
HIV, BLAME AND SHAME:

INTERNALISED HIV STIGMA AMONG
SOUTH AFRICAN ADOLESCENTS LIVING WITH HIV.

Thesis submitted in partial fulfilment of the degree of Doctor of Philosophy in Social Intervention by stand-alone papers at the University of Oxford.

Marija Pantelic
Department of Social Policy and Intervention
Green Templeton College
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ABSTRACT

Background: This is the first epidemiological study of internalised stigma among adolescents living with the human immunodeficiency virus (HIV) in Sub-Saharan Africa. It aims to establish predictors of internalized HIV-stigma among people living with HIV in Sub-Saharan Africa (Paper 1), develop an HIV-stigma scale for use with adolescents (Paper 2) and build and test a model of risk pathways for internalised stigma (Paper 3). The data used for papers 2 and 3 is part of the world's largest social science study of adolescents living with HIV (n=1060).

Paper One systematically reviews evidence on the prevalence and predictors of internalised HIV stigma amongst people living with HIV in Sub-Saharan Africa. PRISMA guidelines were followed. An adapted version of the Cambridge Quality Checklist was used to assess the quality of the findings. A total of 18 papers were included. The prevalence of internalised stigma among adults living with HIV was 27% - 66%. The longitudinal predictors for internalised HIV stigma were poor HIV-related health and psychological distress. The review identifies two critical limitations of the literature. First, no studies on adolescents were found. One of the reasons for this may be the lack of a scale for measuring internalised HIV stigma in this population. Second, only individual-level risk factors for internalised stigma were examined. Papers 2 and 3 aim to address these limitations.

Paper Two develops an HIV stigma scale with and for adolescents living with HIV. First, a multidimensional stigma scale previously used with adolescents in the US was cross-culturally adapted using semi-structured cognitive interviews with nine South African adolescents living with HIV. These data were interpreted through thematic analysis, and items were adapted in consultation with interviewees. Second, the revised version of the scale was administered to 1060 adolescents living with HIV. Confirmatory factor analysis confirmed the predicted 3-factor structure, and associations with hypothesised correlates provided evidence of validity.

Paper Three develops and tests a model of risk pathways to internalised HIV stigma among adolescents living with HIV. Drawing on findings from the systematic review (Paper 1) and using the scale developed in Paper 2, both inter and intrapersonal pathways of risk from HIV-related disability to internalised HIV stigma were hypothesized. Following from modified labelling theory, interpersonal mechanisms were hypothesized to occur through maltreatment within power-unequal relationships, i.e. enacted HIV stigma and violence victimization. Hypothesized intrapersonal risks were anticipated HIV stigma and depression. Structural equation modelling enabled the grouping of theoretically related constructs and assessment of multiple, simultaneous pathways of risk. Prevalence of any internalised HIV stigma among adolescents living with HIV was 26.5%. As hypothesized, significant associations between internalised stigma and anticipated stigma, as well as depression were obtained. Unexpectedly, HIV-related disability, violence victimization, and enacted stigma were not directly associated with internalised stigma. Rather, indirect pathways via intrapersonal risks were observed.

Conclusions: More than a quarter of adolescents living with HIV in this study reported experiencing some level of internalised stigma. Findings suggest a need to expand programmatic responses to internalised HIV stigma, from individualistic, clinic-based programmes to integrative, community-based approaches. Providing mental health support and reducing the maltreatment of adolescents living with HIV might interrupt pathways from HIV-related disability to internalised stigma. This highlights the potential for interventions that do not necessarily target HIV-positive adolescents but are sensitive to their needs. Such efforts must be coupled with rigorous process and outcome evaluations, and longitudinal data is urgently needed. It is hoped that the adolescent-friendly stigma scale developed within this DPhil will enable further research with this understudied population. Prior to this thesis, there were no known epidemiological studies of internalised HIV stigma among adolescents living with HIV. Moreover, the broader, adult-focused corpus of research has overlooked interpersonal risk factors. This thesis highlights the relevance of power inequalities and domination for the study of internalised HIV stigma.

To Bojana, and all the young people who lost their lives to stigma.

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**Unless otherwise noted, all photographs were taken by the DPhil candidate.*

LIST OF APPENDICES

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MANUSCRIPTS FROM THIS THESIS

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ACADEMIC PRESENTATIONS FROM THIS DPHIL

1. 'HIV, violence, blame and shame: Internalised HIV stigma among South African HIV-positive adolescents', *Marija Pantelic, Mark Boyes, Lucie Cluver, Franziska Meinck*, 14 June, Southern African AIDS Conference, Durban, South Africa.
2. 'HIV, blame and shame: Pathways of risk to internalised HIV stigma among South African HIV-positive adolescents', *Marija Pantelic, Mark Boyes, Lucie Cluver, Franziska Meinck*, 17 May 2017, INTEREST Workshop, Lilongwe, Malawi.
3. 'Teen Voice: What do the Sustainable Development Goals mean for HIV-positive adolescents in Southern Africa?', *Hodes, R, Cluver, L. Toska, E. Vale, B. Pantelic, M. Gittings, L. Doubt*, 18 May 2017, INTEREST Workshop, Lilongwe, Malawi.
4. Social and psychological pathways of risk to internalised stigma among HIV-positive adolescents: A structural equation model', 23 Feb 2017, CEBI Research Group, Department of Social Policy and Intervention, University of Oxford.
5. '*HIV is a punishment for bad behaviour*': *Blame and shame among South African HIV-positive adolescents*. 25 May 2016, Green Templeton College, University of Oxford.
6. *How to engage policy makers with your DPhil research? Examples from adolescent HIV research in South Africa*. 6 May 2016, Department of Social Policy and Intervention, University of Oxford.
7. *Violence exposure and internalised HIV stigma among South African adolescents living with HIV*. 4 May 2016, CEBI Research Group, Department of Social Policy and Intervention, University of Oxford.
8. *HIV stigma in the 21st century - a key barrier to eradication*. 26 November 2015. Worcester College, University of Oxford.
9. '*They say HIV is a punishment from God or from ancestors*': *Cross-cultural adaptation of an HIV stigma measurement tool for South African HIV-positive teens*. Pantelic, M., Cluver, L., Thabeng, M. June 2015. Poster presentation, 7th South African AIDS Conference, Durban, South Africa.
10. *Power to Participants? Participatory methodologies within a large quantitative study of adolescents*. 10 June 2015, Oral presentation, 7th South African AIDS Conference, Durban, South Africa.

NOTE ON THE CANDIDATE'S RESEARCH ROLE

MZANTSI WAKHO: ADOLESCENT ADHERENCE STUDY

This DPhil is nested within Mzantsi Wakho, the world's largest social science study of HIV-positive adolescents. Mzantsi Wakho is a mixed-methods cohort study aiming to understand medication taking practices and health seeking behaviours of adolescents living with HIV in the Eastern Cape, South Africa. Internalised HIV stigma is a key risk factor for poor uptake of and adherence to HIV treatment and care services (Katz et al. 2013; Ng and Tsai 2017; Treves-Kagan et al. 2017). Therefore, understanding HIV stigma mechanisms among adolescents living with HIV was a critical component of Mzantsi Wakho.

Mzantsi Wakho consists of a qualitative (PI: Dr. Rebecca Hodes, University of Cape Town) and a quantitative team (PI: Prof Lucie Cluver, University of Oxford). A number of co-investigators, including this DPhil candidate (other co-investigators are Dr. Elona Toska, Dr. Beth Vale, Craig Carty, Prof. Mark Orkin and Dr. Mark Boyes), were extensively involved in conceptualizing the study, planning the study methodology, drafting ethics approval applications, building local, national and international partnerships and designing the questionnaire based on literature reviews and key outcomes of interest. Qualitative baseline data collection was managed by Dr. Beth Vale, whereas quantitative baseline data collection was managed by Dr. Elona Toska, Julia Rosenfeld and this candidate.

MY ROLE WITHIN MZANTSI WAKHO

As the study's lead quantitative investigator on HIV stigma, I led the development of the HIV stigma scale, conducted literature reviews to inform questionnaire development and worked closely with the quantitative PI (Prof. Lucie Cluver) and the research team to design the overall methodology for Mzantsi Wakho. After an extensive review of stigma theory and research literature, I built and tested the measurement model of the multi-dimensional HIV stigma scale, as well as the structural equation model predicting internalised HIV stigma. I conceptualized and drafted all papers presented in this thesis, and designed and executed the data analysis strategies.

I also conducted a total of 14 months of fieldwork acting as Project Manager for Mzantsi Wakho. The initial preparatory fieldwork took place in August-September 2013. During this period, I worked with Dr. Elona Toska and Dr. Beth Vale to set up the study, and build partnerships with healthcare and other service providers, civil society organizations and district and provincial government stakeholders. We also created a network of adolescents living with HIV, who formed a 'Teen Advisory Group' and have since been involved in the study conceptualization and methodology. During these initial months of fieldwork, we also piloted a preliminary version of the questionnaire, recruited and trained research assistants, mapped all government health facilities in the study catchment area and established an office in the study's main field site, East London in the Eastern Cape. In October 2013, I started systematically reviewing predictors of internalised HIV stigma in Sub-Saharan

Africa, which informed inclusion of other key variables into the Mzantsi Wakho survey.

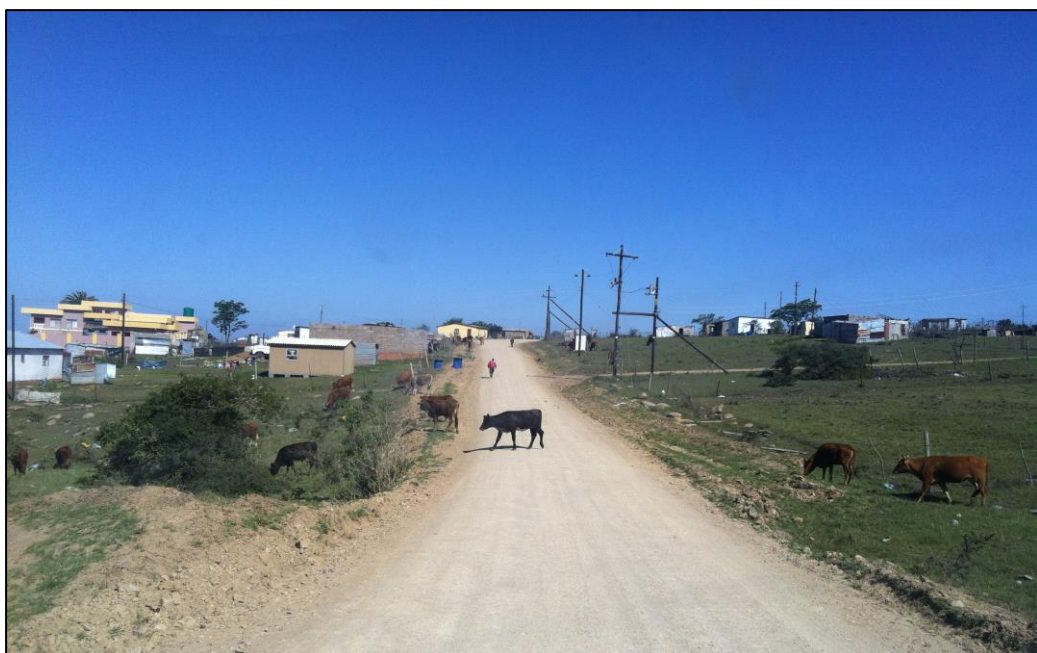
In January 2014, I conducted a second fieldtrip to cross-culturally adapt the HIV stigma scale. During this time I collaborated closely with the qualitative team, Dr. Beth Vale and Mildred Thabeng, who provided essential support in recruiting qualitative research participants. This took place in a site (Grahamstown) outside of the quantitative study catchment area to avoid overlap between qualitative and quantitative participants.

The bulk of fieldwork occurred between September 2014 and September 2015. During this period, I was responsible for the day-to-day management of quantitative data collection in the Eastern Cape. I recruited and trained a team of 30 research assistants, fieldwork coordinators, community liaison officers and clinic data collectors. Together with Dr. Elona Toska and Maya Isaacsohn, I opened an additional project office in King Williams Town to improve reach of rural adolescents (Figure 1). I problem solved day-to-day issues that arose in field and managed emergency referrals of vulnerable children to appropriate health and social services. I was also responsible for data quality control and security, which involved daily data checking, backing up and ensuring confidentiality and anonymity. I drafted quarterly ethics and progress updates for the South African Departments of Health, Basic Education and Social Development, and contributed to yearly reports to funders.

For four years now, I have had the privilege of collaborating with and learning from the principal investigators, other co-investigators and the field team. I have led on all

methodological, conceptual and theoretical aspects related to HIV stigma within this study. In addition to this, I have continued to advise the PIs on overall Mzantsi Wakho ethics, data collection, data analysis and dissemination procedures.

Figure 1 Rural study sites



CHAPTER I. INTRODUCTION

As the first epidemiological study of internalised HIV stigma among adolescents living with HIV in Sub-Saharan Africa, the primary aim of this DPhil is to build and test a theoretical model of risk for internalised HIV stigma in this population. Data from the world's largest study of adolescents living with HIV (Mzantsi Wakho) were used. The thesis consists of 8 chapters, including three stand-alone papers (chapters 3, 6 and 7) as required by the DPhil-by-publication track at the Department of Social Policy and Intervention. Two of these papers have been published in high impact journals, and one is currently under review.

Chapter 2: Background and study rationale contextualizes the thesis by defining stigma and describing the evolution of stigma theory and conceptualization. It starts with *labelling theory*, which focuses on the individual-level factors and cognitive processes that contribute to stigma (Scheff 1974). This approach has been widely criticized for its oversight of the broader social and cultural contexts in which stigma develops (Parker and Aggleton 2003; Link, Cullen, Struening, Shrout, and Dohrenwend 1989). To account for this, *modified labelling theory* built on the *socio-ecological theory of human development* (Bronfenbrenner 1979) to stress that interpersonal relationships and power dynamics play key roles in the creation and persistence of stigma (Link, Cullen, Struening, Shrout, and Bruce 1989).

The second part of this chapter focuses on the stigma associated with HIV and AIDS. The HIV stigma framework is introduced to define various types of HIV stigma experienced by adolescents living with HIV, including internalised HIV stigma, the outcome of interest for this thesis. The chapter provides an overview of the

epidemiological consequences of HIV-related stigma. The challenges of retaining HIV-positive adolescents in treatment and care are discussed, as well as how HIV stigma contributes to this public health problem. Lastly, the chapter provides an overview of gaps in the programmatic response to HIV stigma among African adolescents living with HIV and situates the DPhil objectives in relation to these gaps.

Chapter 3: (Paper 1) is a systematic review aiming to determine (1) prevalence and (2) predictors of internalised HIV stigma in Sub-Saharan Africa. It found consistent evidence that, over time, poor AIDS-related health and poor mental health predict increases in internalised stigma. This paper is published in *Health Psychology Review*.

Chapter 4 positions systematic review findings with a focus on implications for this thesis. The systematic review identified key gaps in the evidence-base on internalised HIV stigma in Sub-Saharan Africa. Firstly, no studies on adolescents or children were found. A key reason for this may be that no tools to measure internalised HIV stigma among youth in the region exist. Secondly, existing (adult-focused) studies identified only individual-level risk factors for internalised HIV stigma. There remains a significant gap in knowledge on inter-personal risk factors for internalised HIV stigma. The empirical chapters of this DPhil aim to address these gaps.

Chapter 5 Methodology contextualizes the empirical papers (Papers 2 and 3) by providing an overview of the methods used. Ethical, practical, and methodological challenges encountered during study design and data collection are discussed.

Chapter 6 (Paper 2) focused on the development of an HIV stigma scale for use with South African HIV-positive adolescents. This work consisted of a qualitative and quantitative component. First, nine one-on-one semi structured cognitive interviews informed the cross-cultural adaptation of a scale previously used with adolescents in the US. Second, the psychometric properties of the adapted scale were assessed within the Mzantsi Wakho study. To ensure measurement specificity, only data from the subsample of HIV-positive adolescents who were fully aware of their HIV-status were used (n=721). Confirmatory factor analysis established the structure and basic reliability and validity of the new measure. This mixed-methods paper is published in *Child Indicators Research*.

Chapter 7 (Paper 3) empirically tests a theoretical model of risk for internalised HIV stigma among HIV-positive adolescents in Sub-Saharan Africa. Data from the Mzantsi Wakho study were used (n=1060 HIV-positive adolescents). This paper expands on findings from the systematic review, and draws on modified labelling theory (Link and Phelan 1999; Goffman 1963; Link, Cullen, Struening, Shrout, and Bruce 1989; Link and Phelan 2006) and other systematic reviews of longitudinal evidence (Chen et al. 2010; Hillberg, Hamilton-Giachritsis, and Dixon 2011; Maniglio 2009; Norman et al. 2012), to hypothesize social and psychological pathways of risk to internalised HIV stigma. Specifically, the paper uses structural equation modelling to assess whether HIV-related disability (a 'label') is associated with internalised HIV stigma via adverse interpersonal mechanisms (enacted HIV stigma and violence victimization) and intrapersonal processes (anticipated HIV stigma and depression). This paper is published in the *Journal of the International AIDS Society*.

Chapter 8: Discussion starts with a summary of the aims and findings of the thesis, followed by a discussion of the study's limitations, strengths and implications for practice and directions for future research. Ethical challenges encountered during data collection are revised. Dissemination strategies used and planned are also summarized. The chapter ends with a brief conclusion section.

CHAPTER II. BACKGROUND AND STUDY RATIONALE

HIV-positive adolescents are the only population for whom AIDS-related mortality is on the rise (WHO 2014). Stigma and the resultant fear of being identified as HIV-positive can keep adolescents from accessing essential HIV treatment and care services (UNAIDS 2007; Katz et al. 2013; Earnshaw et al. 2014; Treves-Kagan et al. 2016; Moshabela et al. 2016; Ng and Tsai 2017). Existing intervention studies focus largely on reducing negative public attitudes or HIV-related discrimination by non-infected individuals, also known as enacted HIV stigma (Stangl et al. 2013). These interventions have targeted a wide range of populations across the globe, including children, adolescents, young adults, caregivers, health workers, teachers and community members (Stangl et al. 2013). The vast majority of these efforts were found to be efficacious in reducing enacted HIV stigma (Stangl et al. 2013), marking important advances in HIV stigma reduction.

But little is known about how to reduce internalised HIV stigma, particularly among adolescents living with HIV (Stangl et al. 2013). Internalised HIV stigma occurs when people living with HIV endorse negative attitudes associated with HIV and accept them as applicable to themselves (Earnshaw et al. 2013). Internalised HIV stigma is a risk factor for non-use of key HIV prevention services such as HIV testing and counselling (Treves-Kagan et al. 2017), condoms (Earnshaw et al. 2014) and prevention of parent-to-child transmission (Ng and Tsai 2017). Importantly, internalised HIV stigma can also compromise adherence to life-saving anti-retroviral treatment (ART) (Sayles et al. 2009; Katz et al. 2013). Sub-Saharan Africa is home to 85% of the world's HIV-positive adolescents (Idele et al. 2014), yet no interventions

to reduce internalised HIV stigma in this population have been tested (Stangl et al. 2013). In order to design and test future interventions, we must first develop a problem theory of internalised HIV stigma in this population. As part of this, it is essential to identify the prevalence and correlates of internalised HIV stigma in this population (Fraser et al. 2009). This DPhil is the first epidemiological study on internalised HIV stigma among HIV-positive adolescents in Sub-Saharan Africa.

WHAT IS STIGMA?

The most commonly used definition of stigma is the one articulated by Goffman in his seminal work 'Stigma: Notes on the Management of a Spoiled Identity' (Goffman 1963). He defined stigma as a process through which individuals are 'disqualified from full social acceptance' due to an undesirable 'mark' or 'label'. This label can be a physical, health or behavioural attribute that is deemed 'deeply discrediting'. Such labels create the perception that the possessors have less desirable identities (or 'spoiled identities') than 'normal' people. Stigma, according to Goffman, reduces the possessor 'from a whole and usual person to a tainted, discounted one' (Goffman 1963).

Importantly, Goffman posited that stigma is rooted in social interactions. He highlighted that stigmatization requires more than mere labels; rather, a 'language of relationships' is essential. 'An attribute that stigmatizes one type of possessor can confirm the usualness of another, and therefore is neither creditable nor discreditable as a thing in itself' (Goffman 1963). Hence, stigma consists of two essential components: (1) recognition of difference based on a mark or label and (2)

consequent devaluation of the possessor of the mark (Dovidio, Major, and Crocker 2000).

Jones and colleagues (1984) identified 6 dimensions that can be used to establish the extent to which a 'label' is stigmatizing:

1. Concealibility: the extent to which the physical/health/cultural attribute is apparent to others
2. Course: the extent to which the condition is reversible;
3. Disruptiveness: the extent to which the condition poses a strain to social structures such as a family, school or community;
4. Aesthetics associated with the condition;
5. Origin: the extent to which the condition is perceived to be a direct (and deserved) result of one's behaviour;
6. Peril: the extent to which the condition is perceived as a threat to others.

Half a century after Goffman's seminal work was first published, interest in stigma has grown exponentially (Bos et al. 2013). A Google Scholar search of articles containing the word 'stigma' in their title between 1963 and 2017 renders 16,000 hits. Conversely, a search for papers on stigma prior to 1963 generates 198 results. The study of stigma has extended beyond sociology (where it originated) to other disciplines – first psychology, then other disciplines such as public health and, perhaps most notably, HIV epidemiology (Bos et al. 2013; Link and Phelan 1999; Scambler 2009). Goffman's designation of stigma as a socially discredited mark or label has considerably shaped the discourse across disciplines.

Most recently, Goffman has been criticized for overlooking the importance of power-unequal relationships in producing stigma (Castro and Farmer 2005; Parker and Aggleton 2003), and for being ‘an armchair theorist’ who relied on anecdotal evidence (Bos et al. 2013). But the on-going debates around Goffman’s work have yielded important advancements and clarifications in stigma theory and terminology. The following sections aim to provide an overview of this evolution.

EARLY STIGMA(TIZING) THEORY

In the years following Goffman’s seminal work, the concept of stigma was applied to psychology, most prominently through Scheff’s labelling theory of mental illness. According to labelling theory, stigma was a product of the behavioural characteristics of both the labellers and the labelled (Scheff 1966; Scheff 1974). Here, labelling and symptoms of mental illness were hypothesized to have a cyclical relationship. Scheff thought that whilst symptoms of mental illness contributed to labelling of a person as having a particular disorder, labelling also affected the mental health and behaviour of individuals because the labelled conformed to the negative expectations. ‘When [...] persons around the deviant react to him uniformly in terms of the stereotypes of insanity, his amorphous and unstructured rule-breaking tends to crystalize in conformity to these expectations, thus becoming similar to behaviour of other deviants classified as mentally ill’, states Scheff (1966).

Early critics of labelling theory thought that symptomatic behaviour alone – and not labelling – contributed to stigma (Gove 1975; Chauncey 1975). In the late 70s and early 80s, such critics dominated the field (Link and Phelan 1999). They rejected the

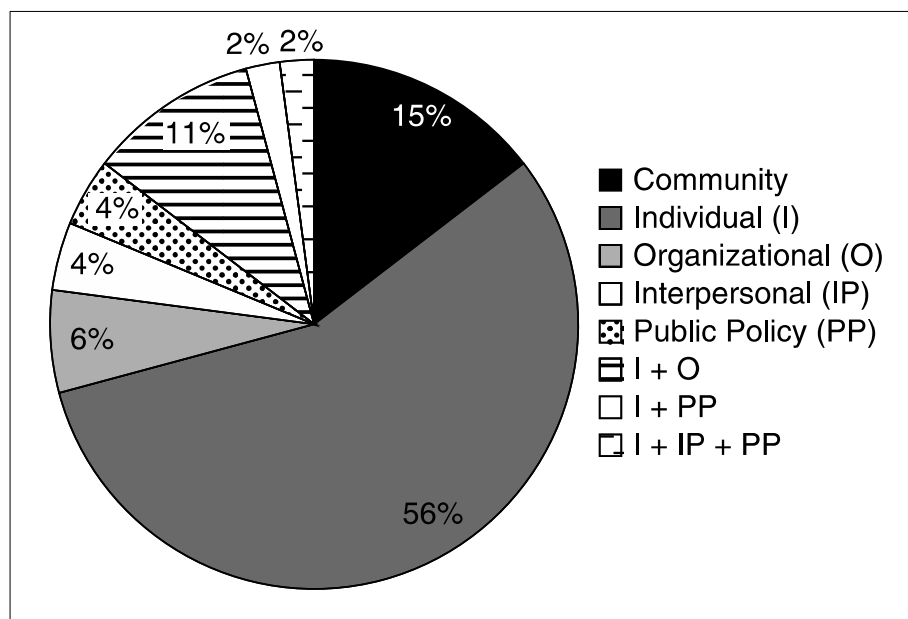
notion that labelling and poor mental health reinforce each other. For example, Gove believed that 'the available evidence indicates that deviant labels are primarily a consequence of deviant behaviour and that deviant labels are *not* a prime cause of deviant careers' (1975, emphasis added). Similar to labelling theory, its early critics placed a strong emphasis on the role of individual attributes in producing stigma. However, unlike proponents of labelling theory, they stressed that stigma was inconsequential. In other words, they denounced the potential outcomes of stigma, and considered stigma to be an outcome of personal traits and behavioural characteristics of people considered as 'deviants'.

