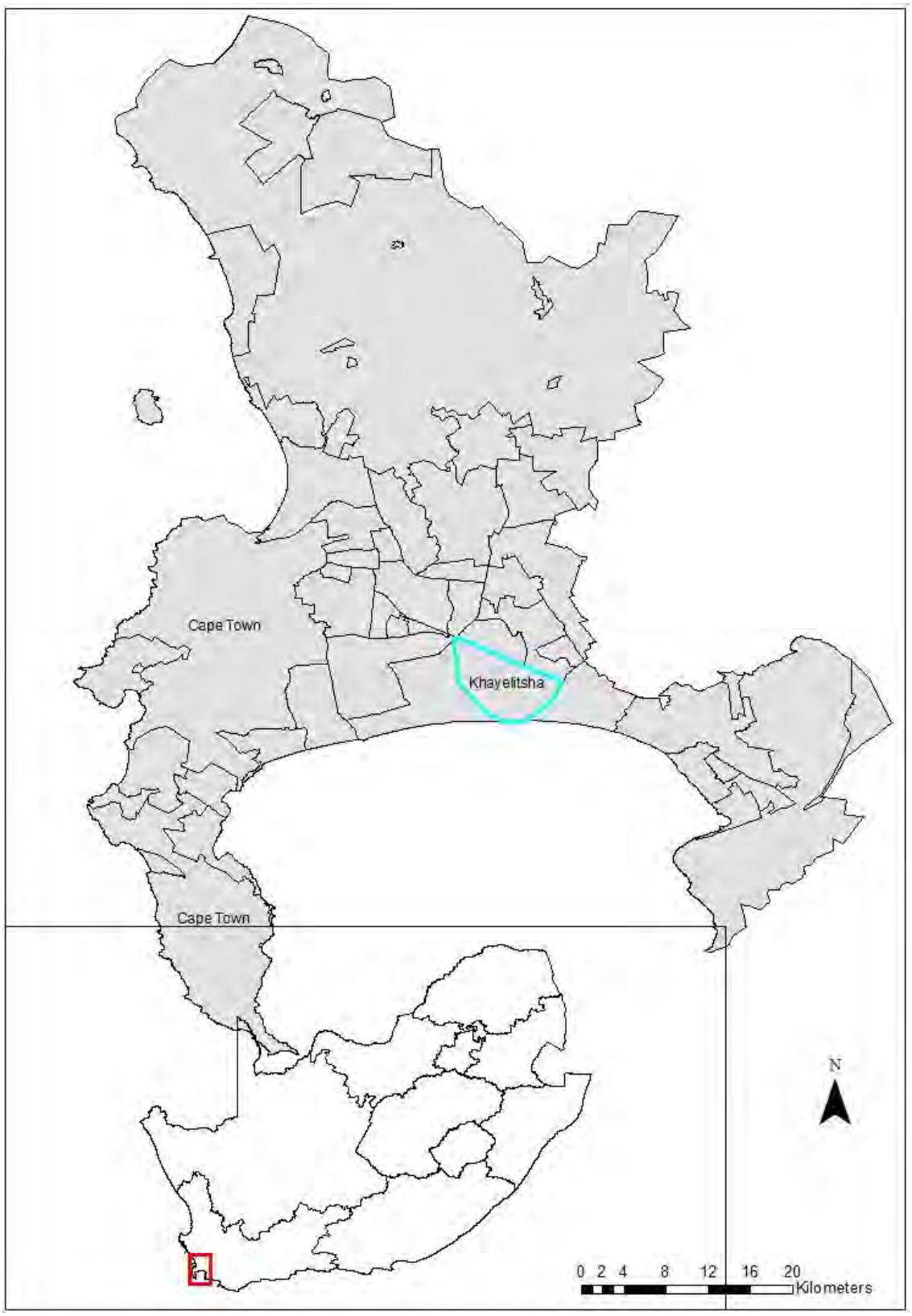
Area	HIV Prevalence (95% Confidence Interval)					
	2000	**2001**	**2002**	**2003**	**2004**	**2005**
Blaauwberg		0.6±1.1	8.2±6*	4.4±3.0	1.2±1	7.3±3.6
Cape Town Central		3.7±3.6	11.9±6*	11.6±5*	13.7 ±4.7	11.5±3.3
Greater Athlone		6.8±4.6	8.9±4	10.1±4.4	16.4 ±3.6	17.7±3.5
Helderberg		19±6	19.1±4.5	19.1±4.2	18.8 ±3.3	12.8±3.0
Khayelitsha		22±5	24.9±4.2	27.2±4.2	33.0 ±3.5	32.6±3.2
Mitchells Plain	5.4 ±0.1	0.7±1.3	4± 4.0	6.3±4	12.9 ±3.5	5.1±2.0
Gugulethu/Nyanga		16.1±6.5	27.8±5.2	28.1±4.2	29.1 ±2.8	29.1±3.9
Oostenberg		5.7±3.3	14.5± 6.	16.1±4.3	14.8 ±3.3	16.2±3.5
South Peninsula		5.9± 3.9	6± 4.1	9.3±3.8	10.8 ±3.2	12.4±3.2
Tygerberg Eastern	5.1 ±3.7	6.1±3.4	10.4±5	8.0±3.9	12.7 ±3.6	15.2±3.5
Tygerberg Western		7.9±3.9	12.7±5	8.1±3.3	15.1 ±4	15.0±3.15

source Shaikh *et al.* (2006: 12)

* Results to be treated with caution given the wide confidence intervals

Khayelitsha is situated on the periphery of the Cape Town municipal area (which is the capital and largest city of the Western Cape Province) as shown in Figure 3.

Figure 3: Map of Cape Town including the location of Khayelitsha



5.2 Background history of Khayelitsha

Khayelitsha was established by the Apartheid South African parliament in 1983 as an area for resettling black African residents who were facing housing shortages (Seekings, Graaff and Joubert, 1990: 8; Cook, 1986: 57). Black Africans who were formally resident in Metropolitan Cape Town areas (mostly in the formal and informal settlement areas of Crossroads, Nyanga, and Gugulethu) were to be resettled in Khayelitsha, which is situated 39km south east of the city centre (Seekings, Graaff and Joubert, 1990: 9). While Khayelitsha was established to provide housing for all Africans in Metropolitan Cape Town, people from other areas (including the "homelands" of Transkei and Ciskei in what is now the Eastern Cape province) also moved into Khayelitsha (Seekings, Graaff and Joubert, 1990: 42-43). Increased in-migration, intra-urban migration, natural population growth, and resettlement resulted in an increase in demand for housing and related services in Khayelitsha (Seekings, Graaff and Joubert, 1990; Ndegwa, Horner and Esau, 2007). As a result, people constructed informal housing in informal areas and, many of which were not suited for housing, as they were prone to flooding (see Bouchard, 2007).

Khayelitsha was initially planned to accommodate a quarter of a million black people and this was subsequently increased to 360,000 people (Seekings, Graaff and Joubert, 1990: 9). The first residents of Khayelitsha were settled in 1983 (at site A) and, by 1988, the population of Khayelitsha was estimated at 150,000, after the construction of two more settlement areas, site C and site B (Seekings, Graaff and Joubert, 1990: 14). Two subsequent South African censuses estimated the population of Khayelitsha at 329,008 in 2001 and 391,742 in 2011 (Statistics South Africa, 2003, 2012). It is also acknowledged that the fluid nature of residence and housing structures in the area makes it difficult to estimate the population of Khayelitsha. Some studies have suggested that, by the mid-1990s, it might already have been more than 1 million (Morris and Pitt, 1995: 80).

Khayelitsha is today characterized by old formal areas and new formal and informal areas (Skuse and Cousins, 2007). The new areas are built around the old areas, and these include mostly informal

settlements. The Post-Apartheid government initiated the Reconstruction and Development Programme (RDP) that built subsidized low cost houses for South Africans who did not have proper housing (African National Congress, 1994). RDP houses form part of the new formal housing found in some areas of Khayelitsha.

As a result of the historical development of Khayelitsha, most of the residents are black African. According to the 2001 South African census, the ethnic group composition of the estimated 329,008 people residing in Khayelitsha was: Black African (99.49%), Coloured (0.48%), Indian or Asian (0.01%) and White (0.02%) (Statistics South Africa, 2003). The majority (96.8%) reported Xhosa as the language they speak most often. There are an estimated 85,984 households and most of the households (57.1%) live in stand-alone informal dwellings (shacks). About 29.9% live in formal housing, or brick structures on a separate stand or yard. About 7.3% live in informal dwellings (shacks) in the back yards of formal houses, and 5.7% live in other forms of housing (Statistics South Africa, 2003). The 2001 census estimated that only 34.6% of all persons aged 15 – 64 years living in Khayelitsha were employed, and the median annual household income was less than R20,000 (with 25% of households having no income) (Statistics South Africa, 2003). In 2005, Khayelitsha was the sub-district in the Western Cape province with the highest HIV prevalence, estimated at 33% compared to 15.7% for the whole province (Draper, Pienaar, Parker *et al.*, 2007: 102).

5.3 HAART treatment in South Africa

5.3.1 Treatment for HIV/AIDS

Advances in the understanding of HIV saw the development of potent antiretroviral agents in the fight against HIV. HAART or combination antiretroviral therapy (cART) comprises a combination of different antiretroviral agents with different viral targets. If treatment is initiated before advanced disease stages, HAART reduces HIV blood concentration to undetectable values, and at the same time builds a robust and sustained immune system (Volberding and Deeks, 2010).

Treatment guidelines for PLWHA have continuously been adjusted, to accommodate more people before advanced disease progression. In 2015, the WHO recommended antiretroviral treatment at any CD4 cell count (World Health Organization, 2015). These latest treatment guidelines are a revision of the 2010 WHO guidelines which recommended earlier antiretroviral therapy initiation for patients with a CD4 T-cell count of lower than 350 cells per μL (World Health Organization, 2010).

Evidence based on studies from different settings shows that HAART prolongs the life of PLWHA, thereby reducing HIV/AIDS mortality (e.g. Bor, Herbst, Newell *et al.*, 2013; Lima, Harrigan, Bangsberg *et al.*, 2009; Johnson, Mossong, Dorrington *et al.*, 2013; Nakagawa, Lodwick, Smith *et al.*, 2012). As a result, HIV/AIDS, seen as a fatal illness before the advent of HAART, has been transformed to a manageable chronic illness. Combination antiretroviral drugs have been available since 1995-96 and, by 2010, more than 20 antiretroviral agents were licensed (Palmisano and Vella, 2011: 46).

5.3.2 Politics of HAART in South Africa

At the time that HIV prevalence was increasing sharply in South Africa, lack of political commitment lead to a slow response to the HIV/AIDS epidemic by the South African government. The Nelson Mandela government was slow to react to the challenges of AIDS and the Thabo Mbeki presidency (1999-2008) was slow to provide HAART through the public sector. The government's poor performance with regard to AIDS treatment has been attributed to Mbeki's AIDS denialism and to suspicion of HAART on the part of his then health minister (Manto Tshabalala-Msimang) (Nattrass, 2007; Geffen, 2010). Both Mbeki and Tshabalala-Msimang questioned the science of HIV/AIDS and as a result were resistant to the introduction of HAART (for AIDS sick people) and PMTCT therapy for pregnant women. They interpreted these scientifically tested drugs as 'toxic' to people and gave their support to traditional and herbal therapies that were not scientifically proven to be effective (see Nattrass, 2007, 2008). This AIDS-denialist approach delayed implementation of the national PMTCT

and HAART programmes, resulting in thousands of new infections and early deaths (Chigwedere, Seage III, Gruskin *et al.*, 2008; Nattrass, 2008). The government's position on HIV and HAART was challenged by civil society organizations, notably TAC. The TAC took the government to court over its failure to provide PMTCT, and launched a civil disobedience campaign in 2003. This political pressure, combined with growing resistance to Mbeki's AIDS policies within the ruling party, forced a policy change, and in 2004, a national HAART rollout was initiated (see Nattrass, 2007; Geffen, 2010).

5.3.3 HAART roll-out programme in Khayelitsha

By the time the national HAART roll-out was initiated in 2004, a pilot HAART programme in the Western Cape Province had already been in operation for several years. The Provincial Government of the Western Cape (PGWC), in partnership with MSF, was the first Province to have a PMTCT programme in South Africa. This was done without the approval of the National Ministry of Health. In early 1999, Zidovudine (AZT) was first introduced at two primary health centres that provide maternity services in Khayelitsha. The clinics in Khayelitsha were chosen to demonstrate the effectiveness of HAART in a primary health care setting with limited resources (Médecins Sans Frontières, University of Cape Town and Western Cape Provincial Department of Health, 2003).

The international non-governmental organization (NGO) MSF collaborated with the Western Cape Provincial Government to support this PMTCT programme when it started in 1999. In addition, their partnership also established dedicated HIV/AIDS clinics for adults and children living with HIV in April 2000 (Médecins Sans Frontières, University of Cape Town and Western Cape Provincial Department of Health, 2003). The HIV clinics were called "infectious disease clinics" in an effort to avoid HIV-related stigma, as this would discourage people living with HIV from accessing these services (Kasper, Coetzee, Louis *et al.*, 2003: 20). The community was soon to know about the real purpose of the services offered at the clinics, but this did not deter people from accessing the services,

as was evidenced by long queues at the clinics. In May 2001, the programme was expanded to offer HAART in government clinics (including Michael M, Site B, and Site C) (Coetzee, Hildebrand, Boulle *et al.*, 2004; Kasper, Coetzee, Louis *et al.*, 2003; Almeleh, 2012).

The national government continued to resist the introduction of PMTCT and HAART until they were forced to do so by a Constitutional Court ruling in 2002 (for PMTCT) and a cabinet revolt in late 2003 (in favour of a HAART rollout). The government introduced Nevirapine (NVP) following the landmark court case brought by the TAC in which the Constitutional Court ruling ordered the government to remove all restrictions on the introduction of PMTCT in public health care centres[4]. By the time the national PMTCT programme was implemented, the Khayelitsha PMTCT sites, initiated in defiance of national policy, were well established, with a wide coverage (Médecins Sans Frontières, University of Cape Town and Western Cape Provincial Department of Health, 2003).

5.4 The Khayelitsha HAART roll-out programme and implications for stigma, psychological outcomes, disclosure and condom use

Our study uses data collected from PLWHA in Khayelitsha. The survey reached two thirds of the starting cohort of HAART patients. It is therefore important to look at how the HAART programme in Khayelitsha influenced the understanding about HIV/AIDS among PLWHA in relation to the constructs that we are interested in. As discussed below, qualitative and quantitative studies based on this cohort suggest that eligibility for treatment and advocacy work by HIV patients may have shaped their experience of stigma, disclosure, and sexual behaviour, such as condom use.

[4] *Minister of Health v Treatment Action Campaign (2) 2002 5 SA 721 (CC)*

5.4.1 Eligibility for HAART treatment

The early HAART programme in Khayelitsha had eligibility criteria for treatment that have important implications for our study. One of the requirements for treatment was that the patient needed to disclose to at least one person (usually a family member) who would then act as a treatment assistant and facilitate support where necessary (Médecins Sans Frontières, University of Cape Town and Western Cape Provincial Department of Health, 2003). MSF had a clear preference for providing treatment to people who were open about their HIV status. MSF wanted to ensure that HAART patients had appropriate support in the home and that, ideally, where disclosure was wider than to close kin, they would help encourage other people who were sick with AIDS to come forward for treatment (Médecins Sans Frontières, University of Cape Town and Western Cape Provincial Department of Health, 2003).

As a result, a sample drawn from these patients was likely to report high levels of disclosure in general, and many were likely to have been activists. Furthermore, MSF provided support groups for these HAART patients. This, coupled with the fact that many of them were also involved in the TAC, could mean that they had higher levels of social support than other HIV-positive people. This may have affected their psychological well-being, and perhaps even the links between psychological state and behaviours such as condom use. We return to this issue below.

An earlier study investigates the impact of HAART on health-related quality of life, using the same cohort of HAART patients surveyed for our study (Jelsma, MacLean, Hughes *et al.*, 2005). That study investigates five domains of health-related quality of life: Mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Results from this study suggest a general improvement in all domains after 12 months of HAART treatment, compared to the baseline survey findings. This demonstrates the physical and psychological benefits of HAART (Jelsma, MacLean, Hughes *et al.*, 2005: 583). The study finds that levels of anxiety and depression in the HAART cohort initially differed significantly from that in a 'control' sample of people in the broader Khayelitsha community.

However, over time, reported levels converged in both samples, as levels of anxiety and depression amongst HAART patients fell (Médecins Sans Frontières, University of Cape Town and Western Cape Provincial Department of Health, 2003: 5).

5.4.2 HIV/AIDS advocacy

Hodes and Naimak (2011) detail roles played by different organizations in facilitating the first HIV-treatment in the public health sector (including in Khayelitsha). The organizations included the Western Cape Provincial Department of Health, independent health providers, notably MSF, civil society organizations, international donors, and academic research institutes. The TAC was the leading civil society organization involved. It was at the forefront of community advocacy work including: Initiating grassroots campaigns for access to HIV treatment, mobilizing community awareness about HIV/AIDS, promoting HIV testing, encouraging HIV treatment, challenging stigma, and promoting disclosure (Nattrass, 2007; Geffen, 2010). The role of the TAC is important for understanding our sample because the TAC branch in Khayelitsha was strongly associated with the clinics that provided HAART.

There were also AIDS advocacy intervention projects such as *Longlife* where women living with HIV/AIDS were involved in public disclosures of their HIV stories, among other advocacy activities (Almeleh, 2012; Almeleh, 2006). The idea around *Longlife* was to have PLWHA who were on HAART narrate their stories in public spaces, as a way of contributing to the greater debate on the need for a national HAART rollout, which was a political issue at the time (see Section 5.3). The community advocacy work of groups such as the TAC and *Longlife* has implications for some of the variables that we are interested in, as the activists challenged HIV/AIDS-related stigma by educating the community and promoting disclosure in both public and private spaces (Nattrass, 2007; Geffen, 2010; Almeleh, 2012).

For example, TAC established *Project Ulwazi* ('knowledge') in which HIV positive activists living openly about their status conducted awareness workshops in various settings (Médecins Sans Frontières, University of Cape Town and Western Cape Provincial Department of Health, 2003; Hodes and Naimak, 2011). The volunteers of *Project Ulwazi* also created mobile HIV exhibitions, focused on promoting HIV testing and disclosure, and support for positive living, all conducted in public spaces (Hodes and Naimak, 2011).

TAC activists also promoted condom use by conducting door-to-door condom distribution (Hodes and Naimak, 2011). This advocacy work is credited with influencing the community's understandings about HIV/AIDS in various ways. For example, a study conducted in 2002 observed that, among selected commuter sites in different South African provinces, Khayelitsha had the highest levels of condom use (Parker, Oyosi, Kelly *et al.*, 2002: 12). This high condom use is attributed to the broad based approach to AIDS care in Khayelisha that involved a number of stakeholder organizations (Hodes and Naimak, 2011; Médecins Sans Frontières, University of Cape Town and Western Cape Provincial Department of Health, 2003).

Qualitative data analysis using data from *LongLife* advocacy group members who were part of the first HAART cohort, finds that in addition to past experiences, women's general perceptions that disclosure to a sexual partner is tricky were also shaped by what they had heard from other women within the *LongLife* advocacy group (Almeleh, 2012: 151-152). Almeleh found that the women tended to disclose 'publicly', for example at art exhibitions, but not in their own community, because of fear of negative reactions or perceived stigma. Almeleh (2012) argues that such perceptions of negative reactions were reasonable, as they were derived from their own experiences and those of others in their communities. Studies of the broader population in Khayelitsha have found evidence of stigmatizing attitudes towards PLWHA (Maughan-Brown, 2008). Almeleh (2012) further finds that some of the women did not see the need to disclose to their partners since they were using a condom,

and disclosure was perceived to have negative consequences, such as rejection. Other women, however, disclosed to their sexual partners, and were prepared to reject the men if they do not want to use a condom.

From the above background on *Longlife* group members, we learn that the women's perceptions of disclosure to sexual partners were also shaped by sharing experiences within the advocacy group. We also learn that whether the women had disclosed to their sexual partners or not, they were well aware of the need to manage their health by avoiding HIV infection through unprotected sex. The condom use awareness may be attributed to HIV/AIDS education, and treatment literacy that was initiated by organizations such MSF, TAC, and the AIDS and Society Research Unit (ASRU) (Almeleh, 2006: 154). This is supported by what Sipho Mthathi wrote in the TAC *Equal Treatment* newsletter:

> *"With treatment literacy, it becomes possible for people to draw conclusions about HIV for themselves and not because they are being told by a priest or doctor, for example that condoms used regularly can prevent HIV infection or that proper eating and taking your medicines correctly will ensure that you live a longer and healthier life…"* (TAC, 2007: 3).

The dataset[5] used in this study comprises about two thirds of the starting HAART cohort from Khayelitsha. Some of these were likely to have been activists of HIV/AIDS advocacy groups such as TAC and *Longlife*. The survey did not ask about membership of activist organizations, but asked about affiliation to support groups whose roles also have implications for this study, as discussed in the following section.

[5] The Khayelitsha HAART Panel Study discussed more in detail in Chapter 6

5.4.3 Support group participation

According to counselling guidelines for this Khayelitsha HAART cohort, patients were encouraged to attend support groups for PLWHA conducted at the community health centres (Young, 2003). More women (95%) in the sample used in our study had attended a support group, compared to men (81%) (Maughan-Brown, 2007: 26). Support groups were run by counsellors who facilitated discussions on "barriers to adherence, adverse events, disclosure and other psychosocial issues", and were also "forums for health promotion and education" (Young, 2003: 4). Particularly relevant to our study is the fact that the support groups also discussed condom use and and gave advice on disclosure of HIV status (Young, 2003: 13). Participating in support groups thus probably influenced disclosure behaviour amongst PLWHA in Khayelitsha. It is also likely that their perceptions about stigma in the social environment were influenced by the shared experiences reported in the support groups.

6 Study methods and data description

This study uses secondary data from two panel studies described in the following sections.

6.1 Khayelitsha HAART Panel Study (KHPS)

Our study uses data from the Khayelitsha HAART Panel Study (KHPS), a longitudinal study beginning in 2004 that collected data from HAART patients living in Khayelitsha. In 2004, the AIDS and Society Research Unit at the University of Cape Town (UCT) recruited 242 patients receiving HAART in Khayelitsha into a panel study, and the first round of interviews were conducted in late 2004 and early 2005. This sample was not random, as respondents were recruited through social networks, clinic support groups, and by word of mouth (Almeleh, 2012: 54-55; Maughan-Brown, 2008: 78). However, the sample can be regarded as broadly representative of people on HAART in Khayelitsha, because two thirds of the first cohort of HAART patients was recruited into the study. All those recruited into the panel study had been on HAART for a year or more when they were first interviewed (Almeleh, 2012: 54-55; Maughan-Brown, 2008: 78). The subsequent rounds of interviews were conducted in Wave 2 of the survey in early 2006 (224 successful interviews) and again in Wave 3, in late 2007 (216 successful interviews).

The individual questionnaire probed information about labour-market participation, household income, household composition, adherence to HAART, HIV status disclosure, HIV/AIDS-related stigma, social and community support, traditional medicine, sexual behaviour, and health-seeking behaviour. Most of the questions asked were consistent across waves of data collection but the second round of interviews, (Wave 2) is the only round that asked respondents about internalized stigma. As a result, we can only explore the influence of internalized stigma on risky sexual behaviour and childbearing desires, using this cross-sectional dataset. We use Wave 1 data to explore the influence of experienced stigma and perceived stigma on childbearing intentions, and also to test whether fertility intentions reported in Wave 1 led to pregnancy by Wave 3. Measures of perceived stigma

were ambiguous in Wave 2 and some of them were reformulated for Wave 3. We use Wave 3 data to explore the influence of perceived stigma on risky sexual behaviour. An example of a Wave 2 question on perceived stigma is, "Other people are less likely to avoid people living with HIV/AIDS", compared to the wave 3 question, "Most people prefer to avoid people with HIV as much as possible". The former question is less clear than the latter, and the wave 3 question is more useful for measuring stigma in a social environment. Table 8 provides an overview of variables from the KHPS study used to test specific relationships in our study.

Table 8: Overview of variables from the KHPS used in this study

Wave	N	Hypotheses tested	Chapter
2004/5	n=242	Experienced stigma predicting childbearing intentions	9
		Perceived stigma predicting childbearing intentions	9
		Other determinants of childbearing intentions	9
2006	n=224	Internalized stigma predicting childbearing intentions	9
		Internalized stigma predicting condom use	8
		Other determinants of childbearing and condom use	8 & 9
2007	n=216	Perceived stigma predicting condom use	8
		Other determinants of condom use	8
		Determinants of pregnancy occurrence	9

The demographic distribution of the KHPS baseline sample is shown in Table 9.

Table 9: KHPS 2004/5 (wave 1) sample characteristics

Characteristics	Male	Female	Total
Age groups			
20-29	8 (16.7%)	59 (30.4%)	67 (27.7%)
30-39	26 (54.2%)	107 (55.2%)	133 (55%)
40-49	8 (16.7%)	22 (11.3%)	30 (12.4%)
50+	6 (12.5%)	6 (3.1%)	12 (5.0%)
Education			
No schooling	0 (0.0%)	5 (2.6%)	5 (2.1%)
Primary education	14 (29.2%)	28 (14.4%)	42 (17.4%)
Secondary education	15 (31.3%)	101 (52.1%)	116 (47.9%)
At least matric	19 (39.6%)	60 (30.9%)	79 (32.6%)
Employed	14 (29.2%)	57 (29.4%)	71 (29.3%)
Mean personal income (Rand)	1323	1128	1170
Lives with a partner	21 (46.7%)	53 (29.6%)	74 (33.0%)
Mean HAART duration (years)	2.14	2.04	2.12
Mean number of children	1.9	1.6	1.7

Most of the respondents, as presented in Table 9 are women (80.2%), and mean ages are 33.3 for women and 36.8 for men. About one in three respondents (32.9%) had at least completed matric, with this proportion higher among men (39.6%) relative to women (30.9%). In the 2004/5 survey an almost equal proportion (about 29%) of men and women were employed. Men had a higher average monthly personal income (R1 323) than women (R1 128). Nearly half the sample of men (46.7%) and about one in three women (29.3%) lived with a partner. The overall average number of children was 1.7 where this was higher for men (1.9) than women (1.6). Both men and women had been on HAART for approximately the same average time period of just over two years.

6.2 The Cape Area Panel Study (CAPS)

Our study also uses data from CAPS, a longitudinal study of young adults in metropolitan Cape Town, aged between 14 and 22 (in 2002) until they were aged 20 to 29 (in 2009). Respondents were asked questions pertaining to their demographic details, and their social and economic situation, and sexual and reproductive health behaviour. Our study uses data from 836 African/Black and Coloured young adults who completed interviews for Wave 4 (2006) and Wave 5 (2009) of CAPS. Data for White young adults were not used because of attrition of this group in the survey (see more details below).

CAPS households were selected using a two stage sampling design. The first stage selected a probability sample of census enumeration areas (EAs) from the 1996 South African census. The EAs were also stratified based on the predominant population group (African/Black, Coloured, and White) in each EA. African/Black and White areas were oversampled to obtain roughly equal numbers of African/Black, Coloured, and White young adults. The second stage randomly sampled households within each selected EA. In each recruited household, a household survey was administered to one adult who was knowledgeable about the household, and full-length youth questionnaire was

administered separately to up to three young people. The first wave of CAPS had successful interviews from 5,256 households and 4,752 young adults.

In 2003/2004, a total of 3,927 young adults were successfully re-interviewed over two periods (1,377 in Wave 2A in 2003 and 2,588 in Wave 2B in 2004). Wave 2A was the first survey that included questions about HIV/AIDS-related stigma. These were repeated in subsequent waves (4 (2006) and 5 (2009)). Wave 4 and Wave 5 successfully re-interviewed 3,439 and 2,915 young adults respectively from the initial Wave 1 sample. Wave 4 and Wave 5 successfully re-interviewed 1,075 and 975 respectively of the Wave 2A sample (the sample that included HIV-related stigma questions).

We use Wave 4 (2006) data on stigma attitudes and perceived risk of infection with HIV to predict changes in sexual risk behaviour between 2006 and 2009. Table 10 shows the demographic distribution of the sample in Wave 4.

Table 10: Wave 4 sample characteristics of individuals who responded in all three waves - CAPS

Characteristics	N	Per cent
Gender		
Male	396	47.7
Female	435	52.4
Age group		
15-19	233	28.1
20-24	475	57.4
25-29	120	14.5
Education level		
Grade 0-7	56	6.7
Grade 8-11	473	56.9
Grade 12	259	31.2
Post Matric Degree/Diploma	43	5.2
Population group		
Black/African	479	57.6
Coloured	352	42.4
Total	831	100

Note: Total of 831 exclude 5 individuals who volunteered to report their HIV status in wave 4 as explained in Chapter 7 to follow.

6.3 Ethical considerations

Several measures were taken to ensure that the CAPS and the KHPS study were conducted in line with appropriate ethical principles. Ethical approval for the KHPS was granted by the Ethics Committee of the Centre for Social Science Research (CSSR). Ethical approval for CAPS was obtained from the respective ethical review bodies at the universities of Cape Town and Michigan. Details regarding ethical approval for CAPS can be found at http://www.caps.uct.ac.za.

For KHPS, informed consent was obtained from all KHPS research participants and appropriately documented. For CAPS, each respondent or a parent of a respondent under 18 years old provided informed consent before the interviews. Since the Khayelitsha community is predominantly Xhosa-speaking, consent forms for the KHPS were translated into Xhosa to ensure that respondents understood the purpose of the study before they agreed to provide any information. Interviews were conducted in Xhosa. An example of the consent form is shown in Appendix A.

In order to ensure the safety of the human subjects involved, KHPS interviews were planned in advance and at a location where both respondents and fieldworkers felt comfortable (Almeleh, 2012: 61-62; Maughan-Brown, 2008: 83-84). To ensure that fieldworkers were not exposed to possible harm, interviews were conducted in areas familiar to the interviewers and where they felt safe to conduct their work. In areas where it was perceived to be less safe, interviewers worked in pairs. Respondents were also involved in choosing interviewing places to ensure their anonymity and confidentiality. Furthermore, efforts were made to ensure that the resultant survey data for each study was anonymised. Finally, respondents for the KHPS study received food vouchers as a token of appreciation for their contribution to the research process (Almeleh, 2012: 61-62; Maughan-Brown, 2008: 83-84).

6.4 Attrition

6.4.1 Attrition in the CAPS sample

Because of attrition, by Wave 5 (2009) the CAPS sample was no longer representative of the general population of young adults in Cape Town (see Lam, Ardington, Branson *et al.*, 2012: 29). Since the first questions on HIV/AIDS-related stigma were asked in Wave 2A (2003), the attrition relevant for this study is that between Wave 2A and Wave 4 (2006) and Wave 5 (2009). Attrition was high among White young adults because of migration out of Cape Town, and refusals. Only 51.6% and 34.4% of the sample that was successfully interviewed in Wave 2 did not attrit in Waves 4 and 5 respectively. White young adults are therefore not included in the analysis. Attrition was much lower in the African/Black population (77.0% and 69.2% of the sample that was successfully interviewed in Wave 2 did not attrit in Waves 4 and Waves 5 respectively). Attrition amongst Africans was mainly due to migration back to the rural Eastern Cape Province (a sending province for Africans living in Cape Town). "Coloured" people in Cape Town have historically strong roots in the area, which possibly accounts for the relatively low attrition rate in this group (87.2% and 83.7% of the sample who were successfully interviewed in Wave 2 did not attrit in Wave 4 and Wave 5 respectively).

According to attrition analysis by Lam, *et al.* (2012: 32-34), wealthier, better educated and older participants were more likely to drop out of panel studies over time. We check how these characteristics in the Wave 2 sample (population group, gender, education, age and per capita household income) are related to the overall attrition in Waves 4 and 5 using attrition probit (see Fitzgerald, Gottschalk and Moffitt, 1998). Table B 1 in Appendix B provides the results for the attrition probit. Our results confirm the significant variation in attrition by ethnicity and age (older respondents were more likely to attrit, and White respondents were more likely, and "Coloured" respondents less likely to attrit than African respondents.

6.4.2 Attrition in the KHPS sample

There was a 7.4% attrition rate (18 respondents) between 2004/5 (242 successful interviews in Wave 1) and 2006 (224 successful interviews in Wave 2). Attrition of the 18 respondents was due to death (2 respondents), moving away from the recorded address and unable to be located (10 respondents) and 6 respondents were not known at recorded address and could not be found. The attrition rate between 2004/5 and 2007 (216 successful interviews in Wave 3) was 10.7% (26 respondents). There was no information on attrition in the 2007 survey and therefore we cannot provide a breakdown of reasons for the attrition. One obviously likely reason for attrition in 2007 is death, as this number includes respondents who had died by the time of the 2006 survey.

An earlier study using the KHPS data found that age was the only demographic variable significantly associated with attrition between Wave 1 (in 2004/5) and Wave 2 (in 2006). This study controlled for gender, years of education, religion, number of years HIV positive, being in employment, and personal income (Maughan-Brown, 2008: 268). Results showed that older respondents were more likely to attrit in Wave 2.

We extend Maughan-Brown's earlier attrition analysis to explore how some Wave 1 characteristics (age, gender, years of education, number of years on HAART, being in employment, and personal income) may have been related to attrition in Waves 2 and 3, using attrition probit (see Fitzgerald, Gottschalk and Moffitt, 1998). Table C 1 in Appendix C provides results for the attrition probit for Wave 2 and Wave 3 attrition. Consistent with the previous analysis (Maughan-Brown, 2008), we observe significant variation in Wave 2 attrition by age, where older respondents were more likely to attrit (coefficient = 0.040, p = 0.043) in Wave 2, controlling for Wave 1 characteristics (gender, years of education, number of years on HAART, being in employment, and personal income). We also observe that respondents with a higher personal income were less likely to attrit (coefficient = -0.00136, p = 0.036) in Wave 2, controlling for Wave 1 characteristics. The other Wave 1

characteristics (gender, years of education, number of years on HAART, being in employment) were not significantly related to attrition in Wave 2, and none of the Wave 1 characteristics predict attrition in Wave 3.