MODIFIED LABELING THEORY

In response to these individualistic approaches to stigma, Link and colleagues constructed a modified labelling theory (Link, Cullen, Struening, Shrout, and Dohrenwend 1989; Link and Phelan 1999; Link and Phelan 2006). They expanded on Goffman's work and labelling theory, but rejected the notion that stigma was a direct product of the behavioural attributes of the stigmatized. According to modified labelling theory, stigma manifests itself 'when elements of labelling, stereotyping, separation, status loss, and discrimination co-occur in a power situation that allows them to unfold' (Link and Phelan 1999). As such, stigma is 'highly situationally specific, dynamic, complex and nonpathological' (Dovidio, Major, and Crocker 2000). A key contribution of this post-individualistic approach is that it stresses that stigma occurs within social contexts characterized by power inequalities rather than a cognitive-behavioural vacuum (Link, Mirotznik, and Cullen 1991).

Parker and Aggleton applied modified labelling theory to the stigma associated with HIV and AIDS (2003). They define HIV/AIDS-related stigma as a social process inherently linked to the maintenance of power inequalities. They note that a major limitation of studies on HIV/AIDS-related stigma is that they fail to frame hypotheses or analyses within ‘any theoretical tradition whatsoever’ (Parker and Aggleton 2003). As a result, they argue, a tendency to conceptualize HIV/AIDS-related stigma as emotional or cognitive processes (such as anger or misconceptions about HIV) developed. This may be the reason why the majority of available anti HIV-stigma interventions have focused on targeting individual-level factors such as cognition and personal development (Figure 2). Parker and Aggleton highlight that in order ‘to move beyond the limitations of current thinking in this area, we need to reframe our understandings of stigmatization and discrimination to conceptualize them as social processes that can only be understood in relation to broader notions of power and domination.’”

Figure 2 Socio-ecological levels targeted in existing stigma interventions (reprinted from Stangl et al. 2013 systematic review)



ECOLOGICAL MODEL FOR HEALTH PROMOTION

The ecological model for health promotion stresses both individual and environmental factors as key contributors to the wellbeing of individuals (Mcleroy et al. 1988). As such, it responds to the concerns about individualistic approaches to HIV stigma raised in the previous section of this DPhil (Parker and Aggleton 2003). This model is based on Bronfenbrenner's ecological model of human development (Bronfenbrenner 1979), which recognizes the role of micro-, meso-, exo- and macro levels of influence. The microsystem refers to inter-personal factors such as interactions within one's immediate surrounding – family, peers and community members. The mesosystem is the 'system of microsystems' and refers to the relationships between various key social structures such as one's family, school, community and church. The exosystem refers to the structural (economic or political) forces in which the individual is embedded. The exosystem does not directly affect the individual; rather, it interacts with the micro- and mesosystem. Lastly, the macrosystem refers to the cultural beliefs and attitudes towards HIV/AIDS, which influences both the microsystem and the macrosystem. The socio-ecological model for health promotion implies a 'reciprocal causation between the individual and the environment' (Mcleroy et al. 1988; Bronfenbrenner 1979). As such, this framework recognizes key levels at which stigma-reduction activities can be targeted: individual (knowledge, attitudes, skills), interpersonal (family, friends, social networks), organizational (school, clinics), community (norms and attitudes) and public policy and legislation (Stangl et al. 2013).

STIGMA ASSOCIATED WITH HIV AND AIDS

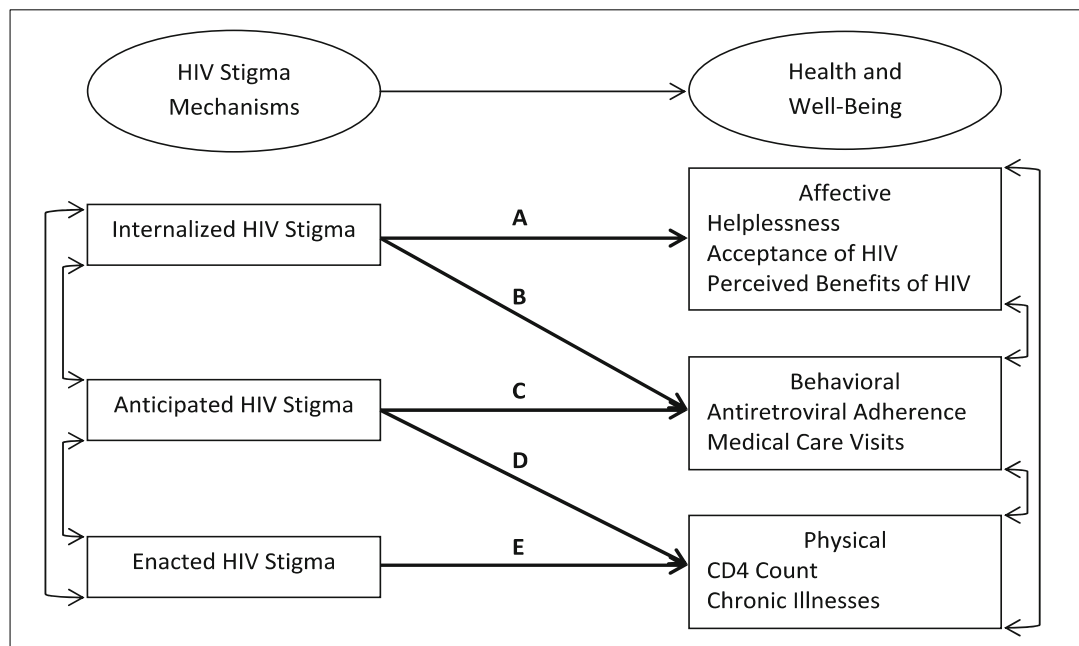
The HIV stigma framework specifies three mechanisms through which people living with HIV experience stigma: enacted, anticipated and internalised stigma (Earnshaw and Chaudoir 2009). *Enacted stigma* refers to experiences of discrimination or having been treated differently due to one's HIV status. *Anticipated stigma* refers to the extent to which an HIV-positive individual anticipates prejudice against them.

Internalised stigma occurs when an HIV-positive person endorses negative attitudes associated with HIV and accepts them as applicable to him or herself (Earnshaw et al. 2013). Internalised HIV stigma is characterised by feelings of shame, guilt, worthlessness and difficulties with HIV status disclosure (Lee, Kochman, and Sikkema 2002; Tsai et al. 2012). Internalisation of HIV stigma can compromise condom use (Earnshaw et al. 2014), potentially by instilling fear of rejection from sexual partners and low self-confidence (Bourne et al. 2012). Internalised HIV stigma may be particularly dangerous for people living with HIV due to a potential cyclical relationship with ART adherence. Namely, internalised HIV stigma can hamper adherence to ART (Katz et al. 2013), whilst consistent ART use has been found to reduce internalised HIV stigma over time (Tsai, Bangsberg, Bwana, et al. 2013).

Earnshaw and colleagues have stressed that these mechanisms are distinct processes, which affect different aspects of healthcare access and health outcomes among people living with HIV. Internalised HIV stigma specifically impacts affective and behavioural aspects of health and well-being among people living with HIV, which may further contribute to adverse physical outcomes (Figure 3). According to

Earnshaw and colleagues, “by differentiating between HIV stigma mechanisms, researchers may [...] better inform targeted interventions to improve specific outcomes among people living with HIV.” (Earnshaw et al. 2013)

Figure 3 Hypothesized associations between different HIV stigma mechanisms and health and well-being outcomes (reprinted from Earnshaw et al. 2013)

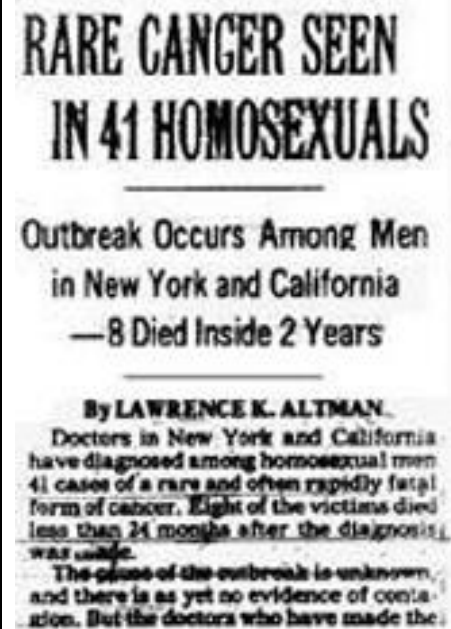


It should also be noted that the three stigma mechanisms may develop independently of one another. For example, people may develop perceptions about public attitudes towards HIV prior to their own diagnosis (Link, Cullen, Struening, Shrout, and Dohrenwend 1989; Scheff 1974). An HIV diagnosis can therefore result in immediate ‘expectations of rejection’ (Link, Cullen, Struening, Shrout, and Dohrenwend 1989), without having experienced enacted stigma. As a result, when a young person is diagnosed with HIV she might decide not to disclose her status to others due to anticipated stigma (Derlega et al. 2004). This situation would make her susceptible to internalised HIV stigma but less so to enacted stigma (Cuca et al. 2012; Holzemer et al. 2007; Neuman and Obermeyer 2013).

THE ORIGINS OF HIV STIGMA

So as to better understand the stigma associated with HIV, it is essential to apprehend the unique pathogenesis, history and epidemiology of this virus. The HI-virus affects the immune system by attacking infection-fighting CD4 cells. However, HIV can remain asymptomatic for years. After HIV infection – and in the absence of treatment – the spread of the virus and diminution of CD4 cells occur in three advancing stages: acute HIV infection, chronic HIV infection and acquired

Figure 4 First New York Times article on HIV (reprinted, 1981)



**RARE CANCER SEEN
IN 41 HOMOSEXUALS**

**Outbreak Occurs Among Men
in New York and California
— 8 Died Inside 2 Years**

By LAWRENCE K. ALTMAN.

Doctors in New York and California have diagnosed among homosexual men 41 cases of a rare and often rapidly fatal form of cancer. Eight of the victims died less than 24 months after the diagnosis was made. The cause of the outbreak is unknown, and there is as yet no evidence of con- tation. But the doctors who have made the

immunodeficiency syndrome (AIDS). Acute HIV infection is the immediate period following HIV infection, and is characterized by short-term flu-like symptoms. During the first four weeks of the first stage, HIV is completely undetectable through blood tests. However, it replicates exponentially and is most transmittable during this period (Hollingsworth, Anderson, and Fraser 2008). The second, chronic stage can last for years during which time HIV continues to replicate. At this stage, HIV is detectable through blood tests and remains highly transmittable but can remain undetectable or asymptomatic (Hollingsworth, Anderson, and Fraser 2008). Acquired immunodeficiency syndrome occurs when the CD4+ cells are depleted and opportunistic infections occur. This can lead to varied types of cancer and death if left untreated (Grulich et al. 2007).

During the early years of the epidemic, misconceptions around HIV, lack of effective treatment, and prejudice against gay men fuelled widespread fear and stigma around HIV/AIDS (Pryor et al. 1989). HIV and AIDS were discovered only after a growing number of gay men presented in US cities with an unknown immunodeficiency disease in the early 1980s (Fee and Brown 2006). Misleading hypotheses about AIDS and its causes followed. What is now known as AIDS was thought to be a sexually-transmitted cancer commonly referred to as 'Gay cancer' (Wright 2006; Centers for Disease Control and Prevention 1982). Confusion around the newly discovered disease coupled with prejudiced beliefs about gay men resulted in the fallacious assumption that AIDS was an inevitable consequence of male-to-male intercourse (Figure 4). These beliefs have been factually discounted by the discovery of HIV as the cause of AIDS in 1984 (Fee and Brown 2006). Since then, a growing body of research has pointed to the social and structural determinants of HIV infection (Dean and Fenton 2010).

Prior to the advent of anti-retroviral treatment (ART), an HIV diagnosis was associated with inevitable AIDS and death. As such, HIV/AIDS met all of Jones' criteria for a highly stigmatizing disease:

1. Concealability: Without efficacious medication, people were unable to conceal AIDS-related symptoms such as severe weight loss and skin rashes or bumps.
2. Course: Prior to ART, a progression from HIV infection to AIDS was not reversible. Unlike today, patients had no reliable way of reaching undetectable viral loads.

3. Disruptiveness: Coupled with ignorance and fear surrounding AIDS, the lack of effective treatment rendered AIDS-related symptoms disruptive to HIV-positive individuals, their communities and healthcare providers.
4. Aesthetics: The images associated with early cases of HIV were inextricably linked to AIDS-related symptoms because people only presented to health facilities once they were AIDS-symptomatic.
5. Origin: Given that the initial diagnoses of HIV were transmitted through male-to-male sex, prejudiced beliefs could create a perception that the source of HIV was 'immoral' behaviour.
6. Peril: Due to common misconceptions about the modes of transmission and origins of what is now known to be AIDS, people living with the disease were commonly considered a threat to others.

Ogden and Nyblade (2005) note that AIDS also corresponds to all three types of stigma specified by Goffman (1963). It is characterized by 'abominations of the body', and is commonly associated with socially perceived 'blemishes of individual character' and stigma relating to membership of a despised social group ('tribal stigma').

HIV STIGMA IN SUB-SAHARAN AFRICA

The AIDS epidemic [...] is simultaneously an epidemic of a transmissible lethal disease and an epidemic of meanings or signification. Both epidemics are equally crucial for us to understand, for, try as we may to treat AIDS as "an infectious disease" and nothing more, meanings continue to multiply wildly and at an extraordinary rate. This epidemic of meanings is readily apparent in the chaotic assemblage of understandings under AIDS that by now exists.

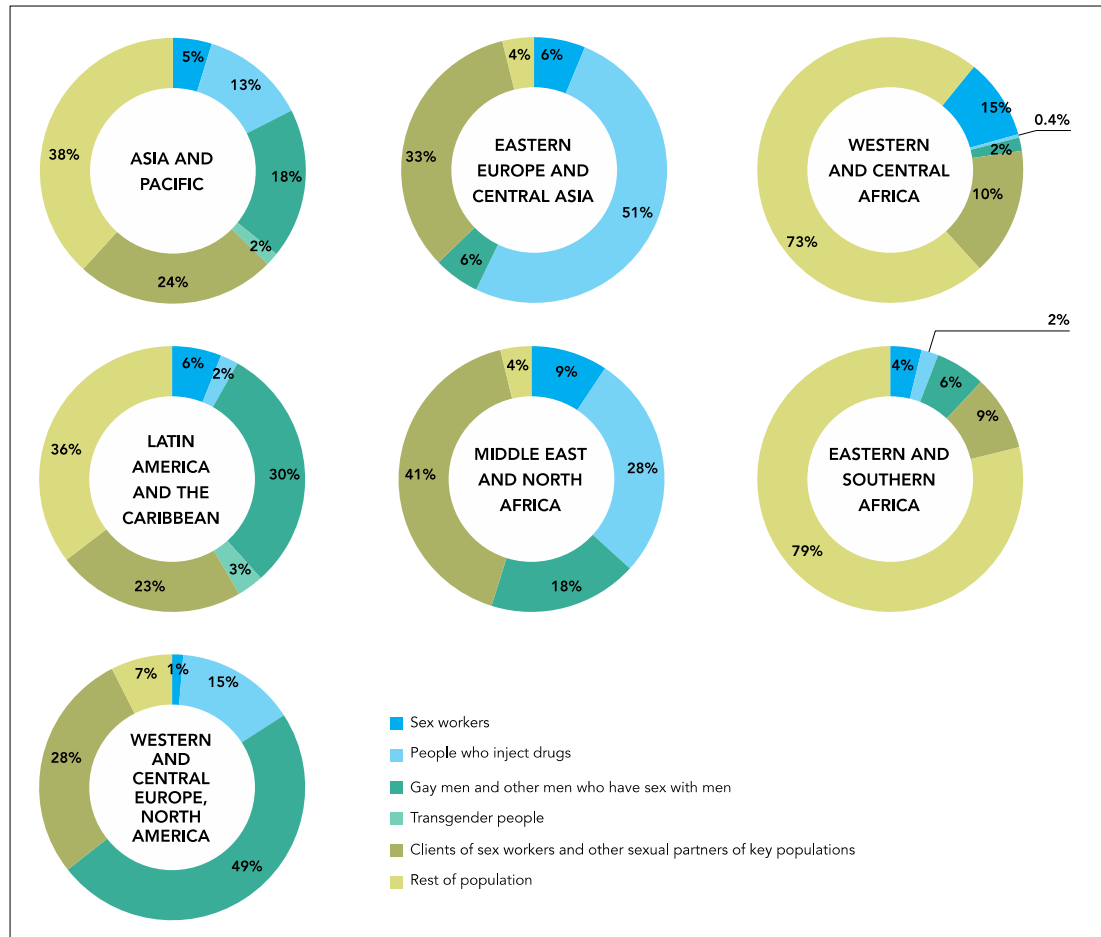
- Treichler, 1987

Although HIV was discovered in the US and France, HIV and AIDS have always disproportionately affected Sub-Saharan Africa (UNAIDS and WHO 2003). The world's most affected region, Eastern and Southern Africa, is home to an estimated 19 million people living with HIV (UNAIDS 2016). Whilst other parts of the world continue to have concentrated epidemics among otherwise stigmatized populations such as men who have sex with men, sex workers and people who inject drugs, epidemics in Sub-Saharan Africa are generalized (UNAIDS 2016). As illustrated in Figure 5, more than two thirds of new HIV infections in Sub-Saharan Africa occur among the general population, through heterosexual intercourse or mother-to-child transmission (UNAIDS 2016).

South Africa is home to the world's largest population of people living with HIV. Despite widespread HIV, or perhaps because of it, HIV-related stigma remains rampant in the country (Pantelic et al. 2015; Human Sciences Research Council, 2014). According to the HIV Stigma Index survey of 10,473 South Africans living with HIV, aged 15 and above, prevalence of enacted, anticipated and internalised HIV stigma was 36%, 39% and 43% respectively (Human Sciences Research Council 2014). Reasons for this remain poorly understood, with data suggesting that enacted

HIV stigma *increased* after the mass rollout of government-funded ART (Maughan-Brown 2010).

Figure 5 Distribution of new HIV infections by region (reprinted from UNAIDS 2016)



Some of this may be attributed to socially constructed meanings attached to HIV and AIDS, which are often rooted within perceived sexual moralities, religion and AIDS denialism (Kalichman 2017; Chigwedere et al. 2008; Campbell, Nair, and Maimane 2006; Treichler 1987). Common beliefs that HIV is a punishment from God or from ancestors often results in a profound fear of stigma and avoidance of evidence-based treatment (Pantelic et al. 2016; Moshabela et al. 2016). Furthermore, the socio-cultural construction of HIV and AIDS as a reflection sexual immorality resulted

in a number of potentially stigmatizing HIV prevention interventions (Campbell, Nair, and Maimane 2006; Leclerc-Madlala 2001). For example, campaigns promoting abstinence outside of marriage, fidelity within marriage and condom use only in case of 'cheating' (Sani et al. 2016) may inadvertently stigmatize. Specifically, these campaigns may create an erroneous understanding of HIV epidemiology, and link HIV transmission to infidelity or sex outside of socially acceptable relationships (Figure 6).

Figure 6 HIV prevention campaign in Khutsong township outside of Johannesburg (source: REUTERS, Sphiwe Sibeko)



The persistence of HIV-related stigma may also be attributed to AIDS denialist propaganda and public policy led by President Thabo Mbeki from 1999 to 2008 (Kalichman 2017). Whilst Mbeki did not directly stigmatize people living with HIV, he questioned whether HIV existed and publicly described ART as 'toxic poisons' put forth as a western conspiracy against Africans (Chigwedere and Essex 2010). The decade-long AIDS denialism within top ranks of government - and the resultant lack

of effective HIV prevention and ART in the country - resulted in 330,000 preventable AIDS-related deaths and 35,000 babies born with HIV (Chigwedere et al. 2008).

In light of these data, HIV and AIDS in South Africa continued to meet Jones' criteria for a highly stigmatizing disease well after the advent of ART. As was the case in the US in the 1980's, misinformation coupled with absence of treatment in South Africa is likely to have increased AIDS-related stigma by fuelling fear of death, rendering the disease unmanageable, and preventing concealability of symptoms (Jones et al. 1984; Goffman 1968).

Evidence from the region partially supports this hypothesis (Stangl et al. 2013). The persistence of enacted HIV stigma has been attributed to a lack of awareness – such as fear of transmission, fear of death, the perceived burden of caring for people living with HIV and a belief that HIV is a reflection of promiscuity and infidelity (Ogden and Nyblade 2005; Maman et al. 2009; Treves-Kagan et al. 2016; Chan, Tsai, and Siedner 2015; Gilbert 2016; Gilbert and Walker 2010). As a result, most available evidence-based interventions aiming to reduce enacted stigma have come so through awareness-raising in the general population (Stangl et al. 2013).

However, research on factors associated with internalised HIV stigma in the region is still in its infancy (Pantelic et al. 2015). Established thus far is a link between internalised stigma and individual-level risk factors, i.e. poor HIV-related health and poor mental health of individuals living with HIV.

HIV, STIGMA AND ADOLESCENTS: A PUBLIC HEALTH CONCERN

The medical advances that have transformed HIV treatment have yet to alter the stark reality for young people, particularly in [...] Africa.

- Linda-Gail Bekker, International AIDS Society President

Globally, there are an estimated 2.1 million HIV-positive adolescents and 85% of them live in Sub-Saharan Africa (Idele et al. 2014). When compared to other parts of the world, the HIV/AIDS epidemic in Sub-Saharan Africa is characterized by a larger proportion of HIV-positive adolescents (Figure 7). South Africa is home to the world's largest number of HIV-positive adolescents (WHO 2014).

High HIV prevalence among adolescents in Sub-Saharan Africa can be attributed to two main epidemiological trends. The first trend is high incidence of new HIV infections due to heterosexual transmission. In 2012, an estimated 300,000 new infections occurred among older adolescents aged 15–19 years and, of these new infections, two thirds were in Sub-Saharan Africa (UNICEF 2013). In addition to high sexual transmission rates, the second reason for high HIV prevalence in this age group is the long-term survival of adolescents born with HIV. Namely, recent years have seen the first generation of perinatally-infected children who survived into adolescence due to the late rollout of ART in the region (Ferrand et al. 2012).

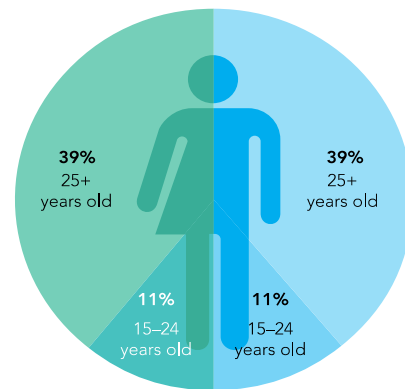
These youth are dying at alarming rates: between 2005 and 2012, AIDS-related mortality decreased by 30% for all age groups except for HIV-positive adolescents, who experienced a 50% increase (Porth et al. 2014). AIDS is the number one cause of death for young people in Sub-Saharan

Africa, and this has been attributed to a number of social and structural barriers to sustained access to HIV prevention, treatment and care (UNAIDS 2016; UNICEF 2013). For example, minimum age requirements for independently accessing services can pose a barrier to access to treatment if adolescents are unwilling or unable to disclose their HIV status to caregivers (UNAIDS 2016; UNICEF 2013). Similarly, dependency on adults, high rates of orphanhood and poverty may limit adolescents' ability to pay for transport to the clinic (Haberer et al. 2010; Tuller et al. 2010). Adolescents, and girls in particular, are vulnerable to child

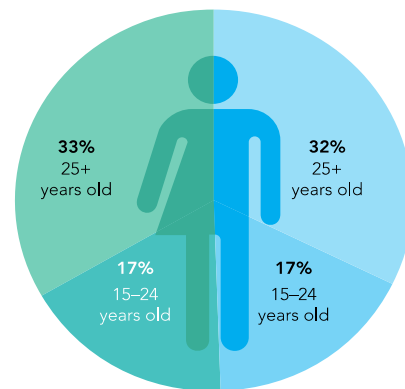
abuse victimization and neglect (Meinck, Cluver, Boyes, and Ndhlovu 2015; Meinck et al. 2014; Abadía-Barrero and Castro 2006). Abusive caregivers may deliberately restrict adolescents' access to services so as to avoid being reported (UNAIDS 2016; UNICEF 2013; Abadía-Barrero and Castro 2006).

Figure 7 Distribution of new HIV infections by age and sex, globally and in Sub-Saharan Africa (reprinted from UNAIDS 2016)

ADULT POPULATION, BY AGE AND SEX, GLOBAL, 2015



ADULT POPULATION, BY AGE AND SEX, SUB-SAHARAN AFRICA, 2015



HIV stigma is likely to compound these risks for HIV-positive adolescents. For example, enacted HIV stigma may increase the risk of neglect and abuse of HIV-positive adolescents (Boyes and Cluver 2013a), limiting their access to basic resources (Abadía-Barrero and Castro 2006; Bond 2006). The resultant food insecurity and inability to pay for transport can hamper adherence to antiretroviral treatment by increasing medication side effects (Anema et al. 2009) and directly disabling clinic visits (Haberer et al. 2010; Tuller et al. 2010). In addition to being a risk factor for non-adherence (Katz et al. 2013), internalised HIV stigma also hampers disclosure of HIV status to others (Tsai, Bangsberg, Kegeles, et al. 2013; Mburu et al. 2014). As explained above, disclosure of status to caregivers could be an essential gateway to accessing life-saving treatment for adolescents who are under age.

South African youth (15-24) are more likely to report experiencing enacted, anticipated and internalised HIV stigma than older age groups (Human Sciences Research Council, 2014). These HIV stigma mechanisms are likely to be contributing to the high morbidity and mortality rates among HIV-positive adolescents. However, considerable gaps in basic knowledge about HIV stigma in this high risk group hamper the development of an evidence-based response to the problem (Stangl et al. 2013; Pantelic et al. 2015).

GAPS IN THE PROGRAMMATIC RESPONSE TO HIV STIGMA

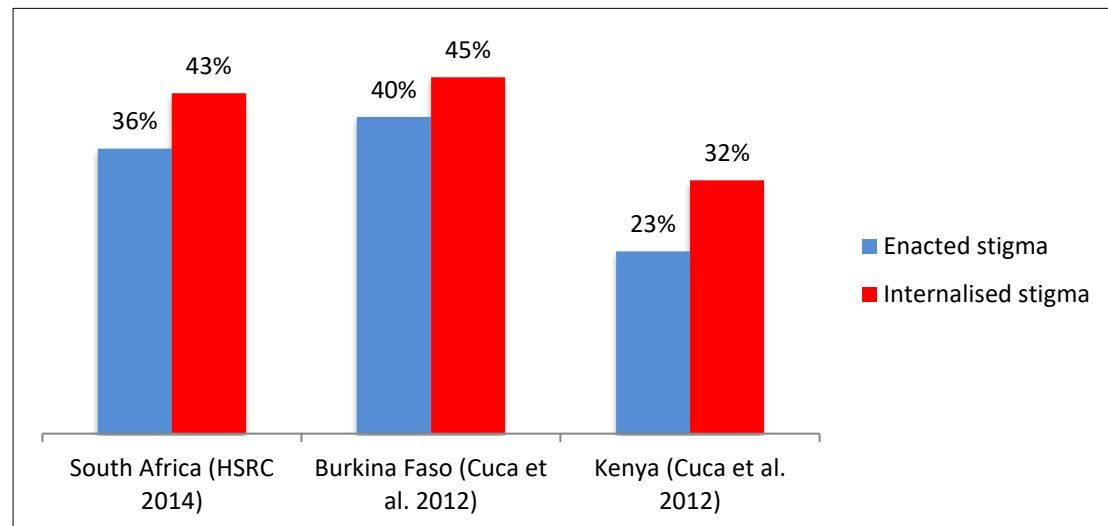
Internalised HIV stigma remains understudied, particularly among adolescents living with HIV (Stangl et al. 2013). A recent global systematic review of stigma reduction interventions found 39 studies targeting enacted HIV stigma and, of these, all but

one have resulted in desired stigma reductions (Stangl et al. 2013). Conversely, only two intervention studies aiming to reduce internalised HIV stigma in Sub-Saharan Africa were found (Uys et al. 2009; Tshabalala and Visser 2011), with another one evaluated after Stangl and colleagues' systematic review (Maluccio et al. 2016). This is concerning as self-reported data from people living with HIV in Lesotho, Malawi, South Africa, Swaziland, Tanzania, Kenya, Burkina Faso, and Uganda (Cuca et al. 2012; Human Sciences Research Council 2014; Neuman and Obermeyer 2013; Holzemer et al. 2007) consistently suggest that prevalence of internalised HIV stigma is higher than prevalence of enacted HIV stigma (Figure 8). Importantly, no studies to reduce internalised HIV stigma among HIV-positive adolescents were identified in the region or globally, despite this being the most-at-risk age group for experiencing all types of HIV stigma (Human Sciences Research Council 2014).

The two interventions included in Stangl and colleagues' systematic review aimed to improve coping through empowerment and knowledge building. Uys et al. (2009) used a multiple-case study approach to evaluate non-standardised programmes designed by small groups of 7-10 nurses and 7-10 HIV-positive patients in five healthcare facilities in Lesotho, Malawi, South Africa, Swaziland, and Tanzania. Taken together, the programmes resulted in a significant reduction in negative self-perception among the patients. Tshabalala and Visser (2011) evaluated a structured cognitive-behavioural therapy intervention in a small mixed methods randomised control trial with HIV-positive women in South Africa (10 women living with HIV in the intervention group and 10 women living with HIV in the waitlist control group).

The intervention resulted in significantly greater reductions in internalised stigma in the intervention group compared to the control group.

Figure 8 Rates of different types of HIV stigma reported by people living with HIV in Sub-Saharan Africa



The only other known intervention offered monthly food assistance for patients living with HIV enrolled in a civil society run clinic in Uganda (Maluccio et al. 2016). The intervention was delivered over the course of a year to n=904 ART naïve adults. Status disclosure to a friend or family member was required for participation. Patients receiving this intervention within one clinic reported greater reductions in internalised HIV stigma than patients within a non-randomized comparison clinic.

However, we should be extremely cautious about making inferences based on these studies given that they excluded children and adolescents, required HIV status disclosure to others and were delivered through clinics. Findings suggest that it might be feasible to reduce internalised HIV stigma by strengthening individual-level coping and food security. However the interventions did not target any inter-personal factors that are likely to contribute to internalised HIV stigma, such as

experiences of discrimination and maltreatment (Link, Cullen, Struening, Shrout, and Dohrenwend 1989; Parker and Aggleton 2003; Tsai, Bangsberg, and Weiser 2013; Campbell and Deacon 2007).

It is especially unclear whether these interventions would be effective or feasible if delivered to adolescents living with HIV. Namely, all three interventions required disclosure of HIV status to others either explicitly (Maluccio et al. 2016), or implicitly through attending HIV-specific sessions (Uys et al. 2009; Tshabalala and Visser 2011). So as to facilitate discussion about living with HIV, such sessions require participants to disclose their HIV status to everyone present. Fear of stigma and discrimination might deter adolescents' willingness to disclose their status to others or participate in HIV-focused sessions (Madiba and Kekana 2013; Madiba and Canti-Sigaqa 2012; Visser et al. 2005; Liamputtong, Haritavorn, and Kiatying-Angsulee 2009). This has been a major challenge with adolescent uptake of other HIV-specific and clinic-based services (WHO 2014).

To that effect, researchers have called for more inclusive, community-based interventions that are sensitive to the needs of HIV-positive adolescents but do not target them specifically (Miller and Samson 2012). Interventions aiming to reduce internalised HIV stigma may also benefit from this approach. However, foundational evidence is needed to first assess the potential for - and inform the design of - community-based interventions to reduce internalised HIV stigma.

RESEARCH AIMS AND QUESTIONS

This is the first epidemiological study of internalised HIV stigma among adolescents living with HIV in Sub-Saharan Africa. It aims to answer four key research questions (RQ) with the overarching aim of building and testing a theoretical model of risk for internalised HIV stigma in adolescents living with HIV in South Africa:

- RQ 1 (Paper 1):** What is the state of quantitative evidence¹ on risk and protective factors for internalised HIV stigma in Sub-Saharan Africa?
- RQ 2 (Paper 2):** How can we measure internalised HIV stigma among adolescents living with HIV in South Africa?
- RQ 3 (Paper 3):** What is the extent of internalised HIV stigma experienced by adolescents living with HIV in South Africa?
- RQ 4 (Paper 3):** What are the potential social and psychological pathways to internalised HIV stigma among South African adolescents living with HIV?

¹ Qualitative evidence was not reviewed to avoid overlap with existing qualitative syntheses of studies on stigma among people living with HIV (Chambers et al. 2015; Barroso and Powell-cope 2000).

CHAPTER III. PAPER 1 – PREDICTORS AND CORRELATES OF INTERNALISED HIV-RELATED STIGMA: A SYSTEMATIC REVIEW OF STUDIES IN SUB-SAHARAN AFRICA

Pantelic, Marija, Yulia Shenderovich, Lucie Cluver, and Mark Boyes. 2015. "Predictors of Internalised HIV-Related Stigma: A Systematic Review of Studies in Sub-Saharan Africa." *Health Psychology Review*. (IF: 8.976)

ABSTRACT

Objective: This systematic review aims to synthesise evidence on predictors of internalised HIV stigma amongst people living with HIV in Sub-Saharan Africa.

Method: PRISMA guidelines were used. Studies were identified through electronic databases, grey literature, reference harvesting and contacts with key researchers. Quality of findings was assessed through an adapted version of the Cambridge Quality Checklists.

Results: A total of 589 potentially relevant titles were identified. Seventeen peer-reviewed articles and one draft book chapter were included. No studies on children or adolescents were found. Prevalence of internalised HIV stigma amongst adults living with HIV ranged between 26.9% and 66%. Studies investigated socio-demographic, HIV-related, intra-personal and inter-personal correlates of internalised stigma. Eleven articles used cross-sectional data, five articles used prospective cohort data and one used both prospective cohort and cross-sectional data to assess correlates or predictors of internalised HIV stigma. Of the longitudinal predictors, only individual-level factors were assessed: poor HIV-related health and poor mental health consistently predicted internalised HIV stigma.

Conclusion: Data on HIV-positive adolescents and youth are urgently needed. The evidence base would benefit from more data on inter-personal predictors of internalised HIV stigma, and integrating these into their hypotheses. Interventions to improve the physical and mental health of people living with HIV may help reduce internalised HIV stigma. However, studies utilizing analysis of change and accounting for confounding factors are necessary before firm inferences for policy and programming can be made.

Keywords: stigma; HIV/AIDS; systematic review; self-perception; self-image; shame

BACKGROUND

In 2011, UN member states committed to eliminating HIV/AIDS-related stigma by 2015 (UNAIDS 2011). Existing intervention studies heavily focus on reducing enacted stigma (Stangl et al. 2013), which refers to negative public attitudes or discrimination towards people living with HIV (Horwitz et al. 2013). Less is known about how to reduce internalised HIV-related stigma, which occurs when an HIV-positive person endorses negative attitudes associated with HIV and accepts them as applicable to his or her self (Earnshaw et al. 2013). Internalised stigma is characterised by feelings of shame, guilt, worthlessness and difficulties around HIV status disclosure (Lee, Kochman, and Sikkema 2002; Tsai et al. 2012).

Reducing internalised HIV stigma may mitigate a range of associated damaging outcomes for people living with HIV. Internalised stigma hinders adherence to antiretroviral treatment (ART) (Sayles et al. 2009; Rintamaki et al. 2006; Susan et al. 2012; Katz et al. 2013), which is essential for preventing virological failure (Gross et

al. 2006) and reducing mortality among people living with HIV (Lima et al. 2009). Over time, internalised stigma has been associated with reductions in health-related quality of life (Peltzer 2012). By inducing fear of rejection and lowering self-confidence (Bourne et al. 2012), internalised stigma may also lead to non-disclosure of HIV status to sexual partners (Tsai, Bangsberg, Kegeles, et al. 2013) and inconsistent condom use (Earnshaw et al. 2014). Therefore, reducing internalised stigma may improve important health outcomes for people living with HIV and mitigate secondary HIV transmission.

Sub-Saharan Africa is home to 70% of the world's people living with HIV but no well-established programmes to reduce internalised HIV stigma have been identified in the region (Stangl et al. 2013). In order to design and test future interventions, we must first understand the full range of known predictors of internalised HIV stigma in Sub-Saharan Africa (Blum and Ireland 2004). To our knowledge, no systematic review on predictors of internalised HIV stigma in sub-Saharan Africa has been conducted to date, despite the region's disproportionate HIV burden. Logie and Gadalla (2009) conducted a systematic review and meta-analysis of health and demographic correlates of both enacted and internalised HIV-stigma in North America, and found one study assessing correlates of internalised stigma in the US (Lee, Kochman, and Sikkema 2002). However we should be extremely cautious about the transferability of North American studies, where HIV disproportionately affects otherwise stigmatised minorities such as men who have sex with men, people who inject drugs and African Americans (CDC 2013). In contrast, in sub-Saharan Africa, HIV is prevalent in the 'general' population.

Therefore, the aim of this systematic review is to synthesise existing evidence on predictors of internalised HIV stigma among people living with HIV in Sub-Saharan Africa. This review assesses observational studies of predictors of internalised HIV stigma to avoid overlap with a recent systematic review of stigma reduction interventions (Stangl et al. 2013). Full details on the scope of this review are provided in Table 1.

Table 1 Scope of the review

Outcome	HIV/AIDS related internalised or self-stigma, shame, negative self- image, negative self-perception
Population	People living with HIV of all ages
Geographic location	Sub-Saharan Africa
Study design	Cross-sectional surveys, case-control studies, cohort studies, psychometric studies (scale validity and reliability studies)

METHODS

SEARCH STRATEGY

This paper adheres to PRISMA guidelines for systematic reviews (Moher et al. 2009).

The full protocol for this systematic review was pre-published online in February 2014.²

Initial searches were conducted November-December 2013, and updated to January 2015. Studies were identified through electronic searches of bibliographic databases and grey literature web sites, examining citations of retrieved studies, and

²<https://static1.squarespace.com/static/54e3c4b3e4b02a415877e452/t/558c03dde4b0c1913178f87e/1435239389374/Pantelic-Shenderovich-Cluver-Boyes-201420140213.pdf>

contacting researchers. Our search was restricted to reports after 1983, the year of the first AIDS diagnoses in Africa (Ras et al. 1983). Larger databases (PsycARTICLES, Embase, Global Health, Ovid MEDLINE, and PsycINFO) were searched utilizing sensitive search terms including subject heading (MeSH) and free-text search terms for sub-Saharan Africa, people living with HIV and internalised HIV-related stigma or shame (see Supplementary file 4). Smaller databases (CINAHL and WHO Afro Library) used a simpler, more inclusive search string. The PROSPERO register of systematic reviews was also searched. References listed in the included studies as well as in other reviews on HIV/AIDS stigma (Stangl et al. 2013; Sengupta et al. 2011; Tsai, Bangsberg, and Weiser 2013; Mbonu, van den Borne, and De Vries 2009) were also reviewed for eligibility. Email requests for unpublished and on-going investigations were sent to key researchers working on HIV stigma. Inclusion and exclusion criteria used are summarized in Table 2.

SCREENING

Following guidelines in the Cochrane Collaboration Handbook (Deeks, Higgins, and Altman 2008), search results were merged and de-duplicated. The initial screening involved the DPhil candidate's examination of titles and abstracts to remove irrelevant reports. Full-text documents were retrieved and examined in detail for compliance with eligibility criteria (Table 2). Where needed, authors were contacted by email to retrieve reports, clarify study eligibility and request additional information.

Table 2 Systematic review inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
Study population: <ul style="list-style-type: none">• HIV-positive people	<ul style="list-style-type: none">• People whose HIV status is unknown or not specified
Sampling: <ul style="list-style-type: none">• Located in sub-Saharan Africa	<ul style="list-style-type: none">• Sub-Saharan African immigrants living outside of sub-Saharan Africa
Study design: <ul style="list-style-type: none">• Quantitative or mixed methods study design measuring internalised HIV stigma as an outcome, including longitudinal studies, cross-sectional surveys or case-control studies• Psychometric studies validating measurements of internalised HIV stigma• Prevalence studies that assess internalised HIV stigma and report on demographic comparisons (e.g. gender differences in internalised stigma)	<ul style="list-style-type: none">• Qualitative studies• Intervention studies
Outcome measure <ul style="list-style-type: none">• A measure of internalised HIV stigma	<ul style="list-style-type: none">• A multidimensional stigma outcome measure without differentiation between enacted stigma and internalised stigma, making it impossible to infer what factors are associated with internalised stigma.

DATA ABSTRACTION AND QUALITY ASSESSMENT

Data were extracted using a pre-designed form (see Appendix 1 for Study Protocol) piloted by the DPhil candidate. This was checked independently by a second reviewer (Yulia Shenderovich) and discrepancies were resolved by discussion. Articles reporting analyses from the same dataset were checked to ensure there was no data duplication. Where data were duplicated, estimates from the largest sample

were used. Quality of findings in included studies was assessed using an adapted version of the Cambridge Quality Checklists (CQC) (Murray, Farrington, and Eisner 2009), developed for drawing conclusions about causes from observational studies (Table 3). The causal predictor score is the most important CQC indicator as it assesses the extent to which the risk factor is causally related to the outcome. The causal score is determined based on two key features: 1) the extent to which within-individual changes in internalised HIV stigma are associated with within-individual changes in the predictor (analysis of change); and 2) whether the study design and/or statistical analysis account for alternative explanations of the findings. Models assessing whether variation in the predictor is related to within-individual change in internalised stigma and controlling for relevant confounding variables score highest among observational studies.

For the purposes of this systematic review, we adapted CQC to capture reporting quality, in addition to methodological rigor. For example, studies not reporting reliability of the internalised HIV stigma measure used were ranked lower than those reporting reliability below 0.70. Response rates were scored for cross-sectional designs. Given that the included prospective cohort studies reported only retention rates (without response rates at baseline), only retention rates were assessed for longitudinal designs. Studies focusing on people living with HIV in sub-Saharan Africa tend to recruit through healthcare facilities. We therefore adapted CQC sampling scores to assess the method used for the selection of facilities, in addition to the sampling of participants within facilities.

As the included studies assessed more than one internalised stigma predictor, CQC

was applied to each association between a correlate and internalised stigma. This allowed for differentiation between the types of analyses used for investigated predictors of internalised stigma. For example, Visser & Sipsma (2013) report a simple correlation between enacted stigma and internalised stigma, whereas other predictors of internalised stigma in the study were assessed in a multivariate model that received a higher causality score (due to accounting for confounders).

Any measures of between group differences (e.g. odds ratio, risk ratio, difference in means) or associations between constructs (e.g. r , $Beta$, B) were extracted. If these were unavailable, where possible *Cohen's d* was calculated to illustrate size of effect.

RISK OF BIAS ACROSS STUDIES

We sought to minimise risk of publication bias by actively searching for grey literature and on-going studies. However, the absence of registration procedures for observational studies limits the ability to assess reporting bias. Specifically, the lack of study protocols does not allow differentiation between hypothesis-driven from post-hoc data analyses (Loder, Groves, and MacAuley 2010).

DATA SYNTHESIS

A meta-analysis was not conducted due to the diversity of primary studies (Furlan et al. 2009). Furthermore, cross-sectional data used in the majority of included studies limit causal inferences (Garg, Hackam, and Tonelli 2008). Meta-analyses can test consistency of a relationship but not causality, so providing a single effect size could be misleading (Weed 2010).

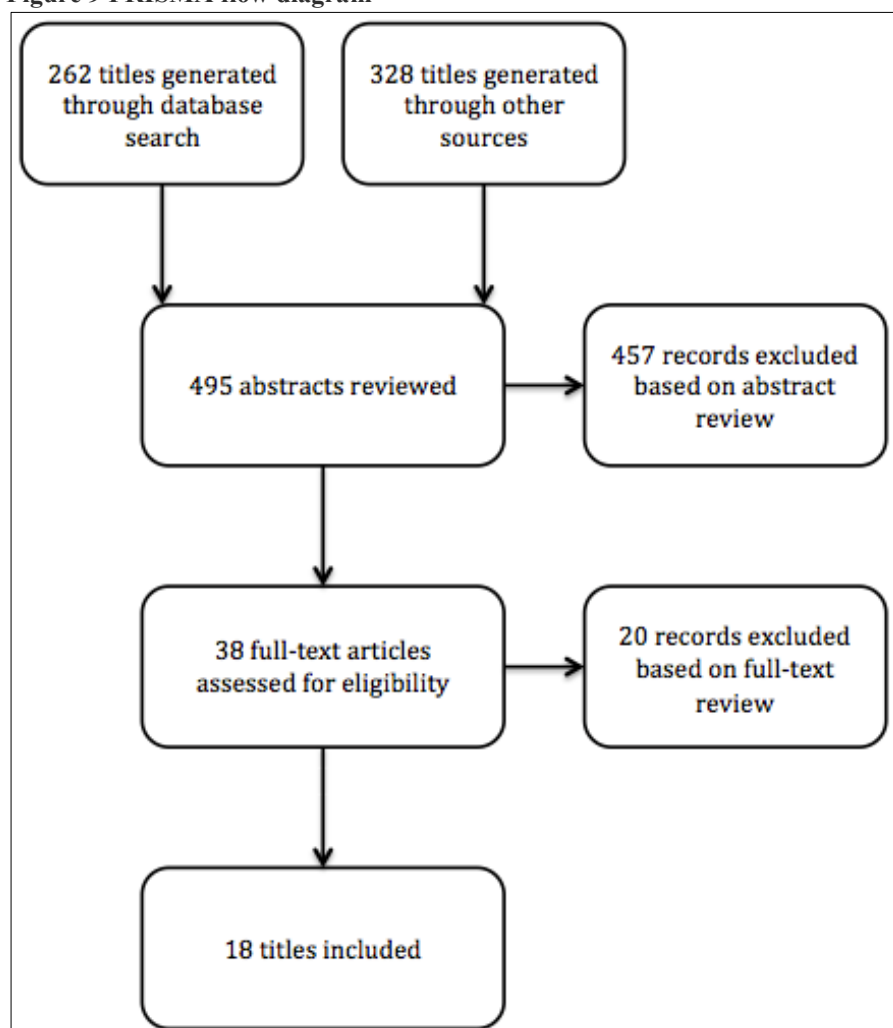
Table 3 Cambridge Quality Checklists for assessment of primary studies (adapted from Murray et al. 2009)

Quality Assessment*	
Facility sampling	
3	Total population or random sampling
2	Purposive sampling
1	Convenience sampling
0	Not reported
Within-facility sampling of participants	
3	Total population or random sampling
2	Purposive sampling
1	Convenience sampling
0	Not reported
Response rates	
2	Response ⁱ or retention ⁱⁱ rates $\geq 70\%$ or differential attrition ⁱⁱⁱ $\leq 10\%$
1	Response rate $< 70\%$ or retention rate $< 70\%$ or differential attrition $> 10\%$
0	Not reported
Sample size score	
1	Sample size ≥ 400
0	Sample size < 400
Internalised stigma measure validity	
3	Use of a validated standardized scale with the same target population OR use of an adapted scale that had been validated with another target population
2	Validation of a newly developed instrument
1	Use of a non-validated measurement
0	Not reported
Internalised stigma measure reliability	
2	Reliability coefficient $\geq .7$
1	Reliability coefficient $< .7$
0	Not reported
Study design score	
3	Prospective cohort data used in analysis
2	Retrospective cohort data used in analysis
1	Cross-sectional data used in analysis
Causal predictor score	
6	Analysis with variation in the predictor and adequately balanced, with analysis of change
5	Analysis with variation in the predictor and adequately balanced, no analysis of change
4	Analysis with variation in the predictor but inadequately balanced, with analysis of change
3	Analysis without variation in the predictor, with analysis of change
2	Analysis with variation in the predictor but inadequately balanced, no analysis of change
1	Analysis without variation in the predictor, no analysis of change
*Scoring to be completed separately for each analyzed association between a correlate and internalised stigma; ⁱ response rate scored for cross-sectional study designs; ⁱⁱ retention rate scored for longitudinal study designs; ⁱⁱⁱ differential attrition scored for case control study designs	

RESULTS

The search process identified 589 potentially relevant articles and reports. Of these, 262 titles were generated through the database search and 327 titles were generated through harvesting references and communicating with authors. After removing duplicates, 494 abstracts were retained for further review (Figure 9). Next, 37 titles were selected for full-text review. Finally, a total of 18 studies, including 17 peer-reviewed articles and one draft book chapter (Visser and Sipsma 2013) were included in this systematic review.

Figure 9 PRISMA flow diagram



STUDY CHARACTERISTICS

Table 4 summarizes the characteristics, quality assessment, findings and effect sizes (where reported) of included studies in chronological order. Represented in the 18 titles are 13 unique samples with 9,088 PLHIV in South Africa, Lesotho, Malawi, Tanzania, Swaziland, Mozambique, Uganda, Kenya and Burkina Faso. There was a general consensus between studies about the definition of internalised HIV stigma: negative self-perception due to HIV status and the resultant feelings of shame, difficulties around disclosure and self-exclusion.