7 HIV/AIDS stigma, risk perception and sexual risk behaviour: An empirical analysis of young adults living in Cape Town, South Africa

7.1 Introduction

As discussed in Chapter 2, there are several studies on stigma in South Africa. Unfortunately, the definition of stigma applied in these studies varies considerably. Additionally, none of the studies explored the relationships between stigma attitudes and sexual behaviour outcomes in general and, more specifically, the mediating effect of self-perceived risk on the relationship between symbolic stigma and sexual behaviour.

Building on the background in Chapter 2, we test the suggested mediation relationship, that is, whether symbolic stigmatizing attitudes are associated with reduced risk perception of infection with HIV, which then leads to engagement in risky sexual behaviours. We test this among young people in Cape Town. In light of the gender differences in perceived risk and sexual risk behaviour observed in previous studies, we test the relationship separately for men and women. In addition, other studies argue that men exaggerate their sexually risky behaviour and downplay their risk of infection (Akwara, Madise and Hinde, 2003; Macintyre, Rutenberg, Brown *et al.*, 2004; Shisana, Rehle, Simbayi *et al.*, 2014). We thus conduct separate analyses for young men and young women to avoid distortions due to these and other possible gender differences. Other quantitative studies testing possible links between stigma and sexually risky behaviour used a broad-based measure of stigma, combining various beliefs about HIV and stigmatizing attitudes (e.g. Burkholder, Harlow and Washkwich, 1999; Riley and Baah-Odoom, 2010). We, however, distinguish more carefully between symbolic and other dimensions of stigma.

7.2 Hypotheses

This part of our study uses data from CAPS discussed in Chapter 6. Using panel data collected at two time points, Time 1 (2006) and Time 2 (2009), we test the following distinct hypotheses:

Hypothesis 1: HIV/AIDS-related symbolic stigma attitudes are associated with perceptions of lower risk of infection with HIV at Time 1. In testing this hypothesis, we assume that symbolic stigma attitudes and perceptions of infection with HIV co-vary i.e. they can change together at the same time.

Hypothesis 2: Perceived risk of infection with HIV (at Time 1) is associated with a reduction in risky sexual behaviour (behaviour motivation hypothesis) at a later point in time (Time 2). Sexual behaviours assessed at each time point are occurrences of the behaviours prior to the survey at the respective time. Using Time 1 measures of risk perception to predict changes in sexual behaviours prior to Time 2 relative to Time 1 allows for proper temporal assessment of the relationships between the two variables.

Hypothesis 3: Perceived risk of infection (at Time 1) mediates the relationship between symbolic stigma attitudes at Time 1 and changes in risky sexual behaviour (at Time 2, relative to Time 1). In this hypothesis, we test the preceding hypotheses 1 and 2 simultaneously using structural equation modeling (SEM) techniques.

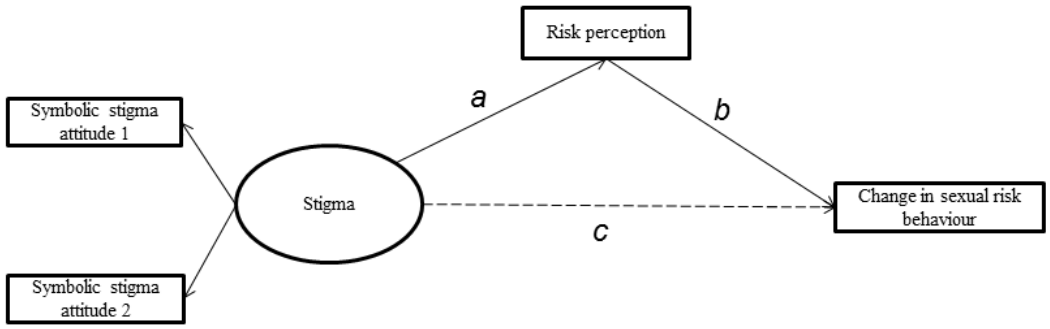
7.3 Methods

7.3.1 Conceptual mediation relationship

Briefly, mediation analysis is used to explore whether the relationship between an independent variable and a dependent variable is facilitated through a third variable called a mediator variable (Baron and Kenny, 1986; Sobel, 1982). Evidence of a mediation relationship is assumed to exist when the mediating variable plays a significant role in influencing the relationship between the independent and dependent variables (Baron and Kenny, 1986). In our study, the independent variable is *symbolic stigma attitude* (a latent variable assessed using multiple measures) which is hypothesized to influence

risk perception of infection with HIV (mediator variable) and this in turn is hypothesized to influence *sexual behaviour* (change in risky sexual behaviour). A conceptual model of this relationship is shown in Figure 4.

Figure 4: Conceptual mediation relationship



In order to proceed with testing this mediation model, we first needed to establish significant relationships between the different pairs of variables: Symbolic stigma attitudes and perceived risk (coefficient *a* in Figure 4), and perceived risk and change in sexual behaviour (coefficient *b* in Figure 4). Early theory for mediation analysis required that the direct relationship between the independent variable and dependent variable (coefficient *c* in Figure 4) be statistically significant before testing the indirect paths that include the mediator variable (Baron and Kenny, 1986; Sobel, 1982). However, other scholars argue that this need not necessarily be the case and that only coefficients, *a* and *b*, in Figure 4 need to be statistically significant (see Iacobucci, Saldanha and Deng, 2007; Rucker, Preacher, Tormala *et al.*, 2011; Zhao, Lynch and Chen, 2010). In our instance we test for all three bivariate relationships as a precursor to the SEM analysis (Figure 4).

In SEM, latent variables measured by multiple variables or indicators are conventionally represented as ellipses (the ellipse would apply to stigma in our study) and the observed variables (including items for stigmatizing attitudes, risk perception, and the derived risky sexual behavior) represented by rectangles. The dotted line shows the effect of the respective stigma attitudes on change in sexual behavior when risk perception is included in the model. In this model, a high measure for stigmatizing attitudes is hypothesized to be associated with reduced risk perception, which in turn is associated with risky sexual behavior.

Structural models with significant coefficients in the relationships between stigma attitudes and risk perception (*coefficient a*), and risk perception and risky sexual behaviour (*coefficient b*) are further analysed by adding covariates for risk perception and sexual behaviour**.** In the SEM model, multiple stigmatizing attitudes, as indicated in Table 12 (following section), are used to measure the latent variable (stigma). Since the model is based on ordinal outcome variables (perceived risk), the robust *mean- and variance-adjusted* (diagonally) weighted least squares (WLSMV) estimator was used (Flora and Curran, 2004).

7.3.1.1 *Model fitness and specification*

Unlike most bivariate and multivariate analyses, model fit in SEM is not determined by a single outcome measure. There are in fact four primary indices used to test how closely the data fit the hypothesized SEM model. Absolute goodness-of-fit is assessed using the χ^2 statistic, and a model is considered a good fit when the analysis produces a non-significant χ^2 value, that is, one that fails to reject the null hypothesis of perfect prediction (Bentler and Bonnet, 1980: 591). However, as the distribution of the χ^2 statistic is skewed based on sample size, large sample sizes invariably produce a statistically significant χ^2 despite the presence of a good fitting model. To correct for this a normed χ^2/df ratio is used as an alternative measure. There are no clear-cut guidelines for the χ^2/df ratio, as some scholars recommend a maximum value of 2 (Tabachnick and Fidell, 2014: 770), whereas others recommend up to a maximum value of 5 (Wheaton, Muthen, Alwin *et al.*, 1977: 99). Another primary

model fit measure is the root mean square error of approximation (RMSEA) which is a measure of the population's approximate or close fit with the hypothesized model, as opposed to an exact fit (Steiger, 1990; Browne and Cudeck, 1993). A model is considered adequate if the RMSEA is close to or less than 0.06 (Hu and Bentler, 1999: 27-28) , though values up to 0.08 are considered acceptable, as they represent reasonable errors of approximation in the sample (Browne and Cudeck, 1993: 144). The Comparative Fit Index (CFI) is used to assess the adequacy of the hypothesized model to a null model. When evaluating model fit, CFI values ≥ 0.90 indicate an adequate fit and CFI values≥0.95 indicate a good fit (Hu and Bentler, 1999: 27). The final primary measure is the Hoelter's Critical N (Hoelter, 1983) which measures the largest sample size deemed adequate for accepting the model. In all instances, the critical minimum threshold of sampling adequacy is 200.

Structural equation models generally differentiate into measurement and structural models. The former specifies the measurement of latent variables by observed variables, and the latter specifies the theoretically hypothesized relationships among latent variables. In the measurement model, a minimum of three observed variables per latent variable is recommended for stable results (Kenny, 2012), and in our case we have only two observed variables for the symbolic stigma attitudes. However, other scholars argue that two observed variables per factor would be acceptable with samples sizes in excess of 400. Their argument is that the increased sample size sufficiently compensates for the diminished number of observed variables (Schermelleh-Engel, Moosbrugger and Müller, 2003; Boomsma and Hoogland, 2001). As our study uses a sample of 831for both sexes, and 435 for young women, we will proceed with using only two observed variables for the latent variable.

7.3.2 Measures and descriptive statistics

HIV/AIDS risk perception

In CAPS Wave 4, respondents were asked the question, "Do you think you have no risk, a small risk, a moderate risk, or a great risk of getting the AIDS virus?" Response categories were: 1 (no risk), 2

(small risk), 3 (moderate risk), 4 (great risk), 5 (If volunteered: Is HIV positive), 8 (Refused) and 9 (Don't know). Table 11 presents a summary of the responses to this question for the 836 African/Black and Coloured young adults who were initially interviewed in Wave 2A and completed interviews for Wave 4 and Wave 5.

Table 11: Distribution of responses to the question on perceived risk of infection with HIV (CAPS Wave 4)

	Male		Female		Total	
Response option	N	%	N	%	N	%
1. No risk	202	50.9	178	40.6	380	45.5
2. Small risk	111	28.0	152	34.6	263	31.5
3. Moderate	36	9.1	39	8.9	75	9.0
4. Great risk	26	6.6	29	6.6	55	6.6
5. (If volunteered: is HIV positive)	1	0.3	4	0.9	5	0.6
9. Don't know	21	5.3	37	8.4	58	6.9
Total	**397**	**47.5**	**439**	**52.5**	**836**	**100.0**

The majority of young adults perceived their risk of infection with HIV to be small (31.5%) or that they were at no risk at all (45.5%). Respondents who were not certain and gave the "don't know" response (6.9%) were treated as missing. The few (5 respondents) who volunteered that they were HIV positive were excluded in further analyses from this point onwards (to remain with 831 respondents).

Stigmatizing attitudes

This study applies the same approach adopted by Maughan-Brown (2010) to operationalize HIV-related stigma. Wave 4 respondents were asked questions (shown in Table 12) about their stigmatizing attitudes. Responses for the questions are on a frequency scale, as follows; 1 (definitely yes), 2 (probably yes), 3 (probably no), 4 (definitely no) and 9 (Don't know). Those who answered 3 or 4 for questions in **section A** are assumed to hold stigmatizing attitudes and there was a similar reasoning for questions in **section B,** in which 1 or 2 show stigma attitudes. From this point onwards, we treat respondents who gave the "don't know" response as missing.

Table 12: Indications of symbolic stigma from CAPS (Wave 4)

Questions asked	Definitely yes	Probably yes	Probably no	Definitely no	Don't know
Section A (An increasing score means an increase in stigma)					
b1. Imagine that you find out that one of your friends is HIV infected. Would you still be friends with them? (**BI**)	80.9%	14.0%	0.5%	4.2%	0.5%
b2. If you knew that a shopkeeper had HIV/AIDS, would you buy fresh vegetables from him or her? (**BI**)	59.7%	22.3%	6.4%	8.9%	2.8%
b3. Would you drink from the same bottle of water as an HIV infected friend? (**BI**)	45.4%	17.6%	10.6%	21.1%	5.4%
Section B (An increasing score means a drop in stigma)					
i1. Would you rather not touch someone with HIV/AIDS because you are scared of infection? (**IN**)	14.2%	11.4%	19.7%	50.5%	4.1%
s1. Do you think HIV/AIDS is a punishment for sleeping around? (**SY**)	24.6%	18.7%	17.6%	31.9%	7.3%
s2. Do you think that many people who get HIV infected through sex have only themselves to blame? (**SY**)	31.7%	21.3%	14.9%	26.8%	5.3%

BI - indicator for behavioural intentions, **IN** - indicator for instrumental stigma, **SY** - indicator for symbolic stigma

Exploratory Factor Analysis and Reliability for stigma items

This section describes the factor analysis used to confirm the estimation of the latent variables in Table 12. The suitability of items for factor analysis was determined by two tests: The Bartlett's Test of Sphericity (BToS) (a significant result indicates sufficient covariance amongst the observed variables to justify the factor analysis) and the Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy (an obtained value of 0.60 or greater confirms suitability). The Kaiser–Meyer–Olkin (KMO)[6] measure of sampling adequacy for these items was 0.60, indicating that the data were reasonably appropriate for this analysis, while the Bartlett's test for sphericity was significant ($\chi 2=737.22$, $p=0.000$), indicating that correlations exist among some of the stigma items. Factor analysis was performed using the maximum likelihood factor extraction method and oblique minimum rotation. The factor analysis using the Kaiser criterion which retains factors with eigenvalues greater than one (Kaiser, 1960), a scree analysis (Cattell, 1966) and parallel analysis (Horn, 1965; Hayton, Allen and Scarpello, 2004) all retained two factors (see Table 13). When loadings less than 0.30 were excluded, the factor analysis yielded a two-factor solution, with a simple structure that confirmed the initial prima facie estimation of two latent variables: Behavioural intentions and symbolic stigma attitudes. The standardized Cronbach's alpha[7] coefficient of reliability for the behavioural intentions items ($\alpha=0.663$) was satisfactory, and very good for the symbolic stigma items ($\alpha=0.752$).

[6] Kaiser recommended a minimum value of 0.6

[7] A value of 0.6 or greater is considered acceptable.

Table 13: Obliquely rotated component loadings for stigma attitudes items from CAPS (Wave 4).

Items	Factor1	Factor2
b1. Imagine that you find out that one of your friends is HIV infected. Would you still be friends with them? (**BI**)	**0.503**	
b2. If you knew that a shopkeeper had HIV/AIDS, would you buy fresh vegetables from him or her? (**BI**)	**0.923**	
b3. Would you drink from the same bottle of water as an HIV infected friend? (**BI**)	**0.516**	
s1. Do you think HIV/AIDS is a punishment for sleeping around? (**SY**)		**0.779**
s2. Do you think that many people who get HIV infected through sex have only themselves to blame? (**SY**)		**0.772**
Eigenvalues	2.022	1.549
Proportion of total variance	0.229	0.220
Number of measures	3	2

Bold numbers indicates factor loadings greater than 0.30
BI - indicator for behavioural intentions, **IN** - indicator for instrumental stigma, **SY** - indicator for symbolic stigma

Sexual behaviour

Sexual behaviour was analysed using variables pertaining to sexual debut, having had more than one sex partner in the 12 months preceding the survey, and condom use at last sex. Respondents were asked the questions: "Have you ever had sexual intercourse, by which I mean full penetration?", "With how many different people have you had sexual intercourse in the last 12 months?" and a combination of questions as follows; "The last time you had sexual intercourse, did you or the other person use any methods to prevent pregnancy or sexually transmitted disease?", followed by, "What method or methods did you or the other person use the last time you had sex?" For the last combination questions, interviewers were not supposed to read out the possible methods and to probe for a method if the respondent indicated that they used one.

We dichotomised responses to these questions according to whether a respondent had ever had sex, whether the respondent had more than one partner (for those who had ever had sex), and whether the respondent used a condom at last sexual encounter. Table 14 shows proportions of the dichotomized variables for Waves 4 (2006) and 5 (2009).

Table 14: Percent distribution of CAPS respondents by categories of sexual behaviour

Sexual behaviour	2006			2009		
	Male	Female	Total	Male	Female	Total
Ever had sex	79.7%	82.0%	80.9%	96.3%	96.0%	96.2%
More than one sex partner in the past 12 months	35.4%	10.5%	22.1%	35.9%	14.5%	24.5%
Condom use at last sex	78.8%	59.3%	68.6%	95.5%	79.8%	87.2%
N	396	435	831	396	435	831

Results from Table 14 show a general increase in the proportion of young adults who reported to have ever had sex between 2006 and 2009 (which is to be expected, as this sample of young adults matures). There was minimal difference in the proportion of young men who reported more than one sex partner in the past 12 months and an increase for young women. Results also show a general increase in the proportion of young adults who reported using a condom the last time they had sex.

The final measure of risky sexual behaviour (for each wave) is a composite score derived by summing dichotomized sexual behavior variables in Table 14. The variables are dichotomized as follows: Ever had sex (1 if ever had sex and 0 if not), multiple sexual partners (1 if respondent had more than one sexual partner in the past 12 months and 0 if not) and condom use (1 if respondent did not use a condom at last sex and 0 if respondent used a condom at last sex.

51 respondents reported that they were married at the time of the 2006 survey, 64 more young adults got married between the two waves, and 10 young adults reported they were no longer married, through separation, divorce or being widowed, between the two waves. For those who were married, condom use is arguably not a good measure of safe sex, especially if people are in committed monogamous relationships. Ideally one would want to include a measure of relationship type (e.g. monogamous or concurrent), but these data were not available for Wave 4, other than marital status.

We created a dichotomous variable for risky sexual behaviour in relation to marital status. Respondents who were not married and never had sex were assigned a value of 0 for no risk and those who were not married but had sex in the 12 months preceding the survey were assigned a value of 1. Further, respondents who were married and had sex are assigned a value of 0 for no risk. This was to account for the fact that sex outside marriage is more of a risk than sex within a marriage, although, of course, this variable cannot account for infidelity.

The dichotomous variables for *ever had sex, multiple sexual partners, condom use, and sex within or outside marriage* were then summed to create a sexual risk behaviour score ranging from 0 (no risk behaviour - never had sex) to 4 (high risk behaviour - have had sex, had more than one sexual partner 12 months prior to the survey, did not use a condom at last sex, and not married) for each wave. In this composite score, married people are safer if they reported using condoms than married people

who were not using condoms regardless of the relationship type. The difference between the composite scores in 2009 relative to 2006 (2009 score minus 2006 score) is the change in sexual behavior (see Table 15 for results).

Table 15: Change in the composite score for risky sexual behaviour

Change	Male		Female		Total	
	N	%	N	%	N	%
-3	1	0.4	0	0.0	1	0.2
-2	8	3.3	9	3.5	17	3.4
-1	58	23.9	47	18.1	105	20.9
0	113	46.5	123	47.3	236	46.9
1	29	11.9	40	15.4	69	13.7
2	22	9.1	28	10.8	50	9.9
3	11	4.5	11	4.2	22	4.4
4	1	0.4	2	0.8	3	0.6

There is a general increase in the number of people with a score of at least one in 2009 relative to 2006 as more young adults engage in sex for the first time. About 12.3% (29) of those with a score change of zero in the combined sample had not had sex in both waves.

Knowledge

In this study, wave 4 respondents were asked questions to assess their knowledge about the transmission of HIV/AIDS, as presented in Table 16. Dummy variables were created for each question, 1 for a correct answer and 0 for the wrong answer. Correct answers assumed in this study are “No” for items (a) and (b), and “Yes” for items (c) and (d). The dummy variables were then summed to create a general knowledge index ranging from 0 to 4.

Table 16: Distribution of knowledge questions about HIV/AIDS - CAPS (Wave 4)

Question asked	Yes	No	Maybe	Don't know
a. Do you think you can get HIV/AIDS by eating food prepared by someone with HIV/AIDS?	9.9	85.9	3.3	1.0
b. Do you think you can get HIV/AIDS by being coughed or sneezed on by someone who has HIV/AIDS?	6.0	87.1	4.0	2.9
c. Can HIV/AIDS be transmitted from a mother to her child?	75.3	9.6	12.3	2.8
d. Is it possible for a healthy-looking person to have HIV?	78.5	16.1	4.1	1.3

Personal knowledge of someone with HIV/AIDS

For this variable, individuals were asked, "Do you personally know anyone who has HIV/AIDS?" About 35.9% of young women (156 young women) and 26.5% of young men (105 young men) personally knew someone who had HIV/AIDS. Two young men (0.2%) were treated as missing because they selected the "don't know" response.

7.3.3 Attrition analysis

We further investigated the effect of overall attrition in Wave 4 and Wave 5 on symbolic stigma and sexual behaviour using the test suggested by Becketti, Gould, Lillard and Welch (1988) (known as the BGLW test). In applying the BGLW test, we regress each of the Wave 2 measures of symbolic stigma and sexual risk behaviour on Wave 2 sample characteristics (population group, age, level of education, and log of household income), a dummy variable for attrition in subsequent waves, and the interaction between the attrition dummy and the other Wave 2 characteristics. Overall differences between the coefficients for attritors and non-attritors are assessed on the joint significance of the dummy variable for attrition and interaction variables, using an F-test (see Baulch and Quisumbing, 2011).

Table B 2 and Table B 3 in Appendix B show results for the BGLW test for attrition bias on symbolic stigma for male and female respondents respectively. Individual coefficients show no significant difference between attritors and non-attritors, for both men and women. Significant differences in the constant term suggest a shift in the location, but no significant difference in the slope. The F- statistic

and p - value for the joint significance test show that data for male (F – statistic = 1.70, p = 0.107) and female (F-statistic = 1.09, p = 0.366) attritors are not different to data for non-attritors. Individual coefficients for risky sexual behaviour for male attritors and non-attritors are different by population group (Table B 4). Generally, Coloured (β = 0.333, p = 0.019) and White (β = -0.061, p = 0.787) male attritors were more likely to engage in risky sexual behaviours than Coloured (β = -0.053, p = 0.551) and White (β = -0.668, p = 0.011) male non-attritors. There was a significant difference in the constant term for both men and women, which suggests a shift in the location of the intercept, but no significant difference in the slope. However, the joint significant test demonstrates no attrition bias for men (F - statistic = 1.33 and p = 0.235). Results for risky sexual behaviour for women (Table B 5) also show no individual coefficient bias and no joint bias (F - statistic = 0.55 and p = 0.800).

Overall, there are indications of possible bias in measures of risky sexual behavior by sex and population group. However, besides the non-random attrition, our analysis found that attrition is unlikely to bias measures for symbolic stigma attitudes and risky sexual behavior.

7.4 Data analysis and results

Descriptive statistics are produced and correlation analyses are undertaken using Stata 13 (StataCorp, 2013). All SEM analysis was performed in R (R Core Team, 2013) using the *lavaan* package version *0.5-16* (Rosseel, 2012). An evaluation of various software programmes that perform SEM shows that the *lavaan* package produces the same results as the other data analysis software programmes (Narayanan, 2012).

7.4.1 Bivariate analysis

Before we proceeded to test the structural equation model, we first needed to establish whether the pairs of variables have statistically significant relationships. These variable pairs are stigma and risk

perception, and risk perception and change in risky sexual behaviour. We tested the statistical significance of major demographic variables (including gender, age, education, and ethnic group) and other covariates (including knowledge about HIV, and knowledge of someone with HIV/AIDS) that might explain differences in perceived risk, and changes in risky sexual behaviour to determine whether to include them in further analyses.

The scales for symbolic stigma attitudes were first reversed for ease of interpretation from this point onwards. Thus a value of 1 stands for "definitely no stigma attitude" and a value of 4 stands for "definitely yes - stigma attitude exists". For the bivariate exploration, a composite index for symbolic stigma was then calculated as the mean of the four frequency scale items. The items range on a scale from 1 to 4. Risk perception is an ordinal variable, and an ordered logistic regression was used on the pairs of variables to give the results shown in Table 17 (results for risk perception). The change in risky sexual behaviour was treated as a continuous variable and the results in Table 17 (for change in risky sexual behaviour) are coefficients from ordinary least square regression.

Table 17: Bivariate relationships between risk perception, change in sexual risk behaviour and selected variables

	Male		Female		Both	
	Risk perception in wave 4	**Change in sexual risk behaviour**	**Risk perception in wave 4**	**Change in sexual risk behaviour**	**Risk perception in wave 4**	**Change in sexual risk behaviour**
Gender						
Female					Ref	Ref
Male					-0.284*	-0.141
					[0.137]	[0.103]
Age	0.0201	-0.113***	0.112**	-0.0820**	0.0649*	-0.0992***
	[0.0387]	[0.0271]	[0.0388]	[0.0287]	[0.0273]	[0.0197]
Age at first sex	-0.0981	0.0084	-0.0229	-0.0232	-0.0294	0.0000754
	[0.0547]	[0.0332]	[0.0535]	[0.0322]	[0.0362]	[0.0220]
Education level						
Grade 0-7	Ref	Ref	Ref	Ref	Ref	Ref
Grade 8-11	-0.518	0.506	-0.0183	0.0674	-0.295	0.321
	[0.381]	[0.274]	[0.484]	[0.345]	[0.299]	[0.216]
Grade 12	-0.897*	0.0548	-0.131	0.422	-0.491	0.332
	[0.410]	[0.295]	[0.494]	[0.354]	[0.310]	[0.226]
Post Matric Degree/Diploma	0.118	0.318	0.0251	0.224	0.0765	0.294
	[0.515]	[0.379]	[0.645]	[0.460]	[0.403]	[0.295]
Population group						
Black/African	Ref	Ref	Ref	Ref	Ref	Ref
Coloured	-0.209	0.361*	-0.983***	0.817***	-0.604***	0.593***
	[0.199]	[0.154]	[0.199]	[0.142]	[0.140]	[0.105]
Knowledge	-0.290*	0.054	-0.0956	0.0602	-0.179	0.0666
	[0.140]	[0.105]	[0.147]	[0.107]	[0.101]	[0.0744]
Know someone with HIV/AIDS	0.338	-0.143	0.774***	-0.443**	0.590***	-0.291**
	[0.220]	[0.163]	[0.199]	[0.144]	[0.146]	[0.108]

Symbolic stigma	-0.0259	0.119	-0.228*	0.150*	-0.140*	0.129**
	[0.0920]	[0.0688]	[0.0892]	[0.0688]	[0.0634]	[0.0485]
Risk perception						
No risk		Ref		Ref		Ref
Very small risk		-0.416*		-0.397*		-0.391***
		[0.174]		[0.163]		[0.118]
Some risk		-0.357		-0.518*		-0.436*
		[0.251]		[0.263]		[0.182]
Great risk		-0.119		-0.618*		-0.366
		[0.280]		[0.279]		[0.198]

Standard errors in brackets
*** p<0.01, ** p<0.05, * p<0.1
NB: Separate models for men and women have no variation by gender, hence the empty cells.

Young men

Results in Table 17 show that there was no statistically significant relationship between symbolic stigma attitudes and perceived risk of infection with HIV (β = -0.026, p = 0.778) for young men. Young men who perceived themselves at "very small risk" of infection with HIV were likely to lower their risk behaviour (i.e. practice safer sex) relative to those who perceived "no risk" of infection with HIV (β = -0.416, p =0.016). The absence of significance for the former relationship indicates that one of the critical requirements for mediation analysis - that all bivariate relationships with the outcome variable be significant – was not met. Accordingly, no mediation analysis was subsequently carried out for the sample of young men.

Since there was a significant difference by population group, we continue the bivariate exploration by population group and gender, with results in Table 18. Separate results for both Black/African and Coloured men show that there were no statistically significant relationships between the pairs of variables: Symbolic stigma attitudes and perceived risk of infection, and perceived risk and change in risky sexual behaviour.

Table 18: Bivariate relationships between risk perception, change in sexual risk behaviour and selected variables – population group and male

	Black - Male		Coloured-Male	
	Risk perception	**Change in sexual risk behaviour**	**Risk perception**	**Change in sexual risk behaviour**
Age	0.111*	-0.106***	-0.132*	-0.111*
	[0.0504]	[0.0296]	[0.0628]	[0.0553]
Age at first sex	-0.0999	-0.0484	-0.0597	0.131
	[0.0682]	[0.0363]	[0.101]	[0.0743]
Education level				
Grade 0-7	Ref	Ref	Ref	Ref
Grade 8-11	-0.107	0.788*	-0.958	0.525
	[0.578]	[0.371]	[0.525]	[0.434]
Grade 12	-0.39	0.301	-1.426*	0.0367
	[0.615]	[0.394]	[0.569]	[0.470]
Post Matric Degree/Diploma	0.409	0.779	-0.16	-0.0833
	[0.710]	[0.454]	[0.820]	[0.772]
Knowledge	-0.194	0.0889	-0.414	-0.0132
	[0.187]	[0.121]	[0.216]	[0.191]
Know someone with HIV/AIDS	0.431	0.00488	-0.25	-0.19
	[0.268]	[0.170]	[0.499]	[0.452]
Symbolic stigma	-0.0633	0.0669	0.104	0.0821
	[0.127]	[0.0804]	[0.155]	[0.152]
Risk perception				
No risk		Ref		Ref
Very small risk		-0.298		-0.646
		[0.195]		[0.330]
Some risk		-0.12		-0.808
		[0.272]		[0.514]
Great risk		-0.12		-0.0163
		[0.301]		[0.582]

Standard errors in brackets
*** p<0.01, ** p<0.05, * p<0.1

Young women

As shown in Table 17, young women who held high symbolic stigma attitudes perceived themselves at reduced risk of infection with HIV (β = -0.228 and p = 0.010). Young women who perceived themselves at "very small risk", "some risk" and "great risk" were likely to reduce their risky sexual behaviour (i.e. practice safer sex), compared to those who perceived themselves at no risk (with respective β coefficients of -0.397, -0.518, -.0618 and p – values of 0.015, 0.049, 0.027). Since these

bivariate relationships were statistically significant, we were able to test for mediation relationships in the sample of young women. Furthermore, it can be seen that older women ($\beta = 0.112$ and $p = 0.004$) and women who personally knew someone with HIV ($\beta = 0.774$ and $p = 0.000$) were more likely to perceive themselves at increased risk of infection with HIV. Coloured women perceived themselves at low risk of infection with HIV, compared to Black/African women ($\beta = -0.983$ and $p = 0.000$). Coloured were also associated with risky sexual behaviour, compared to Black/African women ($\beta = 0.817$ and $p = 0.000$). Young women who personally knew someone with HIV were likely to reduce their risky sexual behaviour ($\beta = -0.443$ and $p = 0.021$). Results for young women also show a direct relationship between high symbolic stigma attitudes and an increase in risky sexual behaviour ($\beta = 0.150$ and $p = 0.030$).

We further tested the bivariate exploration by population group and gender, with results in Table 19. Separate results for both Black/African and Coloured women show no statistically significant relationships between the pairs of variables: Symbolic stigma attitudes and perceived risk of infection, and perceived risk and an increase in risky sexual behaviour.

Table 19: Bivariate relationships between risk perception, change in sexual risk behaviour and selected variables – population group and female

	Black - Female		Coloured - Female	
	Risk perception	**Change in sexual risk behaviour**	**Risk perception**	**Change in sexual risk behaviour**
Age	0.0998*	-0.0549	0.0885	-0.107
	[0.0483]	[0.0305]	[0.0664]	[0.0549]
Age at first sex	0.0338	-0.07	0.00832	-0.0396
	[0.0748]	[0.0433]	[0.0862]	[0.0533]
Education level				
Grade 0-7	Ref	Ref	Ref	Ref
Grade 8-11	-0.888	0.4	-0.276	0.15
	[0.769]	[0.465]	[0.627]	[0.500]
Grade 12	-1.127	0.379	0.212	0.667
	[0.786]	[0.479]	[0.628]	[0.497]
Post Matric Degree/Diploma	-1.44	0.60	1.428	0.238
	[0.915]	[0.557]	[1.118]	[0.839]
Knowledge	-0.288	-0.0643	0.473	0.243
	[0.178]	[0.111]	[0.284]	[0.210]
Know someone with HIV/AIDS	0.416	-0.0111	0.276	-0.768*
	[0.241]	[0.156]	[0.538]	[0.361]
Symbolic stigma	-0.00696	0.112	-0.214	-0.0847
	[0.124]	[0.0778]	[0.152]	[0.129]
Risk perception				
No risk		Ref		Ref
Very small risk		0.0219		-0.574*
		[0.185]		[0.291]
Some risk		-0.121		-0.304
		[0.269]		[0.627]
Great risk		-0.0741		-1.054
		[0.274]		[0.872]

Standard errors in brackets
*** p<0.01, ** p<0.05, * p<0.1

Combined sample (both young men and women)

From results for both sexes combined (Table 17), we see that the relationship between the pairs of variables: Stigma and risk perception (β = -0.140 and p = 0.028), risk perception and change in risky sexual behaviour (β = -0.391 and p = 0.001 for those who perceived themselves at "very small risk" compared to "no risk" and β = -0.436 and p = 0.016 for those who perceived themselves at "some risk" rather than "no risk"). These are statistically significant, and this warrants mediation analysis. In

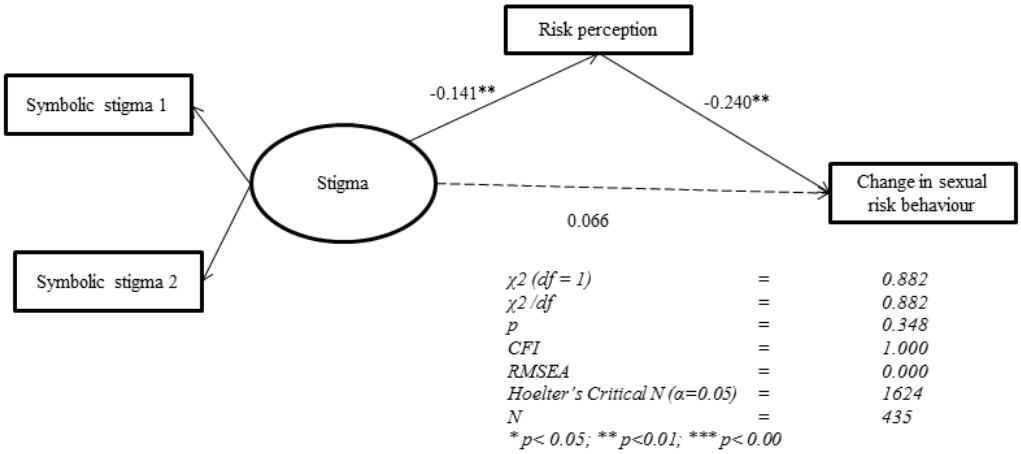
addition, we see that young men (β = -0.284 and p = 0.038) and Coloured respondents (β = -0.604 and p = 0.000) were more likely to perceive themselves at reduced risk of infection, compared to young women and Black/African respectively. Youth who personally knew someone with HIV were more likely to perceive themselves at increased risk of infection than those who did not know anyone with HIV (β = 0.590 and p = 0.000). Those who personally knew someone with HIV (β = -0.291 and p = 0.007), and youth who were older (β = -0.099 and p = 0.000) lowered their risky sexual behaviour. Coloured youth (β = 0.593 and p = 0.000) were associated with an increase in risky sexual behaviour, compared to Black/African youth.