All studies recruited participants through healthcare facilities, and four additionally recruited via support groups, community organizations, social service providers and gay venues (Makoae et al. 2009; Kalichman et al. 2009; Holzemer et al. 2007; Simbayi et al. 2007).

Ten articles assessed predictors of internalised stigma as a primary objective (Table 4). Five articles were psychometric assessments of measurements and analysed correlates of internalised stigma as part of construct validity checks (Holzemer et al., 2007; Kalichman et al., 2009; Kingori et al., 2013; Tsai et al., 2012; Visser et al., 2008). Three articles aimed to assess predictors of another outcome and assessed correlates of internalised stigma as part of exploratory analyses to inform more complex modelling of other outcomes (Neuman and Obermeyer 2013; Simbayi et al. 2007; Pearson et al. 2009).

Most studies included only adults. One study (Nattabi et al. 2011) included adolescents (15-49 age range), however the analysis did not differentiate between

adolescents and adults. No studies included children below the age of 15. One study (Makoae et al. 2009) did not specify the age range of the sample.

In terms of key high-risk populations, three articles focused on women attending antenatal care clinics (Cuca et al. 2012; Visser et al. 2008; Visser and Sipsma 2013). Cloete and colleagues (2008) included men who have sex with men and compared them to men who have sex with women. HIV-positive adolescents were not the focus of any of the studies.

QUALITY ASSESSMENT

Study design

Six articles reported on prospective cohort data (Cuca et al. 2012; Tsai, Bangsberg, Bwana, et al. 2013; Wagner et al. 2013; Makoae et al. 2009; Peltzer 2012) and one reported on both prospective cohort data and cross-sectional data (Pearson et al. 2009). Cross-sectional data were used to assess correlates of internalised stigma in the remaining 11 articles.

Most studies used large samples ($n \geq 400$). All studies recruited from healthcare facilities. Two articles reported purposively sampling the main HIV/AIDS clinics where patients from other health facilities are referred (Nattabi et al. 2011) and clinics with representative HIV testing services and healthcare provision (Neuman and Obermeyer 2013). One study reported convenience sampling of facilities (Sorsdahl et al. 2011) and fourteen did not report a method for selection. None of the studies reported total or random sampling of facilities.

Table 4 Summary of included studies

First author, year	Location	Primary outcome	Target population	n	% Female	Study design	CQC ¹	Predictors/correlates of internalised stigma
Simbayi, 2007	South Africa	N	Adults	1063	60.5	CS	39%	Male gender ($d=.26, p<.01$) 39% Age (<i>NS</i>) 39% Race (<i>NS</i>) 39% Discrimination/enacted stigma ($r=.31, p<.001$) 39% Low social support ($r=-.29, p<.01$) 39% Alcohol use ($r=.1, p<.01$) 39% Drug use ($r=.16, p<.01$) 39% Fewer years HIV+ ($r=-.09, p<.01$) 39% HIV symptoms (<i>NS</i>) 39% ART use (<i>NS</i>)
Holzemer, 2007	Lesotho, Malawi, South Africa, Swaziland, Tanzania	P	Adults	1477	74.1	CS	35%	HIV symptoms ($r=.09, p<.05$) 35% Life satisfaction ($r=-.23, p<.05$) 35% Overall functioning ($r=-.23, p<.05$) 35% Enacted stigma: social isolation ($r=.42, p<.05$) 35% Enacted stigma: fear of contagion ($r=.24, p<.05$) 35% Enacted stigma: workplace stigma ($r=.17, p<.05$) 35% Enacted stigma: healthcare neglect ($r=.23, p<.05$)
Visser, 2008	South Africa	P	Women	317	100	CS	<i>Estimates from Visser 2013 extracted as it reported findings from a larger sample size</i>	
Cloete, 2008	South Africa	Y	Men	422	0	CS	43%	MSM versus MSW (<i>NS</i>)
Kalichman, 2009	South Africa sample	P	Adults	1068	61	CS	44%	Depression ($r=.27, p<.01$) 44% Social support ($r=-.32, p<.01$) 44% HIV symptoms (<i>NS</i>) 44% Enacted stigma (discrimination) ($d=.43, p<.01$)
Kalichman, 2009	Swaziland sample			1087	67		44%	Depression ($r=.31, p<.01$) 44% Social support ($r=-.08, p<.05$) 44% HIV symptoms ($r=.18, p<.01$) 44% Enacted stigma (discrimination) (<i>NS</i>)

First author, year	Location	Primary outcome	Target population	n	% Female	Study design	CQC ¹	Predictors/correlates of internalised stigma
Makoa, 2009	Lesotho, Malawi, South Africa, Swaziland and Tanzania	Y	Adults	1454	54.2 non ART takers; 45.7 ART takers	PCS	61% 61%	Time – internalised stigma significantly decreased over time for everyone, both on ARVs and not ($d=49, p<.001$) Time by ARV use- those taking ARV's showed significantly less reduction in internalised stigma ($d=.18, p<.05$)
Pearson, 2009	Mozambique	N	Adults initiating ART	277	56.3	PCS	74% 57% 57% 57% 57% 57% 57%	Time: internalised stigma significantly increased over time from ART initiation ($t=4.49, p<.001$) Lower depression ($r=-0.13, p<.05$) Lower perceived social support ($r=-0.12, p<.05$) Fewer people disclosed to ($r=-0.24, p<.001$) Disclosure to family member - compared to others ($t=3.41, p<.001$) Disclosure to friend- compared to others ($t=4.21, p<.001$) Disclosure to coworker- compared to others ($t=3.01, p<.01$) Disclosure to spouse or partner (<i>NS</i>)
Nattabi, 2011	Uganda	Y	People aged 15-49	497	50	CS	48% 48% 48% 48% 48% 48% 48% 48%	Age group (30 used as cutoff for dichotomous variable) (<i>NS</i>) Female gender ($r=.09, p<.05$) HIV status of partner (<i>NS</i>) Months on HAART (<i>NS</i>) Months since HIV diagnosis (<i>NS</i>) Months attending HIV clinic (<i>NS</i>) Desire more children (<i>NS</i>) HAART use (<i>NS</i>)
Sorsdahl, 2011	South Africa	Y	Adults	400	78.5	CS	48% 48% 48% 48% 48% 48% 48%	Younger age ($OR=.95, p<.001$) Female gender ($OR=.59, p<.05$) Xhosa language (<i>NS</i>) Years of education ($OR=1.26, p<.01$) Employment (<i>NS</i>) Shorter time of knowing HIV status ($OR=.87, p<.001$) Lack of disclosure ($OR=3.11, p<.05$)

First author, year	Location	Primary outcome	Target population	n	% Female	Study design	CQC ¹	Predictors/correlates of internalised stigma
Peltzer, 2012	South Africa	Y	Adults	499	70.5	CS	61%	Time on ART ($d=0.29, p<.01$)
Tsai, 2012	Uganda	P	Adults	456	69.5	CS	39%	Depression symptom severity ($r=.28, p<.05$)
							39%	Mental health related quality of life ($r=-.38, p<.05$)
							39%	HIV symptom burden ($r=.38, p<.05$)
							39%	Physical health related quality of life ($r=-.24, p<.05$)
Wagner, 2012	Uganda	Y	Adults	602	68	PCS	83%	ART use (<i>NS</i>)
							83%	Time on ART (<i>NS</i>)
							83%	Time by ART use ($\beta=-.30, p<.001$)
							83%	Change in physical health functioning ($\beta=-.008, p<.001$)
Cuca, 2012	Kenya	Y	Pregnant women	147	100	CS	52%	Age (25 cutoff used) (<i>NS</i>)
							52%	Woman's major contribution to support household is housework (<i>NS</i>)
							52%	Family knows HIV+ status (<i>NS</i>)
							52%	Perceives community stigma (<i>NS</i>)
							52%	Post partum depression ($OR= 4.6, 95\% CI: 1.7, 12.9, p<.01$)
Neuman, 2013	Burkina Faso, Kenya, Malawi, Uganda	N	Adults	536	67.4	CS	39%	Female gender (<i>NS</i>)
							39%	Age (categorized into three age groups) (<i>NS</i>)
							39%	Educational attainment (<i>NS</i>)
							39%	Urban location (<i>NS</i>)
Kingori, 2013	Kenya	P	Adults	370	60.4	CS	35%	Depression ($r=.345, p<.000$)
Tsai, 2013	Uganda	Y	Adults	262	66	PCS	83%	Time on ART ($d=.70, p<.05$), mediated by reduced HIV-related symptoms, improved physical and mental health, and lower depression scores
Visser, 2013	South Africa	Y	Pregnant women	609	100	CS	43%	Attributed stigma (perceive other people in community to be highly stigmatizing) ($r=.334, p<.01$)
							57%	Older age ($\beta= .123, p<.01$)
							57%	Lower educational attainment ($\beta= -.115, p<.01$)
							57%	Victim of sexual violence (<i>NS</i>)
							57%	Disclosed HIV status ($\beta= -.085, p<.05$)
							57%	HIV knowledge (<i>NS</i>)
							57%	Low self-esteem ($\beta= -.197, p<.01$)

First author, year	Location	Primary outcome	Target population	n	% Female	Study design	CQC ¹	Predictors/correlates of internalised stigma
							57%	Depression ($\beta = .179, p < .01$)
							57%	Low social support ($\beta = -.114, p < .01$)
Takada, 2014	Uganda	Y	Adults	422	71%	PCS	87%	Age (<i>NS</i>) Gender (<i>NS</i>) Marital status (<i>NS</i>) Education (<i>NS</i>) Household asset wealth (<i>NS</i>) Emotional support (<i>NS</i>) Tangible support (<i>NS</i>) Poor HIV-related physical health ($\beta = -0.018, p < .001$) Depression ($\beta = 0.49, p < .001$)

Notes:

- In the 'Primary outcome' column, 'Y' indicates that internalised stigma was a primary outcome of interest, 'N' indicates that an outcome other than internalised stigma was primary and 'P' indicates that the study was a psychometric assessment of an internalised stigma measurement

- CS indicates a cross-sectional study design; PCS indicates a prospective cohort study design

- In the 'Predictors of internalised stigma column, 'NS' indicates non significant association ($p > .5$)

¹ 100% would indicate the maximum possible score of 23; decimals were rounded up to the nearest whole per cent

Within facilities, five studies used total or random sampling of participants (Tsai, Bangsberg, Bwana, et al. 2013; Cuca et al. 2012; Wagner et al. 2013; Pearson et al. 2009; Takada et al. 2014); one used purposive sampling (Cloete et al. 2008); and five used convenience sampling (Visser et al. 2008; Visser and Sipsma 2013; Neuman and Obermeyer 2013; Kalichman et al. 2009; Sorsdahl et al. 2011). The remaining six articles did not report methods used to sample participants within facilities.

Internalised HIV Stigma Measurement Validity and Reliability

The most common measurement used in seven included articles was the Internalised AIDS-related Stigma Scale (IA-RSS), developed by Kalichman and colleagues (2009) (Cloete et al. 2008; Kalichman et al. 2009; Peltzer 2012; Simbayi et al. 2007; Tsai et al. 2012; Tsai, Bangsberg, Bwana, et al. 2013; Takada et al. 2014). Five articles (Holzemer et al. 2007; Makoae et al. 2009; Cuca et al. 2012; Nattabi et al. 2011; Sorsdahl et al. 2011) reported use of the negative self-perception subscale of the HIV/AIDS Stigma Instrument-PLWA (HASI-P). Two reports used the Serithi Internalised Stigma Scale developed by Visser and colleagues (Visser et al., 2008; Visser & Sipsma, 2013). Kingori and colleagues (2013) used the HIV Felt Stigma Questionnaire, and Pearson and colleagues (2009) used the Berger HIV Stigma Scale. Neuman & Obermeyer (2013) developed two items asking about feelings of worthlessness and guilt to assess internalised stigma.

Thirteen articles used internalised stigma measures that underwent some assessment of construct validity (i.e. correlations with theoretically linked constructs). One article additionally reported assessing face validity of the internalised stigma measurement through expert review (Kingori et al. 2013). One

article tested measurement invariance (both configural and metric) (Holzemer et al. 2007). One article reported use of non-parametric equality-of-medians tests (Tsai et al. 2012). Thirteen articles reported high measurement reliability for internalised stigma, with alphas at or above .70 and one article reported reliability below .70 (Neuman and Obermeyer 2013). However, given that the latter measurement consisted of only two items, Cronbach's alpha $<.70$ might be a result of the measure's brevity. The remaining articles did not report internalised stigma measurement reliability in the study sample.

Response and retention rates

Five articles reported a response or retention rate $\geq 70\%$ (Pearson et al. 2009; Wagner et al. 2013; Tsai, Bangsberg, Bwana, et al. 2013; Simbayi et al. 2007; Nattabi et al. 2011). Three studies (Makoae et al. 2009; Cuca et al. 2012; Peltzer 2012) reported response or retention rates below 70%. Ten articles did not report response or retention rates.

Causality scores

Only two articles assessed within-individual change in internalised stigma over time whilst taking into consideration potential confounding variables (Tsai, Bangsberg, Bwana, et al. 2013; Takada et al. 2014). Another article conducted within-group change in internalised stigma over time while adequately controlling for confounders (Wagner et al. 2013). One article explored within group changes in internalised stigma over time without taking confounders into consideration (Peltzer 2012). Two articles took potential confounds into account without analysis of change (Visser and

Sipsma 2013; Cloete et al. 2008). The remaining articles did not control for confounders or did not explicitly state the choice of confounders when predicting internalised stigma.

INTERNALISED STIGMA PREVALENCE, OBSERVED PREDICTORS AND CORRELATES

Reports of any indicators of internalised stigma among people living with HIV ranged between 26.9% and 66% (Kingori et al. 2013; Cloete et al. 2008; Cuca et al. 2012; Neuman and Obermeyer 2013; Sorsdahl et al. 2011; Visser and Sipsma 2013). We identified four categories of internalised stigma predictors and correlates: (1) socio-demographic, (2) intra-personal (including HIV- and treatment-related) and (4) inter-personal factors. Each category and its correlates are described below. Effect sizes are reported where consistent directionality was observed between an investigated correlate or predictor and internalised stigma.

Socio-demographic factors

Socio-demographic factors assessed were age (Cuca et al. 2012; Nattabi et al. 2011; Neuman and Obermeyer 2013; Simbayi et al. 2007; Sorsdahl et al. 2011; Visser and Sipsma 2013; Takada et al. 2014), gender (Nattabi et al. 2011; Neuman and Obermeyer 2013; Simbayi et al. 2007; Sorsdahl et al. 2011; Takada et al. 2014), urban household location (Neuman and Obermeyer 2013), race (Simbayi et al. 2007), Xhosa language (Sorsdahl et al., 2011), educational attainment (Neuman and Obermeyer 2013; Sorsdahl et al. 2011; Visser and Sipsma 2013; Takada et al. 2014), employment status (Sorsdahl et al. 2011), marital status (Takada et al. 2014) and whether a woman's main contribution to the household was housework (Cuca et al.

2012). Findings on the relationships between internalised stigma and age, gender and educational attainment produced inconsistent directionality. One study found older age to be associated with higher levels of internalised stigma (Visser and Sipsma 2013), another one found younger age to be associated with higher odds of experiencing internalised stigma (Sorsdahl et al. 2011) and another found no significant association (Takada et al. 2014). Two studies found a positive association between female gender and internalised stigma (Sorsdahl et al. 2011; Nattabi et al. 2011). Another study detected more internalised stigma among men than women (Simbayi et al. 2007). One study found no relationship between gender and internalised stigma (Takada et al. 2014). Sorsdahl and colleagues (2011) found higher educational attainment to predict higher odds of internalised stigma, whereas Visser and Sipsma (2013) found higher educational attainment to predict lower levels of internalised stigma. Takada and colleagues (2014) found no relationship between educational attainment and internalised stigma. No other socio-demographic factors were significant internalised stigma correlates. Overall, no consistent relationships between socio-demographic factors and internalised stigma were observed.

Intra-personal factors

At the intra-personal level, depression (Cuca et al. 2012; Kalichman et al. 2009; Kingori et al. 2013; Pearson et al. 2009; Tsai et al. 2012; Visser et al. 2008; Visser and Sipsma 2013; Takada et al. 2014), mental health-related quality of life (Tsai et al., 2012), self-esteem (Visser et al., 2008; Visser & Sipsma, 2013), alcohol and drug use (Simbayi et al. 2007) and the desire to have children (Nattabi et al. 2011) were assessed. Higher mental health-related quality of life was moderately associated

with lower levels of internalised stigma ($r=-.38$) in one cross-sectional study (Tsai et al., 2012). Higher levels of depression were moderately associated with more internalised stigma in six cross-sectional studies ($OR=4.6$ in Cuca et al., 2012; $r=.27$ and $.31$ in Kalichman et al., 2009; $r=.35$ in Kingori et al., 2013; $r=.28$ in Tsai et al., 2012; $\beta=.179$ in Visser & Sipsma, 2013) and with lower levels of internalised stigma in one cross-sectional analysis (Pearson et al. 2009). One prospective cohort study found a weak relationship between poor mental health and internalised stigma with an adjusted incidence rate ratio of $.79$ (Tsai, Bangsberg, Bwana, et al. 2013). Another prospective cohort study found a moderate relationship ($\beta= 0.49$, $p<.001$) between clinical depression and increases in internalised stigma over time (Takada et al. 2014). Higher self-esteem was associated with lower levels of internalised stigma among HIV-positive women ($\beta= -.197$ in Visser & Sipsma, 2013). One study found alcohol and drug use to be weakly correlated with higher levels of internalised stigma cross-sectionally ($r=.1$ and $r=.16$ respectively in Simbayi et al., 2007a).

HIV- and treatment-related factors

The following variables were assessed as potential HIV- and treatment-related correlates of internalised stigma: time since diagnosis (Cloete et al., 2008; Makoae et al., 2009; Nattabi et al., 2011; Sorsdahl et al., 2011), HIV symptomatology and physical health (Holzemer et al. 2007; Kalichman et al. 2009; Simbayi et al. 2007; Tsai et al. 2012; Tsai, Bangsberg, Bwana, et al. 2013; Takada et al. 2014), ART use (Nattabi et al. 2011; Simbayi et al. 2007; Wagner et al. 2013), time on ART (Nattabi et al. 2011; Tsai, Bangsberg, Bwana, et al. 2013; Wagner et al. 2013; Pearson et al. 2009), interaction of time by ART (Makoae et al. 2009), time attending healthcare facility

(Nattabi et al. 2011; Simbayi et al. 2007) and HIV-related knowledge and misconceptions (Visser et al., 2008; Visser & Sipsma, 2013). Time since diagnosis was associated with less internalised stigma in two cross-sectional studies (Simbayi et al. 2007; Sorsdahl et al. 2011) with small effect sizes ($r=-.09$, $p <.01$ and $OR=.87$, 95% CI .80-.95, respectively). Longitudinally, Visser & Sipsma (2013) also detected a significant decrease in internalised stigma since diagnosis over a 3-year time period. This decline became non-significant when accounting for changes in HIV knowledge and knowing someone with HIV, suggesting potential mediation effects but mediation analysis was not conducted. Makoae et al. (2009) also found that internalised stigma decreased over time for both patients taking and not taking ART.

When compared to no ART use, ART use was not associated with internalised stigma in two cross-sectional (Nattabi et al. 2011; Simbayi et al. 2007) and one prospective cohort study (Wagner et al. 2013). Time on ART produced inconsistent effects on internalised stigma. Longer time on ART resulted in an increase in internalised stigma in one study (Pearson et al. 2009), a U trend in another study (Peltzer 2012) and an overall decline in a third study (Tsai, Bangsberg, Bwana, et al. 2013). Peltzer and colleagues found that internalised stigma decreased at 6 and 12 months post ART initiation but then increased to baseline levels at 20-month follow-up. Tsai et al. (2013) found that the relationship between reduction in internalised stigma and time on ART was mediated by a reduction in HIV symptoms, improved physical and mental health, and lower depression scores. However, similarly to Peltzer (2012), they found a slight upward trend in internalised stigma towards the end of the 40-month follow-up.

The interaction between time and ART use on internalised stigma also rendered inconsistent findings. Makoae and colleagues (2009) found that respondents not taking ART experienced a greater decrease in internalised stigma than those taking ART. Conversely, Wagner and colleagues (2013) found that reduction in internalised stigma over time was significantly greater in the ART group compared to the non-ART group. With physical health functioning included in the latter model, the adjusted beta weight for time by ART decreased (from $\beta = -.30$ to $\beta = -.21$), suggesting that the reductions in internalised stigma among ART users might be mediated by improved health. However the paper did not include mediation analysis.

Despite inconsistent findings on how internalised stigma changes over time on ART, indicators of poor HIV-related health and treatment outcomes were consistently associated with more internalised stigma. Specifically, HIV symptom burden weakly correlated ($r = .09-.38$) with more internalised stigma in three cross-sectional studies (Kalichman et al. 2009; Tsai et al. 2012; Holzemer et al. 2007). Poor physical health was also weakly associated with more internalised stigma in one cross sectional (Tsai et al., 2012; $r = .24$) and two prospective cohort studies (Takada et al., 2014, $\beta = -0.018$; Wagner et al., 2013, $\beta = -0.008$). Holzemer and colleagues (2007) found that higher HIV-related life satisfaction and overall functioning were weakly associated with lower levels of internalised stigma ($r = -.23$ and $r = -.23$).

Inter-personal factors

At the inter-personal level, social support (Kalichman et al. 2009; Pearson et al. 2009; Simbayi et al. 2007; Visser and Sipsma 2013; Takada et al. 2014), perceived stigma

(Cuca et al. 2012; Visser and Sipsma 2013), enacted stigma (Simbayi et al. 2007), different types of HIV status disclosure (Cuca et al., 2012; Pearson et al., 2009; Sorsdahl et al., 2011; Visser & Sipsma, 2013), HIV status of partner (Nattabi et al. 2011), homosexual versus heterosexual preferences among men (Cloete et al. 2008) and history of sexual abuse victimization among women (Visser & Sipsma, 2013) were assessed. All cross-sectional studies assessing social support found that it was weakly associated with lower levels of internalised stigma: $r=-.32$ and $r=-.08$ in Kalichman et al. (2009); $r= -0.12$ in Pearson et al. (2009); $r= -.29$ in Simbayi et al. (2007a); $r=-.11$ in Visser & Sipsma, (2013). However, the only prospective cohort study assessing whether social support predicts changes in internalised stigma over time found no significant relationship between emotional and tangible social support and internalised stigma (Takada et al. 2014). Perceived stigma (Visser and Sipsma 2013) and different forms of enacted stigma (Simbayi et al. 2007; Holzemer et al. 2007; Kalichman et al. 2009) were weakly to moderately associated with higher levels of internalised stigma in bivariate cross-sectional analyses ($r=.17-.42$).

Various aspects of serostatus disclosure were assessed. Respondents who had not disclosed their HIV status to others reported higher odds of internalised stigma in one cross-sectional study ($OR=3.11$ in Sorsdahl et al., 2011) and lower levels of internalised stigma in another ($\beta= -0.085$ in Visser and Sipsma 2013). Having disclosed one's HIV status to fewer people was weakly associated with higher levels of internalised stigma ($r=-0.24$) cross-sectionally (Pearson et al. 2009).. Pearson and colleagues (2009) also found that having disclosed to family, friends, or co-workers

was associated with lower levels of internalised stigma when compared to having disclosed to other people.

DISCUSSION

This review included 7 papers on predictors and 11 papers on correlates of internalised HIV stigma. These papers represented 13 unique samples and a total of 9,088 PLHIV across nine Sub-Saharan African countries. Of the factors that were analysed longitudinally:

- 1. Improved HIV-related health (measured as improved physical functioning and fewer HIV-related symptoms) weakly predicted reductions in internalised HIV stigma in three longitudinal studies.** One of these studies tested a lagged mediation model in which fewer HIV-related symptoms and improved physical health mediated the relationship between time on ART and reduced internalised stigma.
- 2. Lower depression scores and improvements in overall mental health predicted reductions in internalised HIV stigma in two longitudinal studies, with moderate and weak effects respectively.** One of these studies tested a lagged mediation model, which suggested that the decrease of internalised stigma over time on ART was mediated via improved mental health (in addition to improved physical health as summarized above).
- 3. Time on ART produced inconsistent findings.** Internalised HIV stigma decreased over time in two studies, increased over time in another two

studies, initially decreased but then returned to baseline levels in one study and produced non-significant effects in one study.

- 4. The interaction of time and ART use produced inconsistent findings.** One study found that internalised stigma decreased more over time for those on ART, compared to those not on ART. Another study found the opposite trend: internalised stigma decreased more for those not on ART, compared to those on ART.
- 5. ART use did not significantly influence internalised HIV stigma in the only study that examined this predictor prospectively.**
- 6. Social support, the only interpersonal factor to have been assessed longitudinally, did not predict reductions in internalised HIV stigma in one study.**

IMPLICATIONS FOR RESEARCH

Longitudinally, only intra-personal predictors of internalised HIV stigma were identified: studies identified by this review suggest that poor HIV-related health and mental health difficulties predict increases in internalised HIV stigma over time. Though the theoretical underpinning for this was not explicitly stated, the analyses used in these studies pivot on the importance of individuals' physical and psychological attributes in the creation of internalised HIV stigma. The field would benefit from incorporating more recent perspectives that hypothesize that interpersonal relations, such as social discrimination and maltreatment, play a key role in the creation of HIV stigma (Scambler 2009; Parker and Aggleton 2003; Castro and Farmer 2005; Farmer 2003; Link, Cullen, Struening, ShROUT, and Bruce 1989; Abadía-

Barrero and Castro 2006). As discussed in Chapter 2 of this thesis, since the late 1980's stigma researchers have shifted from individualistic perspectives to integrative approaches that recognize the potential roles of both social and psychological forces in the creation and maintenance of stigma. However, findings from this systematic review suggest that these perspectives have not yet been taken up by epidemiological research on internalized HIV stigma in Sub-Saharan Africa.

Another notable gap in the literature is that internalised stigma was not assessed among children, nor among adolescents living with HIV, despite high HIV incidence and prevalence in this age group in sub-Saharan Africa (UNAIDS 2013; Idele et al. 2014). One of the reasons for this may be the lack of a validated scale for measuring internalised HIV stigma in this population (McAteer et al. 2016; Stevelink et al. 2012). HIV-positive adolescents face unique challenges in treatment and care (Li et al. 2010), which is reflected in high AIDS-related mortality and HIV transmission rates (UNICEF 2013; Porth et al. 2014). The lack of quantitative foundational research on internalised HIV stigma in this high-risk group may be a key barrier to developing adolescent-friendly interventions to reduce internalised HIV stigma (Stangl et al. 2013). Qualitative evidence suggests that physical and emotional abuse of AIDS-affected youth exacerbates their experiences of HIV stigma (Campbell and Deacon 2007; Abadía-Barrero and Castro 2006; Clay, Bond, and Nyblade 2003; Campbell et al. 2010; Bond 2006; Mahati et al. 2006; Strode and Grant 2001). Given the high rates of abuse victimization among adolescents in Sub-Saharan Africa (CJCP 2016; Meinck, Cluver, Boyes, and Mhlongo 2015), it is essential to apply an integrative, post-individualistic framework in future research with this population.

As is common in a nascent field, the majority of included studies were cross-sectional and many relied on simple bivariate analyses, resulting in suboptimal causality scores. Two thirds of included studies scored below 50% on the Cambridge Quality Checklists. However, it is important to note that many of the studies received low causality scores because they did not aim to assess predictors of internalised stigma. Rather, they were designed to validate measurements of internalised stigma or to predict outcomes other than internalised stigma. Such studies utilised simple bivariate correlations with internalised stigma scores, which was sufficient for psychometric assessments and informing more complex multivariate models but not for generating robust estimates of predictors of internalised stigma. Future studies would make valuable contributions by considering predictors of internalised stigma across multiple domains, ideally using analysis of change and accounting for alternative explanations of findings.

The sampling and recruitment strategies were also prone to bias. All included studies recruited participants through healthcare facilities, and none of them reported total or random sampling of facilities. Within facilities, four studies used total or random sampling of participants whilst the rest used purposive sampling, convenience sampling or did not report methods used to sample participants within facilities. This is likely to have resulted in biased samples, favouring patients who adhere to treatment, are open about their HIV status and are arguably least likely to experience internalised HIV stigma (Tsai, Bangsberg, Kegeles, et al. 2013; Katz et al. 2013).

In line with this, most of the study samples were gender-imbalanced. With the exception of the study that specifically focused on men who have sex with men, the vast majority of studies recruited a substantially higher proportion of female participants than male participants. Only three studies had fewer than 60% of female respondents, which may have been a result of the sampling and recruitment strategies.

Future research is also needed to help resolve inconsistent directionality of findings. The present review highlights inconsistent findings on the relationship between internalised stigma and socio-demographic variables, as well as on how internalised stigma changes over time on ART. The shortage of prospective cohort studies limits our ability to resolve these discrepancies. Therefore longitudinal analysis controlling for planned confounds is urgently needed.

IMPLICATIONS FOR PRACTICE

This review identified only a limited number of studies on predictors of internalised stigma, and much of the evidence was cross-sectional which precludes the determination of casual risk factors. However, we did find consistent evidence on the relationship between internalised stigma and poor HIV-related health and poor mental health. All of these findings are also supported by evidence from the United States (Lee, Kochman, and Sikkema 2002). With this reasonable level of evidence, we have identified four recommendations for practice that may contribute to achieving the 2015 target to eliminate HIV/AIDS stigma (UNAIDS 2011).

1. Addressing factors, other than ART, that contribute to the physical and mental health of people living with HIV may help reduce internalised stigma.

Our findings suggest that ART access, although necessary, is not sufficient to reduce internalised HIV stigma. Sub-Saharan Africa has achieved remarkable progress in ART coverage in the past decade. However, there is a clear need to translate ART use into optimal physical and psychological outcomes. We found that higher HIV symptom burden and poorer physical health were consistently associated with more internalised stigma, suggesting that manifestations of health problems contribute to HIV-related shame. This seems to be irrespective of ART access because ART use alone was not associated with reductions in internalised stigma when compared to non-use. One of the most rigorous studies included in this review found that the reductions in internalised stigma over time on ART were driven by improvements in HIV symptom burden, physical health, cognitive functioning and depression (Tsai, Bangsberg, Bwana, et al. 2013). In light of these findings, enhancing *other* factors that contribute to the physical health and psychological wellbeing of people living with HIV might also help reduce internalised stigma. These factors include ART adherence (Gross et al. 2006), prevention of co-infections (Lawn 2004) and food security (Anema et al. 2009; Maluccio et al. 2016).

2. There is an important need for psychological support for people living with HIV.

Several included studies point to associations between poor mental health and higher levels of internalised stigma. Specifically, higher levels of depression were related to more internalised stigma in five out of six studies exploring this

association. Similarly, alcohol and drug use, poor mental health-related quality of life and low self-esteem were associated with more internalised stigma. However, the link between other mental health indicators and internalised stigma must be interpreted with caution due to the strong likelihood of directionality. Moreover, given that both internalised stigma and mental health indicators were measured via self-report, there is risk of method overlap bias. Nevertheless, these observations suggest that internalised stigma occurs within a syndemic of a number of psychological challenges, highlighting the need for psychological support for people living with HIV.

3. Internalised HIV stigma is salient and warrants more programmatic attention.

Prevalence of internalised stigma among people living with HIV was high: 26.9% - 66%. By contrast, only two interventions targeting internalised stigma have been evaluated in Sub-Saharan Africa. Interventions should aim to address correlates of internalised stigma identified by this review and in future studies, and be evaluated ideally through randomised control trials.

Limitations

The search did not include any language restrictions, but due to resource constraints, we were only able to include records written in English. However, our search did not detect any relevant non-English papers. The review focused on observational studies, and future randomized trials will be valuable in increasing capacity for causality inference (Smith and Ebrahim 2002). However, the current shortage of randomized trials to reduce internalised stigma in sub-Saharan Africa

(Stangl et al. 2013) rendered a review of observational studies necessary. Furthermore, a meta-analysis was not conducted as heterogeneity between studies and cross-sectional findings limit inferences about causality and strength of effect.

Given that this review focused on *predictors* of internalised stigma, only studies that assessed internalised stigma as a dependent variable were included. This resulted in the omission of a considerable amount of cross-sectional work on correlates of internalised stigma. However, such studies were excluded because they hypothesized internalised stigma to be a cause (rather than effect) of the correlates under scrutiny. Findings from such studies by definition lack the needed theoretical underpinning to generate hypotheses about predictors of internalised stigma.

Conclusions

Research on predictors of internalised HIV stigma in sub-Saharan Africa is in its early stages. Therefore, this review generated a wide range of implications for research, with few implications for practice. The extent of the problem remains large: included studies suggest that up to two thirds of people living with HIV in sub-Saharan Africa are experiencing internalised stigma. More foundational research to inform interventions is urgently needed. In particular future studies can contribute to this field by utilizing analyses of change and accounting for planned, literature-informed confounds. It is necessary to carry out studies on high-risk populations, such as HIV-positive adolescents, and on the social drivers of internalised stigma. Improving the physical health and psychological wellbeing of people living with HIV might

contribute to the reduction of internalised HIV stigma. However, such efforts must be coupled with rigorous process and outcome evaluations.

REFERENCES

To avoid repetition, citations used in this paper are provided in the joint references section at the end of this thesis.

CHAPTER IV. SYSTEMATIC REVIEW IMPLICATIONS FOR THIS DPHIL

The systematic review in Chapter III synthesized evidence of predictors of internalised HIV stigma among people living with HIV in Sub-Saharan Africa. This chapter summarizes the implications of the systematic review findings for the body of work in this thesis.

EMERGING EVIDENCE SINCE THE SYSTEMATIC REVIEW

The systematic review search was updated to January 2015. Since then, two additional studies that would have been eligible for the systematic review emerged. Both of these studies were adult-focused, and their findings were in line with systematic review findings. One study found cross-sectional links between poor physical and mental health and internalised HIV stigma (Maluccio et al. 2016). The other found a cross-sectional correlation between low social support and internalised HIV stigma among pregnant women living with HIV (Brittain et al. 2017). There are still no known studies on internalised HIV stigma among adolescents living with HIV.

DPHIL CONTRIBUTIONS

Findings from the systematic review influenced the methodology used for the empirical part of this DPhil. As discussed in the following chapter, the methods for the empirical part of this thesis take a radically different approach to sampling and recruitment of study participants through: a) total population sampling of health facilities that provide treatment to 5 or more adolescents living with HIV, b) within

facilities, total population sampling of adolescents who have ever initiated anti-retroviral treatment, and c) community tracing of sampled adolescents living with HIV. This approach allows for inclusion of adolescents who are defaulting or lost to follow up and permits a natural gender-balance.

This is also the first epidemiological study in the region to explore internalised HIV stigma through a post-individualistic lens. In addition to physical and psychological risks for internalised HIV stigma identified in the systematic review, Paper 3 of this thesis investigates interpersonal pathways as well. Similar to the majority of studies included in the systematic review, this paper is unable to establish order of effects due to the cross-sectional nature of data used. However, unlike most studies identified in the systematic review, the analyses control for relevant confounds and account for the inter-relationships between different explanatory variables through structural equation modelling. Paper 3 also adheres to the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines. This paper is currently being revised for resubmission to the Journal of the International AIDS Society.

In order to enable research on internalised HIV stigma among South African adolescents living with HIV, a culturally relevant and age-appropriate tool was needed. Therefore, *Paper 2* of this thesis reports on 1) a qualitative cross-cultural adaptation of an HIV stigma scale that was previously used with HIV-positive adolescents in the US, and 2) a psychometric assessment and validation of the scale within a large sample of South African HIV-positive adolescents. This mixed-methods paper is published in *Child Indicators Research*.

CHAPTER V. METHODOLOGY

The empirical section of this thesis aims to 1) develop an age-appropriate and context-relevant stigma scale for use with South African adolescents living with HIV (ALHIV) and 2) explore a theoretical model of internalized HIV stigma in this population. Table 5 summarises the methods used for the empirical papers. Furthermore, this chapter contextualizes the empirical papers by providing a detailed description of the study methodology, including information on sampling procedures, recruitment, ethical compliance and practical research obstacles encountered during data collection. The data analysis strategies are briefly summarized in Table 5, with a full description provided within the empirical papers of this thesis (Paper 2, Chapter VI and Paper 3, Chapter VII).

Table 5 Methods employed for each DPhil paper

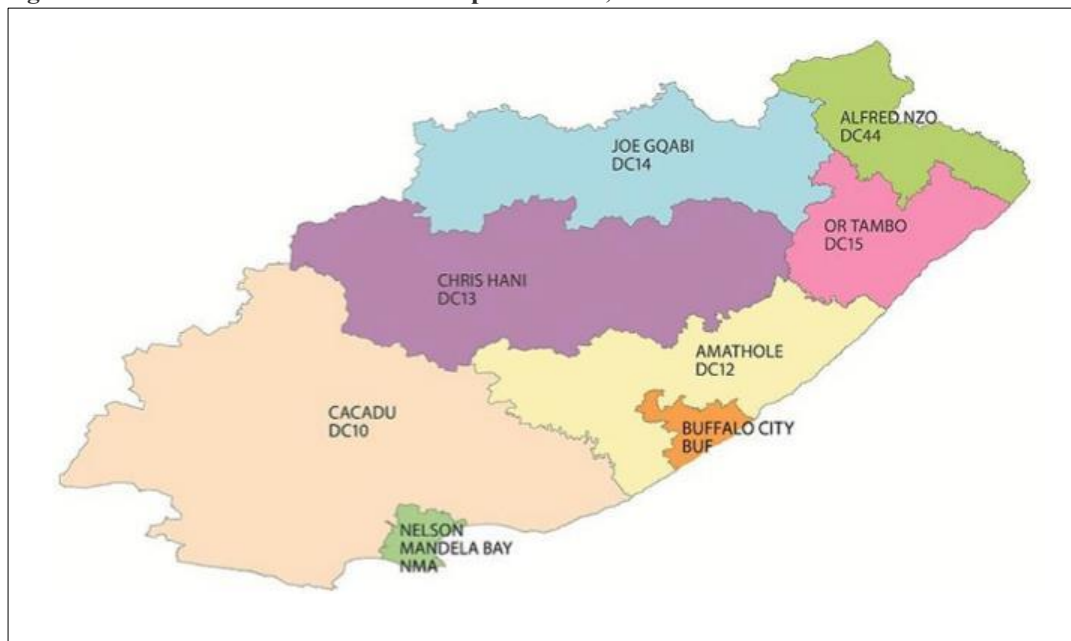
	Objective	Method	Analysis strategy
PAPER 2, PART 1	To cross-culturally adapt an HIV stigma measurement (previously used in the US) for use with South African ALHIV	One-on-one semi-structured cognitive interviews with 9 ALHIV	Thematic analysis
PAPER 2, PART 2	To psychometrically assess the adapted HIV stigma measurement	Baseline data from the Mzantsi Wakho study of 1060 ALHIV in South Africa	Confirmatory factor analysis in MPlus. Reliability was evaluated through item-to-domain correlations and internal consistency (Cronbach's alpha). Validity was assessed via associations between HIV stigma scores and depressive symptoms, social support and HIV symptoms. Only data from ALHIV who were fully aware of their status (n=721) was used.
PAPER 3	To test a theoretical model of risk pathways to internalised HIV stigma among ALHIV		Structural equation modelling in MPlus. Model fit was assessed with: Comparative Fit Index, Tucker Lewis Index, and Root Mean Square Error of Approximation.

CONTEXTUALIZING THE EMPIRICAL PAPERS (PAPERS 2 AND 3)

STUDY SETTING

The primary data used for Papers 2 and 3 was collected in the mixed urban, peri-urban, and rural Health District of Buffalo City Municipality in the Eastern Cape province, South Africa (Figure 10). South Africa was home to the world's largest population of people living with HIV (UNAIDS 2016). The Eastern Cape is South Africa's second largest province, as well as one of its poorest provinces, ranking lowest in key indicators such as access to piped water (Statistics South Africa 2016). At the time of the study set up, the Buffalo City Municipality had the highest recorded HIV prevalence in the Eastern Cape of 34.1%, which was also higher than the national prevalence of 29.5% (National Department of Health 2011). The research teams and offices were based in two towns: East London and King Williams Town.

Figure 10 Districts within the Eastern Cape Province, South Africa



SAMPLING FRAME

The sampling frame was restricted to adolescents living with HIV (aged 10-19). Eligible participants were identified through government health facilities that distributed ART and were traced in their communities (details on recruitment and tracing provided in the procedures section below). Unlike all other known studies on internalised HIV stigma in Sub-Saharan Africa, which were restricted to participants who were actively taking treatment at the time of data collection (Pantelic et al. 2015), the sampling frame used for this study incorporated participants who had been lost-to-follow up in addition to those actively engaged in care. This sampling approach aimed to eliminate bias towards patients actively engaged in the HIV health system. This was essential because meta-analytic evidence suggests that internalised HIV stigma compromises ART adherence (Katz et al. 2013). Therefore, patients who are most vulnerable to internalised HIV stigma are also more likely to be lost-to-follow up and would not be captured by studies that only include active clinic attendees.

HIV-positive adolescents who never tested or never initiated antiretroviral treatment were not included in the study for methodological, ethical, and practical reasons. Including them would have required door-to-door sampling and HIV testing, and a considerably higher sample size, which would have entailed added costs. Secondly, this approach would have captured HIV-positive adolescents who would have tested positive for the first time as part of this study. As such, these adolescents would not have experienced internalised HIV-related stigma prior to data collection and would not have been an appropriate sample for investigating correlates. Most importantly,

community-based HIV testing would have placed participants at risk of stigma due to high risk of inadvertent disclosure of HIV status to their family and community members (Steinberg 2008). Therefore, HIV-positive adolescents were identified as adolescents who have ever initiated antiretroviral treatment (ART).

Sample size

The target sample size was determined based on power calculations, taking into account theoretical, contextual and statistical considerations. Following CONSORT and TREND guidelines, the study was large enough to have a high probability of detecting both statistically significant and clinically important differences in internalised HIV stigma (the outcome) if such differences existed (David Moher et al. 2010; Jarlais et al. 2004).

The sample size for the study was calculated using an open-source online tool – www.OpenEpi.com – that computes sample size for a cross-sectional study of prevalence of an outcome. Based on the existing research literature, the following information was entered into the calculator:

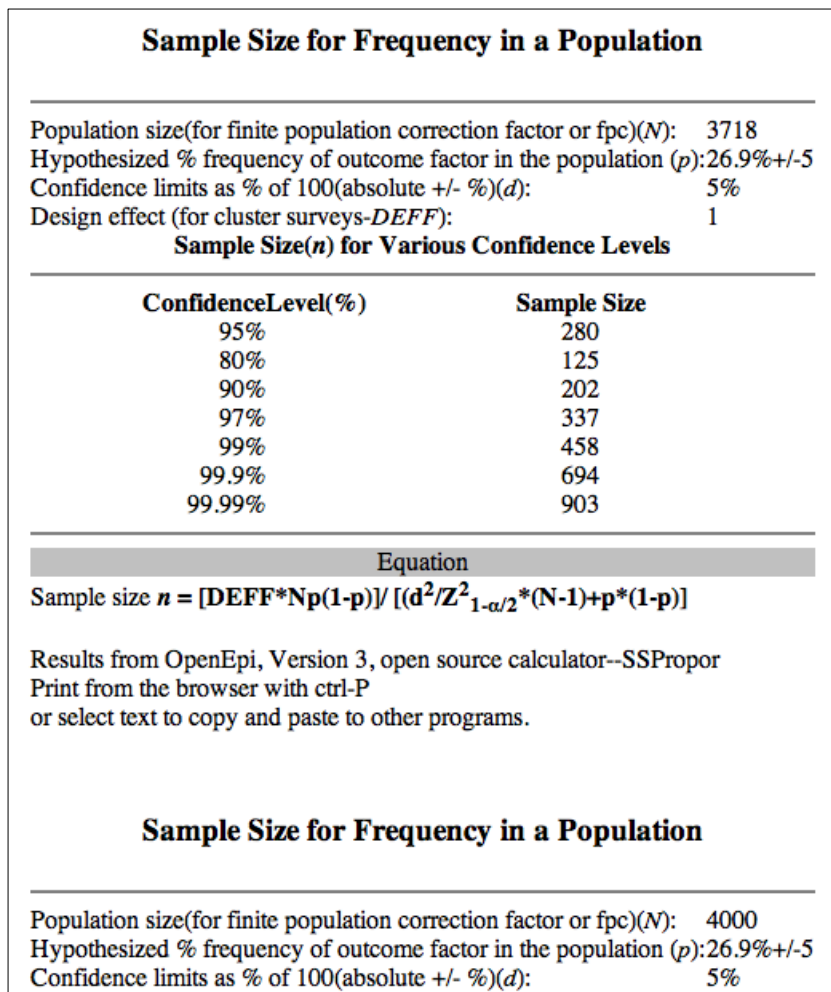
1. **Estimated total population size of HIV-positive adolescents in the study catchment area.** This was calculated based on a) national estimates of the number of adolescents living with HIV in South Africa in 2012, when the study was designed (n=260,000) (Kasedde and Olson 2012) and b) the proportion of the South African population living in the study catchment area (Buffalo City Municipality, 1.53% (Statistics South Africa 2016). Hence, an estimate of

3,718 HIV-positive adolescents living in Buffalo City Municipality was calculated (.0153 x 260,000).

2. **Hypothesized prevalence of internalised HIV stigma.** A conservative estimate of 26.9% was used based on the lowest prevalence reported within primary studies in a systematic review (Pantelic et al. 2015).

A confidence level of 99.99% would require a sample size of 903 HIV-positive adolescents (Figure 11). Based on this and assuming a 10% refusal rate for participation in the study, my target sample size was 1000 adolescents living with HIV.

Figure 11 Sample size calculation output from www.OpenEpi.com



PROCEDURES

Sampling and recruitment

So as to recruit a representative sample of HIV-positive adolescents, this study utilised a stratified total population sampling of health facilities providing ART and, within selected facilities, total population sampling of adolescents who had ever initiated ART. The systematic review on predictors of internalised stigma conducted as part of this DPhil uncovered that all primary studies recruited from healthcare facilities but few reported the method used for selection of these facilities (Pantelic et al. 2015). Of the studies that recruited within healthcare facilities, only 4 reported total or random sampling of participants (Pantelic et al. 2015). The sampling strategy used for this DPhil aimed to address the methodological shortfalls in available evidence, through a 3-phase approach:

1. Sampling of all ART sites with more than 5 registered adolescents living with HIV;
2. Total population sampling of eligible adolescents within ART sites, including those who are on treatment and in care, as well as those who have defaulted or have been lost to follow-up; and
3. Recruitment via clinics or community-tracing to ensure inclusion of lost-to-follow-up patients.

The following sections explain these steps in detail.

1. Sampling of ART sites

First, all existing clinics in the study area were identified via online databases of clinics and the Tier.net system established by the South African National Department of Health. This generated a list of 84 clinics that potentially catered to adolescents living with HIV in the study catchment area, including antenatal care clinics, ART clinics, general clinics, and adult and paediatric clinics. Next, the research team consulted with healthcare providers in these 84 clinics on the approximate numbers of adolescents (aged 10-19) who had ever initiated ART in each clinic. As part of this process, this candidate conducted interviews with healthcare providers in >20% of the clinics in the study catchment area. The remaining scoping visits were conducted by other researchers on the team, led by the study co-investigator Dr. Elona Toska and Ms. Lulama Sidloyi, an experienced researcher in the area.

Only health facilities with more than 5 adolescents who had initiated treatment were included. The initial sample was n=32 facilities: 4 hospitals, 5 community health centres, and 23 primary clinics. Throughout the duration of the study, participants were down-referred from tertiary and secondary health facilities to primary facilities, as part of South Africa's primary health re-engineering programme. As a result, adolescent participants were recruited from a total of 53 health facilities.

2. Sampling of study participants

Within selected clinics, all adolescents who had ever initiated ART were identified through patient files and electronic databases. Clinic cards and patient rosters (provided with the permission of clinic staff, the district, and the provincial Department of Health) were used to identify eligible adolescents living with HIV, including their treatment status (active, transferred or lost-to-follow-up) and addresses (Figure 12). This included vertically and horizontally infected adolescents, as

Figure 12 Assistant Project Manager, Philiswa Sylvia Mjo, identifying eligible adolescents from clinic files in a state hospital



well as both adolescents on treatment at time of sampling and those who were lost to follow-up or had defaulted.

A study roster containing names, birth dates and addresses of all study eligible patients (n=1,176) was developed. This roster was used to plan data collection and avoid duplication of participants who were registered in more than one health facility. Patients were eligible if they met all of the following criteria:

- a) Born between 1 January 1995 and 31 December 2004 to fall within the 10-19 age bracket at the time of data collection.
- b) Tested HIV-positive and was initiated on ART in one of the participating facilities; or initiated elsewhere and continued on ART here.
- c) If the patient was under 18, both the patient and the legal guardian gave written, informed and voluntary consent. If the patient was 18 or above, only adolescent consent was required.