7.4.2 Structural Equation Modeling

Results depicted in Table 17 show that coefficients *a* and *b* are statistically significant at p = 0.05 for young women, and both sexes combined. We thus proceed to test the respective mediation models.

Young women

Figure 5: Preliminary mediation model for young women

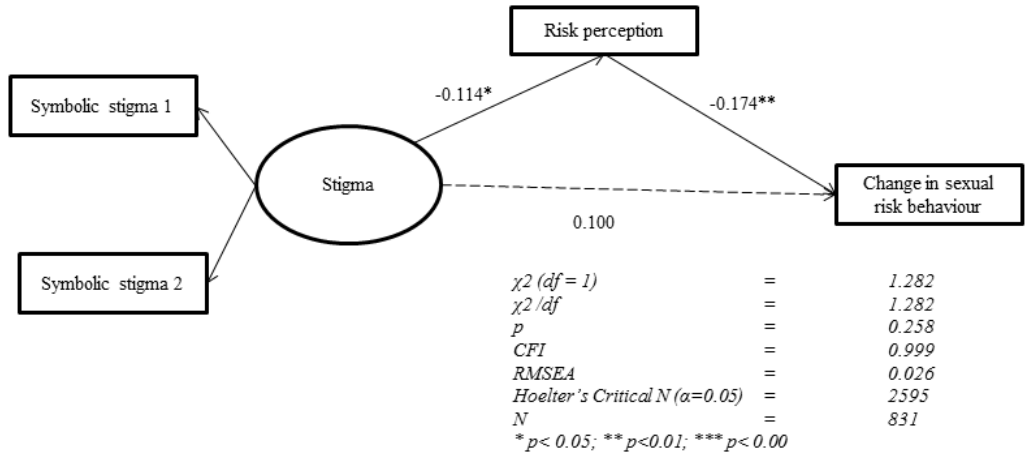


The initial mediation model for young women (Figure 5) indicates excellent fit (χ^2/df = 0.882, CFI = 1.000, Hoelter's Critical N (CN) = 1624, RMSEA = 0.000). Young women who held high symbolic

stigma attitudes perceived themselves at reduced risk of infection with HIV (β= -0.141, p = 0.004), and their perceptions of risk of infection in turn were associated with a reduction in risky sexual behaviour (β = -0.240, p = 0.004). Importantly, the direct path between symbolic stigma and risky sexual behaviour is no longer statistically significant (β = 0.066, p = 0.231) when perceived risk is included in the model, suggesting that risk perception fully mediates this relationship. Since coefficients for path *a* and path *b* are statistically significant, we could later add into this model other variables that might explain variations in both perceived risk, and change in risky sexual behaviour.

Full sample (both man and women)

Figure 6: Preliminary mediation model for both young men and women



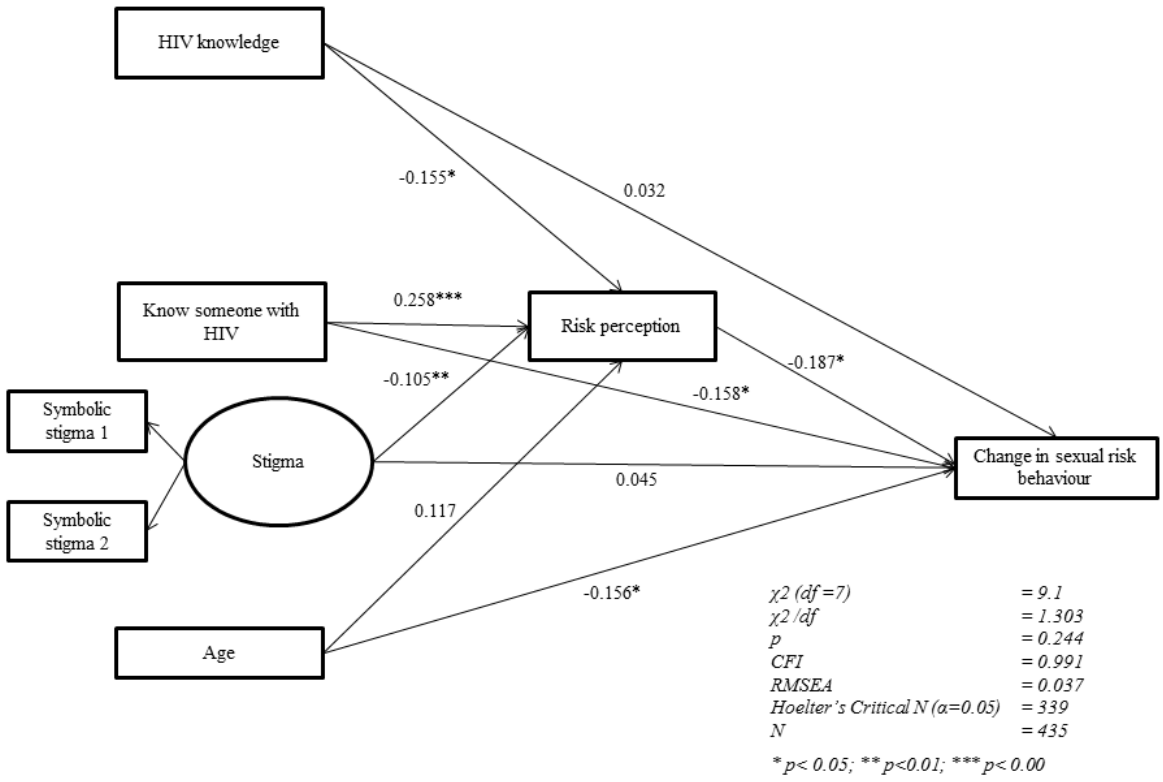
The initial mediation model for the combined sample of young men and women (Figure 6) suggests an excellent fit (χ^2/df = 1.282, CFI = 0.999, Hoelter's Critical N (CN) = 2595, RMSEA = 0.026). Youths who held high symbolic stigma attitudes perceived themselves at reduced risk of infection with HIV (β= -0.114, p = 0.033). Furthermore, youths who perceived themselves at greater risk of infection showed a reduction in risky sexual behaviour (β = -0.174, p = 0.002). The direct path is no longer statistically significant (β = 0.100, p = 0.068) suggesting that risk perception fully mediates the relationship between symbolic stigma attitudes and change in risky sexual behaviour among these youths. Statistically significant coefficients for path *a* and path *b* warrant further exploration of this

model, by addition of other variables that might explain variations in both perceived risk and change in risky sexual behaviour.

SEM for young women with covariates

The mediation model for young women is further tested by including significant predictors of perceived risk and change in risky sexual behaviour, as observed in Table 17. Figure 7 presents the final model from this analysis.

Figure 7: Final mediation model for young women



The final mediation model for young women (Figure 7) suggests an excellent fit (χ^2/df = 1.3, CFI = 0.991, Hoelter's Critical N (CN) = 339, RMSEA = 0.037). Similar to the preliminary model, high symbolic stigma attitudes were associated with perception of reduced risk (β = -0.105, p = 0.007) and perception of increased risk was associated with reduction in risky sexual behaviour (β = -0.187, p = 0.022). It was still observed that risk perception fully mediates the relationship between symbolic

stigma attitudes and change in risky sexual behaviour among the young women, since the direct path was not statistically significant.

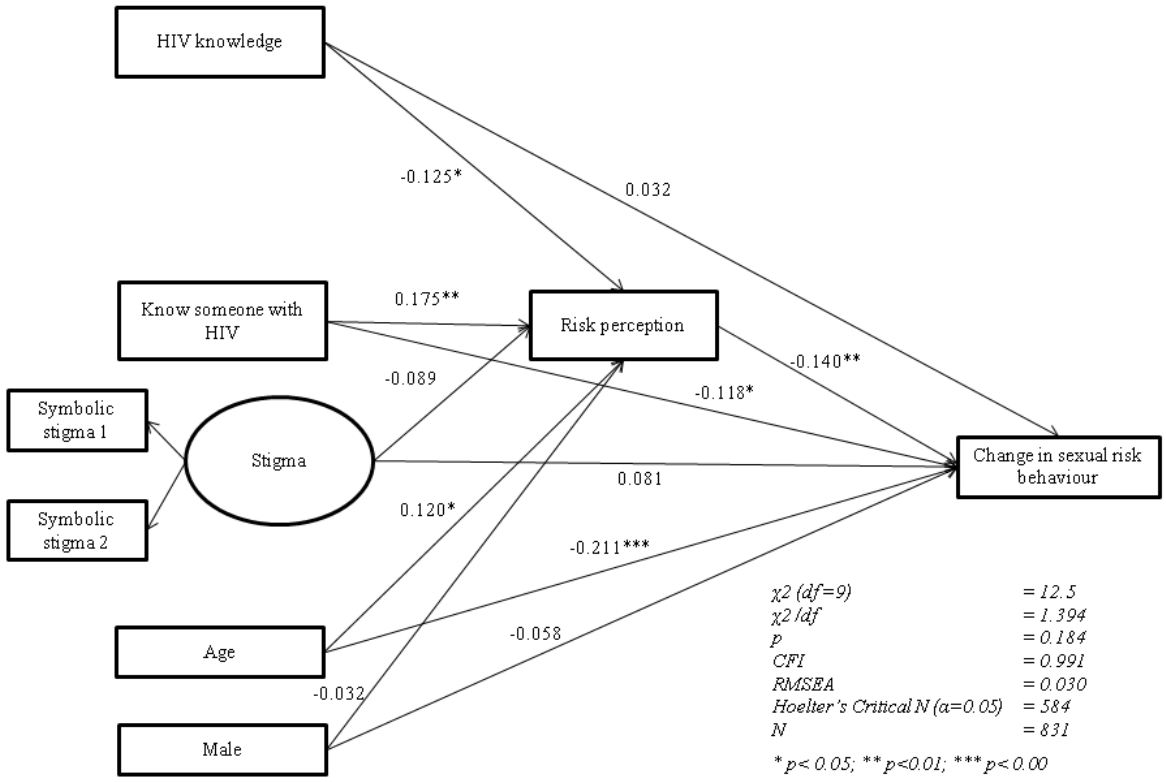
In addition, young women who personally knew someone with HIV perceived themselves at increased risk of infection with HIV/AIDS ($\beta = 0.258$, $p = 0.000$) and were likely to curtail their risky sexual behaviour ($\beta = -0.158$, $p = 0.034$). Increased knowledge about HIV/AIDS was associated with perception of reduced risk ($\beta = -0.155$, $p = 0.028$) and had no significant relationship to change in risky sexual behaviour ($\beta = 0.032$, $p = 0.685$). There was no statistically significant relationship between age and risk perception ($\beta = 0.117$, $p = 0.096$), although older women were associated with a reduction in risky sexual behaviour ($\beta = -0.156$, $p = 0.046$).

These findings can be taken to mean that the relationship between symbolic stigma attitudes and change in risky sexual behaviour was fully mediated by perceived risk of infection with HIV. Young women who held high symbolic stigma attitudes perceived themselves at reduced risk of infection with HIV and the young women who perceived themselves at a reduced risk of infection with HIV were more likely to engage in risky sexual behaviour.

SEM for combined sample of young men and women with covariates

The final mediation model for the combined sample (Figure 8) also suggests a good fit ($\chi^2/df = 1.4$, CFI = 0.991, Hoelter's Critical N (CN) = 584, RMSEA = 0.030). In this model, we observed a weak relationship between stigma attitudes and perceived risk ($\beta = -0.089$, $p = 0.073$). Since this path of the model was not statistically significant, we conclude that the hypothesis that symbolic stigma is associated with perception of reduced risk is not confirmed in our combined sample of young men and women.

Figure 8: Final mediation model for both young men and women



7.5 Discussion

Using data from a sample of youth in Cape Town, South Africa, we examined the hypothesis that individuals who stigmatize PLWHA through moral blaming (symbolic stigma) perceive their risk of infection with HIV to be low, because they attribute the illness to "out-groups" and, as a result, they continue to engage in sexual behaviour that puts them at risk of HIV infection.

Consistent with other studies (Catania, Coates and Kegeles, 1994; Riley and Baah-Odoom, 2010), we found that high symbolic stigma attitudes were generally associated with perceptions of reduced risk of infection with HIV/AIDS. This relationship was not statistically significant for young men. It is, however, significant for young women, and the combined sample of young men and young women. The failure to find a significant relationship for the sample of young men could be a result of different

gender roles which influence their risk perceptions , as argued by other scholars (Akwara, Madise and Hinde, 2003; Macintyre, Rutenberg, Brown *et al.*, 2004; Shisana, Rehle, Simbayi *et al.*, 2014). For example, Macintyre, *et al.* (2004: 246), hypothesize that the risky sexual behaviour of boys is tolerated in certain societies, and this makes boys downplay their own risk.

The youth perceived themselves at no risk at all (45.5%), or at small risk (31.5%) of infection with HIV. This result is not surprising, as other studies observe that young adults in South Africa perceive themselves at low risk of infection with HIV, most likely because they under-estimate their vulnerability (Macintyre, Rutenberg, Brown *et al.*, 2004). One limitation of our study was that risk perception was measured by a single item that may not be reliable compared to a scale.

Our results showed an increase in the proportion of youth who had ever had sex, and this is expected since the young adults in the panel are maturing. This also indicates that abstinence was likely not used to prevent HIV infection among the youth, as observed elsewhere (see Simbayi, Chauveau and Shisana, 2004). There was minimal difference in the proportion of young men who reported more than one sexual partner in the past 12 months preceding each survey (35.4% in 2006 and 35.9% in 2009) and an increase in sexual partners for young women (10.5% in 2006 and 14.5% in 2009). About a quarter of the sample of young adults reported more than one sexual partner in the 12 months prior to each survey.

This increase in sexual partners among youths has been observed in other South African studies, and this increase was more prevalent among men than women (see Shisana, Rehle, Simbayi *et al.*, 2014; Shisana, Rehle, Simbayi *et al.*, 2009; Simbayi, Chauveau and Shisana, 2004; Eaton, Flisher and Aaro, 2003). There was a general increase in the proportion of young adults reporting condom use at last sex

in our study, and this proportion was higher for young men (78.8% in 2006 and 95.5% in 2009, compared to 59.3% in 2006 and 79.8% in 2009 for young women). This increase in condom use was also observed in South African national surveys conducted in 2005 and 2008 and has been attributed to widespread condom distribution (see Shisana, Rehle, Simbayi *et al.*, 2014; Shisana, Rehle, Simbayi *et al.*, 2009: 66). Other South African studies propose that the differential in condom use by gender may be because women fail to negotiate condom use with their older partners (Grebe and Nattrass, 2012; Shisana, Rehle, Simbayi *et al.*, 2014). The increase in multiple partnerships may be offset by condom use to reduce the risk of HIV transmission. However, South Africa's youth still appear to be exposing themselves to the dangers of HIV infection.

Earlier studies using the CAPS sample observed that perception of risk was associated with delays in sexual debut (Anderson, Beutel and Maughan-Brown, 2007; Tenkorang, Rajulton and Maticka-Tyndale, 2009). Our study observed that, even after sexual debut, young women who perceived themselves at increased risk of infection with HIV in 2006 reported increased condom use in 2009, and reduced their compound risk for HIV infection. It is difficult to unravel the reverse causal relationship between risk perception and sexual behaviour beyond sexual debut. This is because those who have had sex might correctly perceive themselves at risk as a result of being sexually active (see Burkholder, Harlow and Washkwich, 1999). However, using longitudinal data helps us to assess the sexual behaviour of youth in the study at a later time period (for example, Wave 2), based on their earlier perceptions of risk (for example, in Wave 1), i.e. whether they continue with the behaviour or not. We found that youth who perceived themselves at reduced risk of infection with HIV are liable to increase their risky sexual behaviour.

After including the mediating effect of perceived risk, the relationship between symbolic stigma attitudes in 2006 and change in risky sexual behaviour by 2009 was not statistically significant for the

young women. This suggests that perceived risk of infection fully mediated the relationship between symbolic stigma attitudes and risky sexual behaviour. Young women who perceived themselves to be at no risk or minimal risk of infection with HIV prior to 2006 (Wave 4) continue to engage in risky sexual behaviour.

The initial findings in the mediation analysis do not change when the covariates are added to the model. Additionally, we observed that young women who personally knew someone with HIV/AIDS perceived themselves at risk of infection. This is consistent with existing studies which argue that witnessing another person ill with HIV/AIDS changes people's perceptions to acceptance of the possibilities of contracting the disease (Macintyre, Rutenberg, Brown *et al.*, 2004: 239). The acceptance of possible risk results in the adoption of safer sexual behaviours in the long term. We also observe that knowledge about HIV/AIDS is associated with increased risky sexual behaviour, through the mediating effect of risk perceptions. This finding is consistent with those of other South African studies that have found no direct relationship between HIV knowledge and safer sexual behaviours (e.g.Peltzer and Promtussananon, 2005; Macintyre, Rutenberg, Brown *et al.*, 2004). This finding also support the argument that factual knowledge about HIV does not necessarily effect change in HIV-related sexual risk behaviours (DeJanes, 2009: 17).

7.5.1 Limitations of the study

Data used in this study do not reflect the national and provincial population in terms of population group, gender, and education, which are the main demographic determinants. This is because the initial sample was designed for metropolitan Cape Town. This limits the generalizability of the research findings to greater Cape Town.

The data was also self-reported and therefore may possibly have limitations that include respondent social desirability bias. For example, young adults in the CAPS sample may have felt uncomfortable answering sensitive questions about their sexual history and safe sex practices. However, the CAPS results concerning sexual behaviour appear to be consistent with findings from other samples of young South Africans interviewed around the same period (Shisana, Rehle, Simbayi *et al.*, 2005; Shisana, Rehle, Simbayi *et al.*, 2009). This allows us to be cautiously optimistic about the validity of the data.

From the sample of individuals who responded in Waves 4 and 5 (836 individuals excluding Whites), there were 5 individuals (in Wave 4) who volunteered to give their HIV status when asked about their perception of getting infected. It is possible that there were other individuals who were HIV positive or found out that they were HIV positive over the course of the survey (between Wave 4 and Wave 5). It is possible that behaviour might change, not only because of fear of contracting HIV, but because individuals find out they are HIV positive. It is important to take this into account when testing changes in constructs such as sexual behaviour in relation to stigma.

Another limitation was that this study examined the mediating effect of risk perception only where it was possible, given the available data. There are no doubt other competing mediators of the relationship between stigma attitudes and change in sexual behaviour.

Finally, it is worth noting that sexual behaviour is not a perfect measure of risk of HIV infection. The risk of HIV infection is driven primarily by the viral load of the sexual partner, and the correlation between sexual behaviour and HIV infection is therefore likely to be weak. As we do not have data on the viral load of sexual partners, we were required to rely on sexual behaviour indicators alone in drawing conclusions about HIV infection risk.

8 Stigma, psychological distress, non-disclosure and risky sexual behaviour: An empirical analysis of PLHWA in Khayelitsha (Cape Town, South Africa)

8.1 Introduction

This chapter builds on the literature discussed in Chapter 3 to explore mediated relationships between HIV/AIDS-related stigma (perceived and internalized) among PLWHA, disclosure of HIV status, depression and anxiety symptoms, and risky sexual behaviour. We explore these relationships because there are very few empirical studies based on samples from developing countries that test these relationships. The few that do explore these find conflicting evidence. In addition, the constructs of stigma, disclosure and risky sexual behaviour are context specific as highlighted in Chapter 3. We explore these constructs, in the context of the unique features defining our area of study, Khayelitsha, as described in Chapter 5. In this chapter we use data from the KHPS study, discussed in Chapter 6, to test the hypotheses discussed below.

8.2 Hypotheses

Hypothesis 1: HIV/AIDS-related stigma (internalized stigma and perceived stigma) is disclosure of HIV status to sexual partners. The literature reviewed in Chapter 3 suggests that PLWHA who experience higher levels of internalized stigma, and/or who perceive higher levels of stigma in their communities, are less likely to disclose their HIV status to sexual partners, for fear of negative consequences.

Hypothesis 2: Non-disclosure of HIV status is associated with unprotected sex. The literature suggests that sexual partners may not initiate condom use in order to prevent HIV infection if one or both partners are not aware that the other partner is HIV positive.

Hypothesis 3: Higher levels of depression symptoms are positively associated with engaging in unprotected sex. Studies that utilise data from the same sample that is analysed in this study observe that experiences of internalized and perceived stigma are associated with higher levels of depression

symptoms and anxiety (Almeleh, 2012; Maughan-Brown, 2008). In this hypothesis, we are testing the assertion that individuals who experience higher levels of stigma are more likely to become distressed and/or depressed, and in turn to try to escape from these depressive symptoms by engaging in risky behaviour, such as unprotected sex.

Hypothesis 4: Stigma among PLWHA (internalized stigma and perceived stigma) is positively associated with non-condom use, through the mediation of, firstly, non-disclosure of HIV status, and, secondly, elevated levels of depression and/or anxiety. In this hypothesis, we test **Hypothesis 1**, **Hypothesis 2** and **Hypothesis 3** simultaneously.

8.3 Methods

8.3.1 Measures and descriptive statistics

The KHPS only asked questions about the internalization of HIV/AIDS-related stigma in Wave 2 (2006). We therefore use data from this wave to test the related hypotheses. We use Wave 3 data (KHPS 2007) to test perceived stigma related hypotheses.

8.3.1.1 *Measures in the KHPS 2006 data*

Internalized stigma

Internalized stigma was measured using an adapted version of the HIV Stigma Scale (Berger, Ferrans and Lashley, 2001) with items shown in Table 20. Respondents were presented with this list of items which are statements about HIV/AIDS, and asked to say to what extent they agreed or disagreed with each statement. We excluded a statement from the scale, "HIV/AIDS is punishment for bad behaviour", as the measurement is conceptually problematic. We argue that the question is more suited to measuring symbolic stigma (moral judgement of someone's behaviour) from the perspective of the general population (see also Chapter 2 on symbolic stigma) than internalized feelings of shame or guilt about being HIV-positive in PLWHA. Failure to agree with such a statement could either

indicate a lack of internalized stigma or simply lack of agreement with the negative moral judgement projected onto PLWHA.

Table 20 shows that the most common emotion associated with internalized stigma was shame, with 50% of respondents disagreeing with the statement: "I never feel ashamed of having HIV". The other measures also show internalized stigma, manifesting in respondents feeling, "like a bad person" (17.4%), "not just as good as others" (15.2%), "unclean" (22.8%), "worse about myself" (16.6%) and "guilty" (21.5%). Responses for items 1 and 3 were reversed and all responses were assigned scores of 1 (Strongly disagree) to 4 (Strongly agree) respectively with a score of 4 indicating extreme feelings of internalized stigma. Any "don't know" responses were treated as missing.

Table 20: Indicators of internalized stigma from KHPS 2006 (wave 2)

To what extent do you agree or disagree with the following?	Strongly disagree	Disagree	Agree	Strongly agree	Don't know
1. I never feel ashamed of having HIV	37(16.5%)	75(33.5%)	76(33.9%)	34(15.2%)	2(0.9%)
2. HIV makes me feel like a bad person	100(44.6%)	84(37.5%)	34(15.2%)	5(2.2%)	1(0.5%)
3. I feel I am just as good as others who are HIV negative	7(3.1%)	27(12.1%)	57(25.5%)	132(58.9%)	1(0.5%)
4. Having HIV makes me feel unclean	92(41.1%)	80(35.7%)	37(16.5%)	14(6.3%)	1(0.5%)
5. People's attitudes about HIV make me feel worse about myself	66(29.5%)	121(54%)	25(11.2%)	12(5.4%)	0(0%)
6. I feel guilty because I have HIV	68(30.4%)	108(48.2%)	40(17.9%)	8(3.6%)	0(0%)

Table 21: Factor loadings for internalized stigma items from KHPS 2006 (wave 2)

Items	Factor1
1. I never feel ashamed of having HIV	-0.182
2. HIV makes me feel like a bad person	0.789
3. I feel I am just as good as others who are HIV negative	0.296
4. Having HIV makes me feel unclean	0.555
5. People's attitudes about HIV make me feel worse about myself	0.602
6. I feel guilty because I have HIV	0.497

Exploratory factor analysis (EFA) for the internalized scale

To begin with, we assessed the suitability of the data for factor analysis. Both the Kaiser–Meyer–Olkin (KMO)[8] measure of sampling adequacy (0.74), and the Bartlett's test for sphericity ($\chi 2$=165.9, p=0.000), confirmed the items were amenable to latent variable analysis. Factor analysis was performed using maximum likelihood estimation and oblique minimum rotation. We employed the Kaiser criterion (Kaiser, 1960) to retain factors with eigenvalues greater than one, and results for the factor analysis are shown in Table 21. The standardized Cronbach's alpha coefficient of reliability for internalized stigma items in Table 20 is 0.638, which indicates satisfactory reliability.

Factor loadings for item 1 and item 3 in the exploratory factor analysis (EFA) for measures of internalized stigma were lower than 0.40, the lowest suggested cut-off value for a sample size of less than 250 (Hair, Black, Babin *et al.*, 2006; Tabachnick and Fidell, 2014; Stevens, 1992). These two items were worded positively, while the other four items are worded negatively, and the wording for these items might have been a problem for respondents or at least not rendered them comparable to the other items, even after reversing the scores for the negatively worded items. Therefore, we performed a further confirmatory factor analysis (CFA) to validate the scale, and test whether excluding these items makes a difference to our measurement model. The two models: (a) including all six items and (b) excluding item 1 and item 3, still suggest an excellent fit, with fit indices shown in Table 22.

Table 22: Goodness-of-fit indices for three measurement models of internalized stigma

Model	χ^2	*df*	χ^2_Δ / df	χ^2_Δ	CFI	TLI	RMSEA
Model A	9.79	9	1.09		0.995	0.992	0.020
Model B	4.73	2	2.37	5.06	0.981	0.944	0.078

Model A - all six items, **Model B** - excluding items 1 and 3

[8] Kaiser recommended a minimum value of 0.6

Model B is nested within Model A and we test whether excluding items 1 and 3 changes the fit of the model. We perform a chi-square difference test (χ^2_Δ) to test the significance of the difference in the models specified.

Model A versus Model B

H_0: Model A and Model B equally fit the data

H_1: Model A is better than Model B

Test statistic: $\chi^2_\Delta = \chi^2_A - \chi^2_B = 5.06 \; and \; df_\Delta = df_A - df_B = 7$

A chi-square distribution with 7 degrees of freedom and at the 0.05 level of significance has a value of 14.07, which is greater than 5.06. This shows that there was no statistically significant difference between Model A and Model B. Therefore, excluding the two items (items 1 and 3) does not significantly diminish the validity of the model.

After excluding items 1 and 3, the alpha coefficient of reliability improved from satisfactory (0.638) to good 0.704. This means that excluding these items (item 1 and item 3) improved the reliability of our internalized stigma scale, at the same time not changing the validity of our measurement model. Based on results from the EFA and CFA, we decided to exclude items 1 and 3 from this point onwards.

Depression and anxiety symptoms (wave 2)

All the three waves of the KHPS asked questions about depression symptoms and anxiety using selected questions adapted from the Virginia Commonwealth University and Rhodes University Eastern Cape Pilot Survey (2004) as shown in Table 23. The responses are based on a five-point frequency scale as follows: never (1), hardly ever (2), sometimes (3), often (4) and all the time (5).

Slightly more than half of the sample never or hardly ever felt depressed, lonely, nervous, or stressed and worn out, or exhausted (items 2-5). At least about one in three of the respondents sometimes experienced each of these states and the most experienced symptom of depression was the feeling of being overcome by mounting problems (item 1).

We, further, performed a factor analysis to check if the items were measuring the same construct. The Kaiser–Meyer–Olkin (KMO) measure of sampling adequacy was 0.833 and the Bartlett's test for sphericity was significant (χ2=483.1, p=0.000). Both tests indicated that conducting factor analysis on the data was appropriate. We then performed an exploratory factor analysis using oblique minimum rotation. Through exploration, we observed that item 1 was not loading on the same factor as the other four items. This could be due to conceptualization problems, because item 1 appears to be a double barrelled question: It asks about problems piling up, and then about failure to overcome them. As a result, we decided to drop item 1 in further analyses. Finally, we performed an exploratory factor analysis using the remaining four items (items 2-5) to produce the results in Table 24. The results show that coefficients for all items are greater than the minimum value of 0.40. We further performed a confirmatory factor analysis using items 2 to 5, and the results suggest an good fitting model ($\chi^2(2) = 0.635$, $\chi^2/df = 0.318$, CFI = 1.000, Hoelter's Critical N (CN) at 0.05 level of significance is 5367, RMSEA = 0.000 with 90% confidence interval of 0.000-0.094).

Table 23: Indicators of depression and anxiety symptoms from KHPS 2006 (wave 2)

In the past year how often have you:	Never	Hardly ever	Sometimes	Often	All the time
1. Felt that problems are piling up so high that you cannot overcome them	63(28.1%)	22(9.8%)	124(55.4%)	13(5.8%)	2(0.9%)
2. Felt that you cannot stop feeling very sad and depressed – even with help from your friends or family?	78(34.8%)	55(24.6%)	84(37.5%)	7(3.1%)	0(0%)
3. Felt lonely?	108(48.2%)	34(15.2%)	68(30.4%)	13(5.8%)	1(0.5%)
4. Felt nervous or stressed?	87(38.8%)	35(15.6%)	93(41.5%)	9(4%)	0(0%)
5. Been so worried or anxious that you have felt tired, worn out or exhausted	91(40.8%)	27(12.1%)	94(42.2%)	9(4%)	2(0.9%)

Table 24: Factor loadings for items measuring depression and anxiety symptoms from KHPS 2006 (Wave 2)

Item	Factor 1
Felt that you cannot stop feeling very sad and depressed – even with help from your friends or family?	**0.774**
Felt lonely?	**0.877**
Felt nervous or stressed?	**0.896**
Been so worried or anxious that you have felt tired, worn out or exhausted	**0.730**

The standardized Cronbach's alpha coefficient of reliability for depressive symptoms and anxiety items (items 2 to 5) was 0.84, which indicates excellent reliability. We then create a depression and anxiety score that was equal to the mean score of the four item measures. The score ranges from 0 to 5, where a higher score indicates higher levels of depression symptoms and anxiety.

Risky sexual behaviour

Individuals who participated in the KHPS 2006 survey were asked questions about specific intimate relationships, for at most four sexual partners in the year preceding the survey. 44 respondents out of the 224 respondents in that wave did not have a sexual relationship in the year preceding the survey. Of the 180 respondents who had sex, most of them reported one sexual partner (94.1%), 3.5% reported two sexual partners, 1.8% reported three sexual partners, and one respondent reported four sexual partners. Here we explore the most recent relationship, which in many cases (167 respondents or 92.8%) was still ongoing at the time of the survey. 38 men and 142 women recorded that they had sex in the 12 months preceding the KHPS 2006 survey.

Condom use

Respondents were asked questions about condom use within specific relationships, as shown in Table 25.

Table 25: Condom use practices with the most recent sexual partner in KHPS 2006 (wave 2)

When you had sex with [**partner**], how often if ever did you use a condom?	Male		Female		Total	
	N	%	N	%	N	%
Always	33	86.8	102	71.8	135	75.0
Usually	1	2.6	6	4.2	7	3.9
Sometimes	3	7.9	28	19.7	31	17.2
Never	0	0.0	6	4.2	6	3.3
Refused	1.0	2.6	0.0	0.0	1.0	0.6
Total	38	100.0	142	100.0	180	100.0

As shown in Table 25, three quarters of those who had sex always used a condom with the most recent partner, and condom use was higher among men (86.8%) than women (71.8%). A higher proportion of women than men usually used condoms, or use condoms some of the time. We can also see that only women reported never having used a condom with their most recent sexual partner.

Female respondents who did not use a condom were asked to state their reasons for not using a condom with their most recent sexual partner. The distribution of the reasons is shown in Table 26. Responses show that the most cited reason for not using a condom was that it reduces pleasure (14 respondents). This was followed by stigma related motivations: Fear of revealing one's HIV status through insistence on condom use (7 respondents), and difficulty in discussing condom use (6 respondents). Some women did not use a condom because their partner was also HIV positive (4 respondents). This might be an indicator of lack of knowledge about HIV/AIDS, but it might also be the result of an informed decision, especially if both partners were on HAART and had undetectable viral loads. Unfortunately the data does not allow us to explore this issue further.