Of the study-eligible sample, 90.1% (n=1,060 HIV-positive adolescents) were interviewed. The remaining 9.9% were excluded for the following reasons:

- The caregiver or adolescent refused to participate (4.1%);
- The adolescent could not be traced (3.7%)
- The adolescent had severe cognitive delays (0.9%); or
- The research team could not interview the adolescent because it was unsafe, the adolescent had moved out of the study area, or had received an emergency referral (1.2%).

No statistically significant differences between the interviewed and excluded HIV-positive adolescents were found based on known socio-demographic data (Table 6).

Table 6 Comparison of included and excluded HIV-positive adolescents

	HIV+ (n=1060)	Excluded (n=116)	Comparison tests
Age (mean, SD)	13.8, 2.834	14.8, 2.91	$z=1.96, p=.671$
Female (n, %)	587, 55.2%	66, 56.9%	$\chi^2(df)=.098(1), p=.769$
Rural (n, %)	228, 21.4%	26, 22.4%	$\chi^2(df)=.050(1), p=.813$

3. Recruitment

Once identified and entered into the study roster, eligible participants were located using the following cascade of recruitment strategies:

i. The first point of contact was the healthcare facility through which the participant was originally identified as eligible. This candidate and clinic liaison officers worked closely with health facilities to ensure interviewers were in the facilities on dates when adolescents had scheduled appointments.

ii. Participants who missed clinic appointments were community-traced using the addresses recorded from their patient files. A community-tracing strategy was devised in careful consultations with experienced healthcare providers, and with the primary aim of preventing any immediate or long-term harm for the participants. Using the study roster, participants who were not met or interviewed in the health facilities were grouped into community clusters based on their addresses. In order to avoid stigma associated with participation in the study and inadvertent disclosure of the adolescents' HIV status to their family and community members, community based recruitment did not mention HIV or AIDS. Rather, the study was presented as investigating overall health, wellbeing and service access among adolescents.

Although the research team knew the names of the HIV-positive adolescents that they were looking for, they never asked for them by their names so as avoid suspicion and stigma. Rather, research assistants would ask for any adolescent aged 10-19 in the given home and prioritized interviewing the child that they knew was HIV-positive. To avoid stigma by study participation, a number of status unknown

adolescents from the community were also interviewed. This convenience sample of 467 'stigma control' participants served primarily to normalize study participation within communities, and the collected data were excluded from the analysis.

Determining participants' awareness of their status

Community-tracing of HIV-positive adolescents brings up ethical and methodological complexities, particularly considering that this population includes: 1) adolescents who do not know their HIV-status whilst their family members and healthcare providers do; 2) adolescents who know their status but have not disclosed their status at home and 3) adolescents who have been told they are HIV-positive but have not yet come to terms with their status.

All potential participants were screened to determine their awareness of their HIV status. Research assistants used a semi-structured qualitative screening tool, which focused on general health history. In order to prevent disclosure of HIV status to adolescents who were unaware of their status, research assistants were trained to never mention HIV, AIDS or ART unless the adolescents brought these up themselves. The screening tool consisted of three stages. First, the research assistant initiated a friendly, face-to-face rapport-building conversation. Second, this was followed by a discussion about which school and clinic the adolescent attended. Lastly, questions about whether the adolescent had ever been sick for two-weeks or longer or on long-term medication for two weeks or longer were asked. Based on feedback from qualitative research, which suggested that adolescents' understanding of their HIV status is nuanced rather than categorical (Vale and

Thabeng 2015) special care was taken to not assume an adolescent's HIV status based on limited information. For example, many adolescents who were aware that they were taking ART were not aware that the medication was for their HIV infection. Therefore, three conditional questions were used to determine adolescents' knowledge of their HIV status: (1) Does the adolescent report being HIV-positive? AND (2) Does the adolescent report taking ARVs? AND (3) Does the adolescent report taking ARVs specifically for HIV? Affirmative answers to all three of these questions were needed for the research assistant to conclude that the adolescent knew that they were HIV-positive.

64% of the sample disclosed their HIV-status to the research assistant during the screening process (n=678), and an additional 11% (n=115) disclosed during or after the interviews. Overall, 75% of the sample was deemed aware of their HIV status and 25% was unaware of their status (n =794 and n=266, respectively), using the above criteria.

Two versions of the questionnaire were available: an HIV-specific version for status-aware adolescents (n=794) and a non-HIV specific for status-unaware adolescents (n=266). The non-HIV specific questionnaire was additionally used for 'stigma control' participants but the resulting data were excluded from the analysis. The non HIV-specific version of the questionnaire replaced HIV-specific terminology like HIV, AIDS and ART with general terms like 'health', 'illness' and 'medication'. Interviewers received extensive training and refresher training sessions on this screening procedure to avoid inadvertent disclosure of HIV status to adolescents who were not aware of their status.

Questionnaire development: groundwork, piloting and cross-cultural adaptation

The questionnaire and measures used for this thesis were informed by a year of formative research. This included a rigorous review of the literature on HIV stigma (including a systematic review of existing studies from the region – Paper 1), consultations with key researchers and practitioners, qualitative research to cross-culturally adapt key measures, expert review, piloting and psychometric assessment of the measures (Paper 2).

The systematic review conducted as this DPhil's first objective (Paper 1, see page 46) found no studies on internalised HIV stigma with the population of interest, HIV-positive adolescents in Southern Africa. Findings from other relevant systematic reviews (Stevenson et al. 2012; Earnshaw and Chaudoir 2009; Stangl et al. 2013) suggested that the only HIV stigma scale for HIV-positive adolescents was one that had been used in the United States (Wright et al. 2007). Paper 2 of this DPhil reports on the cross-cultural adaptation of the US-developed HIV stigma scale to the South African context, as well as the psychometric assessment of the adapted scale (see page 116). Researchers identified through the systematic review were also consulted to ensure inclusion of key dimensions and predictors of HIV stigma in the questionnaire (Table 7).

The DPhil candidate also worked closely with Dr. Elona Toska and Dr. Beth Vale to pilot the full study questionnaire with another n=25 HIV-positive adolescents in a rural (Hamburg) and urban site (Grahamstown). Both of these sites were outside of the study catchment area to avoid overlap between the pilot and study sample. The

pilot interviews also collected process data to examine which order of questions made participants feel more comfortable to answer sensitive questions, which sections took long or were difficult to comprehend and what sorts of breaks and games could be introduced. At the end of piloting, information on comprehension of questions and respondent burden were used to adapt and finalise the questionnaire together with Prof. Lucie Cluver and Dr. Mark Boyes.

Table 7 Experts consulted during the development of the questionnaire

Name	Title, organization	Dates; mode of communication
Dr. Michael Evangeli	Senior Lecturer, Department of Psychology, Royal Holloway University of London	October-December 2013; email and one-on-one consultation meeting in London
Dr. Katherine Sorsdahl	Department of Psychiatry and Mental Health, University of Cape Town	October-November 2013; email
Dr. Nuala McGrath	Reader in Infectious Disease Epidemiology, Faculty of Medicine, University of Southampton	November-December 2013; email
Dr. Mosa Moshabela	Head and Chief Specialist, Department of Rural Health, University of KwaZulu-Natal	November 2013 – January 2014; email
Dr. Alexander Tsai	Assistant Professor of Psychiatry, Massachusetts General Hospital and Harvard Medical School	December 2013- January 2014; email
Dr. Anne L. Stangl	Senior Behavioral Scientist, International Center for Research on Women Director, Stigma Action Network Secretariat	December 2013; email
Prof. Maretha Visser	Department of Psychology, University of Pretoria	December 2013; email
Prof. Seth Kalichman	Department of Psychology, University of Connecticut	December 2013; email
Prof. Leickness Simbayi	Deputy Chief Executive Officer for Research, Human Sciences Research Council	December 2013; email

Scales and measures used



The questionnaire included measure of basic socio-demographics, HIV-related stigma, HIV-related disability, physical, emotional and sexual abuse, bullying victimization, social support and depressive symptoms. All measures that were used for this DPhil – the outcome measure and hypothesized correlates – are described in full detail in the empirical papers of this thesis (Chapters 6 and 7), and the full questionnaire is provided in Appendix 13. The methods sections of the empirical papers provide comprehensive information on the sources of scales and measures, existing validation studies, and reliability scores for the study sample reported in this thesis.

Data collection

The survey was administered through low-cost mobile devices (tablets). Mobile assisted self-interviewing (MASI) has been shown to produce more truthful answers and a stronger sense of confidentiality among adolescent research participants than conventional face-to-face interviewing (Gorbach et al. 2013; Jaspan et al. 2007). The use of MASI helped increase the privacy and confidentiality of the answers to sensitive questions in particular. Participants could choose whether they wanted to complete the interview alone, with the help of a research assistant, or a mix of the two depending on the questions. Youth-friendly graphics were used to maximize participant engagement (Figure 13) and reduce participant burden through skip-patterns for irrelevant questions based on previous answers. Stigma items featured

vignettes with characters in the gender that the adolescent specified at the beginning of the questionnaire (more on this in chapter 6).

Figure 13 Screenshots of the tablet questionnaire for boys (left) and girls (right)

<p>FOR BOYS ONLY: Remember Lundi? He is getting older now and is a cool teenager. But living with HIV is still difficult for him sometimes. Some days Lundi feels ashamed and he struggles to feel good about himself.</p> <p>Could you say how much these things have been true for you in the past year?</p>  <hr/> <p>Sometimes Lundi feels that he is not as good as other kids because he has HIV. Have you felt this way in the past year?</p> <p><input type="radio"/> Never</p> <p><input type="radio"/> Sometimes</p> <p><input type="radio"/> Most of the time</p>	<p>FOR GIRLS ONLY: Remember Nosizi? She is getting older now and is a cool teenager. But living with HIV is still difficult for her sometimes. Some days Nosizi feels ashamed and she struggles to feel good about herself.</p> <p>Could you say how much these things have been true for you in the past year?</p>  <hr/> <p>Sometimes Nosizi feels that she is not as good as other kids because she has HIV. Have you felt this way in the past year?</p> <p><input type="radio"/> Never</p> <p><input type="radio"/> Sometimes</p> <p><input type="radio"/> Most of the time</p>
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Participants also chose the location for the interviews. Interviews were conducted wherever participants felt most comfortable taking into consideration both safety and data confidentiality. Interview locations included participants' homes, post offices, ward counsellor offices, community centres, libraries, city centre, schoolyards and the research vehicles. Research assistants pinned participant homes and interview locations using Google Maps and shared them with the team via Whatsapp to facilitate emergency referrals and follow-up interviews when necessary. All of the team's phone devices were password-protected.

Interviews lasted around 90 minutes including games and breaks. No financial remuneration was provided in line with ethics protocols for minimising pressures to participate in the study. Participants received snacks, small toiletry packs, and a certificate of appreciation.

Each completed questionnaire was assigned a serial number, which was recorded in the study roster. Participant responses were linked to the serial number of their questionnaire and not their name resulting in an anonymised dataset. At the end of each day of data collection, the data stored in the tablet were checked and, if no inconsistencies were found, they were transmitted to a server based in Oxford. This minimized missing data and data entry errors. All data were accessible only on provision of a password known only to the study management team. This ensured data protection from confidentiality breaches. Data backups were conducted on a weekly basis.

ETHICS

Ethical approval was provided by Research Ethics Committees at the Universities of Oxford (SSD/CUREC2/12–21) and Cape Town (CSSR 2013/4), South African National Departments of Health, Basic Education and Social Development, Eastern Cape Departments of Health, Basic Education and Social Development and ethical review boards of participating hospitals.

Starting in August 2012, I supported Dr. Elona Toska, Dr. Beth Vale and Prof. Lucie Cluver who led the process of developing a study protocol that detailed the ethical considerations of this complex study. During fieldwork, I continued working with the

study team to update the protocol as ethical and methodological challenges and solutions were encountered. I also wrote update letters to keep the ethics review boards informed of these adaptations on a regular basis. The following section summarizes the main principles behind the study's ethics framework. The full, most up-to-date study protocol and a sample ethics update letter are provided in Appendices 2-3.

ETHICAL AND REGULATORY COMPLIANCE

Research with vulnerable groups of children and adolescents is mired with ethical complexities, and this is reflected in a considerable body of South African and international literature. The main sources that have helped create ethical guidelines for this study are the literature on informed consent and confidentiality (Morrow 2008), ethical protocols from psychological research institutions, such as the British Psychological Society (The British Psychological Society 2009), and the University of Oxford and University of Cape Town ethical regulations.

Furthermore, several key pieces of South African legislation and research guidelines significantly contributed to this study's ethics protocol:

- Ethics in Health Research Guidelines (Department of Health 2004);
- Guidelines for Good Clinical Practice in South Africa (Department of Health 2006);
- 'Best Practice Guide to HIV Disclosure' of the Open Society Foundation for South Africa (Open Society Foundation for South Africa 2009);

- ‘Selected ethical-legal norms in child and adolescent HIV prevention research: Consent, confidentiality and mandatory reporting’ (Strode and Slack 2012);
- The National Health Act 61 of 2003 (enforced from 2012);
- The Children’s Act (38 of 2005);
- The Children’s Amendment Act (41 of 2007);
- The Sexual Offences Act (32 of 2007).

In addition to guidelines that are specific to South Africa, the study also followed international guidelines, such as the World Health Organisation’s Guidelines on HIV Disclosure and Counselling for Children up to 12 Years of Age (World Health Organisation 2011); and the Helsinki Declaration (World Medical Association 2001).

Finally, the study team collaborated with colleagues at the Health Sciences Research Ethics Committee of the University of Cape Town, the University of the Witwatersrand, and South African Child Welfare, all in the interest of refining the ethical guidelines for this study. The resultant ethical protocol was evaluated and accepted by the Inter-Departmental Research Ethics Committee of the Social Sciences and Humanities Division, University of Oxford (Ref No: SSD/CUREC2/12-21); Centre for Social Science Research, University of Cape Town (CSSR2013/04); Eastern Cape Department of Health ethics approval (29 August 2013); Buffalo City Municipality Health sub-district approval (23 Jan 2014, 2 Oct 2015); Eastern Cape Department of Basic Education approval (4 April 2014); and Frere Hospital. These ethical approvals can be found in Appendices 4-9.

INFORMED CONSENT PROCEDURES

Adolescent consent

Researchers handed out informational material and consent forms (Appendix 10) to prospective participants and their legal guardians. Information was provided in both English and Xhosa, which is the most frequent home language in in the population studies. Members of the fieldwork team also read the information to potential participants and answered any additional questions in whichever language they preferred. This ensured that all participants could make an informed decision about taking part in the study – or not – regardless of their level of literacy. We obtained written consent from adolescents and their guardians when possible. In rare cases when participants were illiterate, they verbally consented to take part in the study and marked the consent form with an ‘X’ in the signature field.

In line with ethical guidelines on research among children, participants were told and reminded throughout the interviews that they had the right to refuse to take part in the study and could withdraw consent whenever they chose, and that this would not affect any government support or services that they receive. Adolescents who avoided participation were deemed as non-consenting and were not interviewed, even in cases when their caregiver encouraged participation in the study. All team members had undergone rigorous training on working with children and young people affected by HIV/AIDS and were recruited for their sensitivity and warmth in addition to understanding of the ethics protocol.

Parent-to-child infection of HIV, also known as vertical infection, has the potential to cause delays in the cognitive development of a child, resulting in lower reading or cognitive levels (Sherr, Croome, et al. 2014). The consequences of these delays are currently under-researched, and thus, there are no clearly established criteria on how to account for potential difficulties when working with vertically infected children (Laughton et al. 2013). Some children and adolescents who have been vertically infected with HIV may appear to be younger than they actually are and could exhibit certain developmental delays. Yet, they may think of themselves as teenagers nonetheless (Dago-Akribi and Adjoua 2004; Lowick, Sawry, and Meyers 2012). As such, it would have been unethical to deny participation to adolescents based on a limited understanding of their developmental delay. The interviewers in this study were trained to recognise when a potential participant seemed to misunderstand the consent-giving process and to seek guidance from research advisors when this happened. Overall, 11 potential participants (0.7%) were left out of the study as a result of severe cognitive delays. Adolescents who had some developmental and cognitive challenges, but for whom these did not present barriers to understanding of the consent process, were included in the study. Researchers and fieldwork team members made every effort to ensure the study was a positive and interactive process for participants, and that all consent was obtained in an informed and voluntary manner.

Caregiver consent for adolescent participation (applicable to adolescents under 18)

Following section 71 of the National Health Act of South Africa consent of a legal caregiver when study participants are younger than 18 years of age was generally

required. In such cases, caregivers of potential participants were provided with written or verbal information on the research in their preferred language. According to the most recent version of the *'HIV status disclosure guidelines for children and adolescents in South Africa'*, a caregiver is an individual who holds primary responsibility for the wellbeing and care of a child. The South Africa Child Health Act identifies the following individuals as caregivers in the absence of biological parent: grandmothers, aunts and other relatives; a foster parent; a child who is 16 years old or above, and who heads the household (child-headed household); the chief of a Child and Youth Care Centre or shelter at which the child resides; a Child and Youth Care employee who supports a child without family in the community.

However, South African researchers (Strode et al. 2005; Zuch et al. 2012) assert that requiring caregiver consent may bring into question adolescents' constitutional right to confidentiality and dignity. This stance is particularly relevant for studies focusing on highly stigmatized topics, such as HIV (Zuch et al. 2012), where raising suspicions about adolescents' HIV status could result in abuse and ostracism (Norman, Chopra, and Kadiyala 2005). Furthermore, caregiver consent requirements may create recruitment biases that favour respondents who are open with their families about their HIV status and therefore less likely to experience internalised HIV stigma (Smith, Rossetto, and Peterson 2008; Tsai, Bangsberg, Kegeles, et al. 2013). Therefore, in some cases, obtaining caregiver consent raised concerns about confidentiality, potential harm to participants, sample representativeness and validity of findings. These cases were addressed on a case-by-case basis and discussed in detail with the study PI and supervisor for this thesis, Prof. Lucie Cluver.

The study abided by the South African Department of Health Ethics in Health Research (Department of Health 2004) and the 2005 Child Care Act criteria for studies involving adolescents. Researchers asked participants to nominate another adult aside from their legal caregiver to consent on their behalf in cases when: a) the legal guardian would not provide consent due to the fact that abuse of the adolescent would be revealed, and b) the participant did not wish to communicate his or her HIV status to the legal caregiver. This procedure for obtaining consent was only utilised in rare occasions for participants in the aforementioned specific situations, and the researchers did not exploit this concession as a way to circumvent the legal guardian when getting consent proved difficult.

Additionally, when an adolescent wanted to take part in the study, but the caregiver was not available due to distance, being out of reach, sickness or death, researchers asked adolescents to suggest an alternate trusted adult. Examples of this included circumstances where adolescents lived in child-headed households or with caregivers who had extreme AIDS-related dementia. In such cases, adolescents could nominate more distant relatives or social workers in place of caregiver consent.

PRIVACY, CONFIDENTIALITY AND POTENTIAL RISKS TO PARTICIPANTS

Great care was taken during the study to guarantee that participants' confidentiality was upheld, with special efforts to avoid stigma associated with participation in the study. Interviews were held privately in a setting picked by each adolescent. Moreover, since the study was introduced as focusing on young people's access to health and social services in general, it was possible to maintain privacy for those

individuals who knew their HIV status, and circumvent exposing the HIV status to those who did not know it. This section describes how the study design and procedures prioritized maximizing benefits and ensuring privacy and confidentiality, while avoiding harm for participants.

There was a notable power inequality between the research assistants and the children taking part in the project, particularly as some of the participants were as young as 10 and the research assistants were over 20 years of age. These age differences were taken into account during the project design phase, as well as during the training of research assistants. In order for researchers to acquire high-quality data, and for the participants to feel comfortable withdrawing consent, rapport building was essential for all stages of the research. Most of the research assistants were women, and the three male researchers only interviewed male participants to avoid additional power imbalance during the interview process.

Several strategies were used to reduce social desirability bias. Participants had the option to use tablets independently when providing answers to sensitive questions on abuse, sexual activity, or adherence to ART. Frequently, participants reported abuse only after the interview concluded. For instance, 5 of the 36 recent, severe abuse cases were reported only after the interview, demonstrating how much time is necessary to build rapport between the participant and the research assistant. Such cases were separately coded. In addition, a dummy variable was added to the dataset in order to guarantee that referrals and any risk were reported in an appropriate manner.

Among the participants who had disclosed their HIV status to the researchers (approximately 75% of the sample), the researchers had the obligation to protect their participants' right to privacy and dignity as guaranteed by the constitution. This duty is especially important in an environment where HIV is still very much stigmatized (Human Sciences Research Council 2014). Thus, researchers did not communicate the status of adolescents to healthcare workers, family members or others, without direct consent, in accordance with the 2003 National Health Act and the Open Society Foundation guidelines (Open Society Foundation for South Africa 2009). Prior to joining the study team, all researchers signed agreements committing to data confidentiality (Appendix 11).

In some instances, HIV-positive adolescents informed researchers of having unprotected sexual intercourse with their partners. If the participant was defaulting from ART while having unprotected sex, participants' right to privacy was in conflict with the public health concern to protect at-risk partners (Reynolds et al. 2012). In such cases, researchers followed the following guidelines.

1. Participants were informed of the risks associated with unprotected sex while virally unsuppressed, both in terms of their own health and the health of their partners;
2. Participants were advised to attend counselling in an effort to find safe ways to disclose their HIV status to their partners; and
3. Participants were invited to a joint meeting with an HIV/AIDS advisor who could help them disclose their status or practice safer sex.

A group of participants in the study had stopped or had not yet begun taking ART or TB medication. In these cases, researchers emphasized the importance of adhering

to medication in order to maintain quality of life and encouraged the participants to seek help from healthcare institutions. Consent forms informed participants that confidentiality rights were restricted when there was a risk of significant harm. For example, when adolescents exhibited signs of TB, pneumonia or other life-threatening infections, they were referred to healthcare workers. None of the participants or caregivers objected to this.

Interviews were often the first opportunity to talk about their lives in-depth, and many disclosed abuse and rape victimisation. The research assistants were prepared for this and followed ethical and legal obligations to seek out help for children who had been identified at risk of harm or requested help (Cluver et al. 2015). Previous studies in South Africa have followed similar procedures. For instance, studies conducted by the Medical Research Council Unit for Anxiety and Stress Disorders frequently sent participants for child psychiatric treatment or to the University of the Western Cape Child Psychology clinic when there was need for such services (Seedat et al. 2000). Research conducted by the University of Cape Town and the Africa Centre on legal guardians and babies who are HIV-positive referred participants to social services (Stein et al. 2005). Relevant ethical and practical guidelines put forth by the South African Children's Institute / ACCESS Child Participatory Poverty Research (Alliance for Children's Entitlement to Social Security, Soul City, and The Children's Institute 2002) and an HSRC / UNICEF study on the psychological adjustment of children in South Africa (Dawes et al. 2004) were followed, guaranteeing privacy rights unless the children were at direct risk of harm.

The study established a procedure by which researchers could respond and refer such cases to the relevant social services at the local level. Interviews with participants and their family members led to 68 (6.4%) referred cases among HIV-positive adolescents. When any potential risk was disclosed or noted and the child consented, researchers offered advice on potential support resources and/or notified the legal guardians. Such cases were brought to the attention of a South African child protection social worker, who was also the study PI and the supervisor of this DPhil (Professor Cluver). Upon an in-depth discussion, the researchers chose the most appropriate response. Professor Cluver closely supervised all referral instances due to the scarcity of social services and child protection professionals available at the site of the study. The field team, led by this candidate, then took the appropriate supportive action.

Three earlier studies on AIDS-affected adolescents in South Africa, during which our researchers worked as investigators, and studies on other vulnerable categories (Bostock 2002) informed the following guidelines for the this study. During the consent process, all participants were advised that confidentiality would be maintained unless it became apparent that their wellbeing was at considerable risk. If an interview revealed that a participant, his or her sexual partner, or a family member were at risk of great harm, then the researcher raised this concern with the interviewee following the interview, before taking any additional action. Researchers discussed referral options with participants if it was deemed that they or their close relations were at direct risk of harm. However, if the participant refused to disclose information and potential harm was determined not to be significant, researchers

provided the participants with information on ChildLine SA, Life Line, FAMSA, and other self-referral organisations. On the other hand, if researchers and coordinators deemed the harm to be significant, they discussed the issue with social service institutions. The participants were notified if action was to be taken.

The research design also took into account the likelihood that adolescents or caregivers may become upset. The study planned for these situations by involving a social worker, a psychologist and HIV counsellors, who oversaw researchers and assisted them in talking through concerns with participants and their families. As mentioned, researchers made referrals when there was a necessity for any participant to receive more support, such as visiting a clinic or speaking with a counsellor. As the quality of the adolescents' regular healthcare services was not always consistent, the research team relied on a network of healthcare providers that offered better quality disclosure support for referrals. The fieldwork team, assistants, social worker, psychologist, and the participants and relatives assessed and resolved difficult cases together.