A few of the women who had sex, (43 respondents) also provided data on who generally made decisions about whether or not to use a condom. We can see (from Table 26) that few women (4 respondents) made the decision and in most cases it was either the partner (16 respondents) or a joint decision (19 respondents). Only about a quarter of the women had ever disagreed with their partners, or argued about using condoms with their most recent partner.

Table 26: Reasons for not using a condom, decision maker for condom use and disagreements about condom use from the KHPS 2006 sample

	N
Why don't/didn't you use condoms with this partner? (females who did not always use a condom)*	
S/he is positive	4
Condoms reduce pleasure	14
Condoms would make my partner suspicious of my positive status	7
Found it difficult to discuss	6
Did not have condoms with me	2
Who generally made the decision not to use a condom? (all women who had sex)	
Myself	4
My partner	16
Joint decision	19
Don't know	-
Have you ever disagreed or had arguments about using condoms with this partner? (all women who had sex)	
Yes	37
No	105
Refused	-

*Not all women provided a reason for not using a condom

Disclosure

Respondents were asked whether they had disclosed their status to a specific sexual partner, as shown below.

Table 27: HIV status disclosure to the most recent sexual partner in the KHPS 2006

Have you disclosed to this partner?	Male		Female		Total	
	N	%	N	%	N	%
Yes	37	100.0	123	86.6	160	89.4
No	0	0.0	19	13.4	19	10.6
Total	37	100.0	142	100.0	179	100.0

Most of the respondents (89.4%) had disclosed to the most recent sexual partner, and 10.6% had not disclosed. All men disclosed their HIV status to the most recent sexual partner and therefore, in some cases where we test variation in disclosure to a sexual partner, we explore data for women only. The

19 women who did not disclose their status to their sexual partner provided reasons for this (see Table 28).

Table 28: Reasons for non-disclosure of HIV status to the most recent sexual partner by women in the KHPS 2006 sample

Why have you not disclosed to your partner?	N
I was afraid my partner would leave me	10
My partner did not like the condom	2
I was economically dependent on my partner	1
I was afraid my partner would tell other people	1
I was afraid my partner would be angry	1
My partner had negative attitudes towards people with HIV/AIDS	2
I was using condoms so I thought s/he was protected	1
Other reason	1

The most cited reason for non-disclosure of HIV status by women was fear of abandonment, as reported by 10 women. Two women did not disclose because their partner had negative attitudes towards PLWHA, and both reasons show fear of stigma. Two women did not disclose because their partner did not like using condoms.

8.3.1.2 *Measures in the KHPS 2007 data*

Perceived stigma

Perceived stigma was assessed using four frequency scale statements which respondents were asked agreement or disagreement with, as shown in Table 29. Table 29 shows that most of the respondents (about 80%) agreed with the statement that most families support an HIV positive family member when they disclose. This suggests that this cohort had or had heard generally good experiences with regard to disclosure within families. A sizable percentage of the sample agreed that PLWHA were often treated unfairly (40.3%), that people say unkind things about them (45.4%) and that they are avoided by most people (32.9%). These responses show that respondents were aware of stigma towards PLWHA. There was a high degree of uncertainty for the last three items, as at least 47% of respondents neither agreed nor disagreed with each of the statements.

Responses for item 1 were reversed and all responses were assigned scores of 1 (strongly disagree) to 5 (strongly agree), with a score of 5 indicating high perception of stigma in the broader community. We performed a factor analysis to check if the items were measuring the same construct, and we used the same criterion employed previously. The Kaiser–Meyer–Olkin (KMO) measure of sampling adequacy was 0.69 and the Bartlett's test for sphericity was significant (χ2=288.7, p=0.000), indicating that the samples met the criteria for factor analysis. The factor loadings are shown in Table 30. Coefficients for items 2 to 4 are all greater than the minimum value of 0.40, and the coefficient for item 1 is 0.2466. The lower coefficient for item 1 could be a result of this item being a poor measure, as it asked about perceptions of stigma within the family. This differs from the other items, which asked about perceptions of stigma from people in general. However, it was not possible to drop this item and conduct the CFA, as such a model would have been just identified and therefore have no degrees of freedom. As an alternative solution, we conducted a confirmatory factor analysis using all four items on the perceived stigma scale, and this analysis indicated an excellent fitting model ($\chi^2(2)$ = 2.503, χ^2/df = 1.2515, CFI = 0.998, RMSEA = 0.036). Given these results, we assumed that excluding item 1 (already found to be the weakest), will improve the validity of the scale. Further, the Cronbach's alpha coefficient of reliability for perceived stigma items including item 1 was 0.747 and excluding item 1 was 0.842. The increase in reliability confirmed that removing item 1 from the scale was both correct and appropriate.

Table 29: Indicators of perceived stigma from KHPS 2007

Please tell us how strongly you agree or disagree with the following statements	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know
1. Most people with HIV are supported by their families when they disclose their HIV status	0(0.0%)	2(0.9%)	29(13.4%)	128(59.3%)	54(25%)	3(1.4%)
2. People with HIV often get treated unfairly or badly by others	0(0.0%)	11(5.1%)	115(53.2%)	84(38.9%)	3(1.4%)	3(1.4%)
3. People say unkind things about HIV positive people	0(0.0%)	11(5.1%)	104(48.2%)	92(42.6%)	6(2.8%)	3(1.4%)
4. Most people prefer to avoid people with HIV as much as possible	1(0.5%)	26(12%)	102(47.2%)	67(31%)	4(1.9%)	16(7.4%)

Table 30: Factor loadings for perceived stigma items from KHPS 2007

Items	Factor 1
Most people with HIV are supported by their families when they disclose their HIV status	0.2466
People with HIV often get treated unfairly or badly by others	0.7849
People say unkind things about HIV positive people	0.9631
Most people prefer to avoid people with HIV as much as possible	0.6854

Depression and anxiety symptoms (wave 3)

Responses for the measures of depression and anxiety symptoms in the KHPS 2007 are shown in Table 31. Most of the respondents (more than half of the sample) never or hardly ever felt depressed, lonely, nervous or stressed, or worn out, or exhausted. About one in three of the respondents sometimes felt each of these depression and anxiety symptoms.

The Kaiser-Meyer Olkin (KMO) and Bartlett's test of sampling adequacy was used to examine the appropriateness of factor analysis on the measures of depression symptoms in the KHPS 2007. The KMO value was 0.828 and Bartlett's test was significant ($\chi 2=545.2$, $p=0.000$). Therefore the data was suitable for factor analysis. Similar to our analysis in the wave 2 data for depression symptoms and anxiety, we performed an exploratory factor analysis using oblique minimum rotation and maximum likelihood estimation. As with the Wave 2 data, we drop item 1 because it is conceptually problematic. Results for the exploratory factor analysis are shown in Table 32. Coefficients for all items are greater than the minimum value of 0.40. We performed a confirmatory factor analysis using items 2 to 5, and the results suggest an excellent fit ($\chi^2(2) = 2.609$, $\chi^2/df = 1.305$, CFI = 0.999, Hoelter's Critical N (CN) at 0.05 level of significance is 944, RMSEA = 0.038 with 90% confidence interval of 0.000-0.146). The standardized Cronbach's alpha coefficient of reliability for depression symptoms and anxiety items was 0.84, which indicates very good reliability.

Table 31: Indicators of depression and anxiety symptoms from KHPS 2007 (wave 3)

In the past year how often have you:	Never	Hardly ever	Sometimes	Often	All the time
1. Felt that problems are piling up so high that you cannot overcome them	88(40.7%)	19(8.8%)	94(43.5%)	12(5.6%)	3(1.4%)
2. Felt that you cannot stop feeling very sad and depressed – even with help from your friends or family?	80(37%)	39(18.1%)	88(40.7%)	8(3.7%)	1(0.5%)
3. Felt lonely?	94(43.5%)	29(13.4%)	80(37%)	7(3.2%)	6(2.8%)
4. Felt nervous or stressed?	69(31.9%)	39(18.1%)	97(44.9%)	9(4.2%)	2(0.9%)
6. Been so worried or anxious that you have felt tired, worn out or exhausted	85(39.4%)	52(24.1%)	71(32.9%)	6(2.8%)	2(0.9%)

Table 32: Factor loadings for items measuring depression and anxiety symptoms from KHPS 2007 (Wave 3)

Item	Factor 1
Felt that you cannot stop feeling very sad and depressed – even with help from your friends or family?	**0.846**
Felt lonely?	**0.813**
Felt nervous or stressed?	**0.876**
Been so worried or anxious that you have felt tired, worn out or exhausted	**0.790**

Risky sexual behaviour and disclosure

There were 216 respondents in the Wave 3 KHPS 2007 sample, and 48 of these did not have sex in the 12 months preceding the survey. The 168 people who did have sex were asked about condom use practices, and the results are reported in Table 33.

Similar to Wave 2, a higher proportion of men (70%) reported having used a condom every time they had sex in the year preceding the survey, compared to women (58%). The KHPS 2007 did not ask whether respondents had disclosed their HIV status to their sexual partners. Instead, the survey asked respondents whether they knew the HIV status of the person they last had sex with, and also whether the partner knew their status. We used the two variables to test whether knowing each other's HIV status was associated with condom use.

Results in Table 33 show that about two thirds of the sample knew their last sexual partner's status, with men more likely to have known than women. About four in five respondents reported that their last sexual partner knew the respondent's HIV status, with a lower proportion of women than men. Two thirds of the sample had their last sexual encounter with a person they were not married to, but someone they said they loved. Non-marital sex was more common among women (70%) than men (56%).

Table 33: Risky sexual behaviour and disclosure related variables from the KHPS 2007

		Male	Female
How often did you use condoms when you had sex during the past year?		N (%)	N (%)
	None of the time	5(13.5)	12(9.2)
	Some of the time	4(10.8)	32(24.4)
	Most of the time	2(5.4)	11(8.4)
	All of the time	26(70.3)	76(58)
What is the HIV-status of the last person you had sexual intercourse with?	Positive	27(39.9)	69(44.4)
	Negative	9(24.3)	42(23.6)
	Don't know	7(35.8)	62(31.9)
Did your last sexual partner know your HIV status?	Yes	38(88.4)	141(81.5)
	No	3(7)	24(13.9)
	Don't know	2(4.7)	8(4.6)
What was your relationship with him or her?	Spouse/married	19(44.2)	52(30.1)
	Someone you loved but were not married to	24(55.8)	121(69.9)
N		43	173

8.3.2 KHPS attrition analysis

We investigated the possible effect of attrition in Wave 2 and Wave 3 on our variables of interest. These are: perceived stigma, depression and anxiety symptoms, disclosure of HIV status to a sexual partner, and condom use. We were not able to test the possible effect of attrition on internalized stigma, as questions on this were not included in the baseline survey. We carried out a multivariate regression for each of these variables on attrition, while controlling for some demographic variables in Wave 1 (age, gender, years of education, number of years HAART duration, employment status, and personal income). Perceived stigma scores (ranging from 1 to 5) and depression symptoms and anxiety scores (ranging from 1 to 5) were derived as the mean of the respective frequency scale measures (discussed in the preceding sections), and ordinary least squares regression was used. Disclosure of HIV status to a sexual partner is a binary variable and condom use is an ordinal variable (see Table 25 and Table 33). A binary logistic regression was applied for the disclosure outcome variable, and an ordered logistic regression applied for the condom use variable. Results for these multivariate analyses for attrition are shown in Table C 2 (for Wave 2 attritors) and Table C 3 (for Wave 3 attritors) in Appendix C.

Wave 2 attritors were more likely to report higher levels of depression and anxiety symptoms relative to non-attritors (coefficient = 0.498, p=0.032) while controlling for Wave 1 characteristics (age, gender, years of completed education, number of years HAART duration, employment status, and personal income). There was no statistically significant relationship between Wave 2 attrition and either disclosure of HIV status to sexual partner (coefficient = -0.675, p = 0.477) or condom use (coefficient = 1.056, p = 0.337). Wave 3 attrition was not significantly related to each of our main variables of interest, that is, perceived stigma (coefficient = 0.214, p=0.175), depression and anxiety symptoms (coefficient = -0.130, p = 0.523), disclosure of HIV status to sexual partner (coefficient = -0.009, p = 0.992) and condom use in the preceding year (coefficient = -0.321, p = 0.663). In summary, Wave 2 of the KHPS lost significantly older respondents and respondents who had lower personal

incomes, relative to Wave 1 (see Chapter 6). Attritors were also more likely to report higher levels of depression and anxiety symptoms. However, besides the non-random attrition in relation to these variables, our analysis shows that attrition was unlikely to bias measures for perceived stigma, disclosure of HIV status to a sexual partner, and condom use.

8.4 Data analysis and results

8.4.1 Bivariate and multivariate analysis for internalized stigma (KHPS 2006)

We explored bivariate relationships to test whether internalized stigma predicts non-disclosure and higher levels of depression and anxiety. We also tested whether non-disclosure and higher levels of depression symptoms predicted non-condom use. The disclosure of HIV status to a sexual partner outcome variable is binary (see Table 27) (an individual either disclosed or did not disclose) and a bivariate logistic regression analysis was applied (Odd ratios (OR) are presented). The depression variable, derived as the mean of the depression and anxiety item scores, is a continuous variable, and therefore ordinary least squares regression was applied. The predictor variable is an internalized stigma score derived as the mean of the stigma item scores shown in Table 20. For the condom use outcome variable, we use an ordered logistic regression since this is an ordinal variable (see Table 25). Results of the bivariate analysis for women are shown in Table 34, and for the combined sample in Table 35.

Women respondents who lived with a partner were more than five times likely to disclose to their sexual partner (OR = 5.284, p = 0.031) and more likely to have experienced lower levels of depression and anxiety symptoms (coefficient = -0.268, p=0.050). Older age was associated with increased levels of depression and anxiety symptoms (coefficient = 0.020, p=0.028) and the predicted odds of reporting inconsistent condom use (combined categories of ‘usually’, ‘sometimes’ and ‘never’) versus consistent condom use (‘always’) were 8.2% less likely for each unit increase in age (OR=0.918, p=0.030).

The bivariate analysis shows that there was no statistically significant relationship between experiences of internalized stigma and disclosure (OR = 0.635, p = 0.256) among women. There was also no statistically significant relationship between disclosure of HIV status to a sexual partner and condom use (OR = 0.864, p = 0.796).

Table 34: Bivariate relationships between internalized stigma, disclosure, depression and condom use - KHPS 2006 females

Variable	Disclosure Odds ratio	Depression symptoms β - coefficient	Condom use Odds ratio
Age	1	0.0202*	0.918*
	[0.0451]	[0.00919]	[0.0364]
Years of completed education	0.981	-0.0701**	0.897
	[0.0971]	[0.0237]	[0.0593]
HAART duration	1.094	0.0586	1.058
	[0.257]	[0.0579]	[0.180]
Lives with a partner	5.284*	-0.268*	1.409
	[4.073]	[0.136]	[0.540]
Support group affiliation	0.961	0.0132	0.965
	[0.479]	[0.123]	[0.360]
Internalized stigma	0.635	0.300**	1.603
	[0.256]	[0.0977]	[0.513]
Disclosure		0.261	0.864
		[0.203]	[0.488]
Depression symptoms			1.968**
			[0.461]

Standard errors in brackets
* p<0.05, ** p<0.01, *** p<0.001

Results show that women respondents who had experiences of internalized stigma also reported higher levels of depression and anxiety symptoms (coefficient = 0.300, p = 0.002) and the predicted odds of reporting inconsistent or no condom use (combined categories of 'usually', 'sometimes' and 'never') versus consistent condom use ('always') were almost twice (OR=1.968, p=0.004) that of those who experienced increased levels of depression and anxiety symptoms. There was no statistically significant relationship between disclosure of HIV status to a sexual partner and depression and anxiety symptoms (coefficient = 0.261, p=0.198).

We also tested if there was a direct relationship between internalized stigma and condom use. If a statistically significant relationship was observed, then this was a result of the effect of at least one intervening variable, since the literature does not suggest any direct relationship between the two. We found no statistically significant relationship between internalized stigma and condom use (OR = 1.603, p = 0.140) among the women.

Table 35: Bivariate relationships between internalized stigma, disclosure, depression and condom use - KHPS 2006 both sexes

Variable	Disclosure Odds ratio	Depression symptoms β - coefficient	Condom use Odds ratio
Male	1	-0.164	0.302*
	[.]	[0.141]	[0.169]
Age	1.025	0.015	0.907**
	[0.0431]	[0.00799]	[0.0334]
Years of completed education	0.949	-0.0484*	0.933
	[0.0867]	[0.0193]	[0.0515]
HAART duration	1.078	0.079	1.047
	[0.255]	[0.0530]	[0.171]
Lives with a partner	5.849*	-0.338**	1.039
	[4.475]	[0.117]	[0.370]
Support group affiliation	0.935	0.0587	0.965
	[0.459]	[0.111]	[0.335]
Internalized stigma	0.643	0.257**	1.661
	[0.258]	[0.0901]	[0.499]
Disclosure		0.206	0.71
		[0.199]	[0.398]
Depression symptoms			1.915**
			[0.413]

Standard errors in brackets
* p<0.05, ** p<0.01, *** p<0.001

Results for the combined sample of men and women who responded in the KHPS 2006, shown in Table 35 suggest that respondents who lived with a partner were more likely to disclose their HIV status to the partner (OR=5.849, p=0.021) relative to those who did not live with a partner. Respondents who lived with a partner were also more likely to experience reduced level of depression symptoms (coefficient =-0.338, p=0.004). More experience of internalized stigma are associated with

increased depression and anxiety symptoms (coefficient =0.257, p=0.004). Predicted odds of reporting inconsistent or no condom use ('usually', 'sometimes' or 'never') versus consistent condom use ('always') for men (OR = 0.302, p = 0.032) and increasing age (OR = 0.907, p = 0.008) show that both were associated with increased consistent condom use. We also observed that respondents who experienced higher levels of depression and anxiety symptoms were more likely to report inconsistent condom use (OR = 1.915, p = 0.003). There were no statistically significant relationships between internalized stigma and disclosure of HIV status to a sexual partner (OR = 0.643, p = 0.271), disclosure of HIV status to a sexual partner and depression and anxiety symptoms (coefficient = 0.206, p = 0.299), and disclosure of HIV status to a sexual partner and condom use (OR = 0.71, p = 0.541).

We further explored a multivariate relationship between condom use and the hypothesized predictors (internalized stigma, disclosure of HIV status to a sexual partner, depression and anxiety symptoms) while controlling for demographic variables (age, years of completed education, living with a partner and HAART duration). Results for the multivariate analysis are shown in Table 36.

Results in Table 36 show that there was still no statistically significant relationship between disclosure of HIV status to a sexual partner and condom use, after controlling for demographic variables and the other predictors, for women (OR = 0.675, p = 0.544) and all respondents (OR = 0.749, p = 0.648). The predicted odds of reporting inconsistent condom use (combined categories of 'usually', 'sometimes' and 'never') versus consistent condom use ('always') were more than twice as high for women (OR = 2.349, p = 0.002) and all respondents (OR = 2.061, p = 0.003) who reported increased levels of depression and anxiety symptoms relative to men.

Table 36: Multivariate ordered logistic regression for condom use in the KHPS 2006 - females

Variable	Condom use - women only OR	Condom use - both sexes
Male		0.352
		[0.215]
Age	0.879**	0.885**
	[0.0405]	[0.0374]
Years of completed education	0.89	0.895
	[0.0705]	[0.0591]
HAART duration	1.042	0.98
	[0.202]	[0.180]
Lives with a partner	2.321	1.83
	[1.029]	[0.744]
Support group affiliation	0.94	0.874
	[0.397]	[0.341]
Internalized stigma	1.637	1.826
	[0.595]	[0.611]
Disclosure	0.675	0.749
	[0.436]	[0.475]
Depression symptoms	2.349**	2.061**
	[0.635]	[0.508]

Standard errors in brackets
* p<0.05, ** p<0.01, *** p<0.001

8.4.2 Bivariate and multivariate analysis for perceived stigma (KHPS 2007)

We again began by exploring bivariate relationships between combinations of variables: Perceived stigma and partner knowing respondent's HIV status, and partner knowing respondent's HIV status and condom use. We also examined the role of depression by testing the relationship between perceived stigma and depression and anxiety symptoms, and depression and anxiety symptoms and condom use. The disclosure outcome variable is binary (see Table 33), that is an individual's partner either knows the respondent's HIV status or doesn't know their status, and a bivariate logistic regression analysis was applied. The predictor variable was the perceived stigma score computed as the mean of the three stigma item scores (item 2 to item 4) shown in Table 29. The condom use outcome variable is an ordinal variable (see Table 33) and an ordered logistic regression was used. Where depression and anxiety was an outcome variable, the ordinary least squares regression was

applied. Results for the bivariate analysis for samples of women and both sexes are shown in Table 37 and Table 38 respectively.

Table 37: Bivariate relationships between perceived stigma, disclosure and condom use - KHPS 2007 women

Variable	Partner knew respondent's HIV status	Depression symptoms	Condom use
	Odds ratio	β - coefficient	Odds ratio
Age	0.953	0.015	1.06
	[0.0294]	[0.00949]	[0.0350]
Years of completed education	0.911	-0.0406	1.059
	[0.0925]	[0.0240]	[0.0704]
HAART duration	0.861	0.0399	1.086
	[0.175]	[0.0598]	[0.187]
Lives with a partner	9.484*	-0.0621	0.737
	[9.851]	[0.153]	[0.267]
Perceived stigma	1.017	0.479***	1.035
	[0.395]	[0.109]	[0.310]
Partner knew respondent's HIV status		0.00345	1.9
		[0.0382]	[1.107]
Depression symptoms			1.1
			[0.227]

Standard errors in brackets
* p<0.05, ** p<0.01, *** p<0.001

Living with a partner was the only variable that was significantly related to some of our hypothesized variables for women. Women who were living with a partner were more than nine times more likely to report that their partner knew about their HIV status (OR=9.484, p=0.030) than those not living with a partner.

Results also show that women who perceived higher levels of stigma in the community were more likely to report higher levels of depression and anxiety symptoms (coefficient = 0.479, p = 0.000). There was no statistically significant relationship between condom use and both partners knowing about the respondent's HIV status, and depression and anxiety symptoms. Therefore, there was no further exploration of the hypothesised mediation relationship between these variables.

Table 38: Bivariate relationships between perceived stigma, disclosure and condom use - KHPS 2007 both sexes

Variable	Partner knew respondent's HIV status	Depression symptoms	Condom use
	Odds ratio	β - coefficient	Odds ratio
Male	2.156	-0.0153	1.521
	[1.378]	[0.143]	[0.604]
Age	0.965	0.011	1.045
	[0.0276]	[0.00826]	[0.0286]
Years of completed education	0.921	-0.0421*	1.064
	[0.0784]	[0.0195]	[0.0554]
HAART duration	0.916	0.0379	1.127
	[0.180]	[0.0545]	[0.177]
Lives with a partner	13.23*	-0.121	0.75
	[13.65]	[0.127]	[0.241]
Perceived stigma	0.968	0.411***	1.019
	[0.350]	[0.0969]	[0.272]
Partner knew respondent's HIV status		0.0183	2.08
		[0.0337]	[1.187]
Depression symptoms			1.078
			[0.202]

Standard errors in brackets
* p<0.05, ** p<0.01, *** p<0.001

Results for the combined sample of men and women, depicted in Table 38, also show that years of completed education and living with a partner statistically are significantly related to some of our variables of interest. Respondents who were living with a partner were about thirteen times more likely to disclose (OR=13.23, p=0.012) than those who were not. Increased years of education was associated with decreased levels of depression and anxiety symptoms (OR = -0.0421, p=0.031). Respondents who perceived higher levels of stigma in the community were more likely to report higher levels of depression and anxiety symptoms (coefficient = 0.411, p = 0.000). There was no statistically significant relationship between condom use, and both partners knowing the respondent's status, and depression and anxiety symptoms.

We further explored a multivariate relationship between condom use and the hypothesized predictors (perceived stigma, disclosure of HIV status to sexual partner, depression and anxiety symptoms)

while controlling for demographic and other variables (age, years of completed education, living with a partnership and HAART duration). Results for the multivariate analysis for women and both sexes combined are shown in Table 39.

Table 39 shows that there were no statistically significant relationships between disclosure of HIV status to sexual partner and depression and anxiety symptoms, and disclosure of HIV status to sexual partner and condom use, after controlling for demographic variables and the other predictors. The odds ratios for women (disclosure of HIV status to sexual partner = 0.554, p = 0.348, depression and anxiety symptoms = 1.095, p = 0.680), and both sexes (disclosure of HIV status to sexual partner = 0.503, p = 0.261, depression and anxiety symptoms = 1.152, p = 0.488) are all not statistically significant.

Table 39: Multivariate ordered logistic regression for condom use in the KHPS 2007 – women and both sexes

Variable	Condom use – women only	Condom use – both sexes
	OR	OR
Male		1.891
		[0.860]
Age	1.079*	1.05
	[0.0392]	[0.0336]
Years of completed education	1.115	1.101
	[0.0858]	[0.0675]
HAART duration	1.029	1.11
	[0.189]	[0.187]
Lives with a partner	0.755	0.754
	[0.287]	[0.259]
Perceived stigma	0.937	0.973
	[0.303]	[0.281]
Disclosure	0.554	0.503
	[0.349]	[0.307]
Depression symptoms	1.095	1.152
	[0.242]	[0.234]

Standard errors in brackets, * p<0.05, ** p<0.01, *** p<0.001

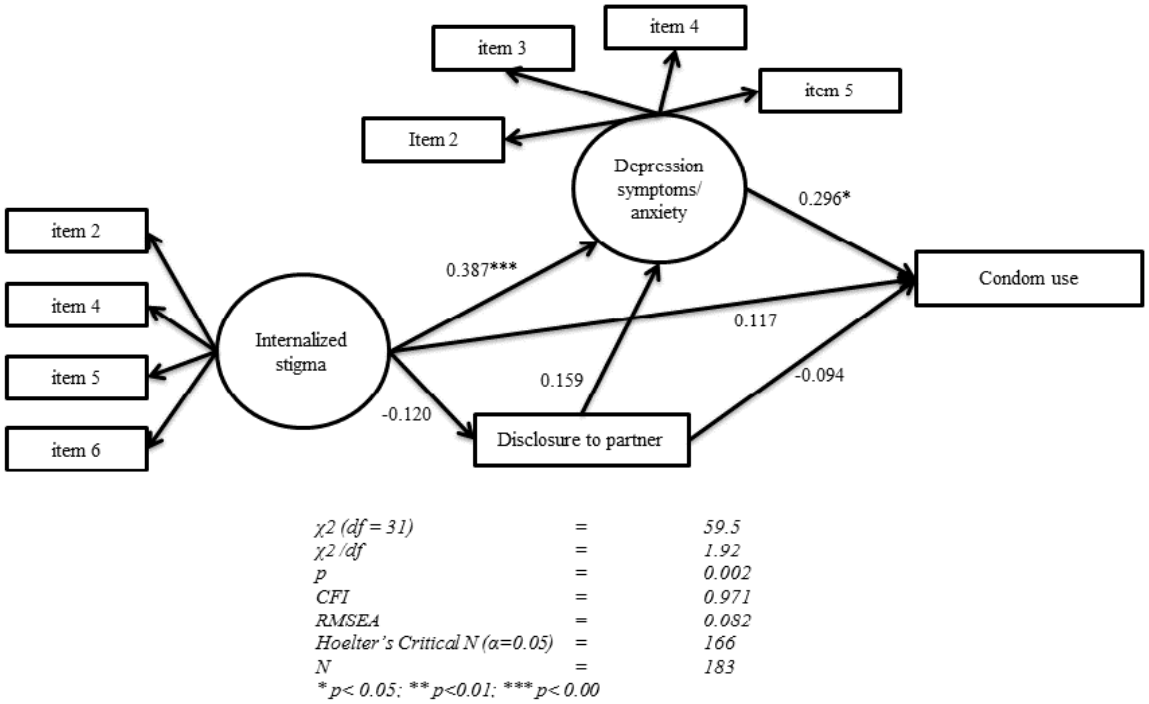
We now turn to an exploration of the potential mediating influence of HIV status disclosure to a sexual partner, and depression and anxiety symptoms, on the relationship between stigma

(internalized and perceived) and risky sexual behavior (not using a condom). Results for Wave 2 suggest that individuals who experienced higher levels of internalized stigma were more likely to report increased symptoms of depression and anxiety and were in turn less likely to use condoms frequently or consistently. We further test these relationships using structural equation modeling techniques, as presented in the following sections.

8.4.3 Structural Equation Modeling

Here we test whether internalized stigma among PLWHA could influence non-condom use through the mediation of increased depression and anxiety symptoms, and non-disclosure of HIV status to sexual partners. In the SEM model, internalized stigma measures, shown in Table 20 were used to measure the latent variable (internalized stigma) with multiple items. Similarly, the depression and anxiety symptoms measures in Table 23 were used to measure the latent variable (depression and anxiety symptoms) with multiple items. Since the model was based on ordinal outcome variables (internalized stigma and depression symptoms), the robust *mean- and variance-adjusted* (diagonally) weighted least squares estimator was used (Flora and Curran, 2004). The mediation models for internalized stigma based on Wave 2 data are shown in Figure 9 (women only) and Figure 11 (combined sample of men and women).

Figure 9: Mediation model for internalized stigma in the KHPS 2006 (wave 2) –women only



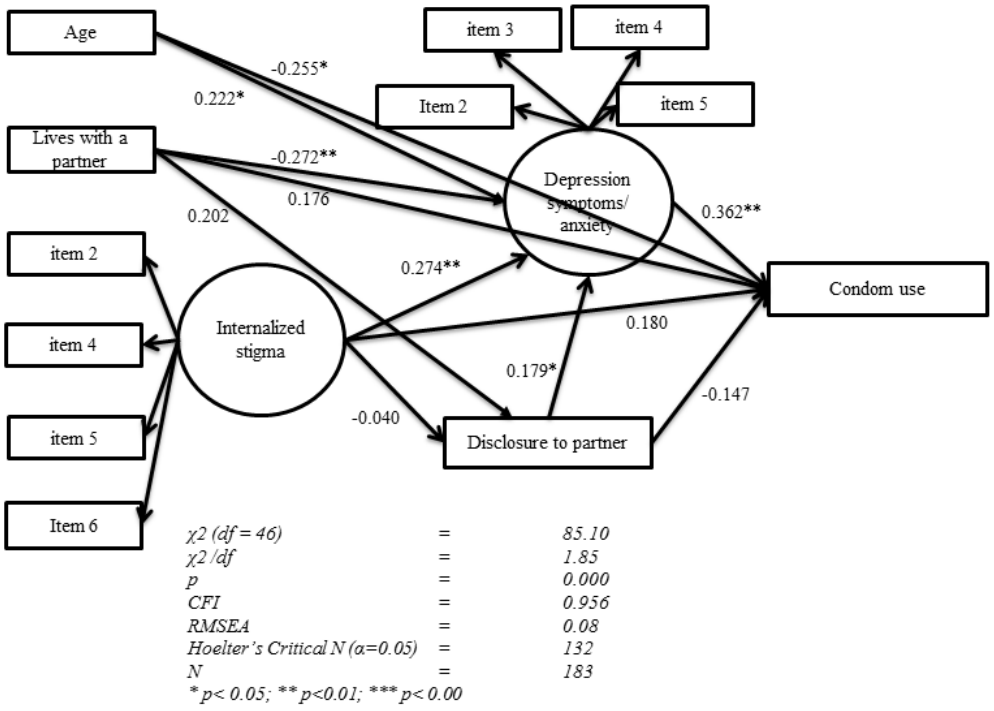
Note: The "condom use" variable in wave 2 is reported as follows: "When you had sex with [**partner**], how often if ever did you use a condom?" Responses are: (1) Always (2) Usually (3) Sometimes 4 (Never) (5) Refused. Those who refused are treated as missing.

Results for women, as presented in Figure 9, suggest a reasonable model fit ($\chi^2(31) = 59.5$, $\chi^2/df = 1.92$, CFI = 0.971, Hoelter's Critical N (α=0.05) = 166, RMSEA = 0.082). We can see that experiences of internalized stigma were associated with increasing levels of depression and anxiety symptoms (coefficient = 0.387, p = 0.000) which was then associated with increased reports of not using condoms all the time or not at all (coefficient = 0.296, p = 0.022). There were no statistically significant relationships between internalized stigma and disclosure to sexual partner (coefficient = -0.120, p = 0.249), disclosure to sexual partner and condom use (coefficient = -0.094, p = 0.273), disclosure to sexual partner and depression and anxiety symptoms (coefficient = 0.159, p = 0.086), and the direct path between internalized stigma and condom use (coefficient = 0.117, p = 0.392). Therefore, results suggest that women who experienced high levels of internalized stigma were more

likely to report increased symptoms of depression and anxiety. The increased symptoms of depression and anxiety were in turn associated with reduced levels of condom use.

We further test the fitness of the structural equation modeling shown in Figure 9 after including some covariates, including age, whether or not respondent lives with a partner and duration on HAART. The new model that includes covariates also suggests a reasonable model fit ($\chi^2(46) = 85.10$, $\chi^2/df = 1.85$, CFI = 0.956, Hoelter's Critical N (α=0.05) = 132, RMSEA = 0.08).