Finally, all individuals who expressed interest in or had participated in the study were given a landline and a cell phone number that they could call. If they did not have airtime, they could also send a free 'please call me' text message, and someone from the research team called them back. When participants did share contact information with the members of the research team, such personal details were kept private in password-protected databases.

REIMBURSEMENT FOR PARTICIPATION

Financial incentives were not offered to participants in this study. The primary reasons for this were 1) to protect the voluntary aspect of consent, and 2) to avoid interference of the community or family in the adolescent consent process. Instead, participants were given 'participant packs', which consisted of a toothbrush, toothpaste, fruit juice and snacks, and a certificate of participation. Pregnant girls and new mothers were also given a 'baby pack' with items such as diapers and baby cream. In some instances, research assistants looked after participants' children during the interviews. Travel costs were covered if a participant travelled to interviews as a way of preserving privacy or ensuring safety. All of the above were provided regardless of whether the participant finished the interview or not.

RESEARCH CONSTRAINTS AND SOLUTIONS

This study aimed to assess internalised HIV stigma in a sample of HIV-positive adolescents in one of South Africa's poorest provinces. The research team and this candidate encountered a number of complexities with regards to the context, as well as the population of interest – adolescents living with HIV. The following section describes the major challenges encountered throughout this research. Each challenge was carefully considered on a case-by-case basis. When necessary, protocol adaptations were made together with the study management team and principal investigators. Ethics review boards were kept informed about all challenges and protocol adaptations.

Challenges specific to research with adolescents living with HIV

The study sample included three high-risk groups: 1) adolescents who were at risk of dying due to non-access or non-adherence to life-saving treatment, 2) adolescents who knew their status but had not disclosed their status to others; and 3) adolescents who did not know their status whilst their family members and healthcare providers did.

This study had beneficence as a core guiding principle: the priority was to collect meaningful data that would maximize possible benefits for adolescents living with HIV, while avoiding risks to participants. Given that mortality rates are exceptionally high in this population (Porth et al. 2014), it was essential to interview the high-risk group of adolescents who were defaulting from treatment and not actively engaged in the healthcare system. Therefore, community tracing was essential. However, following up with HIV-positive adolescents outside of healthcare facilities posed additional challenges around preserving participant confidentiality and preventing stigma-by-association in the study.

In particular, inadvertent disclosure of adolescent HIV status to their family, peers or community members was a major concern, as this would have increased the risk of discrimination, abuse and neglect (Norman, Chopra, and Kadiyala 2005). As such, the study had to be presented as an overall study on adolescent health and access to services. However additional complexities were introduced when a participant would attempt to refer their friend for participation in the study, and in doing so disclose their friend's HIV-status to the researcher. In such instances, research

assistants were trained to remind the participant that the study was not HIV-specific and that any adolescent was welcome to participate.

Equally, inadvertent disclosure of the adolescent's HIV status to the adolescent (when the adolescent was unaware of their own status) was a risk. As explained earlier in this chapter, our screening tool for determining adolescent HIV status awareness was carefully devised to avoid inadvertent disclosure of HIV status to the adolescent. The tool allowed adolescents to disclose their status to the research assistants without the research assistants ever mentioning HIV/AIDS or anti-retroviral treatment. If the adolescent did not disclose their HIV status, a non HIV-specific version of the questionnaire was used replacing words HIV, AIDS and ART with general terms like health, illness and medication. This method relied on participant self-disclosure of HIV status, and prevented researcher disclosure of HIV status to status-unaware participant.

Unfortunately, 42 adolescents had passed away before the team traced them. In such instances the research assistants paid respects to their families, and informed clinics to update their records in order to avoid additional trauma for the family.

Context-specific challenges

The study took place in one of South Africa's poorest provinces, the Eastern Cape (Statistics South Africa 2016), and many of our participants lacked access to basic necessities. 17.2% (n=182) of the sample reported not having enough food to eat in the past week, which rendered sitting through and concentrating for the interviews difficult. In cases where children reported not having enough to eat for more than

two days in the past week, the research team delivered emergency food parcels for the family.

Nearly half of the participants (48%, n=509) reported having been emotionally, physically or sexually abused in the past year. As described earlier in this chapter, the team had an extensive referral protocol following South African legislation for child protection and built on experiences from former research in the country. However, the under-resourced public healthcare system and social services limited the referral process. For example, for all of the King Williams Town study site and its surrounding villages, only one trauma counsellor was available and all of the safe children's homes were operating at full capacity and with several yearlong waitlists. If a participant was at immediate risk of severe harm, the research assistants and this candidate discussed the possibilities for referral with the participant at risk. The team worked closely with adolescents, their family and social services to find solutions within the under-resourced public service system whenever possible. At times, this blurred the lines between our roles as researchers and service providers. A total of 68 (6.4%) referrals were made within the study sample.

Crime

The study took place in communities where both adolescent participants and the research team members were at risk of crime and violence victimization. Nearly half of our participants (45%) reported being attacked or robbed in their community within the past year. This candidate worked closely with the study principal investigator Prof. Lucie Cluver and co-investigator Dr. Elona Toska to conduct a risk

assessment, and draft a detailed safety protocol that was amended as issues arose throughout fieldwork (Appendix 12). The candidate attended two fieldwork safety courses at Oxford University and led fieldwork safety training sessions for the field team. Data collection only took place during daylight, and working hours were modified depending on the month and typical sunset hours. The candidate worked closely with research assistants to identify areas that were deemed too unsafe to work in, and arranging for alternative locations to meet adolescents when possible. Only 0.3% of the eligible sample (n=4) was excluded due to safety concerns.

Professional burnout and vicarious trauma

The research team (including this candidate) were exposed to trauma on a day-to-day basis. In addition to conducting emotionally taxing interviews, the team referred children who were at immediate risk of serious harm to under-resourced social services, were exposed to high levels of child morbidity and mortality, and worked in crime-ridden areas. As is common in work and research with vulnerable children, our team members experienced professional burnout, vicarious trauma, secondary traumatic stress and compassion fatigue (Knight 2013; Newell and Macneil 2010; Beck 2011). Our research staff were specifically recruited for their sensitivity and empathy towards adolescents. These traits made them strong interviewers but also made them vulnerable to emotional distress.


Based on recommendations from clinicians and researchers working with vulnerable populations, we implemented procedures for self-care and counselling (Knight 2013; Newell et al. 2014). Counselling sessions with psychologists specializing in trauma

were offered during work hours and paid for through research funds. Information sheets for staff aiming to normalize psychological distress and offering resources for support were regularly distributed (Figure 14). In addition, an opt-out evidence-based 8-week training in mindfulness meditation was organized during work hours, and structured time off was given to team members most in need.

Despite these efforts, a few team members refused to attend counselling and meditation sessions, choosing to work during these hours instead. Helping professionals see their own suffering as less relevant in comparison to that of their clients (Barron 1999) but we were unable to find any evidence-based recommendations on how to best support researchers when this occurs. This candidate scheduled regular monthly supervision meetings where she encouraged the team to cultivate fulfilling personal lives, relationships with family and friends and hobbies as 'positive counterparts to the work' (Knight 2013). The candidate expanded on traditional supervision formats that focus on technical aspects of the supervisees' work, to incorporate 'affective check' in (Knight 2013). Affective check in involves conversations about supervisees' emotional responses, so as to normalize their feelings and identify areas for support (Knight 2013).

Halfway through fieldwork, this candidate started to have online counselling sessions with a psychologist specializing in vicarious trauma twice a week. Upon return to Oxford, she continued with less frequent counselling sessions, went to a vicarious trauma workshop and practiced rigorous self-care and mindfulness to help process the trauma.

Figure 14 Mental health information sheets for the research team



YOU AND YOUR MENTAL HEALTH

Working on our studies is hard!

It requires dealing with terrible referrals, poverty, hardship, illness and death. We specifically choose people to work with us who care and show a lot of empathy because we want the best possible outcome for our participants. Every single person who has ever worked on one of our studies has been affected by the work we do and has sought professional help at some stage during their involvement with our projects. This is nothing to be embarrassed about, in fact, we would like to encourage you to do more for your mental health.

When do you need help?

Everyone reacts differently to stress. Some of the things many members on the project have experienced are:

- Nightmares and sleeplessness
- Feeling sad or angry all the time
- Bursting into tears for no apparent reason
- Feeling like everything is getting too much
- Lacking motivation and drive, feeling tired
- Negative thoughts
- Losing your appetite or not being able to stop eating
- Drinking too much

Things that have helped others to deal with what we see and hear:

- Counselling
- Mindfulness
- Running
- Going for walks
- Protecting weekends and holidays
- Being in close contact with friends and family
- Huge amounts of chocolate and caramel popcorn
- Team debriefing
- Writing a journal or diary
- Before going to sleep list all the things you are grateful for that day. This can help you think positively.
- Watching comedy shows
- Going to church
- Sleeping

Where can you get professional help?

Anyone working on the project can access counselling completely confidentially and free of charge by calling

LIFELINE (043) 743 5123

If you name Mzantsi Wakho they will invoice us and we will pay for the sessions. Some of our staff have good experiences with and recommend Vuvu from Lifeline. You may want to try a few counsellors and select the right one for you.

Remember, you make this study possible! You are our most important asset. Please help us by taking care of yourselves and seeking support when you need it.

If you feel stressed and you need extra support, don't be shy or embarrassed. You can e-mail, whatsapp or talk to any Manager or Coordinator on the team. We are here to help.

Marija, Izzie, Mavis, Louis, Lauren, Jess, Nokubonga

The research limitations flagged here are re-visited in more detail in the discussion chapter of this thesis.

CHAPTER VI. PAPER 2 – ‘THEY SAY HIV IS A PUNISHMENT FROM GOD OR FROM ANCESTORS’: CROSS-CULTURAL ADAPTATION AND PSYCHOMETRIC ASSESSMENT OF AN HIV STIGMA SCALE FOR SOUTH AFRICAN ADOLESCENTS LIVING WITH HIV (ALHIV-SS)

This is the first empirical paper of the thesis. It aims to enable future research on internalised HIV stigma among Southern African adolescents living with HIV, by developing a culturally relevant, age appropriate, and psychometrically sound HIV stigma scale. This paper has been published:

Pantelic, Marija, Mark Boyes, Lucie Cluver, and Mildred Thabeng. 2016. “They Say HIV Is a Punishment from God or from Ancestors’: Cross-Cultural Adaptation and Psychometric Assessment of an HIV Stigma Scale for South African Adolescents Living with HIV (ALHIV-SS).” *Child Indicators Research* (November 23). doi:10.1007/s12187-016-9428-5. <http://link.springer.com/10.1007/s12187-016-9428-5>.

Figure 15 Preschool spaces used for cross-cultural adaptation of the HIV stigma scale, 2014



ABSTRACT

HIV-stigma and the resultant fear of being identified as HIV-positive can compromise the survival of adolescents living with HIV (ALHIV) by undermining anti-retroviral treatment initiation and adherence. To date, no HIV-stigma measures have been validated for use with ALHIV in Sub-Saharan Africa. This paper reports on a two-stage study in the Eastern Cape, South Africa. Firstly, we conducted a cross-cultural adaptation of an HIV stigma scale, previously used with US ALHIV. One-on-one semi-structured cognitive interviews were conducted with 9 urban and rural ALHIV. Three main themes emerged: 1) participants spoke about experiences of HIV stigma specific to a Southern African context, such as anticipating stigma from community members due to 'punishment from God or ancestors'; 2) participants' responses uncovered discrepancies between what the items intended to capture and how they understood them and 3) participants' interpretation of wording uncovered redundant items. Items were revised or removed in consultation with participants. Secondly, we psychometrically assessed and validated this adapted ALHIV stigma scale (ALHIV-SS). We used total population sampling in 53 public healthcare facilities with community tracing. 721 ALHIV who were fully aware of their status were identified and interviewed for the psychometric assessment. Confirmatory factor analysis confirmed a 3-factor structure of enacted, anticipated and internalised stigma. The removal of 3 items resulted in a significant improvement in model fit (χ^2 (df)=189.83 (33), $p<.001$) and the restricted model fitted the data well (RMSEA=.017; CFI/TLI=.985/.980; SRMR=.032). Standardized factor loadings of indicators onto the latent variable were acceptable for all three measures (.41-.96). Concurrent criterion validity confirmed hypothesized relationships. Enacted stigma was associated with higher AIDS symptomatology ($r=.146$, $p<.01$) and depression ($r=.092$, $p<.01$). Internalised stigma was correlated with higher depression ($r=.340$, $p<.01$), higher AIDS symptomatology ($r=.228$, $p<.01$) and low social support ($r=-.265$, $p<.01$). Anticipated stigma was associated with higher depression ($r=.203$, $p<.01$) and lower social support ($r=-.142$, $p<.01$). The resulting ALHIV-SS has 10 items capturing all three HIV stigma mechanisms experienced by ALHIV. ALHIV-SS will be valuable for evaluating rates and types of stigma, as well as effectiveness of stigma-reduction interventions among ALHIV in Southern Africa.

INTRODUCTION

Stigma is defined as a process by which individuals are “disqualified from full social acceptance” due to possessing physical, health or behavioural attributes that are deemed “deeply discrediting”(Goffman 1968). The HIV stigma framework specifies three distinct mechanisms through which HIV-positive individuals experience stigma: enacted, anticipated and internalised stigma (Earnshaw and Chaudoir 2009). Enacted stigma refers to experiences of discrimination or having been treated differently due to one’s HIV status. Anticipated stigma refers to the extent to which HIV-positive people perceive or anticipate prejudice against themselves. Internalised stigma occurs when an HIV-positive person endorses negative attitudes associated with HIV and accepts them as applicable to his or her self (Earnshaw et al. 2013).

Systematic review evidence suggests that globally 12 scales are available for measuring HIV stigma among HIV-positive people (Earnshaw and Chaudoir 2009; Stevelink et al. 2012). Of the 12 measures, three were developed in Sub-Saharan Africa (Holzemer et al. 2007; Kalichman et al. 2009; Visser et al. 2008) and none were designed for adolescents living with HIV. Holzemer developed a 33-item multi-dimensional stigma scale that was validated in a sample of 1,477 HIV-positive adults in Lesotho, Malawi, South Africa, Swaziland and Tanzania (Holzemer et al. 2007). The scale captures internalised stigma and five dimensions of enacted stigma. Kalichman and colleagues’ Internalised AIDS-Related Stigma Scale showed good reliability in South African, Swaziland and the US samples of HIV-positive adults. (Kalichman et al. 2009) Visser and colleagues developed two parallel scales, one for measuring stigma among general community members and one for measuring stigma among HIV-

positive adult women (Visser et al. 2008). The latter scale measured internalised and anticipated stigma but not enacted stigma (Earnshaw et al. 2013; Visser et al. 2008). These three African stigma scales were pioneering in HIV stigma research in the region. Unfortunately, they were not developed for use with adolescents and none of them capture all three HIV stigma mechanisms.

We conducted a two-stage study in South Africa to address these gaps. The first stage used qualitative methods to cross-culturally adapt an HIV stigma scale previously used with adolescents living with HIV (ALHIV) in the US (Wright et al. 2007). The second stage psychometrically assessed and validated the adapted ALHIV stigma scale (ALHIV-SS) within the world's largest survey of HIV-positive adolescents. Ethical approval was provided by Research Ethics Committees at the Universities of Oxford (SSD/CUREC2/12–21) and Cape Town (CSSR 2013/4), Eastern Cape Departments of Health and Basic Education, and ethical review boards of participating hospitals.

STAGE 1: QUALITATIVE CROSS-CULTURAL ADAPTATION

1.1 METHOD: COGNITIVE INTERVIEWS

We used Wright and colleagues' abbreviated version of the Berger stigma scale previously used with ALHIV in the US (Wright et al. 2007). To our knowledge, this was the only HIV stigma scale that measured all three HIV stigma mechanisms among ALHIV (McAteer et al. 2016). Items were translated and back translated independently by different Xhosa and English-speaking research assistants.

Two adaptations to the scale were made prior to the cognitive interviews. First, for context-specific reasons response options were reduced from a five-point likert scale to a three-point likert scale. This adaptation was deemed necessary to reduce respondent burden, particularly in light of low literacy rates and widespread cognitive delay among South African adolescents living with HIV due to the late roll-out of anti-retroviral treatment in the country (Ferrand et al. 2012; Sherr, Croome, et al. 2014).

Second, research participants prefer explicitly non-judgmental environments when being interviewed on sensitive topics (Bourne and Robson 2015). In an attempt to reduce fear of judgement and social desirability bias, vignettes were added to the questions. For example, prior to enacted stigma items a vignette was inserted: “[Lundi] is having a hard time because of his HIV status. Sometimes people treat Lundi differently from other kids just because he is HIV-positive. This is not fair. Could you say how much these things have been true for you?” (Table 8).

Cross-cultural adaptation of this scale was conducted via one-on-one semi-structured cognitive interviews with 4 rural and 5 urban ALHIV in the Eastern Cape, South Africa. Respondents were recruited from peri-urban and rural areas (age range: 10-19, mean age: 15.6). Voluntary written informed consent was obtained from caregivers and adolescents for a 60-minute interview including breaks and games. No incentives were provided, but all adolescents were given certificates and lunch. Cognitive interviewing is a method that is commonly used to uncover inconsistencies between what the measurement items are meant to ask and the way in which members of the target population interpret items (De Silva et al. 2006). If

not detected and addressed, such inconsistencies can introduce bias into conclusions drawn from empirical data. Cognitive interviewing involves probing of respondents to interpret the meaning of items and specific terms within the items.

When needed, interpretation was provided by a bilingual research assistant who was trained in qualitative research with ALHIV. Respondents were regularly reminded that they were not expected to respond to the items and that their primary role in the study was to help make the items clearer, easier to respond to and more adolescent-friendly. Respondents were also informed that the interviewers did not design the scale so as to eliminate possible inhibition from suggesting improvements. Respondents were probed to: (1) Read out loud each vignette and each question; (2) Paraphrase the vignette/question in their own words; (3) Provide an example of the concepts mentioned in the vignettes/questions (i.e. 'Could you tell me an example of when Lundi struggles to feel good about himself?'); (4) Tell the research team 'How difficult or easy would it be to respond to this question?'; and (5) Where appropriate, propose alternative wording for the vignette/item.

1.2 ANALYSIS OF COGNITIVE INTERVIEW DATA

Data were reviewed using thematic analysis to identify evidence of problems with vignettes, items, and response options. Codes were assigned to summarize and describe responses. These codes were entered into a summary table and listed under the respective item, vignette or response options. Codes were grouped into themes after each interview. A theme consisted of agreement in the codes from two or more participants. Measure adaptations were initiated once a theme emerged

from the codes, and draft revisions were used in subsequent rounds of interviews with new participants.

Table 8 Stigma items and vignettes used in the cognitive interviews

<p><u>Internalised stigma vignette and items:</u> This is Lundi. Living with HIV is difficult for him sometimes. Some days Lundi struggles to feel good about himself. Could you say how much these things are true for you? (Nosizi for female respondents)</p> <ol style="list-style-type: none"> 1. I am very careful who I tell that I have HIV. 2. I worry that people who know I have HIV will tell others. 3. I feel that I am not as good as other kids because I have HIV. 4. Having HIV makes me feel unclean/dirty. 5. Having HIV makes me feel that I'm a bad person.
<p><u>Anticipated stigma vignette and items:</u> Could you tell us a little bit about what people in your community think about HIV?</p> <ol style="list-style-type: none"> 1. Most people think that a person with HIV is disgusting. 2. Most people with HIV are rejected when others find out.
<p><u>Enacted stigma vignette and items:</u> Remember Lundi? He is having a hard time because of his HIV status. Sometimes people treat Lundi differently from other kids just because he is HIV-positive. This is not fair. Could you say how much these things have been true for you? (Nosizi for female respondents)</p> <ol style="list-style-type: none"> 1. I have been hurt by how people reacted when they learnt about my HIV status. 2. I have stopped socializing with some kids because of their reactions to my HIV status 3. I have lost friends by telling them I have HIV.
<p>Responses options: never, sometimes, most of the time</p>

1.3 COGNITIVE INTERVIEW RESULTS

HIV stigma mechanisms according to South African ALHIV

The cognitive interviews elicited common types of enacted, anticipated and internalised stigma relevant to ALHIV in South Africa that had not been captured in the original measurement used in the US. Findings informed adaptations to the scale prior to psychometric assessment; the adapted items are presented in Table 9.

Enacted stigma: In open-ended discussions of the vignette describing Lundi, an ALHIV who is 'treated differently' because of his HIV status, respondents repeatedly provided examples of being teased. This was in line with previous research with

AIDS-affected adolescents in South Africa (Boyes et al. 2013) and items measuring this were included prior to the psychometric assessment.

Internalised stigma: When probed to provide examples of what Lundi experiences when he ‘struggles to feel good about himself’ because of his HIV status, respondents provided examples of shame, guilt and suicidality. One respondent said ‘He is shy to walk on the street because people will point fingers’ and many suggested that Lundi might feel like HIV infection was his fault. Participants also spoke about suicidal ideation and attempts among adolescents who struggle to accept seropositivity. They provided examples of ALHIV ending their life by purposefully defaulting from ART, as well as attempting to overdose from ART. Feelings of shame, guilt and suicidality have already been captured in tools measuring internalised stigma among South African HIV-positive adults (Kalichman et al. 2009; Visser et al. 2008; Holzemer et al. 2007). Items were adapted from existing measurements in consultation with participants.

Anticipated stigma: When probed to provide examples of stigma, respondents spoke about people in the community believing that ALHIV have been punished with HIV for bad behaviour. Respondents anticipated being judged for ‘bad behaviours’ if they were sexually active, poor or unable to attend school, for example: ‘If I don’t go to school they will say I am bad and this is why I have HIV’, ‘They will say I deserve this because I am poor’. Punishment was often thought to come from God or from ancestors. This finding coincides with earlier community-based studies in South Africa (Kalichman and Simbayi 2004). We therefore included an item on this in consultation with participants (Table 9).

Table 9 Variable names and items generated through cognitive interviews and used in the psychometric assessment

Stigma construct	Observed variables/ indicators/ item wording	Response options
Vignette preceding anticipated stigma items: 'Could you tell us a little bit about what people in your community think about HIV?'		
Anticipated stigma	'People in my community think that a person with HIV is disgusting.'	Never, sometimes, most of the time
	'People in my community think that HIV is a punishment from God or from ancestors.'	Never, sometimes, most of the time
Vignette preceding enacted stigma items: 'Lundi is having a hard time because of his HIV status. Sometimes people treat Lundi differently from other kids just because he is HIV-positive. This is not fair. Could you say how much these things have been true for you in the past year?' [Nosizi for girls]		
Enacted stigma	'I have been hurt by how people reacted when they found out I have HIV'*	Never, sometimes, most of the time
	'I have stopped spending time with some kids because of their reactions to my HIV status.'	Never, sometimes, most of the time
	'I have lost friends by telling them I have HIV.'	Never, sometimes, most of the time
	'I've been teased because of my HIV'	Never, sometimes, most of the time
Vignette preceding internalised stigma items: 'This is Lundi [Nosizi for girls]. Living with HIV is difficult for him sometimes. Some days Lundi feels ashamed and he struggles to feel good about himself. Could you say how much these things have been true for you in the past year?'		
Internalised stigma	'Lundi is very careful who he tells he has HIV. Are you careful who you tell?'	Never, sometimes, most of the time
	'Sometimes Lundi feels that he/she is not as good as other kids because he has HIV. Do you ever feel this way?'	Never, sometimes, most of the time
	'Sometimes Lundi feels like he/she would rather die than live with HIV. Do you ever feel this way?'	Never, sometimes, most of the time
	'Sometimes Lundi feels like he/she is a bad person because he has HIV. Do you ever feel this way?'	Never, sometimes, most of the time
	'Sometimes Lundi feels ashamed that he is HIV-positive. Do you ever feel this way?'	Never, sometimes, most of the time
	'Sometimes Lundi feels that it is his/her fault that he is HIV-positive. Do you ever feel this way?'	Never, sometimes, most of the time
	'Sometimes having HIV makes Lundi feels contaminated and dirty inside. Do you ever feel this way?'	Never, sometimes, most of the time

** item later deleted due to poor factor loading in the confirmatory factor analysis*

Vignette utility

Respondents found the vignettes to provide a sense of comfort in knowing that other youth experience HIV stigma as well. In four instances, respondents were confused about internalised stigma questions originally being phrased in first person. Even though they acknowledged that the given examples of internalised stigma

commonly happened to ALHIV, two respondents felt that the original items suggested that they *should* feel this way. They suggested that all internalised stigma items refer to Lundi, the character from the vignette and we made adaptations accordingly, for example: 'Sometimes Lundi feels that he/she is not as good as other kids because he has HIV. Do you ever feel this way?' (Table 9).