Figure 10: Mediation model for internalized stigma in the KHPS 2006 (wave 2) – including covariates and for women only

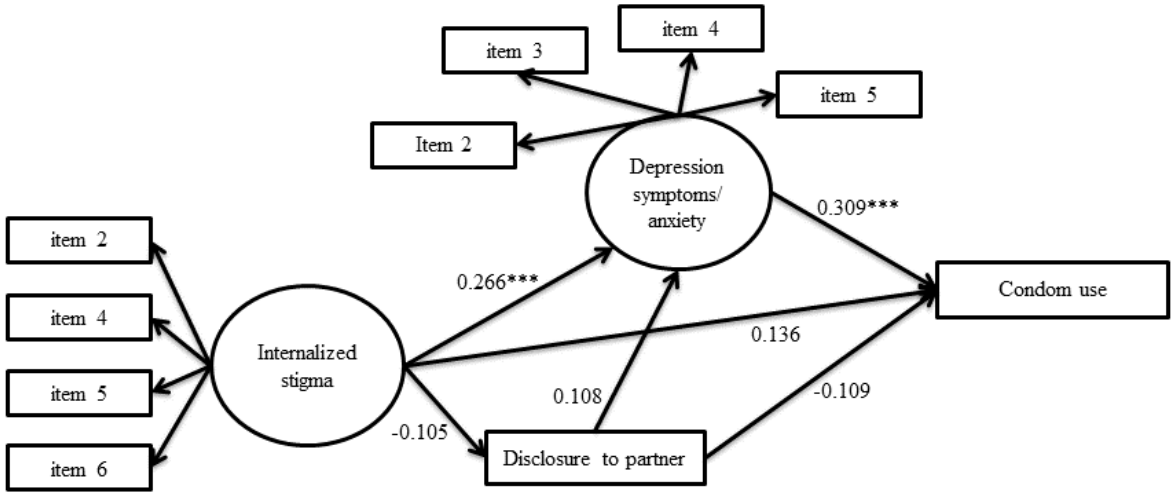


Findings for the mediation analysis did not change after including covariates. Experiences of internalized stigma were still associated with higher levels of depression and anxiety symptoms (coefficient = 0.274, p = 0.005), and higher levels of depression and anxiety symptoms were associated with increased reports of not using condoms all the time (coefficient = 0.362, p = 0.001). However, after including covariates, disclosure of HIV status to a sexual partner was associated with increased depression and anxiety symptoms (coefficient = 0.179, p = 0.024). There were still no statistically significant relationships between internalized stigma and disclosure of HIV status to

sexual partner (coefficient = -0.040, p = 0.687), disclosure of HIV status to a sexual partner and condom use (coefficient = -0.147, p = 0.073), or the direct path between internalized stigma and condom use (coefficient = 0.180, p = 0.146).

With reference to the covariates in the structural equation model, the results show that age was associated with increased depression and anxiety symptoms (coefficient = 0.222, p = 0.013) and respondents who lived with a partner were more likely to experience fewer symptoms of depression and anxiety (coefficient = -0.272, p = 0.008) than those who did not. Whether an individual lives with a partner (coefficient = 0.202, p = 0.165) was not associated with disclosure of HIV to a sexual partner. Increasing age was associated with reduced condom use (coefficient = -0.255, p = 0.048) and whether or not respondent lives with a partner did not have a statistically significant relationship with condom use (coefficient = 0.176, p = 0.165).

Figure 11: Mediation model for internalized stigma in the KHPS 2006 – both men and women



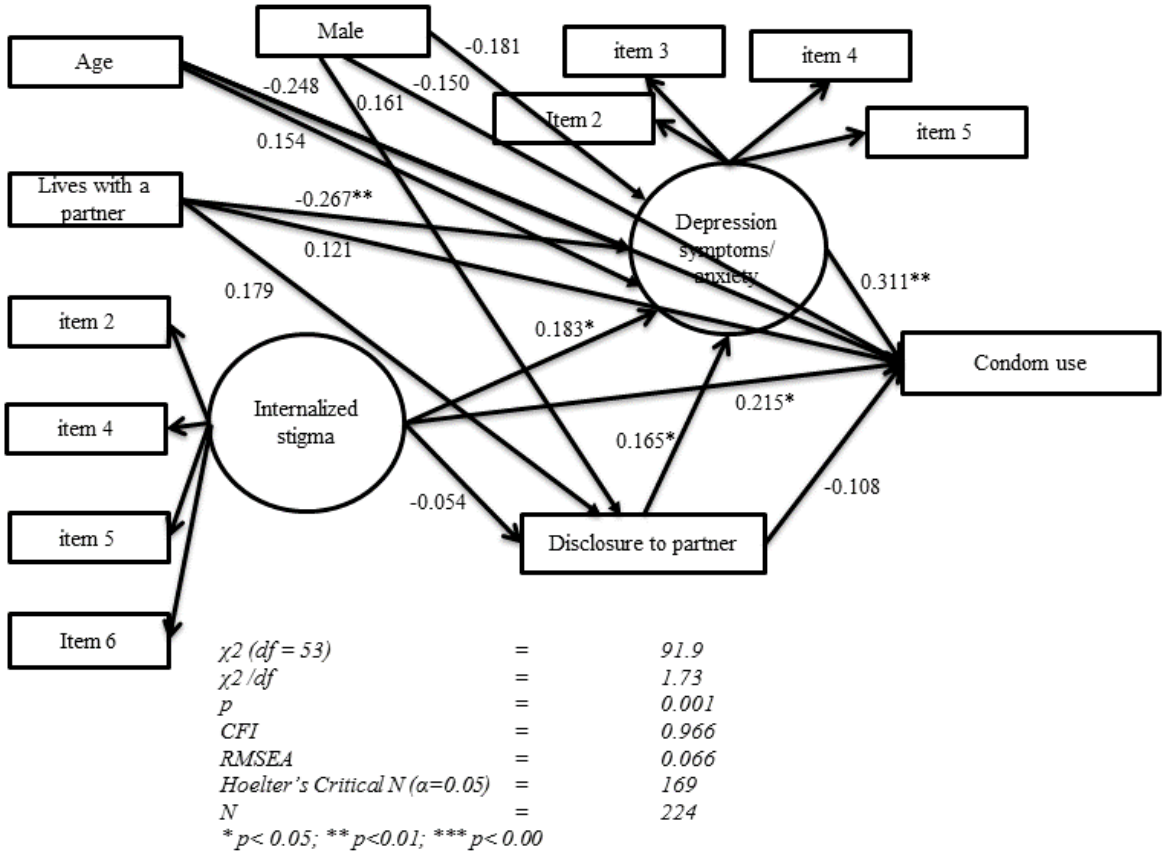
χ2 (df = 31)	=	*56.0*
χ2 /df	=	*1.81*
p	=	*0.004*
CFI	=	*0.980*
RMSEA	=	*0.068*
Hoelter's Critical N (α=0.05)	=	*217*
N	=	*224*

** p< 0.05; ** p<0.01; *** p< 0.00*

Results for the combined sample of men and women, as presented in Figure 11 suggest very good model fit ($\chi^2(31) = 56.0$, $\chi^2/df = 1.81$, CFI = 0.980, Hoelter's Critical N (α=0.05) = 217, RMSEA = 0.068). Experiences of internalized stigma were associated with higher levels of depression and anxiety symptoms (coefficient = 0.266, p = 0.004), which were then associated with increased reports of not using condoms all the time (coefficient = 0.309, p = 0.003). There were no statistically significant relationships between internalized stigma and disclosure to a sexual partner (coefficient = -0.105, p = 0.262), disclosure to a sexual partner and condom use (coefficient = -0.109, p = 0.132), disclosure to a sexual partner and depression symptoms (coefficient = 0.108, p = 0.199), or the direct path between internalized stigma and condom use (coefficient = 0.136, p = 0.233). Results suggest that respondents who experienced increased levels of internalized stigma were more likely to report higher levels of depression and anxiety symptoms and that those with higher levels of depression and anxiety symptoms were more likely to report reduced condom use.

We further test the fitness of the structural equation modeling shown in Figure 11, after including some covariates (age, whether or not respondent lives with a partner and sex). The new model that includes covariates also suggests a good fitting model ($\chi^2(53) = 91.9$, $\chi^2/df = 1.73$, CFI = 0.966, Hoelter's Critical N (α=0.05) = 169, RMSEA = 0.066).

Figure 12: Mediation model for internalized stigma in the KHPS 2006 – including covariates for both men and women



General findings for the mediation analysis did not change after including covariates. Experiences of internalized stigma were associated with higher levels of depression and anxiety symptoms (coefficient = 0.183, p = 0.031), and higher levels of depression and anxiety symptoms were associated with more likelihood of not using condoms all the time (coefficient = 0.311, p = 0.001). However, after including covariates, disclosure of HIV status to sexual partner was associated with increased depression and anxiety symptoms (coefficient = 0.165, p = 0.025), and the direct path between internalized stigma and

condom use was now statistically significant (coefficient = 0.215, p = 0.050). Respondents who experienced higher levels of internalized stigma were more likely not to use condoms consistently. There was still no statistically significant relationships between internalized stigma and disclosure of HIV status to sexual partner (coefficient = -0.054, p = 0.538), and disclosure of HIV status to sexual partner and condom use (coefficient = -0.108, p = 0.119).

With regard to covariates in the structural equation model, there was no statistically significant relationship between age and symptoms of depression and anxiety (coefficient = 0.154, p = 0.063). Respondents who lived with a partner were less likely to experience symptoms of depression and anxiety (coefficient = -0.267, p = 0.003). Gender was not associated with depression and anxiety symptoms (coefficient = -0.181, p = 0.080). Whether or not an individual lives with a partner (coefficient = 0.179, p = 0.118) and gender (coefficient = 0.161, p = 0.666) were not associated with disclosure of HIV to a sexual partner. None of the three covariates were associated with condom use, including age (coefficient = -0.248, p = 0.053), sex (coefficient = -0.150, p = 0.288), whether or not respondent lives with a partner (coefficient = 0.121, p = 0.293).

8.5 Discussion

We used data from the KHPS to test if internalized stigma and perceived stigma among PLWHA was associated with higher levels of negative psychological outcomes, measured by symptoms of depression and anxiety, and not disclosing their HIV status to sexual partners. We also tested the hypotheses that symptoms of depression and anxiety and non-disclosure of HIV status were associated with not using condoms during sex. Our sample comprises people who were part of the first HAART programme in South Africa, living in a society with high HIV prevalence. In testing these hypotheses, we were trying to understand why people living with HIV/AIDS who were aware of their HIV status might still continue to

engage in unsafe sexual practices. We hypothesized that stigma may have played a role in these behaviours.

An earlier qualitative analysis based on PLWHA residing in urban and peri-urban areas of Cape Town (including Khayelitsha, Nyanga, New Crossroads, Somerset West, and Hout Bay) suggests that there was:

> *"…a circular dynamic in which the risk of stigma undermines testing and disclosure, which in turn makes men and women more vulnerable to HIV (re)infection through unprotected sex"* (Mills, de Paoli and Grønningsæter, 2009: 13).

This argument captures some of the hypotheses we tested using quantitative data. Our study area was a social context where the general population holds stigmatizing attitudes towards PLWHA (Maughan-Brown, 2008). It was highly probable that some PLWHA residing in Khayelitsha had either experienced HIV/AIDS-related stigma or heard about other people's experiences (most likely through support groups and networks of PLWHA). Both qualitative and quantitative studies show that most PLWHA experienced 'gossip' about their status by members of their community (Maughan-Brown, 2008: 170; Almeleh, 2012: 103). Several studies indicated that gossip was one of the difficulties faced by PLWHA in this society, and was experienced as a hurtful form of stigma that potentially exposes them to other social dangers (Almeleh, 2012: 103). Mills, *et al.* (2009: 12) narrate a case of a woman whose partner abandoned her after she disclosed her HIV status to him. Such findings highlight the social and psychological challenges posed by HIV/AIDS-related stigma for our sample of PLWHA (and especially women) in Khayelitsha.

The experience of stigma, or awareness of the experience of stigma by others, drives perceptions that one lives in a stigmatizing social environment. This probably fuels the internalization of stigma, that is, the acceptance of the negative designation and negative attitudes towards PLWHA. Maughan-Brown (2008: 211-222) found that experiences of stigma among PLWHA in Khayelitsha significantly predicted both higher perceptions of a stigmatizing community, and internalized stigma. Data from the KHPS 2006 show that half of the respondents in our sample had internalized stigma in the form of shame. At least 15.2% of the sample indicated that they had experienced at least one form of the internalized stigma measured. The

KHPS 2007 data shows that respondents were more likely to agree with statements about unfair treatment towards PLWHA. This suggests that a high proportion of participants in the KHPS 2007 perceived stigma in the general society. A high proportion of individuals were also uncertain about stigma in society, as they neither agreed nor disagreed with statements used to assess perceived stigma. Maughan-Brown (2008: 205) also found a similar pattern in the KHPS 2004/5 (Wave 1) data, and suggested that this may have implications for behaviours that seek to minimize experiences of stigma, for example, not disclosing one's HIV status.

Previous studies of PLWHA in Khayelitsha have suggested that perceptions of stigma influence disclosure decisions. That is PLWHA do not to disclose for fear of exposing themselves to stigma experiences (Almeleh, 2006; Almeleh, 2012; Maughan-Brown, 2008; Mills, de Paoli and Grønningsæter, 2009). For example, more than half of the respondents in the KHPS 2004/5 (wave 1) survey had not disclosed to their sexual partners, because they were afraid that they might be rejected, lose financial support, or be physically hurt (Maughan-Brown, 2008: 208). Almeleh (2012) supplemented his quantitative study with rich qualitative data to depict the social context of Khayelitsha, in which sexual relationships are generally fragile. Disclosing one's HIV status to a sexual partner was perceived by women as a reason for these partners to abandon them (Almeleh, 2012: 152). Some of the previous studies also provided examples of women who depended on their husbands/partners for financial support, and who suffer after abandonment (Mills, de Paoli and Grønningsæter, 2009: 12). The qualitative research observed that non-disclosure was also motivated by these women's need to protect their financial wellbeing (Almeleh, 2012; Mills and Maughan-Brown, 2009: 20).

Almeleh (2012) provides an in-depth exploration of the differences between disclosure of HIV status in public and private settings, finding it to be a complicated process affected by relationship dynamics within the family and between sexual partners. Among the factors affecting the decision by women to

disclose to sexual partners was whether they had learned about their HIV status before the relationship, whether they were in a long term relationship, whether the women harboured cynical and distrusting views about men, and whether they were using condoms (Almeleh, 2012: 151-161). All these factors played their part in relation to people with different health statuses and social needs (Almeleh, 2012; Mills and Maughan-Brown, 2009). One limitation of our quantitative study was that it was not able to analyse all of these dynamics

The KHPS 2006 data shows that all the men and about 88% of women reported that they had disclosed their HIV status to their most recent sexual partner in 2006 (Almeleh, 2012: 178; Maughan-Brown, 2008). In KHPS 2007, about 88% of men and 82% of women respondents reported that their last sexual partner knew about their HIV status. The general trend across all waves of the KHPS was that men are more likely to disclose to sexual partners than women. The most frequent reason for non-disclosure among women in the KHPS 2006 survey was fear of abandonment, and this may be a reflection of women's vulnerability in sexual relationships. Almeleh (2012) notes that the KHPS sample was drawn from a gendered society, in which women find it difficult to disclose because of the general perception that men are not trustworthy. In this environment, negotiating condom use is difficult (Xhosa men are perceived to have negative attitudes towards condom use) and disclosure often leads to rejection. Almelah argues that in such a gendered society, "power and vulnerability" play a role in disclosure (Almeleh, 2012: 7). Reasons for non-disclosure reported in the KHPS 2006 include fear of abandonment and knowledge that sexual partners have negative attitudes towards people with HIV/AIDS. This indicates that fear of stigma plays a role in influencing disclosure of HIV status to a sexual partner.

Bivariate and multivariate analysis did not reveal a statistically significant relationship between stigma among PLWHA (internalized stigma and perceived stigma) and disclosure of HIV status to a sexual partner. The results thus do not support our hypothesis, as we would have expected higher experiences of

each stigma aspect to be significantly associated with non-disclosure of HIV status to a sexual partner. Rather, our findings support Almeleh's (2012) conclusion that disclosure within sexual relationships is highly complex, and that relationship dynamics and strategic decision-making cannot easily be captured through a purely quantitative analysis. For example, he found that women in long term relationships disclose to sexual partners when they are seriously ill, to obtain social support. Other HIV positive women disclose to challenge their partner's false perceptions about HIV. Others disclose to initiate negotiations about condom use, or to build trust and intimacy. (Almeleh, 2006; Almeleh, 2012). Some of the reported reasons for non-disclosure included fear of stigma related negative reactions. Some women felt that they were under no moral obligation to disclose, as long as they were using a condom during sex.

The dynamics within relationships clearly makes disclosure of one's HIV status to a sexual partner a complicated process, because disclosure is not only constrained by fear of stigma, but other factors as well. This could be the reason why there was no significant relationship between stigma among PLWHA (internalized stigma and perceived stigma) and disclosure of HIV status to a sexual partner, because our quantitative analysis could not adequately control for these factors. This is one of the limitations of a quantitative analysis that it fails to capture the more fine-grained lived experiences of PLWHA, in relation to stigma and disclosure.

We also hypothesized that perceptions of potential stigma and internalization of stigma was related to the presence of depression and anxiety symptoms. At least one in three respondents sometimes or often experienced symptoms of depression and/or anxiety. We also found that elevated perceptions of stigma, and internalization of stigma predicted higher levels of depression and anxiety symptoms. These results are not surprising, as they are in agreement with our hypothesis, based on previous findings (e.g. Maughan-Brown, 2008; Berger, Ferrans and Lashley, 2001; Simbayi, Kalichman, Strebel *et al.*, 2007a). We also acknowledge, however, that depression and anxiety among PLWHA may not be a result of

stigma only. For example, an HIV diagnosis can be stressful to the bearer, leading to failure to cope. Women who participated in qualitative studies based in Khayelistaha highlighted stresses involved in relationships, decisions to disclose (Almeleh, 2012), daily challenges, such as poverty and unemployment (Abrahams and Jewkes, 2012; Cloete, Strebel, Simbayi *et al.*, 2010) which in some cases may overshadow the fear of stigma.

Previous studies observed that disclosure lowers stress levels, and helps PLWHA to cope with an HIV diagnosis (Almeleh, 2006). For example, disclosure was seen as a form of 'medicine for the mind' by some participants of a qualitative study (Almeleh, 2006: 159). In our study, we tested whether this was the case when PLWHA disclosed to sexual partners, using the available quantitative measures. Both studies found no significant relationship between disclosure of one's HIV status to a sexual partner and symptoms of depression and/or anxiety. This finding is not surprising, given that previous studies found that, for example, women living with HIV disclosed more to female relatives (mostly their mothers and sisters) for social support and in most cases they provided the expected support (Almeleh, 2012: 129). Therefore, disclosure to a sexual partner can probably be expected to have a minimal effect on their psychological well-being, considering that some disclose to sexual partners for reasons other than social support. However, we also acknowledge that experiences of depression and anxiety resulting from stigma can be a cause rather than a consequence of non-disclosure, as found elsewhere (e.g. Okello, Wagner, Ghosh-Dastidar *et al.*, 2015).

Disclosure of one's HIV status within a sexual relationship was generally encouraged by health providers (notably MSF in Khayelitsha), on the assumption that it increases social support and helps facilitate protected sex. Bivariate and multivariate analyses using both the KHPS 2006 and KHPS 2007 data show no statistically significant relationships between either disclosure of HIV status to a sexual partner or 'partner knowing respondent's HIV status' and condom use. This result was no doubt affected by the

complexity of relationships and the difficulties involved of capturing them through social surveys. For example, Almeleh (2012: 162) found that some women did not disclose their HIV status to a sexual partner as long as they were using a condom, for fear of a stigmatizing reaction. Other women disclosed to their sexual partner, but still found it difficult to negotiate condom use with the partner afterwards (Almeleh, 2012: 164-165; Mills and Maughan-Brown, 2009: 20). While intended results of initiating condom use may be the same, women living with HIV/AIDS are achieving this in ways that may not captured by a statistical analysis. There are also accounts of women who did not disclose and continued to have unprotected sex (Almeleh, 2012: 165; Mills and Maughan-Brown, 2009: 20).We learn, therefore, that disclosure alone does not necessarily lead to condom use, and that non-disclosure does not necessarily lead to unprotected sex. Complex relationship dynamics and strategic choices inevitably generated 'noise' for our hypothesis.

Both bivariate and multivariate analysis, using the KHPS Wave 2 data for women suggested that higher levels of depression and anxiety were associated with inconsistent condom use, or not using condoms. We found that the predicted odds of reporting inconsistent condom use (combined categories of 'usually', 'sometimes' and 'never') versus consistent condom use ('always') were more than twice as high for women who reported higher levels of depression and anxiety symptoms, while controlling for a number of variables (age, education, living with a partner, support group affiliation, and HAART duration). We also control for experiences of internalized stigma, and disclosure of HIV status to sexual partner. This result supports our hypothesis.

The same relationship was observed in a sample of patrons of alcohol-serving venues in a Cape Town township (Sikkema, Watt, Meade *et al.*, 2011). The study found that women with depression were 1.53 times more likely to engage in unprotected sexual intercourse, than those without depression (Sikkema, Watt, Meade *et al.*, 2011: 235). Both this finding and our results support the argument that unprotected

sex can be a result of depression or anxiety. We could not establish the same result in the KHPS 2007 (wave 3). This could be a result of different measures of condom use in the KHPS 2007, which asked about general condom use in the preceding year, as opposed to condom use within specific relationships where disclosure or non-disclosure occurred.

Our structural equation modeling shows that respondents who experienced high levels of internalized stigma were more likely to report greater levels of depression and anxiety symptoms, with these higher levels of depression and anxiety being associated with inconsistent condom use or no condom use[9]. These relationships were observed even after controlling for age, whether or not respondent lives with a partner, and respondent's duration on HAART. We further observed that, after including the covariates, disclosure of HIV status to a sexual partner was associated with increased levels of depression and anxiety symptoms, for both women, and the combined sample of men and women. This suggests that disclosure to a sexual partner may have negative psychological outcomes. After including covariates, data for women suggested a marginally statistically significant relationship, in which disclosure of HIV status to a sexual partner was associated with increased condom use. Data for all respondents (both men and women) suggests that internalized stigma was directly related to less consistent condom use when covariates were included, in addition to the indirect relationship through depression and anxiety symptoms. This suggests that depression and anxiety partially mediated the relationship between internalized stigma and condom use. This finding is also an indication that there are possibly other pathways connecting internalized stigma and condom use practices that have not been explored in this study.

[9] A reminder that the condom use variable is measured as follows: "When you had sex with [partner], how often, if ever did you use a condom?" Responses are: (1) Always (2) Usually (3) Sometimes 4 (Never) (5) Refused. Those who refused are treated as missing.

8.5.1 Limitations of the study

The sample for the KHPS was not a random sample, and this limits the generalizability of the findings. Most participants in this sample were recruited through HIV/AIDS support groups, and participation in these groups most probably shaped their perceptions in relation to stigma, disclosure and condom use. As a result, respondents in the KHPS may have different experiences to PLWHA in other contexts.

There is lack of agreement or standardized measurements of HIV/AIDS-related stigma. As a result, measures of stigma used were limited to elements that were asked in the survey questionnaire. While the questions adapted to measure stigma may not have been optimal, we are confident that they adequately cover aspects related to each stigma dimension.

The sample was biased towards women, partly due to the disproportionate effect of HIV/AIDS on women and the greater likelihood of women knowing their HIV status because of their more frequent use of health care services. The sample of men was too small for any meaningful analysis. However, our study is not interested in the proportional representation of PLWHA, but PLWHA who know their HIV status. Therefore this sample might be representative of PLWHA who know their HIV status.

The data was self-reported and may possibly have limitations that include respondent social desirability bias, especially with regard to disclosure and condom use.

9 Stigma, childbearing intentions and childbearing: An empirical analysis of PLHWA in Khayelitsha

This Chapter contributes to the literature discussed in Chapter 4 by exploring how childbearing intentions may be related to different dimensions of HIV/AIDS-related stigma, as experienced by PLWHA in Khayelitsha (Cape Town). We use data from the third wave of the KHPS (2007) (see Chapter 6). Our area of study, Khayelitsha, is a resource limited setting, where most of the technology-intensive safer conception methods (assisted reproduction) for PLWHA were either not readily available, or not affordable for most people.

Respondents to the KHPS (2007) were asked what advice, if any, they had received about childbearing as HIV-positive women. None of the response options[10] covered assisted reproductive techniques. Furthermore, responses to the open ended option for the same question also indicated a general lack of awareness among respondents about assisted reproductive techniques (see Table 40). Therefore, we assume that most of the conception among PLWHA in this setting at the time of the KHPS surveys (2003 to 2007) was through unprotected sexual intercourse.

[10] (1) I must make sure I do not have a TB infection (9.3%), (2) I must only have sex with one partner to avoid opportunistic infections (10.2%), (3) I must live healthily (eat a balanced diet and no smoking or drinking) (14.8%), (4) The doctor must check which medication (e.g. Efivirenz), I am taking in case it will cause harm to the baby (15.7%), (5) My viral load must be undetectable (15.3%), (6) I was advised against having a child (4.6%), (7) I must have been with my partner for at least one year (0.9%), (8) I was advised not to become pregnant/have a baby with my partner because I was HIV-positive (4.2%)

Table 40: Open ended responses for advice about childbearing – KHPS 2007 (Wave 3)

Other advice received	N	Per cent
Because of age advised not to have children	1	0.5
Check CD4 cells and check partner viral load + CD4	1	0.5
Condomize	6	2. 8
Condomize and no breastfeeding	1	0.5
Get tablets when I'm 7 months pregnant (AZT)	1	0.5
Make sure that I know my partner's status	1	0.5
Not to breastfeed my child	1	0.5
Not to get pregnant because my child will be deformed	1	0.5
Not to miss my appointments	1	0.5
Take my medication regularly	1	0.5
To do abortion	1	0.5
Non-response	200	92.6

Furthermore, health care services in some communities of South Africa appear to have been discouraging reproduction by PLWHA. A study conducted in 2005 found that protocols at some clinics in Cape Town required women to be on the contraceptive injection as a pre-requisite for HAART initiation (Richey, 2006: 16-17). A multi-country study in sub-Saharan Africa conducted in 2007/2008 found that 17% of family planning providers offering HIV services, referrals, counselling, and messaging for HIV-positive women in South Africa advised HIV-positive women not to become pregnant (Adamchak, Janowitz, Liku *et al.*, 2010: 43). In addition to evidence that the social environment in Cape Town's African townships was stigmatizing for PLWHA (Maughan-Brown, 2008), there are also indications that people did not approve of PLWHA having children (Myer, Morroni and Cooper, 2006). There are also documented cases of women living with HIV/AIDS in South Africa who were forced into sterilization in order to prevent them from bearing children (Strode, Mthembu and Essack, 2012; Mthembu, 2012). Therefore, it was reasonable to assume that the PLWHA in our social context (Khayelitsha) were living in a stigmatizing environment, with limited reproductive options, and health care services that discouraged childbearing on their part.

Given this context, we are interested to explore how experienced stigma, perceived stigma, and internalized stigma (see Chapter 3) influenced childbearing intentions in this sample. First we explore whether and how HIV/AIDS-related stigma (experienced, perceived, and internalized) was related to childbearing intentions. The literature reviewed in Chapter 4 suggests that fear of stigma can discourage childbearing desires, but that it might also encourage childbearing, as HIV-positive women attempt to find love and or to fit in with social norms. Most of the studies use qualitative methods that depict specific contexts, making it difficult to generalize about such relationships. Our study uses quantitative methods to explore if there are generalizable relationships between HIV/AIDS-related stigma and childbearing desires among PLWHA in Khayelitsha.

Second, we test if childbearing intentions among PLWHA in Khayelitsha during the mid-2000s were associated with reduced or inconsistent condom use. In this regard, we are exploring whether PLWHA who desired to bear children might have actually been taking risks (potential re-infection from an HIV-positive partner, or exposing an HIV-negative partner to infection) in order to conceive.

Third, we test if childbearing intentions among PLWHA were associated with pregnancy or actual child bearing. This was another test of whether PLWHA who intended to bear children (potentially influenced by stigma) actually took the risk to do so. It also allows us to test whether the intention to bear children actually lead to a pregnancy within the short time-span of the panel study (two years).

9.1 Methods

9.1.1 Data

This section of the study again uses data from all three waves of the KHPS, discussed in Chapter 6. Wave 1 (KHPS 2004/5) and wave 2 (KHPS 2006) data were used to test the relationship between HIV stigma (experienced and perceived) and intentions to have children. This dataset was also used to test whether those who wanted children were less likely to use condoms. Data from Waves 1 and 3 were used to test whether fertility intentions revealed in Wave 1 (date) led to the occurrence of pregnancy by Wave 3 (date).

9.1.2 Measures

Fertility intentions

In both the 2004/5 and 2006 surveys, individuals were asked about their intentions to have children, or more children. The distribution of responses is shown in Table 41.

Table 41: Measure for childbearing intentions – wave 1 (KHPS2004/5) and wave 2 (KHPS 2006)

Do you intend to have children (or more children)?	wave 1 (2004/5)			wave 2 (2006)		
	Male	Female	Total	Male	Female	Total
Yes	22 (45.8%)	60 (31.1%)	82 (34%)	20 (48.8%)	55 (30.4%)	75 (33.8%)
No	26 (54.2%)	133 (68.9%)	159 (66%)	21 (51.2%)	126 (69.6%)	147 (66.2%)

Results, shown in Table 41, consistently show that more than one in three (about 34%) of all respondents intended to have children, or more children, and that this was consistent across the two waves. The proportion of men (45.8% in Wave 1 and 48.8% in Wave 2) who intended to have children was higher than that of women (31.1% in Wave 1 and 33.8% in Wave 2).

Experienced Stigma

The first wave of the KHPS was conducted between August 2004 and February 2005, and it asked respondents about their experienced stigma over the period prior to the survey. There were nine measures of experienced stigma, as shown in Table 42. According to Maughan-Brown (2008), who was involved in the collection of the survey data, some respondents neither agreed nor disagreed with some of these statements because they felt that the statement applied to some but not all people. He thus included the 'neither agree nor disagree' answer as indicating some experiences of stigma from some people, and we do the same here.

As shown in Table 42 about 84% of respondents denied that they had lost friends because of their HIV status, 93% confirmed that family members and friends had not treated them badly because of their HIV status, and about 96% confirmed that close family members were willing to take care of them when HIV made them very sick. This suggests that close family members and friends of respondents in this sample were supportive rather than stigmatizing.

A number of respondents had experienced stigma from people in general: About 3% reported that people felt uncomfortable in their presence, 5% were of the opinion that people were concerned about catching HIV from the food they prepared or from touching them, 17% were of the opinion that some people unreasonably worried about catching HIV from them, 6% felt treated with less respect because of their HIV status, 36% reported that people said unkind things behind their back, and 4% were of the opinion that people avoided them because of their HIV status.

Table 42: Indicators of experienced stigma from KHPS 2004/5 (wave 1)

To what extent do you agree or disagree with the following?	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
1. I have lost friends because I am HIV positive	36(14.9%)	168(69.4%)	13(5.4%)	24(9.9%)	1(0.4%)
2. Family members and friends have treated me badly because I am HIV positive	57(23.6%)	169(69.8%)	12(5%)	2(0.8%)	2(0.8%)
3. When HIV made me very sick my close family members were willing to take care of me	2(0.8%)	4(1.7%)	4(1.7%)	119(49.6%)	111(46.3%)
4. When people find out I am HIV positive, they feel uncomfortable in my presence	15(6.2%)	154(63.6%)	65(26.9%)	7(2.9%)	1(0.4%)
5. People are concerned that they could "catch" HIV from the food I prepare or from touching me	34(14.3%)	157(66%)	36(15.1%)	9(3.8%)	2(0.8%)
6. People who have no reason to fear still worry that they will catch HIV from me	35(14.8%)	95(40.1%)	66(27.9%)	36(15.2%)	5(2.1%)
7. People treat me with less respect when they find out I am HIV positive	56(23.1%)	142(58.7%)	29(12%)	15(6.2%)	0(0%)
8. Because I am HIV positive, people say unkind things behind my back	24(9.9%)	56(23.1%)	76(31.4%)	82(33.9%)	4(1.7%)
9. Many people avoid me because I am HIV positive	35(14.5%)	141(58.5%)	56(23.2%)	9(3.7%)	0(0%)

We reversed responses for item 3 and all responses were assigned scores 1 (strongly disagree) to 5 (strongly agree), with a score of 5 indicating more experiences of stigma. This scale for experienced stigma was developed earlier by Maughan-Brown and found to be measuring the underlying dimension with a Cronbach's alpha coefficient of reliability of 0.82 (Maughan-Brown, 2008: 182-183). In further exploration, our study used a mean score of these items, ranging from 1 to 5, as a measure of experienced stigma (higher scores mean more experiences of stigma).

Perceived stigma

Perceived stigma was assessed using responses to four statements as shown in Table 43. Results in Table 43 show that most of the respondents (about 62%) agreed that most families support an HIV positive family member when they disclose. At least 56% of the sample agreed that PLWHA were often treated unfairly, 66% agreed that people say unkind things about them, and 30% agreed that most people prefer to avoid people with HIV as much as possible. Responses for item 1 were reversed and all responses were assigned scores 1 (strongly disagree) to 5 (strongly agree), with a score of 5 indicating a more pronounced perception of stigma in the broader community.

An exploratory factor analysis was performed to examine if the items were measuring the same latent construct, specifying maximum likelihood estimation and oblique minimum rotation. The Kaiser–Meyer–Olkin (KMO) measure of sampling adequacy was 0.55 and the Bartlett's test for sphericity was significant ($\chi 2=80.6$, $p=0.000$), confirming suitability of the data for factor analysis. The factor loadings are shown in Table 44. Only coefficients for items 2 and 3 load highly, with a very low coefficient for item 1. A similar pattern of factor loadings was also observed in the analysis in Chapter 8, when using the same scale for Wave 2 data. It was argued in that chapter that item 1 was a poor measure, relative to the other items as it asked about perceptions of stigma within the family as opposed to among people in general. The measurement analysis of this scale was further complicated by the fact that exclusion of this

low-loading item would render the factor analysis invalid due to lack of degrees of freedom. To circumvent this, a confirmatory factor analysis was conducted using all four items of the perceived stigma scale, and this analysis indicated an excellent fitting model ($\chi^2(2) = 3.523$, $\chi^2/df = 1.762$, CFI = 0.992, RMSEA = 0.057, Hoelter =555). Based on this, it was assumed that excluding item 1, already established to be the weakest indicator, would undoubtedly improve the validity of the scale. Looking at reliability, the analysis indicated an improvement in the Cronbach's alpha for perceived stigma items when item 1 was excluded (0.540) compared to when it was retained in the model (0.508). However, both scenarios generally indicate poor reliability of the scale. Consistent with our decision in Chapter 8, we decided to exclude item 1 for reasons relating to both poor conceptualization and measurement. Further, while item 4 has a low loading of 0.293, we decided to retain it, since its loading was close to the generally utilised threshold value of 0.3 (e.g. Holzemer, Uys, Chirwa *et al.*, 2007; Sayles, Hays, Sarkisian *et al.*, 2008).

Table 43: Indicators of perceived stigma from KHPS 2004/5 (wave 1)

Please tell us how strongly you agree or disagree with the following statements	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know
Most people with HIV are supported by their families when they disclose their HIV status	0(0%)	6(2.5%)	86(35.5%)	126(52.1%)	24(9.9%)	0(0%)
People with HIV often get treated unfairly or badly by others	2(0.8%)	13(5.4%)	90(37.2%)	112(46.3%)	25(10.3%)	0(0%)
People say unkind things about HIV positive people	1(0.4%)	14(5.8%)	66(27.3%)	136(56.2%)	25(10.3%)	0(0%)
Most people prefer to avoid people with HIV as much as possible	2(0.9%)	21(8.9%)	142(60.2%)	56(23.7%)	15(6.4%)	0(0%)

Table 44: Factor loadings for perceived stigma items from KHPS 2004/5 (wave 1)

Items	Factor 1
1. Most people with HIV are supported by their families when they disclose their HIV status	0.166
2. People with HIV often get treated unfairly or badly by others	0.449
3. People say unkind things about HIV positive people	0.991
4. Most people prefer to avoid people with HIV as much as possible	0.293

Internalized stigma

The measurement scale for internalized stigma remains as tested and validated in Chapter 8.

9.2 Analysis

9.2.1 Bivariate analysis for childbearing intentions among PLWHA

We began by conducting bivariate logistic regression analyses to explore the determinants of childbearing intentions. Bivariate analysis results for experienced stigma and perceived stigma are shown in Table 45, and results for internalized stigma are shown in Table 46. Table 45 shows that, independent of other variables, older respondents (women: unadjusted odds ratio = 0.863 and p = 0.000, all respondents: unadjusted odds ratio = 0.899 and p = 0.000) and increased number of living children (women: unadjusted odds ratio = 0.364 and p = 0.000, all respondents: unadjusted odds ratio = 0.355 and p = 0.000) were significantly associated with less intention to bear children, or more children. Respondents who were living with a partner had more intention to bear children, with this being higher for women who were living with a partner (unadjusted odds ratio =3.081, p = 0.001) relative to the full sample (unadjusted odds ratio = 2.605, p = 0.001). Women who had more years of completed education were also more likely to intend to have children/more children (unadjusted odds ratio = 1.193, p = 0.014). Experiences of stigma, perceptions of stigma, log transformed personal income and household income and gender of the respondent were all not statistically significantly associated in a bivariate manner with childbearing intentions.

Table 45: Bivariate relationships (unadjusted odds ratio) for fertility intentions - KHPS 2004/5

Characteristics	Female only	All
Experienced stigma	1.500	1.333
	[0.535]	[0.407]
Perceived stigma	0.949	1.141
	[0.297]	[0.285]
Number of children	0.364***	0.355***
	[0.0708]	[0.0610]
Age	0.863***	0.899***
	[0.0291]	[0.0230]
Years of completed education	1.193*	1.080
	[0.0860]	[0.0535]
Personal income (natural log form)	1.222	1.211
	[0.356]	[0.298]
Household income (natural log form)	1.350	1.119
	[0.328]	[0.231]
Lives with a partner	3.081**	2.605**
	[1.064]	[0.774]
Male		1.876
		[0.617]

Standard errors in brackets, * p<0.05, ** p<0.01, *** p<0.001

Bivariate analysis results for Wave 2 data, presented in Table 46, show that women (unadjusted odds ratio =0.490, p = 0.015) and all respondents (unadjusted odds ratio =0.575, p = 0.029) who reported more internalized stigma were less likely to intend to have children or more children, independent of other variables. Consistent with Wave 1 data, older respondents (women: unadjusted odds ratio = 0.801 and p = 0.000, all respondents: unadjusted odds ratio = 0.851 and p = 0.000) and increased number of living children (women: unadjusted odds ratio = 0.159 and p = 0.000, all respondents: unadjusted odds ratio = 0.201 and p = 0.000) were less likely to intend to bear children, or more children. Results in Table 46 also suggest that men were about twice (unadjusted odds ratio = 2.182, p = 0.027) as likely to have intentions to bear children relative to women. Women who had more years of completed education were also more likely to intend to have children/more children (unadjusted odds ratio = 1.342, p = 0.002). Log

transformed household income and whether or not one was living with a partner were both not significantly associated with childbearing intentions, independent of other variables.

Table 46: Bivariate relationships (unadjusted odds ratio) for fertility intentions - KHPS 2006

Characteristics	Female only	All
Internalized stigma	0.490*	0.575*
	[0.144]	[0.146]
Number of children	0.159***	0.201***
	[0.0480]	[0.0483]
Age	0.801***	0.851***
	[0.0344]	[0.0274]
Years of completed education	1.342**	1.072
	[0.126]	[0.0583]
Household income (natural log form)	1.316	1.067
	[0.267]	[0.178]
Lives with a partner	1.629	1.417
	[0.583]	[0.434]
Male		2.182*
		[0.767]

Standard errors in brackets, * p<0.05, ** p<0.01, *** p<0.001

9.2.2 Multivariate analysis of childbearing intentions among PLWHA

Predictor variables for our multivariate models are perceived stigma, experienced stigma and internalized stigma. Our multivariate analyses included the following control variables: number of living children; age; years of completed education; log transformed income (personal and household income); and whether or not respondent was living with a partner. We also have separate models for women only and the combined sample of men and women as we could not conduct regression models for men only because of the small sample size.

Through further exploration, we observed that whether a respondent was living with a partner or not significantly modified the relationships between experienced stigma and childbearing intentions. We therefore decided to conduct four multivariate analysis models: Model 1 for women without controlling

for living with a partner, Model 2 for women controlling for living with a partner, Model 3 for the whole sample without controlling for living with a partner, and Model 4 for the whole sample, and also controlling for living with a partner as shown in Table 47 (for experienced stigma), Table 48 (for perceived stigma) and Table 49 (for internalized stigma).

Experienced stigma

The results reported in Table 47 generally suggest that more experiences of HIV-related stigma were associated with increased childbearing intentions, after controlling for number of biological children, age, years of completed education, log transformed personal income, log transformed household income, whether or not respondent was living with a partner, and sex. The multivariate analysis in Model 1 shows that women who experienced more HIV/AIDS-related stigma were more than four times as likely (Odds ratio= 4.542, p = 0.010) to intend to have children or more children after controlling for number of children, age, years of completed education, log transformed personal and household income. Model 2, which was obtained after adjusting Model 1 by additionally controlling for whether or not one was living with a partner, shows a marginally statistically significant relationship between more experiences of HIV/AIDS-related stigma and child bearing intentions (Odds ratio= 3.342, p = 0.053). This general pattern of results was also observed in models for the full sample (Model 3 and Model 4).

In addition, the models, shown in Table 47, show that number of biological children, whether respondent was living with a partner and gender of respondent were important factors in predicting childbearing intentions. For example, Model 2 for women shows that having more biological children was associated with reduced childbearing intentions (odds ratio = 0.294, p= 0.000) and that women who were living with a partner were more than seven times (Odds ratio = 7.004, p= 0.000) likely to intend to have children. Similarly, Model 4 for the full sample shows that the number of biological children was positively

associated with reduced childbearing intentions (odds ratio = 0.196, p= 0.000) and that respondents who were living with a partner (odds ratio = 5.860, p= 0.000) and male (Odds ratio = 3.494, p= 0.015) were both statistically significantly more likely to have childbearing intentions.

Table 47: Multivariate relationships (odds ratios) for experienced stigma predicting fertility intentions - KHPS 2004/5

Characteristics	Women		All respondents	
	Model 1	Model 2	Model 3	Model 4
Experienced stigma	4.542*	3.342	3.847**	3.496*
	[2.680]	[2.087]	[1.889]	[1.807]
Number of children	0.294***	0.237***	0.242***	0.196***
	[0.0857]	[0.0772]	[0.0641]	[0.0583]
Age	0.935	0.952	0.950	0.955
	[0.0433]	[0.0453]	[0.0361]	[0.0374]
Years of completed education	0.982	1.011	0.915	0.935
	[0.0918]	[0.0994]	[0.0662]	[0.0694]
Personal income (natural log form)	0.829	1.052	0.855	0.852
	[0.356]	[0.478]	[0.324]	[0.342]
Household income (natural log form)	1.553	1.285	1.487	1.350
	[0.633]	[0.585]	[0.528]	[0.540]
Lives with a partner		7.004***		5.860***
		[3.903]		[2.740]
Male			4.661**	3.494*
			[2.262]	[1.798]
N	149	146	191	187
Pseudo R-Square	0.280	0.359	0.303	0.369

Standard errors in brackets,* p<0 .05, ** p<0.01, *** p<0.001, pseudo R-Square is the McFadden's (1974) R-square and is only indicative

Perceived stigma

Results in Table 48 show that perceived stigma was generally not associated with childbearing intentions for all models, controlling for the number of biological children, age, years of completed education, log transformed personal and household income, whether the respondent was living with a partner and gender. Similar to results for experienced stigma, increased number of biological children was generally associated with reduced intentions to bear more children. Women who were living with a partner were

more than eight times as likely (Odds ratio= 8.087, p = 0.000) to intend to have children or more children (Model 2 in Table 48). Similarly, results for the full sample (Model 4 in Table 48) show that respondents who were living with a partner were more likely (Odds ratio= 5.878, p = 0.000) to intend to have children or more children than those who were not living with a partner. Model 4 (Table 48) also indicates that men were more likely to intend to have children or more children than women (Odds ratio= 3.149, p = 0.025).

Table 48: Multivariate relationships (odds ratios) for perceived stigma predicting fertility intentions - KHPS 2004/5

Characteristics	Women		All respondents	
	Model 1	Model 2	Model 3	Model 4
Perceived stigma	1.024	0.752	1.244	1.137
	[0.419]	[0.347]	[0.414]	[0.404]
Number of children	0.318***	0.247***	0.272***	0.219***
	[0.0884]	[0.0788]	[0.0692]	[0.0627]
Age	0.929	0.946	0.952	0.957
	[0.0419]	[0.0448]	[0.0349]	[0.0365]
Years of completed education	0.956	0.983	0.911	0.929
	[0.0893]	[0.0971]	[0.0671]	[0.0714]
Personal income (natural log form)	0.875	1.185	0.897	0.914
	[0.363]	[0.530]	[0.329]	[0.356]
Household income (natural log form)	1.715	1.326	1.571	1.378
	[0.685]	[0.600]	[0.553]	[0.547]
Lives with a partner		8.087***		5.878***
		[4.462]		[2.677]
Male			4.213**	3.149*
			[1.999]	[1.607]
N	149	146	191	187
Pseudo R-Square	0.241	0.339	0.272	0.344

Standard errors in brackets,* p<0 .05, ** p<0.01, *** p<0.001, pseudo R-Square is the McFadden's (1974) R-square and is only indicative

Internalized stigma

All models in Table 49 show that after controlling for the selected covariates (number of biological children, age, years of completed education, income, whether the respondent was living with a partner and gender), the relationships between internalized stigma and childbearing intentions were no longer statistically significant. Except for whether or not the respondent was living with a partner, the addition of each of the control variables changed the statistical significance observed in the bivariate relationships between internalized stigma and childbearing intentions. Increased number of biological children (Model 4: Odds ratio= 0.217, p = 0.000) and increasing age (Model 4: Odds ratio= 0.901, p = 0.011) were both generally associated with less intention to bear children. Men were more likely to have childbearing intentions relative to women (Model 4: Odds ratio= 4.185, p = 0.005).

Table 49: Multivariate relationships (odds ratios) for internalized stigma predicting fertility intentions - KHPS 2006

Characteristics	Women		All respondents	
	Model 1	Model 2	Model 3	Model 4
Internalized stigma	0.749	0.843	0.756	0.792
	[0.318]	[0.367]	[0.256]	[0.271]
Number of children	0.176***	0.170***	0.226***	0.217***
	[0.0597]	[0.0586]	[0.0609]	[0.0600]
Age	0.865**	0.871*	0.897**	0.901*
	[0.0456]	[0.0466]	[0.0366]	[0.0371]
Years of completed education	1.071	1.096	0.964	0.972
	[0.124]	[0.132]	[0.0750]	[0.0762]
Household income (natural log form)	1.153	1.116	0.975	0.944
	[0.321]	[0.312]	[0.231]	[0.226]
Lives with a partner		1.736		1.578
		[0.924]		[0.683]
Male			4.379**	4.185**
			[2.195]	[2.114]
N	166	165	205	204
Pseudo R-Square	0.415	0.423	0.352	0.357

Standard errors in brackets,* p<0 .05, ** p<0.01, *** p<0.001, pseudo R-Square is the McFadden's (1974) R-square and is only indicative

9.2.3 Childbearing intentions and condom use

We further test if childbearing intentions were associated with inconsistent condom use. Table 50 reports condom use during the 12 months preceding the Wave 1 survey (date).

Table 50: Condom use practices during the past year - KHPS 2004/5 (wave 1)

How often did you use condoms when you had sex during the past year?	Male N (%)	Female N (%)	All N (%)
None of the time	1(2.1)	0(0)	1(0.4)
Some of the time	10(20.8)	24(12.4)	34(14.1)
Most of the time	1(2.1)	9(4.7)	10(4.2)
All of the time	32(66.7)	117(60.6)	149(61.8)
I haven't had sex in the past year	4(8.3)	43(22.3)	47(19.5)

Respondents who did not have sex in the year preceding the survey were treated as missing. The predicted odds of reporting consistent condom use ('all of the time') versus no condom use, or inconsistent condom use ('none of the time', 'some of the time' or 'most of the time') in a bivariate relationship suggest that childbearing intention was not statistically significantly associated with condom use practices for women (unadjusted odds ratio = 0.555, p = 0.143) and the full sample (unadjusted odds ratio = 0.632, p = 0.182).

We further explore a multivariate analysis predicting condom use from child bearing intentions and controlling for number of biological children, age, years of completed education, income, and gender. Results in Table 51 show that condom use was not statistically significantly associated with childbearing intentions for both women (Odds ratio= 0.638, p = 0.422) and the full sample (Odds ratio= 0.626, p = 0.325). The model for women suggests that increasing age was associated with increased condom use (Odds ratio= 1.127, p = 0.049).

Table 51: Multivariate relationships (odds ratios) for childbearing intentions predicting no condom use - KHPS 2004/5

Characteristics	Women	Full sample
Intention to have children	0.638	0.626
	[0.357]	[0.298]
Number of children	0.800	0.829
	[0.235]	[0.179]
Age	1.127*	1.02
	[0.0685]	[0.0426]
Years of completed education	1.045	1.02
	[0.0959]	[0.0707]
Personal income (natural log form)	0.474	0.505
	[0.239]	[0.209]
Household income (natural log form)	1.643	1.137
	[0.747]	[0.457]
Lives with a partner	0.963	0.677
	[0.507]	[0.283]
Male		0.854
		[0.405]
N	**115**	**152**

Standard errors in brackets,* p<0 .05, ** p<0.01, *** p<0.001

9.2.4 Childbearing intentions and actual childbearing

In this section, we test whether childbearing intentions among women were associated with pregnancy or actual fertility.

Birth after learning of HIV positive status

In Wave 1 of the KHPS, respondents were asked when they learned about their HIV positive status (T0) and the time they started ARV treatment (T1). The time between knowing their HIV status and ARV treatment ranged from less than a year to 11 years, with a mean of 1 year 8 months. The time between starting ARV treatment and the Wave 1 interview (T2) ranged from 0 to 4 years. Twenty (10.3%) respondents had at least one child after learning of their HIV positive status but before they started ARV

treatment, and six respondents had at least one child between their ARV enrolment date and the Wave 1 interview.

Pregnancy after learning of HIV positive status

Women respondents were asked at the time of Wave 3 (2007) about the number of times they had been pregnant since HIV diagnosis. Of the 173 respondents, 45% (78) had become pregnant at least once after learning of their HIV positive status, and about 11% had become pregnant between Wave 1 and Wave 3. A bivariate logistic regression shows that women who registered their intentions to bear children in Wave 1 (2004/5) were more than four times as likely (Odds ratio = 4.247, p = 0.004) to have become pregnant at least once between Wave 1 and Wave 3.

A further multivariate analysis was performed using childbearing intentions reported in Wave 1 to predict occurrence of at least one pregnancy by Wave 3. We also controlled for Wave 1 covariates. These include experienced stigma, number of biological children, age, years of completed education, log transformed household income and living with a partner (see Table 52).

Model 1 in Table 52 shows that women who reported intentions to bear children at the time of Wave 1 (2004/5) were more than four times (odds ratio = 4.276, p = 0.026) as likely to have become pregnant within the relatively short time period of about two years by the time of Wave 3 interviews (2007), controlling for the above items. The same model also shows that increasing age was associated with reduced chances of pregnancy (odds ratio = 0.794, p = 0.006). Model 2 additionally shows that when controlling for whether the respondent was living with a partner or not, childbearing intentions become marginally statistically significantly associated with pregnancy (odds ratio = 3.378, p = 0.081) and

increasing natural log household income becomes significantly associated with at least a pregnancy (odds ratio = 2.907, p = 0.041).

Table 52: Multivariate relationships (odds ratios) for childbearing intentions predicting occurrence of pregnancy among women respondents - KHPS 2004/7

Characteristics	Model 1	Model 2
Intention to have children	4.276*	3.378
	[2.790]	[2.357]
Experienced stigma	1.247	0.792
	[0.850]	[0.569]
Number of children	1.387	1.257
	[0.502]	[0.466]
Age	0.794**	0.817*
	[0.0664]	[0.0674]
Years of completed education	0.947	0.915
	[0.128]	[0.124]
Household income (natural log form)	2.261	2.907*
	[1.061]	[1.518]
Lives with a partner		2.227
		[1.307]
N	181	171
Pseudo R-Square	0.219	0.225

Standard errors in brackets,* p<0 .05, ** p<0.01, *** p<0.001, pseudo R-Square is the McFadden's (1974) R-square and is only indicative

9.3 Discussion

We used data from the 2007 KHPS to test whether experienced stigma, perceived stigma, and internalized stigma among PLWHA was associated with their fertility desires. In testing this relationship, we were trying to understand whether PLWHA's decision to bear children might have been influenced by various experiences of stigma. If any significant relationship was established, we were also interested in the general direction of the relationships, since previous studies suggested that experiences of stigma could either encourage or discourage childbearing among PLWHA (Craft, Delaney, Bautista *et al.*, 2007; Nattabi, Li, Thompson *et al.*, 2009).

We explored the relationship between HIV/AIDS-related stigma and childbearing among PLWHA, against a background of South African communities which do not approve of childbearing among PLWHA (Myer, Morroni and Cooper, 2006). This was perhaps a result of the moral scrutiny that childbearing among PLWHA attracts because of the possibilities of infecting the child or the partner with the HIV virus. South African studies show that despite living in such a judgemental environment, women living with HIV/AIDS still value motherhood in their lives (e.g. MacGregor and Mills, 2011; Cooper and Harries, 2009). Data from the KHPS 2004/5 showed that about one in three of all respondents intended to have children, or more children, and this proportion was higher among men. These results are consistent in magnitude and gender distribution with other South African studies based on HAART patients (e.g. Kaida, Laher, Strathdee *et al.*, 2011; Myer, Morroni and Rebe, 2007). For example, Kaida, *et al*. (2011: 352) found that 31% of women using HAART intended to have children or more children. Myer, *et al.* (2007: 280) found these proportions to be about 36% for men and 26% for women.

We found experienced stigma and perceived stigma not to be statistically significantly associated with childbearing intentions, independent of other variables. However, after controlling for number of biological children, age, women's years of completed education, and income (personal and household income), we show that respondents who experienced more stigma were more than four times more likely to have intentions to bear children or more children. This applied to women, and the combined sample of men and women. One possible explanation as to why PLWHA who experienced stigma might be motivated to have children (or more children) is their need to prove their own health and appear 'normal' to society, thereby avoiding stigma, as observed in some samples of PLWHA in South Africa (Cooper, Harries, Myer *et al.*, 2007: 278; Van Zyl and Visser, 2015). It is also suggested that PLWHA who experienced stigma may bear children to have someone to love or love them back (Craft, Delaney, Bautista *et al.*, 2007: 933).

The multivariate analysis for experienced stigma also shows that childbearing intentions were associated with being male, having fewer biological children, and living with a partner. These findings are consistent with other South African studies on PLWHA (Myer, Morroni and Rebe, 2007; Cooper, Moodley, Zweigenthal *et al.*, 2009). Increased desire for children among men from patrilineal societies is linked to their desire to continue their lineage after they die, as observed in other samples of South African men living with HIV/AIDS (Cooper, Harries, Myer *et al.*, 2007: 277). Myer, *et al.* (2007: 281) also observed that respondents in a sample of HAART patients from Cape Town who did not intend to have children had already achieved their desired family size. This could be the reason why those with fewer biological children had increased odds of childbearing intentions, as they may still have wanted to achieve their fertility goals. We propose that future related work should incorporate the measurement of desired family size more directly.

Previous South African studies showed that women living with HIV/AIDS expressed childbearing intentions if they could find a partner in the future (MacGregor and Mills, 2011). This study also found that those who were living with a partner had increased childbearing intentions. We also found that the effect of experienced stigma on childbearing intentions of women disappeared when we controlled for whether or not they were living with a partner. In a previous qualitative study in Cape Town, Cooper, *et al*. (2007: 278) found that regardless of their HIV status, married women's partners expected them to have children, or threaten abandonment. Some respondents from the same study were of the opinion that children within marriage are 'a must'. Another South African study found that some women living with HIV/AIDS wanted to have a biological child with their current partner in order to help secure their relationship (Mindry, Crankshaw, Maharaj *et al.*, 2015: 27). Therefore, high expectations of childbearing within committed relationships could be the reason why women who were living with a partner were more likely to desire children. The effect of live-in partners also appeared to overshadow the effect of

experienced stigma on childbearing decisions of women living with HIV/AIDS. This finding points to the importance of intimate relationships in assisting PLWHA deal with stigma.

Perceived stigma among PLWHA in our sample had no significant influence on their childbearing intentions, both independently, and when regarded alongside other variables. Results for perceived stigma may have been distorted by the poor measurement scale. The measurement scale for perceived stigma initially had four measurement items and two of them loaded poorly (factor loading less than 0.4) in an exploratory factor analysis. The selected measurement model based on the three remaining items suggests poor reliability, based on the Cronbach's alpha coefficient of reliability of about 0.54. As a result, overall assessment of the perceived stigma scale was that it was poor. However, perceived stigma can plausibly be expected to both encourage and discourage childbearing among PLWHA, depending on individual circumstances. Similar to arguments for experienced stigma above, some South African PLWHA, and especially women who anticipate stigma from the surrounding community, have been found to have children in order to conceal their HIV status, and be accepted by their partners and relatives (Van Zyl and Visser, 2015; Oni, Ross and van der Linde, 2013). On the other hand, other studies of women living with HIV in South Africa and the US indicate that perceived stigma discouraged some of them from having children as they did not want to be blamed by society for taking risks that could lead to transmission of the HIV virus to their child and partner (Craft, Delaney, Bautista *et al.*, 2007: 933; Cooper, Harries, Myer *et al.*, 2007: 278).

Similar to the analysis for experienced stigma, we found that more biological children were statistically significantly associated with less intention to bear children. Being male, and living with a partner, are shown to be associated with increased odds of childbearing intentions, in the model for perceived stigma.

Internalized stigma was independently associated with less intention to bear children. However, no statistically significant relationship is found when our multivariate analysis controlled for number of biological children, age, years of completed education, log transformed household income, whether respondent was living with a partner and gender of the respondent. According to a qualitative South African study, some women newly diagnosed with HIV lost interest in childbearing as a result of blaming sex (which is also the most likely mode of conception in this context) for their HIV positive status. They may also feel guilty about burdening others with the responsibility of taking care of their child, should they die early (Cooper and Harries, 2009). This observation was supported by the bivariate analysis for internalized stigma, but not by the multivariate analysis.

In an attempt to gain some qualitative insight into the social context within which the PLWHA in Khayelitsha decided to have children, we conducted an extensive interview[11] with Zinzi (not her real name) who had been an HIV treatment activist and was one of the KHPS respondents. She was of the opinion that HIV/AIDS-related stigma generally still existed in Khayelitsha, but probably at a reduced level than that experienced at the time of the surveys (from 2004 to 2007). In relation to childbearing, she pointed out that the general community still did not approve of PLWHA having children. In her particular case, she had a baby born around the time of the surveys, that is mid-2000s, and she did it for two reasons: (1) she wanted a baby; (2) she wanted to prove her own health to others around her. The decision to have a child was mutually agreed between her and her partner who was also HIV-positive. It is worth noting that the survey was unable to collect adequate data on the HIV-status of respondent's sexual partners and that this could be an important limitation of the study. Decision-making is clearly very different if both partners are HIV-positive. Coping with HIV-stigma is also probably easier if both partners are HIV-positive.

[11] On the 15th of February 2016

At the time of making the decision to have the child, Zinzi was on HAART treatment, which had dramatically improved her health. She was also employed and she felt both financially and emotionally ready to have a child. She explained that her personal circumstances to have a child were not influenced by experiences of HIV/AIDS-related stigma.

Zinzi also commented on the social background and related circumstances of other women she interacted with over the course of the survey period (from 2004 to 2007). She pointed out that there was a belief in the community that if a woman is HIV-positive then she cannot bear children. Therefore, childbearing by some of the HIV-positive women (including herself) was one way of proving their normality. As indicated by the literature review, the assumed linkage between HIV stigma and child-bearing intentions was that it either discouraged people from having children (fear of stigma) or encouraged them to have children (to fit in with broader social norms and to disguise their HIV status). Zinzi points here to a third possible motivation: An activist motivation, to show the community that PLWHA can lead normal lives. Her observations remind us of the specific context of the KHPS study: It examined the first cohort of HAART patients in South Africa, many of whom were drawn into activist roles in the struggle for antiretroviral treatment.

Those who chose to have children at the time had another problem to deal with as they were prescribed formula milk for their child, and formula milk was known to be used by HIV-positive women (see also Almeleh, 2012: 123). These women faced challenges of hiding the formula milk, or having to justify to others why they were not breast-feeding. Zinzi highlighted this challenge, describing other women who were worried about their HIV status and deciding not to bear children as they feared infecting the child or dying early and leaving a young child to be taken care of by other people. In her assessment, she felt that it is easier now for one to have a baby due to accessibility of HIV treatment drugs which improves one's health. She also mentioned that there is now less need to consult a medical doctor before becoming

pregnant compared to the situation in the mid-2000s when HIV-treatment was still being piloted among this study sample. At the time, the standard recommendation for women on HAART was to avoid breastfeeding. Now the recommendation is to breastfeed as long as their viral load is undetectable.

The study could not establish a statistically significant relationship between condom use in the 12 months preceding the survey and childbearing intentions. This finding is comparable to a Zimbabwean study conducted in 2007 that found no significant relationship between condom use and pregnancy desires among a sample of women diagnosed with HIV (McClellan, Patel, Kadzirange *et al.*, 2010). The lack of a statistically significant relationship in our study could well be a consequence of our empirical strategy of predicting previous condom use from intended childbearing desires. A better method would be to predict current condom use or intended condom use from intended childbearing desires – but the data were not available to do this. According to a study of HIV-patients in Uganda (2010-2012), condom use in the 6 months prior to the study was significantly higher among those with no fertility desires (Wagner and Wanyenze, 2013). This suggests an inconsistent relationship between condom use and childbearing intentions, or the need for a time reference when studying this topic.

We further tested whether childbearing intentions were associated with eventual childbearing. We found that there was a statistically significant relationship between reported childbearing desires in 2004/5 and occurrence of at least one pregnancy by 2007, controlling for stigma experiences, number of biological children, age, years of completed education, and log transformed household income. This result reinforces the notion that childbearing intentions will most likely lead to eventual childbearing, as observed in general populations (Schoen, Astone, Kim *et al.*, 1999; Pritchett, 1994). We also observed that when we control for whether women were living with a partner in addition to the other covariates, household income become significantly associated with pregnancy. This suggests that men bring financial stability or an extra income into relationships where richer households are more likely to attempt pregnancy. When

controlling for whether women were living with a partner, the effect of expressed childbearing desires on occurrence of a pregnancy disappears. This suggests that childbearing desires of women were profoundly influenced by whether they live with a partner or not.

9.3.1 Limitations of the study

The processes by which people make reproductive decisions are complex and there are inevitably other important factors that were not measured or controlled for in this study. One of the factors is whether the respondent has a biological child with their current partner/spouse as this was observed to be an important factor in some South Africa samples of PLWHA (Mindry, Crankshaw, Maharaj *et al.*, 2015: 27). The same study suggests that the need for biological children within a relationship can motivate childbearing, as the children can be a tool for securing the relationship especially if the partner desires children (or more children).

10 Conclusion

HIV/AIDS-related stigma is widely recognized as an impediment to HIV prevention, treatment and care, yet the precise pathways from stigma to risky sexual practices is less well understood. This study explored possible influences of various HIV/AIDS-related stigmas on the practice of risky sexual behaviour for HIV infection. We explored these relationships for people in the general population and for PLWHA in Cape Town.

We investigated the hypothesis that individuals who hold symbolic stigma attitudes towards PLWHA are more likely to perceive themselves at a reduced risk of infection with HIV, and, as a result continue to engage in risky sexual behaviour. This is shown to be consistent with data for a sample of young Black and Coloured women from Cape Town. We could not find evidence to support the same hypothesis in a sample of their male counterparts. The young women's self-perceived risk of HIV infection fully mediated the relationship between symbolic stigma attitudes and changes in risky sexual behaviour. This was in the form of increased number of sexual partners and reduced condom use. This suggests the need to continue educating people in the general population that HIV is not a disease for certain groups, and that anyone who is sexually active needs to practice safer sex. The observation that the mediation model is not consistent with data for young men calls for further investigation into the generalizability of this finding. There are also indications that race and gender might influence risk perceptions and change in risky sexual behaviour differently. This highlights the need to consider gender and race differences in understanding drivers of change in risky sexual behaviour among young adults (at least in Cape Town if not elsewhere).

Our study established that the relationships between HIV/AIDS-related stigma (perceived stigma and internalized stigma) among PLWHA, disclosure of HIV sero-status to sexual partners and the practice of risky sexual behaviour are complex and contingent, but that some empirical regularities are evident. In our sample of PLWHA from Khayelitsha, all men had disclosed to their sexual partners (for Wave 2 of the KHPS) and data indicated that women felt vulnerable, prompting some not to disclose for fear of negative consequences, such as abandonment and rejection. We could not establish a statistically significant relationship between HIV/AIDS-related stigma among PLWHA and condom use that was mediated by disclosure of HIV status to sexual partners. However, a few open ended responses suggested that disclosure alone did not easily translate to initiation of safer sex practices. Our study also found that non-disclosure of HIV status to a sexual partner did not necessarily translate into unprotected sex. This was because some women managed to negotiate condom use without disclosing their HIV status. This shows the complex and contingent nature of the relationship between disclosure of HIV status to a sexual partner and condom use.

Our study found that internalized stigma among PLWHA was associated with more symptoms of depression and anxiety, which in turn was associated with inconsistent condom use or no condom use, for both women only and the full sample. For women, disclosure of HIV status to a sexual partner was also associated with more symptoms of depression and anxiety and this in turn was associated with more chances of inconsistent condom use or no condom use. There was a marginally statistically significant result, indicating that some women who disclosed to their sexual partners reported increased condom use, and this relationship was not mediated by depression/anxiety. There are undoubtedly pathways connecting internalized stigma and condom use other than depression and anxiety and disclosure of HIV status to a sexual partner that were not explored in our study.

We found more experienced stigma to be associated with childbearing desires. However, we could not establish the same relationship for perceived stigma. Internalized stigma was independently associated with reduced childbearing intentions, and there were no significant relationships in a multivariate system. Reported childbearing intentions among this sample of PLWHA were associated with the occurrence of at least one pregnancy for women in the sample, but were not significantly related to condom use.

10.1 Recommendations for further research

We found some support for the hypothesis that symbolic stigma attitudes create a sense of invulnerability, and that therefore stigmatizers continue to engage in risky sexual behaviour, but we found this to be the case for young women only. The study also observed significant differences in perceived risk of infection with the HIV virus and risky sexual behaviour by population group and gender, among the young adults. We therefore recommend further exploration of these differences and specifically on what contexts shape perceptions of risk of infection with the HIV virus, and their potential influences on sexual behaviour.

The Khayelitsha context of our sample of PLWHA is unique in many ways, as discussed in Chapter 5. It is thus highly likely that other South African contexts of PLWHA have different HIV/AIDS-related stigmas, disclosure challenges, and other factors that may contribute to the practice of risky sexual behaviour. We therefore recommend exploration of the mediated relationships between HIV stigma (perceived and internalized stigma) and risky sexual behaviour in other contexts, in order to explore their more general validity. Given that the scale for perceived stigma employed in this study was of marginal validity and reliability, future studies need to develop better measures of perceived stigma, or to adapt validated scales.

Our sample of men living with HIV/AIDS was too small to enable any meaningful analysis. Given that men in this study context appear to be the ones who influence sexual decisions, it is important to understand better the social factors shaping their risky sexual behaviour, which may be less influenced by fear of stigma than women's responses. This calls for analysing larger samples of men living with HIV/AIDS in order to understand their situation better and to help formulate prevention strategies. The data analysed are also based on one of the partners who was living with HIV/AIDS and it may be useful to have data for both partners. This would help us understand the more personal strategic factors limiting condom use within sexual relationships where at least one of the partners is living with HIV/AIDS.

We found that depression and anxiety symptoms partially mediated the relationship between internalized stigma and reduced condom use, among women. Other potential mediators such as social support (which has been hypothesised to diminish for PLWHA, because of HIV stigma), may also influence sexual risk taking (Clum, Chung, Ellen *et al.*, 2009) and could also be explored.

References

Abrahams, N. and R. Jewkes. 2012. "Managing and resisting stigma: a qualitative study among people living with HIV in South Africa", *Journal of the International AIDS Society* **15**(2):17330.

Actuarial Society of South Africa. 2011. *ASSA2008 AIDS and Demographic Model*. Cape Town: Actuarial Society of South Africa.

Adam, M.A. and L.F. Johnson. 2009. "Estimation of adult antiretroviral treatment coverage in South Africa", *S Afr Med J* **99**(9):661-667.

Adamchak, S., B. Janowitz, J. Liku *et al.* 2010. "Study of family planning and HIV integrated services in five countries", *Family Health International, Research Triangle Park, NC, USA*

African National Congress. 1994. *The Reconstruction and Development Programme: A Policy Framework*. African National Congress.

Airhihenbuwa, C., T. Okoror, T. Shefer *et al.* 2009. "Stigma, culture, and HIV and AIDS in the Western Cape, South Africa: An application of the PEN-3 cultural model for community-based research", *Journal of Black Psychology* **35**(4):407-432.

Aka-Dago-Akribi, H., A.D. Du Lou, Msellati, P, R. Dossou *et al.* 1999. "Issues surrounding reproductive choice for women lying with HIV in Abidjan, Côte d'Ivoire", *Reproductive health matters* **7**(13):20-29.

Akwara, P.A., N.J. Madise and A. Hinde. 2003. "Perception of risk of HIV/AIDS and sexual behaviour in Kenya", *J. biosoc. Sci.* **35**(3):385-411.

Almeleh, C. 2006. "Why do People Disclose their HIV Status? Qualitative Evidence from a Group of Activist Women in Khayelitsha", *Social Dynamics: A journal of African studies* **32**(2):136-169.

Almeleh, C.J. 2012. "HIV Disclosure in 'Public' and Personal Spaces: A Mixed Methods Study of People Living with HIV in Khayelitsha, South Africa." Unpublished dissertation, Cape Town: University of Cape Town.

Anderson, K.G., A.M. Beutel and B. Maughan-Brown. 2007. "HIV risk perceptions and first sexual intercourse among youth in Cape Town, South Africa", *International family planning perspectives* **33**(3):98-105.

Anglewicz, P. and J. Chintsanya. 2011. "Disclosure of HIV status between spouses in rural Malawi", *AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV,* **23**(8):998-1005.

Antelman, G., M.C.S. Fawzi, S. Kaaya *et al.* 2001. "Predictors of HIV-1 serostatus disclosure: a prospective study among HIV-infected pregnant women in Dar es Salaam, Tanzania", *AIDS* **15**(14):1865-1874.

Attia, S., M. Egger, M. Müller *et al.* 2009. "Sexual transmission of HIV according to viral load and antiretroviral therapy: systematic review and meta-analysis", *AIDS* **23**(11):1397-1404.

Baleta, A. 1999. "Widespread horror over killing of AIDS activist in South Africa", *THE LANCET* **353**(9147):130.

Baron, R.M. and D.A. Kenny. 1986. "The moderator-mediation variable distinction in social psychological research: Conceptual, strategic, and statistical considerations", *Journal of Personality and Social Psychology* **51**(6):1173–1182.

Barreiro, P., A. Duerr, K. Beckerman *et al.* 2006. "Reproductive options for HIV-serodiscordant couples", *AIDS Rev* **8**(3):158-170.

Baulch, B. and A. Quisumbing. 2011. "Testing and adjusting for attrition in household panel data", *Chronic Poverty Research Centre (CPRC) Toolkit Note*

Becker, G. 1981. *A treatise on the family.* Cambridge, MA: Harvard University Press.

Becketti, S., W. Gould, L. Lillard *et al.* 1988. "The panel study of income dynamics after fourteen years: An evaluation", *Journal of Labor Economics* **6**(4):472-492.

Bekker, L., V. Black, L. Myer *et al.* 2011. "Guideline on safer conception in fertile HIV-infected individuals and couples: guideline", *Southern African Journal of HIV Medicine* **12**(2):31-44.

Benotsch, E.G., V.M. Rodrı´guez, K. Hood *et al.* 2012. "Misleading Sexual Partners About HIV Status Among Persons Living with HIV/AIDS", *J Community Health* **37**:1049–1057.

Bentler, P.M. and D.C. Bonnet. 1980. "Significance Tests and Goodness of Fit in the Analysis of Covariance Structures", *Psychological Bulletin* **88**(3):588-606.

Berger, B.E., C.E. Ferrans and F.R. Lashley. 2001. "Measuring Stigma in People With HIV: Psychometric Assessment of the HIV Stigma Scale", *Research in Nursing & Health* **24**(6):518-529.

Beutel, A.M. and K.G. Anderson. 2013. "Change over time in the human immunodeficiency virus risk perceptions of youth", *Journal of Social Sciences* **9**(1):1-10.

Bogart, L.M., B.O. Cowgill, D. Kennedy *et al.* 2008. "HIV-related stigma among people with HIV and their families: a qualitative analysis", *AIDS and Behavior* **12**(2):244-254.

Boomsma, A. and J.J. Hoogland. 2001. "The robustness of LISREL modeling revisited," in Cudeck, R, S du Toit and D Sörbom (eds). *Structural equation models: Present and future. A Festschrift in honor of Karl Jöreskog*. Chicago: Scientific Software International, pp. 139-168.

Bor, J., A.J. Herbst, M.L. Newell *et al.* 2013. "Increases in adult life expectancy in rural South Africa: valuing the scale-up of HIV treatment", *Science* **339**(6122):961–965.

Bott, S. and C.M. Obermeyer. 2013. "The social and gender context of HIV disclosure in sub-Saharan Africa: a review of policies and practices", *SAHARA-J: Journal of Social Aspects of HIV/AIDS* **10**(sup1):S5-S16.

Bouchard, B. 2007. "Improving flood risk management in informal settlements of Cape Town." Unpublished dissertation, Worcester Polytechnic Institute.

Brandt, R. 2007. "Does HIV matter when you are poor and how?: the impact of HIV/AIDS on the psychological adjustment of South African mothers in the era of HAART." Unpublished dissertation, University of Cape Town.

Brewer, N.T., N.D. Weinstein, C.L. Cuite, & *et al.* 2004. "Risk perceptions and their relation to risk behavior", *Annals of Behavioral Medicine* **27**(2):125-130.

Brouard, P. and C. Wills. 2006. *A closer look: the internalization of stigma related to HIV*. United States Agency for International Development (USAID).

Browne, M.W. and R. Cudeck. 1993. "Alternative ways of assessing model fit," in Bollen, K. A and J. S Long (eds). *Testing structural equation models* Newbury Park, CA: Sage, pp. 136−162

Bryan, A., S.J. Schmiege and M.R. Broaddus. 2007. "Mediational analysis in HIV/AIDS research: estimating multivariate path analytic models in a structural equation modeling framework", *AIDS and Behavior* **11**(3):365-383.

Burkholder, G.J., L.L. Harlow and J.L. Washkwich. 1999. "Social Stigma, HIV/AIDS Knowledge, and Sexual ", *Journal of Applied Biobehavioral Research* **4**(1):27-44.

Camlin, C.S. and R.C. Snow. 2008. "Parental Investment, Club Membership, and Youth Sexual Risk Behavior in Cape Town", *Health Educ Behav* **35** (4):522–540.

Castilla, J., J. Del Romero, V. Hernando *et al.* 2005. "Effectiveness of highly active antiretroviral therapy in reducing heterosexual transmission of HIV", *J Acquir Immune Defic Syndr* **40**(1):96–101.

Catania, J.A., T.J. Coates and S. Kegeles. 1994. "A test of the AIDS Risk Reduction Model: Psychosocial correlates of condom use in the AMEN cohort survey", *Health Psychology* **13**(6):548-555.

Catania, J.A., S.M. Kegeles and T.J. Coates. 1990. "Towards understanding of risk behavior: An AIDS Risk Reduction Model (AARM)", *Health Education & Behavior* **17**(1):53–72.

Cattell, R.B. 1966. "The scree test for the number of factors", *Multivariate Behavioral Research* **1**(2):245-276.

Centers for Disease Control. 1985. "Recommendations for assisting in the prevention of perinatal transmission of human T-lymphotropic virus type III/lymphadenopathy-associated virus and acquired immunodeficiency syndrome", *MMWR. Morbidity and mortality weekly report* **34**(48):721.

Chandra, P.S., S. Deepthivarma and V. Manjula. 2003. "Disclosure of HIV infection in South India: patterns, reasons and reactions", *AIDS care* **15**(2):207-215.

Chaudoir, S.R., V.A. Earnshaw and S. Andel. 2013. "“Discredited” versus “discreditable”: understanding how shared and unique stigma mechanisms affect psychological and physical health disparities", *Basic and applied social psychology* **35**(1):75-87.

Chesney, M. and A. Smith. 1999. "Critical delays in HIV testing and care: The potential role of stigma", *American Behavioral Scientist* **42**(7):1162–1174.

Chigwedere, P., G.R. Seage III, S. Gruskin *et al.* 2008. "Estimating the lost benefits of antiretroviral drug use in South Africa", *JAIDS Journal of Acquired Immune Deficiency Syndromes* **49**(4):410-415.

Clark, H.J., G. Lindner, L. Armistead *et al.* 2004. "Stigma, Disclosure, and Psychological Functioning Among HIV-Infected and Non-Infected African-American Women", *Women & health* **38**(4):57-71.

Cloete, A., L.C. Simbayi, S.C. Kalichman *et al.* 2008. "Stigma and discrimination experiences of HIV-positive men who have sex with men in Cape Town, South Africa", *AIDS care* **20** (9):1105-1110.

Cloete, A., A. Strebel, L. Simbayi *et al.* 2010. "Challenges faced by people living with HIV/AIDS in Cape Town, South Africa: Issues for group risk reduction interventions", *AIDS research and treatment* **2010**:1-8.

Clum, G., S.E. Chung, J.M. Ellen *et al.* 2009. "Mediators of HIV-related stigma and risk behavior in HIV infected young women", *AIDS care* **21**(11):1455–1462.

Coetzee, D., K. Hildebrand, A. Boulle *et al.* 2004. "Outcomes after two years of providing antiretroviral treatment in Khayelitsha, South Africa", *AIDS* **18**(6):887–895.

Cohen, M.S., Y.Q. Chen, M. McCauley *et al.* 2011. "Prevention of HIV-1 infection with early antiretroviral therapy", *New England journal of medicine* **365**(6):493-505.

Cook, G.P. 1986. "Khayelitsha: Policy Change or Crisis Response?", *Transactions of the Institute of British Geographers* **11**(1):57-66.

Cook, J.E., H. Arrow and B.F. Malle. 2011. "The effect of feeling stereotyped on social power and inhibition", *Personality and Social Psychology Bulletin* **37**(2):165–180.

Coombs, R.W., P.S. Reichelderfer and A.L. Landay. 2003. "Recent observations on HIV type-1 infection in the genital tract of men and women", *AIDS* **17**(4):455-480.

Cooper, D., J. Harries, L. Myer *et al.* 2007. "‘‘Life is still going on’’: Reproductive intentions among HIV-positive women and men in South Africa", *Social Science & Medicine* **65**(2):274–283.

Cooper, D., J. Moodley, V. Zweigenthal *et al.* 2009. "Fertility Intentions and Reproductive Health Care Needs of People Living with HIV in Cape Town, South Africa: Implications for Integrating Reproductive Health and HIV Care Services", *AIDS Behav* **13**(1):38–46.

Cooper, S. and J. Harries. 2009. "‘If I Could Properly Understand and Get the Right Information’: A Qualitative Study on the Sexual and Reproductive Health Needs and Rights of HIV-positive Women", *CSSR Working Paper* **256**

Courtenay-Quirk, C., R.J. Wolitski, J.T. Parsons *et al.* 2006. "Is HIV/AIDS stigma dividing the gay community? Perceptions of HIV–positive men who have sex with men", *AIDS Education and Prevention* **18**(1):56–67.

Craft, S.M., R.O. Delaney, D.T. Bautista *et al.* 2007. "Pregnancy decisions among women with HIV", *AIDS Behav* **11**(6):927-935.

Crepaz, N. and G. Marks. 2003. "Serostatus disclosure, sexual communication and safer sex in HIV-positive men", *AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV* **15**(3):379-387.

Deacon, H., I. Stephney and S. Prosalendis. 2005. *Understanding HIV/AIDS stigma: a theoretical and methodological analysis.* Cape Town, HSRC Press.

DeJanes, W. 2009. "Knowledge, substance use, and gender differences associated with HIV infection risk among youth in a South African township", *Med Sociol Online* **4**(2):3-25.

Department of Health, Medical Research Council and M. DHS+. 2002. *South Africa Demographic and Health Survey 1998, Full Report*. Pretoria: National Department of Health.

Department of Health, Medical Research Council and OrcMacro. 2007. *South Africa Demographic and Health Survey 2003*. Pretoria: Department of Health.

Deribe, K., K. Woldemichael, B.J. Njau *et al.* 2010. "Gender differences regarding barriers and motivators of HIV status disclosure among HIV-positive service users", *SAHARA J (Journal of Social Aspects of HIV/AIDS Research Alliance)* **7**(1):30-39.

Derlega, V.J., B.A. Winstead, K. Greene *et al.* 2004. "Reasons for HIV disclosure/nondisclosure in close relationships: testing a model of HIV–disclosure decision making", *Journal of Social and Clinical Psychology* **23**(6):747-767.

Donnell, D., J.M. Baeten, J. Kiarie *et al.* 2010. "Heterosexual HIV-1 transmission after initiation of antiretroviral therapy: a prospective cohort analysis", *THE LANCET* **375**(9731):2092-2098.

dos Santos, M.M.L., P. Kruger, S.E. Mellors *et al.* 2014. "An exploratory survey measuring stigma and discrimination experienced by people living with HIV/AIDS in South Africa: the People Living with HIV Stigma Index", *BMC Public Health* **14**:80.

Draper, B., D. Pienaar, W. Parker *et al.* 2007. *Recommendations for policy in the Western Cape province for the prevention of major infectious diseases, including HIV/AIDS and tuberculosis* Cape Town.

Dyer, S.J. 2007. "The value of children in African countries – Insights from studies on infertility", *Journal of Psychosomatic Obstetrics & Gynecology* **28**(2):69–77.

Dyer, S.J., N. Abrahams, M. Hoffman *et al.* 2002. "'Men leave me as I cannot have children': women's experience with involuntary childlessness", *Human Reproduction* **17**(6):1663-1668.

Earnshaw, V.A. and S.R. Chaudoir. 2009. "From conceptualizing to measuring HIV stigma: a review of HIV stigma mechanism measures", *AIDS and Behavior* **13**(6):1160-1177.

Earnshaw, V.A. and S.C. Kalichman. 2013. "Stigma experienced by people living with HIV/AIDS," in *Discrimination and Living with HIV/AIDS*. Springer Netherlands, pp. 23-38.

Earnshaw, V.A., L.R. Smith, P.A. Shuper *et al.* 2014. "HIV stigma and unprotected sex among PLWH in KwaZulu-Natal, South Africa: a longitudinal exploration of mediating mechanisms", *AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV* **26**(12):1506-1513.

Eaton, L., A.J. Flisher and L.E. Aaro. 2003. "Unsafe sexual behaviour in South African youth", *Social Science & Medicine* **56**(1):149–165.

Eisele, T.P., C. Mathews, M. Chopra *et al.* 2008. "High levels of risk behavior among people living with HIV Initiating and waiting to start antiretroviral therapy in Cape Town South Africa", *AIDS and Behavior* **12**(4):570-577.

Emlet, C.A. 2007. "Experiences of stigma in older adults living with HIV/AIDS: A mixed-methods analysis", *AIDS patient care and STDs* **21**(10):740-752.

Famoroti, T.O., L. Fernandes and S.C. Chima. 2013. "Stigmatization of people living with HIV/AIDS by healthcare workers at a tertiary hospital in KwaZulu-Natal, South Africa: a cross-sectional descriptive study", *BMC medical ethics* **14**(Suppl 1):S6.

Fife, B.L. and E.R. Wright. 2000. "The Dimensionality of Stigma: A Comparison of Its Impact on the Self of Persons with HIV/AIDS and Cancer", *Journal of Health and Social Behavior* **41**(1):50-67.

Fitzgerald, J., P. Gottschalk and R. Moffitt. 1998. "An Analysis of Sample Attrition in Panel Data: The Michigan Panel Study of Income Dynamics", *Journal of Human Resources* **33**(2):251-299.

Flora, D.B. and P.J. Curran. 2004. "An empirical evaluation of alternative methods of estimation for confirmatory factor analysis with ordinal data", *Psychological methods* **9**(4):466-491.

Fraser-Hurt, N., K. Zuma, P. Njuho *et al.* 2011. *The HIV epidemic in South Africa: What do we know and how has it changed?* Cape Town: HSRC Press.

Geffen, N. 2010. *Debunking delusions: The inside story of the Treatment Action Campaign.* Jacana Media.

Gerrard, M., F.X. Gibbons and B.J. Bushman. 1996. "Relation Between Perceived Vulnerability to HIV and Precautionary Sexual Behavior", *Psychological Bulletin* **119**(3):390-409.

Goffman, E. 1963. *Stigma:Notes on the management of spoiled identity.* New York: Simon & Shuster.

Gray, R.H., M.J. Wawer, R. Brookmeyer *et al.* 2001. "Probability of HIV-1 transmission per coital act in monogamous, heterosexual, HIV-1-discordant couples in Rakai, Uganda", *THE LANCET* **357**(9263):1149-1153.

Grebe, E. and N. Nattrass. 2012. "AIDS Conspiracy Beliefs and Unsafe Sex in Cape Town", *AIDS Behav* **16**(3):761–773.

Green, G. 1995. "Attitudes towards people with HIV: Are they as stigmatizing as people with HIV perceive them to be?", *Social Science & Medicine* **41**(4):557-568.

Hair, J.F., W.C. Black, B.J. Babin *et al.* 2006. *Multivariate data analysis.* Pearson Prentice Hall Upper Saddle River, NJ.

Harrison, A. and L.F. O'Sullivan. 2010. "In the absence of marriage: long-term concurrent partnerships, pregnancy, and HIV risk dynamics among South African young adults", *AIDS and Behavior* **14**(5):991-1000.

Hatzenbuehler, M.L., S. Nolen-Hoeksema and J. Dovidio. 2009. "How does stigma "get under the skin"? ", *Psychological Science* **20**(10):1282–1289.

Hatzenbuehler, M.L., C. O'Cleirigh, K.H. Mayer *et al.* 2011. "Prospective associations between HIV-related stigma, transmission risk behaviors, and adverse mental health outcomes in men who have sex with men", *Annals of Behavioral Medicine* **42**(2):227–234.

Hayton, J.C., D.G. Allen and V. Scarpello. 2004. "Factor retention decisions in exploratory factor analysis: A tutorial on parallel analysis", *Organizational research methods* **7**(2):191-205.

Herek, G.M. 1991. "Stigma, Prejudice, and Violence Against Lesbians and Gay Men," in John, C. G and D James (eds). *Homosexuality: Research implications for public policy*. Newbury Park, CA: Sage, pp. 60-80.

Herek, G.M. 1999. "AIDS and Stigma", *American Behavioral Scientist* **42**(7):1106-1116.

Herek, G.M. 2002. "Thinking about AIDS and stigma: A psychologist's perspective", *Journal of Law, Medicine and Ethics* **30**(4):594–607.

Herek, G.M. and J.P. Capitanio. 1998. "Symbolic prejudice or fear of infection? A functional analysis of AIDS-related stigma among heterosexual adults", *Basic and applied social psychology* **20**(3):230-241.

Herek, G.M., S. Saha and J. Burack. 2013. "Stigma and Psychological Distress in People With HIV/AIDS", *Basic and applied social psychology* **35**(1):41-54.

Herek, G.M., K.F. Widaman and J.P. Capitanio. 2005. "When sex equals AIDS: Symbolic stigma and heterosexual adults' inaccurate beliefs about sexual transmission of AIDS", *Social Problems* **52**(1):15-37.

Hodes, R. and T.H. Naimak. 2011. "Piloting antiretroviral treatment in South Africa: the role of partnerships in the Western Cape's provincial roll-out", *African Journal of AIDS Research* **10**(4):415-425.

Hoelter, J.W. 1983. "The analysis of covariance structures goodness-of-fit indices", *Sociological Methods & Research* **11**(3):325-344.

Holzemer, W.L., L.R. Uys, M.L. Chirwa *et al.* 2007. "Validation of the HIV/AIDS Stigma Instrument—PLWA (HASI-P)", *AIDS care* **19**(8):1002-1012.

Homsy, J., R. Bunnell, D. Moore *et al.* 2009. "Reproductive Intentions and Outcomes among Women on Antiretroviral Therapy in Rural Uganda: A Prospective Cohort Study", **4**(1):e4149.

Horn, J.L. 1965. "A rationale and test for the number of factors in factor analysis", *Psychometrika* **30**(2):179–185.

Hotz, V.J., J.A. Klerman and R.J. Willis. 1997. "The economics of fertility in developed countries," in Rosenzweig, M. R and O Stark (eds). *Handbook of population and family economics*. pp. 275-347.

Hu, L. and P.M. Bentler. 1999. "Cutoff criteria for fit indexes in covariance structure analysis: Conventional criteria versus new alternatives", *Structural EquationModeling* **6**(1):1−55.

Iacobucci, D., N. Saldanha and X. Deng. 2007. "A meditation on mediation: Evidence that structural equations models perform better than regressions", *Journal of Consumer Psychology* **17**(2):139-153.

Ingram, D. and S.A. Hutchinson. 2000. "Double Binds and the Reproductive and Mothering Experiences of HIV-Positive Women", *Qualitative Health Research* **10**(1):117-132.

Janz, N.K. and M.H. Becker. 1984. "The health belief model: A decade later", *Health Education Quarterly* **11**(1):1-47.

Jelsma, J., E. MacLean, J. Hughes *et al.* 2005. "An investigation into the health-related quality of life of individuals living with HIV who are receiving HAART", *AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV* **17**(5):579-588.

Jewkes, R., K. Dunkle, M. Nduna *et al.* 2006. "Factors associated with HIV sero-status in young rural South African women: connections between intimate partner violence and HIV", *International Journal of Epidemiology* **35**(6):1461–1468.

Johnson, L.F., J. Mossong, R.E. Dorrington *et al.* 2013. "Life expectancies of South African adults starting antiretroviral treatment: collaborative analysis of cohort studies", *PLoS medicine* **10**(4):e1001418.

Joint United Nations Programme on HIV/AIDS (UNAIDS). 2000. *National AIDS programmes: a guide to monitoring and evaluation.* UNAIDS.

Kaida, A., F. Laher, S.A. Strathdee *et al.* 2011. "Childbearing Intentions of HIV-Positive Women of Reproductive Age in Soweto, South Africa: The Influence of Expanding Access to HAART in an HIV Hyperendemic Setting", *American journal of public health* **101**(2):350-358.

Kaiser, H.F. 1960. "The application of electronic computers to factor analysis", *Educational and psychological measurement* **20**:141-151.

Kaiser, H.F. 1974. "An index of factorial simplicity", *Psychometrika* **39**(1):31-36.

Kalichman, S.C., M. DiMarco, J. Austin *et al.* 2003. "Stress, Social Support, and HIV-Status Disclosure to Family and Friends Among HIV-Positive Men and Women", *Journal of Behavioral Medicine* **26**(4):315-332.

Kalichman, S.C., L. Simbayi and D. Cain. 2010. "HIV transmission risk behaviours among HIV seropositive sexually transmitted infection clinic patients in Cape Town, South Africa", *European Journal of Public Health* **20**(2):202–206.

Kalichman, S.C. and L.C. Simbayi. 2003. "HIV testing attitudes, AIDS stigma, and voluntary HIV counselling and testing in a black township in Cape Town, South Africa", *Sex Transm Infect* **79**(6):442–447.

Kalichman, S.C., L.C. Simbayi, S. Jooste *et al.* 2005. "Development of a brief scale to measure AIDS-related stigma in South Africa", *AIDS and Behavior* **9**(2):135-143.

Kanniappan, S., M. Jeyapaul and S. Kalyanwala. 2008. "Desire for motherhood: exploring HIV-positive women's desires, intentions and decision-making in attaining motherhood", *AIDS care* **20**(6):625-630.

Kasper, T., D. Coetzee, F. Louis *et al.* 2003. "Demystifying antiretroviral therapy in resource-poor settings", *Essential Drugs Monitor* **32**:20-21.

Kenny, D.A. 2012. *Multiple Latent Variable Models: Confirmatory Factor Analysis*. http://davidakenny.net/cm/mfactor.htm. Accessed: 25 July 2014.

Kheswa, G. 2014. "Exploring HIV and AIDS Stigmatisation: Children's Perspectives", *Mediterranean Journal of Social Sciences* **5**(15):529-514.

Kiene, S.M., S. Christie, D.H. Cornman *et al.* 2006. "Sexual Risk Behaviour among HIV-Positive Individuals in Clinical Care in Urban KwaZulu-Natal, South Africa", *CHIP Documents* **Paper 28**

King, R. 1999. *Sexual behavioural change for HIV: Where have theories taken us?* Geneva: UNAIDS.

Kohi, T., L. Makoae, M. Chirwa *et al.* 2006. "HIV and AIDS stigma violates human rights in five African countries", *Nursing Ethics* **13**(4):404-415.

Lam, D., C. Ardington, N. Branson *et al.* 2012. *The Cape Area Panel Study: Overview and Technical Documentation Waves 1-2-3-4-5 (2002-2009)*. University of Cape Town.

Lee, R.S., A. Kochman and K.J. Sikkema. 2002. "Internalized Stigma Among People Living with HIV-AIDS", *AIDS and Behavior* **6**(4):309-319.

Lima, V.D., R. Harrigan, D.R. Bangsberg *et al.* 2009. "The combined effect of modern highly active antiretroviral therapy regimens and adherence on mortality over time", *Journal of acquired immune deficiency syndromes (1999)* **50**(5):529–536.

Link, B.G. and J.C. Phelan. 2001. "Conceptualizing Stigma", *Annual Review of Sociology* **27**:363-385.

London, L., P.J. Orner and L. Myer. 2008. "'EVEN IF YOU'RE POSITIVE, YOU STILL HAVE RIGHTS BECAUSE YOU ARE A PERSON': HUMAN RIGHTS AND THE REPRODUCTIVE CHOICE OF HIV-POSITIVE PERSONS", *Developing World Bioethics* **8**(1):11-22.

Lurie, M., P. Pronyk, E. de Moor *et al.* 2008. "Sexual Behavior and Reproductive Health Among HIV-Infected Patients in Urban and Rural South Africa", *J Acquir Immune Defic Syndr* **47**(4):484–493.

MacGregor, H. and E. Mills. 2011. "Framing rights and responsibilities: accounts of women with a history of AIDS activism", *BMC international health and human rights* **11**(Suppl 3):S7.

Macintyre, K., N. Rutenberg, L. Brown *et al.* 2004. "Understanding Perceptions of HIV Risk Among Adolescents in KwaZulu-Natal", *AIDS and Behavior* **8**(3):237-250.

Mahajan, A.P., J.N. Sayles, V.A. Patel *et al.* 2008. "Stigma in the HIV/AIDS epidemic: A review of the literature and recommendations for the way forward", *AIDS* **22**(Suppl 2):S67–S79.

Mak, W.W.S., R.Y.M. Cheung, R.W. Law *et al.* 2007. "Examining attribution model of self-stigma on social support and psychological well-being among people with HIV+/AIDS", *Social Science & Medicine* **64**(8):1549–1559.

Makin, J.D., B.W. Forsyth, M.J. Visser *et al.* 2008. "Factors affecting disclosure in South African HIV-positive pregnant women", *AIDS patient care and STDs* **22**(11):907-916.

Maman, S. and A. Medley. 2003. "Gender dimensions of HIV status disclosure to sexual partners: rates barriers and outcomes. A review paper",

Mantell, J.E., J.A. Smit and Z.A. Stein. 2009. "The right to choose parenthood among HIV-infected women and men", *Journal of Public Health Policy* **30**(4):367–378.

Marteleto, L., D. Lam and V. Ranchhod. 2008. "Sexual behavior, pregnancy, and schooling among young people in urban South Africa", *Studies in Family Planning* **39** (4):351–368.

Mathews, C., L. Kuhn, D. Fransman *et al.* 1999. "Disclosure of HIV status and its consequences", *South Afican Medical Journal* **89**(12):1238-1238.

Maticka-Tyndale, E. 2012. "Condoms in sub-Saharan Africa", *Sexual Health* **9**(1):59-72.

Maughan-Brown, B. 2007. "Experiences And Perceptions Of HIV/AIDS-Related Stigma Amongst People On Antiretroviral Treatment In Khayelitsha, South Africa", *CSSR Working Paper No 185*

Maughan-Brown, B. 2008. "A multidimensional quantitative evaluation of HIV/AIDS-related stigma in Cape Town, South Africa." Unpublished dissertation, Cape Town: University of Cape Town.

Maughan-Brown, B. 2010. "Stigma rises despite antiretroviral roll-out: A longitudinal analysis in South Africa", *Social Science & Medicine* **70**(3):368–374.

Maughan-Brown, B.G. 2004. "Measuring HIV/AIDS Stigma", *CSSR Working Paper No. 74*

Maughan-Brown, B.G. 2006. "Attitudes towards people with HIV/AIDS: stigma and its determinants amongst young adults in Cape Town, South Africa", *South African Review of Sociology* **37**(2):165-188.

Mbonu, N.C., B. van den Borne and N.K. De Vries. 2009. "Stigma of people with HIV/AIDS in Sub-Saharan Africa: a literature review", *Journal of tropical medicine* **2009**

McClellan, M.K., R. Patel, G. Kadzirange *et al.* 2010. "Fertility desires and condom use among HIV-positive women at an antiretroviral roll-out program in Zimbabwe: original research", *African Journal of Reproductive Health* **14**(2):27-35.

McFadden, D. 1974. "Conditional logit analysis of qualitative choice behavior," in Zarembka, P (ed). *Frontiers in Econometrics*. Academic Press, pp. 105-142.

Médecins Sans Frontières, University of Cape Town and Western Cape Provincial Department of Health. 2003. *Antiretroviral Therapy in Primary Health Care: Experience of the Khayelitsha Programme in South Africa: Case Study*. Geneva: Word Health Organization.

Medley, A., C. Garcia-Moreno, S. McGill *et al.* 2004. "Rates, barriers and outcomes of HIV serostatus disclosure among women in developing countries: implications for prevention of mother-to-child transmission programmes", *Bulletin of the World Health Organization* **82**(4):299-307.

Mills, E., M.M. de Paoli and A.B. Grønningsæter. 2009. "Love in the Time of AIDS: The Relational Gender Dynamics of Prevention, Testing and Treatment", *CSSR Working Paper No. 252*

Mills, E. and B. Maughan-Brown. 2009. "Ties that Bind: HIV-Disclosure as Consequence and Catalyst of Stigma and Support in Households", *CSSR Working Paper No. 266*

Mindry, D., T. Crankshaw, P. Maharaj *et al.* 2015. "“We have to try and have this child before it is too late”: missed opportunities in client–provider communication on reproductive intentions of people living with HIV", *AIDS care* **27**(1):25-30.

Morris, M.H. and L.F. Pitt. 1995. "Informal sector activity as entrepreneurship: insights from a South African township", *Journal of Small Business Management* **33**(1):78.

Morrison, K. 2006. *Breaking the cycle: Stigma, discrimination, internal stigma, and HIV*. United States Agency for International Development (USAID).

Mthembu, S. 2012. "Cervical cancer and women living with HIV in South Africa: Failure of AIDS treatment policy or gendered exclusions in health care?", *Agenda* **26**(2):35-43.

Murphy, D.A., S.J. Durako, A.-B. Moscicki *et al.* 2001. "No Change in Health Risk Behaviors Over Time Among HIV Infected Adolescents in Care: Role of Psychological Distress", *Journal of Adolescent Health* **29**(3S):57–63.

Mustanski, B., R. Garofalo, A. Herrick *et al.* 2007. "Psychosocial health problems increase risk for HIV among urban young men who have sex with men: Preliminary evidence of a syndemic in need of attention", *Annals of Behavioral Medicine* **34**(1):37–45.

Muyinda, H., J. Seeley, H. Pickering *et al.* 1997. "Social aspects of AIDS-related stigma in rural Uganda", *Health & Place* **3**(3):143-147.

Myer, L., R.J. Carter, M. Katyal *et al.* 2010. "Impact of antiretroviral therapy on incidence of pregnancy among HIV-infected women in Sub-Saharan Africa: a cohort study", *PLoS medicine* **7**(2):194.

Myer, L., C. Morroni and D. Cooper. 2006. "Community attitudes towards sexual activity and childbearing by HIV-positive people in South Africa", *AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV* **18**(7):772-776.

Myer, L., C. Morroni and K. Rebe. 2007. "Prevalence and Determinants of Fertility Intentions of HIV-Infected Women and Men Receiving Antiretroviral Therapy in South Africa", *AIDS Patient Care STDS* **21**(4):278–285.

Nakagawa, F., R.K. Lodwick, C.J. Smith *et al.* 2012. "Projected life expectancy of people with HIV according to timing of diagnosis", *AIDS* **26**(3):335-343.

Napper, L.E., D.G. Fisher and G.L. Reynolds. 2012. "Development of the perceived risk of HIV scale", *AIDS and Behavior* **16**(4):1075-1083.

Narayanan, A. 2012. "A review of eight software packages for structural equation modeling", *The American Statistician* **66**(2):129-138.

National Department of Health (2007) National Department of health document.

National Department of Health. 2010. *National antenatal sentinel HIV and syphilis prevalence survey, South Africa*.

National Department of Health and National Treasury. 2003. *Full Report of the Joint Health and Treasury Task Team Charged with Examining Treatment Options to Supplement Comprehensive Care for HIV/AIDS in the Public Health Sector*. Pretoria: National Department of Health, National Treasury.

Nattabi, B., J. Li, S.C. Thompson *et al.* 2009. "A Systematic Review of Factors Influencing Fertility Desires and Intentions Among People Living with HIV/AIDS: Implications for Policy and Service Delivery", *AIDS Behav* **13**(5):949–968.

Nattabi, B., J. Li, S.C. Thompson *et al.* 2012. "Between a rock and a hard place: stigma and the desire to have children among people living with HIV in northern Uganda", *Journal of the International AIDS Society* **15**(2):17421.

Nattrass, N. 2007. *Mortal combat: AIDS denialism and the fight for antiretrovirals in South Africa* Pietermaritzburg, South Africa: University of KwaZulu-Natal Press.

Nattrass, N. 2008. "AIDS and the scientific governance of medicine in post-apartheid South Africa", *African affairs* **107**(427):157-176.

Nattrass, N., B. Maughan-Brown, J. Seekings *et al.* 2012. "Poverty, sexual behaviour, gender and HIV infection among young black men and women in Cape Town, South Africa", *African Journal of AIDS Research* **11**(4):307–317.

Ndegwa, D., D. Horner and F. Esau. 2007. "The links between migration, poverty and health: evidence from Khayelitsha and Mitchells Plain", *Social Indicators Research* **81**(2):223–234.

Ndou, T.V., P.R. Risenga and M.S. Maputle. 2013. "Experiences of HIV Positive Patients on ARV Treatment at the Thulamela Municipality in the Vhembe District of Limpopo Province, South Africa", *Journal of Antivirals & Antiretrovirals* **5**(5):123-131.

Noar, S.M. 2007. "An interventionist's guide to AIDS behavioral theories", *AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV* **19**(3):392-402.

Nyblade, L.C. 2006. "Measuring HIV stigma: Existing knowledge and gaps", *Psychology, Health & Medicine* **11**(3):335 – 345.

Okello, E.S., G.J. Wagner, B. Ghosh-Dastidar *et al.* 2015. "Depression, Internalized HIV Stigma and HIV Disclosure", *World Journal of AIDS* **5**(01):30.

Okoror, T.A., C.O. Airhihenbuwa, M. Zungu *et al.* 2007. ""My Mother Told Me I Must Not Cook Anymore" - Food, Culture, and the Context of HIV-and AIDS-Related Stigma in Three Communities in South Africa", *International quarterly of community health education* **28**(3):201-213.

Okoror, T.A., R. BeLue, N. Zungu *et al.* 2014. "HIV Positive Women's Perceptions of Stigma in Health Care Settings in Western Cape, South Africa", *Health care for women international* **35**(1):27-49.

Olley, B.O., S. Seedat, F. Gxamza *et al.* 2005. "Determinants of unprotected sex among HIV-positive patients in South Africa", *AIDS Care: Care: Psychological and Sociomedical Aspects of AIDS/HIV* **17**(1):1-9.

Olley, B.O., S. Seedat and D.J. Stein. 2004. "Self-Disclosure of HIV Serostatus in Recently Diagnosed Patients with HIV in South Africa", *African Journal of Reproductive Health* **8**(2):71-76.

Oni, E.E., A. Ross and S. van der Linde. 2013. "Contraceptive practices amongst HIV-positive women on antiretroviral therapy attending an ART clinic in South Africa", *African Journal of Primary Health Care & Family Medicine* **5**(1):461-466.

Palmisano, L. and S. Vella. 2011. "A brief history of antiretroviral therapy of HIV infection: success and challenges", *Annali dell'Istituto superiore di sanita* **47**(1):44-48.

Parker, R. and P. Aggleton. 2003. "HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action", *Social Science & Medicine* **57**(1):13–24.

Parker, W., S. Oyosi, K. Kelly *et al.* 2002. *On the move: The response of public transport commuters to HIV/AIDS in South Africa*. http://www.cadre.org.za. Accessed: 22 June 2015.

Peltzer, K. and S. Promtussananon. 2005. "HIV/AIDS Knowledge and Sexual Behavior Among Junior Secondary School Students in South Africa", *Journal of Social Sciences* **1**(1):1-8.

Petros, G., C.O. Airhihenbuwa, L. Simbayi *et al.* 2006. "HIV/AIDS and 'othering' in South Africa: The blame goes on", *Culture, Health & Sexuality* **8**(1):67–77.

Pettifor, A., H.V. Rees, I. Kleinschmidt *et al.* 2005. "Young people's sexual health in South Africa: HIV prevalence and sexual behaviours from a nationally representative household survey", *AIDS* **19**(14):1525–1534.

Pettifor, A.E., H.V. Rees, A. Steffenson *et al.* 2004. *HIV and sexual behaviour among young South Africans: a national survey of 15-24 year olds*.

Phillips, K.D., L. Moneyham and A. Tavakoli. 2011. "Development of an Instrument to Measure Internalized Stigma in Those with HIV/AIDS", *Issues in Mental Health Nursing* **32**(6):359–366.

Pinkerton, S.D. and C.L. Galletly. 2007. "Reducing HIV transmission risk by increasing serostatus disclosure: a mathematical modeling analysis", *AIDS and Behavior* **11**(5):698-705.

Preston, D.B., A.R. D'Augelli, C.D. Kassab *et al.* 2004. "The influence of stigma on the sexual risk behavior of rural men who have sex with men", *AIDS Education and Prevention* **16**(4):291–303.

Preston, D.B., A.R. D'Augelli, C.D. Kassab *et al.* 2007. "The relationship of stigma to the sexual risk behavior of rural men who have sex with men", *AIDS Education and Prevention* **19**(3):218-230.

Pritchett, L.H. 1994. "Desired fertility and the impact of population policies", *Popul Dev Rev* **20**(1):1-55.

Prohaska, T.R., G. Albrecht, J.A. Levy *et al.* 1990. "Determinants of self-perceived risk for AIDS", *Journal of Health and Social Behavior* **31**(4):384-339.

Quinn, T.C., M.J. Wawer, N. Sewankambo *et al.* 2000. "Viral load and heterosexual transmission of human immunodeficiency virus type 1", *New England journal of medicine* **342**(13):921-929.

R Core Team. 2013. *R: A language and environment for statistical computing* R Foundation for Statistical Computing, Vienna, Austria: http://www.R-project.org/.

Radloff, L.S. and B.Z. Locke. 1986. "The community mental health assessment survey and the CES-D Scale," in Weissman, M. M , J. K Myers and C. E Ross (eds). *Community surveys of psychiatric disorders*. New Brunswick, NJ: Rutgers University Press, pp. 177-189.

Rankin, W.W., S. Brennan, E. Schell *et al.* 2005. "The stigma of being HIV-positive in Africa", *PLoS medicine* **2**(8):e247.

Ras, G.J., I.W. Simson, R. Anderson *et al.* 1983. "Acquired immunodeficiency syndrome", *S Afr Med J* **64** (4):140-142.

Richey, L.A. 2006. "Gendering the therapeutic citizen: ARVS and reproductive and health", *CSSR Working Paper* **175**

Riley, G.A. and D. Baah-Odoom. 2010. "Do stigma, blame and stereotyping contribute to unsafe sexual behaviour? A test of claims about the spread of HIV/AIDS arising from social representation theory and the AIDS risk reduction model", *Social Science & Medicine* **71** (3):600-607.

Rogers, M.F., M.G. Fowler and M.L. Lindegren. 2001. "Revised recommendations for HIV screening of pregnant women", *Morbidity and Mortality Weekly Report: Recommendations and Reports*:59-85.

Rohleder, P. and K. Gibson. 2006. "'We are not fresh': HIV-positive women talk of their experience of living with their 'spoiled identity'", *South African Journal of Psychology* **36**(1):25–44.

Rosenstock, I., V. Strecher and M. Becker. 1994. "The Health Belief Model and HIV risk behavior change," in DiClemente, R. J and J. L Peterson (eds). *Preventing AIDS: Theories and Methods of Behavioral Interventions*. New York: Plenum Press, pp. 5-24.

Rosseel, Y. 2012. "lavaan: An R package for structural equation modeling", *Journal of Statistical Software* **48**(2):1-36.

Rucker, D.D., K.J. Preacher, Z.L. Tormala *et al.* 2011. "Mediation analysis in social psychology: Current practices and new recommendations", *Social and Personality Psychology Compass* **5**(6):359-371.

SADC. 2006. "Expert Think Tank Meeting on HIV Prevention in High Prevalence Countries.," Paper presented at Meeting Report. Maseru, May. SADC HIV and AIDS Unit.

Sandelowski, M., C. Lambe and J. Barroso. 2004. "Stigma in HIV-Positive Women", *Journal of Nursing Scholarship* **36**(2):122-128.

Sayles, J.N., R.D. Hays, C.A. Sarkisian *et al.* 2008. "Development and psychometric assessment of a multidimensional measure of internalized HIV stigma in a sample of HIV-positive adults", *AIDS and Behavior* **12**(5):748-758.

Scambler, G. 1998. "Stigma and disease: Changing paradigms", *THE LANCET* **352**(9133):1054-1055.

Scambler, G. 2009. "Health-related stigma", *Sociology of Health & Illness,* **31**(3):441-455.

Scambler, G. and A. Hopkins. 1986. "Being epileptic, coming to terms with stigma", *Sociology of Health and Illness* **8**(1):26–43.

Schermelleh-Engel, K., H. Moosbrugger and H. Müller. 2003. "Evaluating the fit of structural equation models: Tests of significance and descriptive goodness-of-fit measures", *Methods of psychological research online* **8**(2):23-74.

Schoen, R., N.M. Astone, Y.J. Kim *et al.* 1999. "Do fertility intentions affect fertility behavior?", *Journal of Marriage and the Family* **61**(3):790-799.

Seekings, J., J. Graaff and P. Joubert. 1990. "Survey of residential and migration histories of residents of the shack areas of Khayelitsha", *Research Unit for Sociology of Development, University of Stellenbosch, Occasional Paper 15*

Shaikh, N., L. Smit and K. Cloete. 2006. *The 2005 HIV antenatal provincial & area surveys*. Western Cape. Cape Town, South Africa: Department of Health: Provincial Government of the Western Cape, 12.

Shisana, O., T. Rehle, L.C. Simbayi *et al.* 2005. *South African national HIV prevalence, HIV incidence, behavior and communication survey, 2005*. Cape Town, South Africa Human Sciences Research Council Publishers.

Shisana, O., T. Rehle, L.C. Simbayi *et al.* 2009. *South African national HIV prevalence, incidence, behaviour and communication survey 2008: A turning tide among teenagers?* Cape Town: HSRC Press.

Shisana, O., T. Rehle, L.C. Simbayi *et al.* 2014. *South African National HIV Prevalence, Incidence and Behaviour Survey, 2012* Cape Town: HSRC Press.

Shisana, O. and L.C. Simbayi (eds). 2002. *Nelson Mandela/HSRC study of HIV/AIDS: South African national HIV prevalence, behavioural risks and mass media: household survey 2002*. HSRC Press.

Shuper, P.A., S.M. Kiene, G. Mahlase *et al.* 2014. "HIV transmission risk behavior among hiv-positive patients receiving antiretroviral therapy in KwaZulu-Natal, South Africa", *AIDS and Behavior* **18**(8):1532-1540.

Sigxashe, T.A., R. Baggaley and C. Mathews. 2001. "Attitudes to disclosure of HIV status to sexual partners [letter]", *South African Medical Journal* **91**(11):908-909.

Sikkema, K.J., M.H. Watt, C.S. Meade *et al.* 2011. "Mental health and HIV sexual risk behavior among patrons of alcohol serving venues in Cape Town, South Africa", *Journal of acquired immune deficiency syndromes (1999)* **57**(3):230.

Simbayi, L.C., J. Chauveau and O. Shisana. 2004. "Behavioural responses of South African youth to the HIV/AIDS epidemic: a nationwide survey", *AIDS Care: Psychological and Sociomedical Aspects of AIDS/HIV* **16**(5):605-618.

Simbayi, L.C., S. Kalichman, A. Strebel *et al.* 2007a. "Internalized stigma, discrimination, and depression among men and women living with HIV/AIDS in Cape Town, South Africa", *Social Science & Medicine* **64**(9):1823–1831.

Simbayi, L.C., S.C. Kalichman, A. Strebel *et al.* 2007b. "Disclosure of HIV status to sex partners and sexual risk behaviours among HIV-positive men and women, Cape Town, South Africa", *Sex Transm Infect* **83**(1):29–34.

Simoni, J.M., H.R. Mason, G. Marks *et al.* 1995. "Women's self-disclosure of HIV infection: Rates, reasons, and reactions", *Journal of Consulting and Clinical Psychology* **63**(3):474.

Simoni, J.M. and D.W. Pantalone. 2004. "Secrets and Safety in the Age of AIDS: Does HIV Disclosure Lead to Safer Sex?", *Topics in HIV Medicine* **12**(4):109-118.

Skhosana, N.L., H. Struthers, G.E. Gray *et al.* 2006. "HIV disclosure and other factors that impact on adherence to antiretroviral therapy: the case of Soweto, South Africa", *African Journal of AIDS Research* **5**(1):17-26.

Skinner, D. and S. Mfecane. 2004. "Stigma, discrimination and the implications for people living with HIV/AIDS in South Africa", *Journal of Social Aspects of HIV/AIDS* **1**(3):157-164.

Skuse, A. and T. Cousins. 2007. "Spaces of resistance: informal settlement, communication and community organisation in a Cape Town township", *Urban Studies* **44**(5/6):979–995.

Sobel, M.E. 1982. "Asymptotic confidence intervals for indirect effects in structural equation models", *Sociological methodology* **13**(1982):290-312.

StataCorp. 2013. *Stata Statistical Software: Release 13*. College Station, TX: StataCorp LP.

Statistics South Africa. 2003. *Census 2001: Community profiles in SuperCross*.

Statistics South Africa. 2012. *Census 2011: Community profiles in SuperCross*.

Statistics South Africa. 2014. *Mid-year population estimates, 2014*. Pretoria: Statistics South Africa.

Steiger, J.H. 1990. "Structural model evaluation and modification: An interval estimation approach", *Multivariate Behavioral Research* **25**(2):173−180.

Stein, J. 2003. "HIV/AIDS stigma: The latest dirty secret", *African Journal of AIDS Research* **2**(2):95-101.

Stevens, J.P. 1992. *Applied multivariate statistics for the social sciences.* Hillsdale, NJ: Erlbaum.

Strebel, A., M. Crawford, T. Shefer *et al.* 2006. "Social constructions of gender roles, gender-based violence and HIV/AIDS in two communities of the Western Cape, South Africa: original article", *SAHARA: Journal of Social Aspects of HIV/AIDS Research Alliance* **3**(3):p. 516-528.

Strode, A., S. Mthembu and Z. Essack. 2012. "“She made up a choice for me”: 22 HIV-positive women's experiences of involuntary sterilization in two South African provinces", *Reproductive health matters* **20**(39):61-69.

Stutterheim, S.E., A.E. Bos, J.B. Pryor *et al.* 2011. "Psychological and social correlates of HIV status disclosure: The significance of stigma visibility", *AIDS Education and Prevention* **23**(4):382-392.

Tabachnick, B.G. and L.S. Fidell. 2014. *Using multivariate statistics.* Pearson Education Inc.

TAC. 2007. "Equal Treatment", **Issue 22**

Tenkorang, E.Y. 2013. "A Multilevel Path Analysis of Risk Perception and Risky Sexual Behavior Under the Framework of the Health Belief Model", *Journal of HIV/AIDS & Social Services* **12**(2):125-145.

Tenkorang, E.Y., E. Maticka-Tyndale and F. Rajulton. 2011. "A multi-level analysis of risk perception, poverty and sexual risk-taking among young people in Cape Town, South Africa", *Health & Place* **17**(2):525-535.

Tenkorang, E.Y., F. Rajulton and E. Maticka-Tyndale. 2009. "Perceived risks of HIV/AIDS and first sexual intercourse among youth in Cape Town, South Africa", *AIDS and Behavior* **13**(2):234-245.

Thornton, A.C., F. Romanelli and J.D. Collins. 2004. "Reproduction Decision Making for Couples Affected by HIV: A Review of the Literature", *Top HIV Med* **12**(2):61-67.

Treatment Action Campaign. 2000. *Mourn Mpho Motloung! Change HIV/AIDS messages to show hope now! False message increase violence against women*. http://www.tac.org.za. Accessed: 25 May 2015.

Tshweneagae, G.T., V.M. Oss and T. Mgutshini. 2015. "Disclosure of HIV status to sexual partners by people living with HIV", *curationis* **38**(1):1-6.

UNAIDS. 2013. *Regional Report – Getting to zero: HIV in Eastern and Southern Africa*. Geneva: UNAIDS.

US Public Health Service Task Force. *Recommendations for use of antiretroviral drugs in pregnant HIV-1-infected women for maternal health and interventions to reduce perinatal HIV-1 transmission in the United States*. https://aidsinfo.nih.gov/contentfiles/lvguidelines/PerinatalGL.pdf. Accessed: 4 November 2015.

Van Zyl, C. and M.J. Visser. 2015. "Reproductive desires of men and women living with HIV: implications for family planning counselling", *Reproductive biomedicine online* **31**(3):434-442.

Vanable, P.A., M.P. Carey, D.C. Blair *et al.* 2006. "Impact of HIV-Related Stigma on Health Behaviors and Psychological Adjustment Among HIV-Positive Men and Women", *AIDS and Behavior* **10**(5):473-482.

Varga, C.A., G. Sherman and S. Jones. 2006. "HIV-disclosure in the context of vertical transmission: HIV-positive mothers in Johannesburg, South Africa", *AIDS care* **18**(8):952-960.

Varni, S.E., C.T. Miller, T. McCuin *et al.* 2012. "Disengagement and engagement coping with HIV/AIDS stigma and psychological well-being of people with HIV/AIDS", *Journal of Social and Clinical Psychology* **31**(2):123-150.

Varni, S.E., C.T. Miller and S.E. Solomon. 2012. "Sexual Behavior as a Function of Stigma and Coping with Stigma Among People with HIV/AIDS in Rural New England", *AIDS Behav* **16**(8):2330–2339.

Volberding, P.A. and S.G. Deeks. 2010. "Antiretroviral therapy and management of HIV infection", *THE LANCET* **376**(9734):49-62.

Vu, L., K. Andrinopoulos, C. Mathews *et al.* 2012. "Disclosure of HIV Status to Sex Partners Among HIV-Infected Men and Women in Cape Town, South Africa", *AIDS Behav* **16**(1):132–138.

Wagner, G.J. and R. Wanyenze. 2013. "Fertility desires and intentions and the relationship to consistent condom use and provider communication regarding childbearing among HIV clients in Uganda", *ISRN infectious diseases* **2013**:1-7.

Wasti, S.P., P. Simkhada, J. Randall *et al.* 2012. "Factors influencing adherence to antiretroviral treatment in Nepal: a mixed-methods study", *PLoS ONE* **75**(5):e35547.

Wheaton, B., B. Muthen, D.F. Alwin *et al.* 1977. "Assessing reliability and stability in panel models", *Sociological methodology* **8**(1):84-136.

WHO, UNAIDS and Unicef. 2011. "Global HIV/AIDS response: epidemic update and health sector progress towards universal access", *Progress report 2011*

Wolitski, R.J., S.L. Pals, D.P. Kidder *et al.* 2009. "The Effects of HIV Stigma on Health, Disclosure of HIV Status, and Risk Behavior of Homeless and Unstably Housed Persons Living with HIV", *AIDS Behav* **13**(6):1222–1232.

Wong, L.H., H. Van Rooyen, P. Modiba *et al.* 2009. "Test and tell: correlates and consequences of testing and disclosure of HIV status in South Africa (HPTN 043 Project Accept)", *Journal of acquired immune deficiency syndromes (1999)* **50**(2):215–222.

World Health Organization. 2010. *Antiretroviral therapy for HIV infection in adults and adolescents: recommendations for a public health approach. 2010 revision* http://whqlibdoc.who.int/publications/2010/9789241599764_eng.pdf. Accessed: 8 April 2015.

World Health Organization. 2012. *Guidance on couples HIV testing and counselling including antiretroviral therapy for treatment and prevention in serodiscordant couples: recommendations for a public health approach*.

World Health Organization. 2015. *Guideline on when to start antiretroviral therapy and on pre-exposure prophylaxis for HIV*.

Wright, K., S. Naar-King, P. Lam *et al.* 2007. "Stigma scale revised: reliability and validity of a brief measure of stigma for HIV+ youth", *Journal of Adolescent Health* **40**(1):96-98.

Young, T. 2003. *HIV clinics Khayelitsha counselling guideline*. https://www.msf.org.za/download/file/fid/2956. Accessed: 22 August 2015.

Zaidi, J., E. Grapsa, F. Tanser *et al.* 2012. "HIV prevalence trends after scaleup of antiretroviral treatment: a population-based study in a poor rural community in KwaZulu-Natal. Late breaking abstract," Paper presented at International AIDS Conference Washington D.C. , July 22-27, 2012.

Zamberia, A.M. 2009. "Sexual activity and condom use among people living with HIV in Swaziland", *African Journal of AIDS Research* **8**(1):69-81.

Zhao, X., J.G. Lynch and Q. Chen. 2010. "Reconsidering Baron and Kenny: Myths and truths about mediation analysis", *Journal of consumer research* **37**(2):197-206.

Datasets

University of Michigan and University of Cape Town. Cape Area Panel Study 2002-2009, Waves 1-5. 2012 [dataset]. Version 1210. Cape Town and Ann Arbor: University of Cape Town and University of Michigan [producers], 2012. Cape Town: DataFirst [distributor], 2012.

University of Cape Town. Khayelitsha HAART Panel Study 2004-2007, Waves 1-3. 2008 [dataset]. Version 1. Cape Town: University of Cape Town [producers], 2008. Cape Town: AIDS and Society Research Unit [distributor], 2008.

Appendices

Appendix A: Example of the KHPS consent form

Centre for Social Science Research, University of Cape Town
Private Bag, Rondebosch 7701
http://www.uct.ac.za/depts/cssr

CONSENT FORM

Last year you generously agreed to be a part of this panel study. A panel study is one in which we re-interview people regularly. This panel study explores the lives of people using anti-retroviral treatment. It is run by researchers at the University of Cape Town. We would like to re-interview you now.

You are kindly invited to participate in the 2006 survey. Before you decide whether to take part, we want to make sure that you understand the following information about the study.

What is the purpose of the study?
The University of Cape Town is doing research to assess the experiences of people using anti-retrovirals. The questionnaire again asks about work, living arrangements, health and sexual relationships. It is our expectation that the results from this study will improve our understanding of the health and work experience of many South Africans today.

What are the possible benefits of participating?
There will be no direct benefit to you; however the information we obtain from this study will give policy makers a better understanding of the lives of people living with HIV who are taking antiretrovirals. What you have to say could play an important role in improving the lives of people living with HIV, those who need antiretroviral treatment and those who are currently taking treatment- including yourselves.

What are the possible drawbacks or discomforts in participating?
This is only a survey; however, the issue of HIV/AIDS is very personal and sensitive. Some people may find it painful to recall and discuss their own experience.

Do I have to participate?

Your participation in this study is voluntary. Should you agree to participate, you are required to sign this form. You are free to withdraw from the study at any stage and this will in no way affect your ARV treatment.

What will happen to me if I participate?

Information regarding your experience with anti-retrovirals will be recorded and treated confidentially.

Will the information be treated confidentially?

Yes, should you agree to participate in the study, all information collected for this study will be kept strictly confidential. Individual responses to our questions will never be made public, and no information which could identify you or your household will ever be released.

Contact details: If you have questions about this interview contact Nondumiso Hlwele (Tel 021-650-5117 fax 021-650-4657 or Email: nhlwele@commerce.uct.ac.za).

This study has been reviewed and approved by the Centre for Social Science Research Ethics Committee.

I, ... (name of respondent in block letters) have read and understood all the information given to me about my participation in this study and I was given the opportunity to discuss it and ask questions. I volunteer to take part in this study. I have received a copy of this consent form.

Signature of respondent	Date

Interviewer/fieldworker: I have:

Explained the nature and purpose of the study to the respondent	N	Y
Handed over a copy of the consent form	N	Y

Signature of interviewer/fieldworker	Date

Appendix B: Results for attrition analysis – CAPS

Table B 1: Predictors of overall attrition in both wave 4 (2006) and wave 5 (2009) relative to wave 2 (2003): probit regression results

	Coeff.	SE
Male	-0.0708	0.0724
Population group		
Black/African		Ref
Coloured	-0.456***	0.0881
White	0.969***	0.172
Age	0.0415*	0.0164
Education		
Grade 0-7		Ref
Grade 8-11	-0.189	0.106
Grade 12	-0.183	0.138
Post Matric Degree/Diploma		
Log pc hh income	0.0468	0.0435
N	1374	
pseudo R-sq (McFadden's (1974) R-square)	0.076	

* p<0.05, ** p<0.01, *** p<0.001, Outcome variable is 1 if young adult was not successfully re-interviewed in either wave 4 or wave 5 and 0 otherwise. All predicting variables are measured in 2003 (wave 2A).

Table B 2: Test for attrition bias, symbolic stigma attitudes regressions - male

	Non-attritors		Attritors		Difference	
	Coeff.	p - value	Coeff.	p - value	Coeff.	p - value
Population group						
Black/African	Ref		Ref			
Coloured	1.154	0.000	1.283	0.000	-0.129	0.479
White	0.670	0.028	0.989	0.000	-0.319	0.379
Age	0.022	0.285	0.032	0.202	-0.010	0.765
Education						
Grade 0-7	Ref		Ref		Ref	
Grade 8-11	-0.097	0.440	-0.204	0.175	0.107	0.624
Grade 12	-0.330	0.056	-0.264	0.207	-0.066	0.812
Post Matric Degree/Diploma						
Log pc hh income	-0.042	0.461	-0.042	0.494	0.000	0.997
Constant	1.700	0.000	1.265	0.024	0.435	0.001
N	405		218			
R-Square	0.265		0.322			
Joint significance of the differences (F - test)						0.1068

Table B 3: Test for attrition bias, symbolic stigma attitudes regressions - female

	Non-attritors		Attritors		Difference	
	Coeff.	p - value	Coeff.	p - value	Coeff.	p - value
Population group						
Black/African	Ref		Ref			
Coloured	1.010	0.000	0.770	0.000	0.240	0.169
White	0.646	0.028	0.691	0.001	-0.045	0.883
Age	0.000	0.999	-0.002	0.936	0.002	0.954
Education						
Grade 0-7	Ref		Ref		Ref	
Grade 8-11	-0.180	0.216	-0.162	0.336	-0.018	0.938
Grade 12	-0.310	0.094	-0.207	0.313	-0.103	0.717
Post Matric Degree/Diploma	-0.241	0.800	0.000		0.000	
Log pc hh income	-0.007	0.907	-0.011	0.864	0.004	0.960
Constant	1.788	0.000	1.710	0.001	0.078	0.000
N	449		292			
R-Square	0.2211		0.1438			
Joint significance of the differences (F - test)						0.366

Table B 4: Test for attrition bias, sexual risk behaviour regressions - male

	Non-attritors		Attritors		Difference	
	Coeff.	p - value	Coeff.	p - value	Coeff.	p - value
Population group						
Black/African	Ref		Ref			
Coloured	-0.053	0.551	0.333	0.019	-0.386	0.023
White	-0.668	0.011	-0.0613	0.787	-0.607	0.046
Age	0.157	0.000	0.176	0.000	-0.019	0.469
Education						
Grade 0-7	Ref		Ref		Ref	
Grade 8-11	0.042	0.698	-0.087	0.560	0.129	0.469
Grade 12	-0.070	0.638	-0.116	0.575	0.046	0.859
Post Matric Degree/Diploma						-
Log pc hh income	0.078	0.112	0.001	0.989	0.077	0.320
Constant	-2.533	0.000	-2.430	0.000	-0.103	0.000
N	408		221			
R-Square	0.2148		0.2357			
Joint significance of the differences (F - test)						0.2347

Table B 5: Test for attrition bias, sexual risk behaviour regressions - female

	Non-attritors		Attritors		Difference	
	Coeff.	p - value	Coeff.	p - value	Coeff.	p - value
Population group						
Black/African	Ref		Ref			
Coloured	-0.253	0.003	-0.106	0.472	-0.147	0.396
White	0.237	0.312	-0.117	0.553	0.354	0.271
Age	0.174	0.000	0.165	0.000	0.009	0.739
Education						
Grade 0-7	Ref		Ref		Ref	
Grade 8-11	0.078	0.524	-0.023	0.891	0.101	0.579
Grade 12	0.076	0.622	0.017	0.935	0.059	0.801
Post Matric Degree/Diploma	-0.449	0.572	0.000		0.000	-
Log pc hh income	-0.048	0.310	-0.049	0.412	0.001	0.992
Constant	-2.051	0.000	-1.835	0.001	-0.216	0.000
N	451		295			
R-Square	0.267		0.218			
Joint significance of the differences (F - test)						0.8001

Appendix C: Results for attrition analysis - KHPS

Table C 1: Predictors of attrition in wave 2 (2006) and wave 3 (2007) relative to wave 1 (2004/5): probit regression results

Characteristics	**Wave 2** coefficient	**Wave 3** coefficient
Male	0.545	-0.469
	[0.341]	[0.363]
Age	0.0401*	0.0319
	[0.0198]	[0.0183]
Education level		
No schooling	Ref	Ref
Grade 1-7	-0.112	0.0775
	[0.754]	[0.396]
Grade 8-11	-0.378	-0.328
	[0.735]	[0.313]
Grade 12+	-0.834	-
	[0.798]	-
Employed	0.529	-0.612
	[0.550]	[0.456]
HAART duration	-0.0356	0.0656
	[0.166]	[0.145]
Personal income	-0.00136*	0.0000223
	[0.000650]	[0.000271]
Constant	-1.44	-2.179**
	[1.188]	[0.707]
N	194	189
pseudo R-sq	0.198	0.083

Table C 2: Test for attrition bias on perceived stigma, depression, disclosure and condom use

Characteristics	Depression symptoms/anxiety coefficient	Disclosure coefficient	Condom use coefficient
Attrition	0.498*	-0.675	1.056
	[0.231]	[0.948]	[1.100]
Male	-0.182	0.827	-0.514
	[0.129]	[0.641]	[0.449]
Age	0.00483	0.0436	0.00229
	[0.00829]	[0.0522]	[0.0355]
Education level			
No schooling	Ref	Ref	Ref
Grade 1-7	-0.231	-1.096	-0.0241
	[0.407]	[0.764]	[1.169]
Grade 8-11	-0.499	-0.316	0.254
	[0.398]	[0.551]	[1.101]
Grade 12+	-0.513	0	-0.0467
	[0.414]	0	[1.154]
Employed	-0.0644	0.277	-0.68
	[0.154]	[0.649]	[0.548]
HAART duration	0.0877	-0.212	-0.218
	[0.0585]	[0.252]	[0.208]
Personal income	0.0000174	-0.000302	0.0000502
	[0.000118]	[0.000313]	[0.000269]
Constant	2.555***	1.384	
	[0.529]	[1.666]	
N	194	153	154
R-sq/pseudo R-sq	0.102	0.052	0.032

Table C 3: Test for attrition bias on perceived stigma, depression, disclosure and condom use

Characteristics	Perceived stigma coefficient	Depression coefficient	Disclosure coefficient	Condom use coefficient
Attrition	0.214	-0.13	-0.00855	-0.321
	[0.157]	[0.204]	[0.826]	[0.738]
Male	-0.0257	-0.159	0.818	-0.488
	[0.125]	[0.139]	[0.682]	[0.445]
Age	-0.00685	0.00897	0.0385	0.0074
	[0.00684]	[0.00873]	[0.0505]	[0.0367]
Education level				
No schooling	Ref	Ref	Ref	Ref
Grade 1-7	-0.0335	-0.219	-1.186	0.151
	[0.168]	[0.439]	[0.760]	[1.115]
Grade 8-11	-0.0389	-0.52	-0.328	0.388
	[0.149]	[0.426]	[0.546]	[1.085]
Grade 12+	-0.102	-0.54	0	0.0702
	[0.165]	[0.436]	0	[1.137]
Employed	0.0217	-0.0836	0.296	-0.735
	[0.120]	[0.157]	[0.648]	[0.542]
HAART duration	0.0689	0.0836	-0.203	-0.204
	[0.0446]	[0.0592]	[0.242]	[0.203]
Personal income	-0.0000237	0.00000175	-0.000287	0.0000217
	[0.0000562]	[0.000118]	[0.000319]	[0.000269]
Constant	3.674***	2.511***	1.476	
	[0.307]	[0.557]	[1.640]	
N	194	194	153	154
R-sq/pseudo R-sq	0.031	0.074	0.048	0.032