Redundancy

Two items were eliminated because repetitive interpretations were provided when participants were asked to paraphrase items. The two anticipated stigma items originally provided in the US measurement ('Most people think that a person with HIV is disgusting' and 'Most people with HIV are rejected when others find out') were interpreted similarly. Therefore we retained the item that was easier to interpret by participants (Table 9). Similarly, the two items about disclosure ('I am very careful who I tell that I have HIV' and 'I worry that people who know I have HIV will tell others') overlapped in terms of the respondents' comprehension. Here too, only the item that was found easier to interpret by adolescents was retained (Table 9).

Linguistic adaptation

Participants' interpretation of items and specific words within items detected areas for improvement of wording. For example, in the original item on internalised stigma '*Having HIV makes me feel unclean or dirty*', the words dirty and unclean were both interpreted as 'not having showered'. These words were substituted for 'contaminated or dirty inside' to capture subjective feelings of uncleanliness

documented through qualitative work on internalised HIV stigma(Lawless, Kippax, and Crawford 1996). Also, the phrase ‘when they learned about my HIV status’ was understood as reading about one’s HIV status ‘in a book’. This phrase was changed to the Xhosa equivalent of ‘when they found out that I have HIV’ based on consultation with participants.

STAGE 2: PSYCHOMETRIC ASSESSMENT OF THE ADAPTED ALHIV STIGMA SCALE (ALHIV-SS)

2.1 METHODS: QUANTITATIVE SURVEY AND PSYCHOMETRIC ASSESSMENT

As part of a larger study on ART adherence among ALHIV, we used total population sampling in public healthcare facilities with community tracing in a mixed urban, peri-urban and rural health district of the Eastern Cape, South Africa. From 2014-2015, all public health facilities that provided ART to 5 or more adolescents (aged 10-19) were identified (n=53). Within these facilities, all adolescents who had ever initiated ART were identified through patient files and computerized records (n=1176) and their addresses were recorded for community-tracing purposes. Adolescents were met in the facilities or followed up in their homes so as to ensure inclusion regardless of clinic attendance, treatment defaulting or being lost-to-follow-up. None of the participants from Stage 1 were included in the quantitative stage of the study.

90.1% (n=1060) of the eligible sample was interviewed. Of the remainder, 4.1% refused participation (either adolescent or caregiver), 0.9% had such severe cognitive disability that they were unable to participate, 1.2% were unable to be

interviewed for safety reasons (such as those living in gang homes) and 3.7% were unable to be traced. Because of the explicit mention of HIV in the stigma scale, only the subsample of ALHIV who were fully aware of their status were asked HIV stigma questions (n=721, 67.7%) and were included in the present study.

Voluntary informed consent was obtained from caregivers and adolescents for a 90-minute interview. No incentives were provided, but all adolescents were given a certificate, snack, toothbrush and toothpaste. So as to prevent inadvertent disclosure of HIV status to community and family members, and to reduce stigma associated with participation in the study, the research was presented in communities as focusing on general needs of adolescents using social and health services, and 467 additional adolescents who were co-resident but HIV-negative, or who lived in neighbouring homes, were also interviewed (not included in these analyses).

Questionnaires were translated and back translated into isi-Xhosa and used mobile-assisted self-interview technology on tablets. Xhosa, English and Afrikaans-speaking interviewers, trained in working with HIV-affected adolescents, read questions in case of low literacy levels or cognitive delay. Confidentiality was maintained, except in cases of significant harm or when participants requested assistance. Where participants reported recent abuse, rape, suicidal attempt or other risk of significant harm, referrals were made to child protection and health services, with follow-up support from the research team.

Measures

Measures of depressive symptoms, social support and AIDS symptomatology were included to assess external validity of each stigma mechanism. Based on a previous systematic review, internalised stigma was hypothesized to be associated with low social support, more AIDS-related symptoms and poor mental health (Pantelic et al. 2015). We hypothesized negative relationships between anticipated stigma and social support and mental health based on consistent associations found in previous research (Earnshaw and Chaudoir 2009). We hypothesized enacted stigma to be associated with higher AIDS symptomatology and poor mental health (Earnshaw and Chaudoir 2009; Smith, Rossetto, and Peterson 2008).

Depressive symptoms were measured via the Child Depression Inventory short form (CDI-S), which has comparable results with the full CDI (Kovacs 1995). CDI-S has been used with AIDS-affected adolescents in South Africa, displaying acceptable internal consistency ($\alpha=.67-.69$) (Cluver et al. 2012). CDI-S also demonstrated acceptable internal consistency in the present sample of ALHIV ($\alpha=.62$).

Social support was measured using 9 tangible and emotional support items from the Medical Outcome Study (MOS) Social Support Survey (Sherbourne and Stewart 1991). Items included “How often do you have someone to take you to the doctor if you needed it?” and “How often do you have someone to give you good advice about a crisis?”. Responses were offered on a 3-point likert scale (0:‘Never’; 1:‘Sometimes’; 2:‘Always’). The scale demonstrated strong internal consistency in the present sample of ALHIV ($\alpha=.85$).

AIDS symptomatology was measured via response to the 16-item verbal autopsy, a questionnaire developed to identify symptoms of AIDS in areas with over 20% HIV prevalence and where data on cause of illness are unavailable or unreliable. Verbal Autopsy is increasingly being used for determining AIDS mortality in generalized epidemics (Cluver et al. 2012; Doctor and Weinreb 2003; Hosegood, Vanneste, and Timæus 2004) and recent research found the method to have 75%-83% sensitivity and 74%-79% specificity among adult subjects (Lopman et al. 2010). Items included 'asthma, lung problems and trouble breathing for more than two days', 'sores in the mouth, hands and feet, parts of the body', and 'diarrhoea or runny tummy for more than two days'. Responses were offered on a 3-point scale (0: 'Never'; 1: 'Sometimes'; 2: 'Most of the time').

Age, gender, rural household location, receipt of child-focused welfare grants and place of interview were recorded for descriptive purposes. *Receipt of child-focused welfare grants* was assessed via participant response to 'How many child support grants does your household receive?' and 'How many foster care grants does your household receive?'. Responses were recoded as a dichotomous variable to determine household receipt of any child-focused grant (0: no access to child-focused grants; 1: access to one or more child-focused grants at the household level). *Place of interview* was recorded by the research assistant at the start of the interview. The tablet offered the following options: participant's home, clinic, hospital, school, church, community centre and other. This was later recoded into participant's home, healthcare facility, school and other.

2.2 PSYCHOMETRIC ASSESSMENT ANALYSIS

All psychometric assessment analyses were conducted within the subsample of ALHIV who were aware of their status (n=721) using MPlus7. Confirmatory factor analysis tested whether ALHIV-SS consisted of the three hypothesized factors: anticipated, enacted and internalised stigma. Items loading below .4 were excluded from the scale (Bowen and Guo 2012). Model fit was assessed via multiple goodness-of-fit measures. Comparative Fit Index (CFI) and Tucker Lewis Index (TLI) above .95 (Bentler 1990; Li-tze Hu and Bentler 1995), and Root Mean Square Error of Approximation (RMSEA) and standardized root mean-square residual (SRMR) values below .05 indicated good model fit (Bowen and Guo 2012). χ^2 is not recommended for assessing goodness-of-fit in large samples as it is sensitive to sample size and is prone to Type 2 error and should not be used with the maximum likelihood robust estimator (Schermelleh-Engel, Moosbrugger and Müller 2003; Vandenberg 2006). χ^2 was therefore only noted to compute changes in χ^2 and assess improvement in model fit after modification ($\Delta\chi^2$). Internal consistency (Cronbach's α) assessed reliability. As detailed in the measures section of this paper, concurrent criterion validity was assessed through associations between HIV stigma constructs and correlates identified in earlier reviews and meta-analyses of quantitative research.

2.3 PSYCHOMETRIC ASSESSMENT RESULTS

Table 10 reports socio-demographic characteristics of the sample of ALHIV who were fully aware of their status (n=721). The mean age was 14.6 (SD=2.75). 56.6% of the sample was female and 19% lived in rural areas. 81.6% of the sample received a

child-focused grant, indicative of relative material deprivation in the sample. The majority of participants were interviewed in their home (84%), 11.8% were interviewed in clinics or hospitals and 5.7% were interviewed in other spaces such as their schools or community centres.

Table 10 Sample characteristics (n=721)

	Mean (SD) or N (%)
Age	14.65 (2.75)
Female	408 (56.6)
Rural household	137 (19.0)
Child-focused grant recipient	588 (81.6)
Place of interview	
Participant's home	602 (84.0)
Healthcare facility	85 (11.8)
Other	41 (5.7)

Confirmatory Factor Analysis (CFA) Results

Table 11 summarizes item phrasing, response options and frequencies for indicators that were included in the CFA. So as to account for non-normal data, CFA was run on a 3-factor robust maximum likelihood (MLR) model (Muthen and Muthen 2001). Enacted stigma items were constrained to load onto the enacted stigma factor; anticipated stigma items were constrained to load onto the anticipated stigma factor; and internalised stigma items were constrained to load onto the internalised stigma factor.

Results of the full model CFA are presented in Table 12. Fit indices indicated that the model fitted the data well (RMSEA=.016; CFI/TLI=.983/.978; SRMR=.038). However, factor loadings ranged between .39-.96, with three items failing to meet the pre-specified loading cut-off of .40 (Bowen & Guo, 2012). Further inspection of wording

confirmed that these items were ambiguous or vague in relation to the intended theoretical stigma constructs. For example one of the items was ‘I have been hurt by how people reacted when they found out I have HIV’. By asking about other people’s behaviours as well as the respondent’s subjective response to these behaviours, this item taps into both enacted and internalised stigma constructs. Such items were removed from further analysis and CFA was rerun on the restricted model.

Table 11 Response option frequencies for each stigma item (n=721)

Stigma construct	Indicator	N (%)		
		Never	Sometimes	Most of the time
Anticipated stigma	‘People in my community think that a person with HIV is disgusting.’	520 (72.1)	158 (21.9)	43 (6.0)
	‘People in my community think that HIV is a punishment from God or from ancestors.’	578 (80.2)	115 (16.0)	28 (3.9)
Enacted stigma	‘I have been hurt by how people reacted when they found out I have HIV’*	663 (92.0)	45 (6.2)	13 (1.8)
	‘I have stopped spending time with some kids because of their reactions to my HIV status.’	698 (96.8)	19 (2.6)	4 (0.6)
	‘I have lost friends by telling them I have HIV.’	706 (97.9)	13 (1.8)	2 (0.3)
	‘I’ve been teased because of my HIV’	702 (97.4)	14 (1.9)	5 (0.7)
Internalised stigma	‘Lundi is very careful who he tells he has HIV. Are you careful who you tell?’*	145 (20.1)	81 (11.2)	480 (66.6)
	‘Sometimes Lundi feels that he/she is not as good as other kids because he has HIV. Do you ever feel this way?’	596 (82.7)	87 (12.1)	23 (3.2)
	‘Sometimes Lundi feels like he/she would rather die than live with HIV. Do you ever feel this way?’	652 (90.4)	49 (6.8)	5 (0.7)
	‘Sometimes Lundi feels like he/she is a bad person because he has HIV. Do you ever feel this way?’	661 (91.7)	43 (6.0)	2 (0.3)
	‘Sometimes Lundi feels ashamed that he is HIV-positive. Do you ever feel this way?’	605 (83.9)	90 (12.5)	11 (1.5)
	‘Sometimes Lundi feels that it is his/her fault that he is HIV-positive. Do you ever feel this way?’*	644 (89.3)	51 (7.1)	11 (1.5)
	‘Sometimes having HIV makes Lundi feels contaminated and dirty inside. Do you ever feel this way?’	657 (91.1)	45 (6.2)	4 (0.6)

** item later deleted due to poor factor loading in the confirmatory factor analysis*

When CFA was run on the restricted model (Table 13), fit indices indicated that it fitted the data well (RMSEA=.017; CFI/TLI=.985/.980; SRMR=.032). The removal of 3

items resulted in a significant improvement in model fit ($\Delta\chi^2$ (df)=189.83 (33), $p<.001$). Overall, standardized factor loadings of indicators onto the latent variable were acceptable for all three measures, ranging between .57-.96 for anticipated stigma, .41-.68 for enacted stigma and .62-.65 for internalised stigma. Latent correlations between internalised stigma and anticipated ($r=.239$, $p<.01$) and enacted stigma ($r=.092$, $p<.01$) were significant with weak effect sizes. Anticipated and enacted stigma were not significantly correlated ($r =.117$). Additional modifications to the measurement model were not carried out due to the very good fit of the model.

Table 12 Results of the first CFA, full model

Stigma domain: Item:	Anticipated		Enacted		Internalised	
	β	SE	β	SE	β	SE
Participant thinks that people in community think HIV+ people are disgusting	.957***	.115				
Participant thinks that people in community think HIV is a punishment from God or ancestors	.567***	.076				
Participant has been teased because of HIV status			.643***	.114		
Participant has been hurt by people's reactions to their HIV status			.388***	.070		
Participant has stopped spending time with some kids because of his/her HIV status			.605***	.118		
Participant has lost friends because of his/her HIV status			.409*	.167		
Participant is ashamed of their HIV status					.639***	.052
Participant feels they aren't as good as other kids because of HIV status					.608***	.055
Participant feels that they would rather die than be living with HIV					.622***	.061
Participant feels like a bad person because of HIV					.657***	.062
Participant feels that HIV is their fault					.390***	.078
Participant feels that HIV makes them dirty inside					.653***	.066
Participant is very careful who they tell about their status					.102**	.034

Model fit: RMSEA=.016; CFI/TLI=.983/.978; χ^2 (df)= 705.787(78)***; SRMR=.038

The final ALHIV-SS resulted in 10 items: 2 anticipated, 3 enacted and 5 internalised stigma items. Internal consistency / Cronbach's α levels were .70, .57 and .75 for anticipated, enacted and internalised stigma respectively.

Concurrent criterion validity

Correlations testing concurrent criterion validity confirmed hypothesized relationships. Enacted stigma was associated with higher AIDS symptomatology ($r=.146, p<.01$) and depression ($r=.092, p<.01$). Internalised stigma was correlated with depression ($r=.340, p<.01$), AIDS symptomatology ($r=.228, p<.01$) and low social support ($r=-.265, p<.01$). Anticipated stigma was associated with depression ($r=.203, p<.01$) and low social support ($r=-.142, p<.01$).

Table 13 Results of the final CFA, restricted model

Stigma mechanism:	Anticipated		Enacted		Internalised	
Item:	β	SE	β	SE	β	SE
Participant thinks that people in community think HIV+ people are disgusting	.961***	.122				
Participant thinks that people in community think HIV is a punishment from God or ancestors	.565***	.079				
Participant has been teased because of HIV status			.681***	.098		
Participant stopped spending time with kids because of his/her HIV status			.577***	.133		
Participant has lost friends because of his/her HIV status			.412*	.173		
Participant is ashamed of their HIV status					.647***	.053
Participant feels they aren't as good as other kids because of HIV status					.618***	.055
Participant feels that they would rather die than be living with HIV					.624***	.061
Participant feels like a bad person because of HIV					.646***	.064
Participant feels that HIV makes them dirty inside					.646***	.066
Model fit: RMSEA=.017; CFI/TLI=.985/.980; χ^2 (df)= 515.957 (45)***; SRMR=.032						
Improvement in model fit: $\Delta\chi^2$ (df)=189.83 (33)***						

DISCUSSION

This paper provides a comprehensive report of the qualitative and quantitative adaptation process of an ALHIV stigma scale from the US to the South African context. Two linked stages were presented. The first stage used cognitive interviews to cross-culturally adapt an HIV stigma scale previously used with ALHIV in the US (K. Wright et al. 2007). The second stage conducted a psychometric assessment and validation of the adapted ALHIV stigma scale (ALHIV-SS) in a representative sample of 721 HIV-positive adolescents who were aware of their status.

The resulting ALHIV-SS has 10 items and measures all three HIV stigma mechanisms experienced by ALHIV: enacted, anticipated and internalised stigma. To our knowledge, this is the first HIV stigma measurement to measure all three HIV stigma mechanisms within an HIV-positive sample in Sub-Saharan Africa. This is also the first HIV stigma tool specifically designed for and in collaboration with ALHIV in the region. The mixed-methods approach to the scale adaptation has minimized potential bias for future empirical research utilizing ALHIV-SS. For example, cognitive interviews uncovered ambiguities in Xhosa wording that standard translation and back translations did not detect. On the other hand, by identifying items with poor factor loadings, the psychometric assessment helped recognize and remove theoretically ambiguous items in the measurement.

ALHIV-SS was validated within a large sample of ALHIV, of which only 11.8% were interviewed in healthcare facilities. The community tracing used in this study is likely to have generated a more representative sample of ALHIV than would have been the

case with a sample of ALHIV who actively access services. To our knowledge, previous quantitative studies on HIV stigma among HIV-positive individuals recruited through healthcare facilities, community organizations or other service providers (Pantelic et al. 2015; Stangl et al. 2013). Such recruitment approaches may have excluded the most vulnerable ALHIV, whose access to health and other services can be limited due to high anticipated or internalised stigma.

This scale is not without limitations. Firstly, although the consistency of internalised stigma (key outcome for this DPhil) and anticipated stigma subscales were good, the enacted stigma subscale displayed an alpha of 0.57. Given that Cronbach's alpha is affected by the number of items (only 3 in this subscale), there may be value in devising a longer scale for more detailed research on enacted HIV stigma among adolescents living with HIV. Care should be taken to involve the target population, ALHIV, in the development of such a scale. It should also be noted that shorter questionnaires are essential for reducing research burden for ALHIV, many of whom are cognitively delayed (Sherr, Croome, et al. 2014). Cronbach's alpha of the enacted stigma sub-scale might also have been affected by the inter-correlations between items. This problem is not unique to the present scale. Similar measurements of bullying or abuse victimization also commonly display poor internal consistency because the phenomena are not one-dimensional. For example, a recent systematic review of bullying scales found that internal consistency of included measures ranged between $\alpha = 0.25$ and $\alpha = 0.96$ (Vivolo-Kantor et al. 2014).

Secondly, while the scale showed good psychometric properties, it is important to note that it was cross-culturally adapted and validated within a sample of Xhosa-

speaking ALHIV in the Eastern Cape, South Africa. Given that stigma manifestations are culturally and socially embedded, the scale's generalizability and usability within other Southern African contexts might be limited. Nevertheless, future research with HIV-positive adolescents could benefit from the present scale as a starting point for further adaptations and translations.

In line with previous research, our findings confirm that enacted, anticipated and internalised stigma are separate constructs (Earnshaw and Chaudoir 2009; V. Earnshaw et al. 2013). But to our knowledge, this is the first time that the relationship between the three HIV stigma mechanisms has been assessed among adolescents living with HIV in Southern Africa. Anticipated and enacted stigma factors were not significantly correlated, confirming that the factors measure divergent constructs. There was a statistically significant correlation between internalised and enacted stigma but the strength of this relationship was very close to the line of no effect suggesting that they too are independent constructs. This has important implications for theory and intervention development, which has so far heavily focused on reducing HIV-related prejudice and discrimination among the general public rather than reducing HIV stigma as experienced by HIV-positive individuals. While reducing discriminative behaviours among the general public might reduce experiences of enacted stigma among ALHIV, our findings suggest that enacted stigma occurs independently of anticipated and internalised stigma. Therefore, more interventions aiming to reduce anticipated and internalised stigma are urgently needed.

The ALHIV-SS will be valuable for evaluating rates and types of stigma, and effectiveness of interventions aiming to reduce HIV stigma among ALHIV in Southern Africa. Such interventions are urgently needed: between 2005 and 2012 there has been a 50% increase in reported AIDS-related deaths among ALHIV compared with the 30% decline seen in the general population (WHO 2014). This alarming trend has been attributed to “poor prioritization of adolescents in national HIV plans, inadequate provision of accessible and acceptable HIV testing and counselling and treatment services and lack of support for adolescents to remain in care and adhere to [life-saving] ART” (WHO 2013). World Health Organization recommendations for policy makers and program managers frequently cite stigma as a key barrier to service access and utilization among ALHIV (WHO 2013). But to our knowledge, no well-established HIV stigma reduction interventions exist for Southern African ALHIV (Stangl et al. 2013). A validated HIV stigma measure such as ALHIV-SS, designed specifically for this population, is a prerequisite for developing such interventions and assessing their effectiveness.

REFERENCES

To avoid repetition, citations used in this paper are provided in the joint references section at the end of this thesis.

CHAPTER VII. PAPER 3 – HIV, VIOLENCE, BLAME AND SHAME: PATHWAYS OF RISK TO INTERNALISED HIV STIGMA AMONG SOUTH AFRICAN HIV-POSITIVE ADOLESCENTS

This is the first quantitative study on factors associated with internalised HIV stigma among adolescents living with HIV in Sub-Saharan Africa. It builds on findings from the systematic review and post-individualistic stigma perspectives to explore a theoretical model of risk for internalised HIV stigma among adolescents living with HIV. The systematic review found no studies on children or adolescents (Pantelic et al. 2015). To enable such research, Paper 2 cross-culturally adapted a multidimensional HIV stigma scale and established its basic validity and reliability for use with South African adolescents living with HIV (Pantelic et al. 2016). The resultant scale is used in Paper 3, with internalised, enacted and anticipated stigma sub-scales hypothesized to be distinct, inter-related constructs (Earnshaw and Chaudoir 2009; Earnshaw et al. 2013). This paper is published:

Pantelic, M., Boyes, M., Cluver, L., & Meinck, F. (2017). HIV, violence, blame and shame : pathways of risk to internalized HIV stigma among South African adolescents living with HIV. *Journal of the International AIDS Society*, 20(1), 1–9. doi:10.7448/IAS.20.1.21771 (IF: 6.296).

Figure 16 A peri-urban data collection site



ABSTRACT

Introduction: Internalised HIV-stigma is a key risk factor for negative outcomes amongst HIV-positive adolescents, including non-adherence to anti-retroviral treatment, loss-to-follow-up and morbidity. However, no quantitative studies have investigated the prevalence or drivers of internalised HIV stigma in this high-risk group. This study tested a theoretical model of multi-level risk pathways to internalised HIV stigma among HIV+ South African adolescents.

Methods: Total population sampling of HIV-positive adolescents who had ever initiated anti-retroviral treatment in 53 public health facilities in the Eastern Cape, South Africa was used. 90.1% of eligible HIV-positive adolescents were interviewed (n=1060, 55% female, mean age = 13.8, 21% living in rural locations). HIV stigma mechanisms (internalised, enacted, and anticipated), HIV-related disability, violence victimization (physical, emotional, sexual abuse, bullying victimization) were assessed using well-validated self-report measures. Structural equation modelling was used to test a theoretically-informed model of risk pathways from HIV-related disability to internalised HIV-stigma. Following from modified labelling theory and supporting evidence, five hypotheses were derived: 1) HIV-related disability is directly associated with internalised HIV stigma; 2) The association between HIV-related disability and internalised HIV-stigma is mediated by inter-personal risks; 3) Inter-personal risks are directly associated with internalised HIV stigma; 4) The associations between inter-personal risks and internalised HIV stigma are also mediated by intra-personal risks; and 5) Intrapersonal risks are correlated with

internalised HIV stigma. The model controlled for age, gender and urban/rural address.

Results: Prevalence of internalised HIV stigma among adolescents living with HIV was 26.5%. As hypothesized, significant associations between internalised stigma and anticipated stigma, as well as depression were obtained. Unexpectedly, HIV-related disability, victimization, and enacted stigma were not directly associated with internalised stigma. Instead significant pathways were identified via anticipated HIV stigma and depression. The model fitted the data well (RMSEA=.023; CFI=.94; TLI=.95; WRMR=1.070)³.

Conclusions: These findings highlight the complicated nature of internalised HIV stigma. Whilst it is often thought to be a purely psychological process, indirect pathways suggest multi-level mechanisms leading to internalised HIV stigma. Findings suggest that a multi-level, inter-sectoral approach to addressing internalised HIV stigma among HIV-positive adolescents is needed. Namely, reducing HIV-related health problems, tackling maltreatment of adolescents living with HIV as well as child abuse, and mental health support could play important roles in stigma reduction strategies.

³ In the present paper (Paper 3), a dichotomous variable is included in the model (HIV-related disability) rendering the weighted root mean square residual (WRMR) statistic more appropriate. WRMR uses a variance-weighted approach specifically suited for models containing variables that are measured on different scales (Muthen and Muthen 2001). It is robust against non-normally distributed data and is recommended for modelling categorical or ordered data (Brown 2006). Conversely, Paper 2 reported the square root mean residual (SRMR) because all included variables used 3-point scales and were treated as continuous data via the maximum likelihood ratio estimator.

INTRODUCTION

Of all age groups, South African youth living with HIV are at highest risk of experiencing internalised HIV-related stigma (Human Sciences Research Council 2014) and dying to AIDS-related causes (Porth et al. 2014). Internalised HIV stigma occurs when an HIV-positive person internalizes perceived negative public attitudes towards people living with HIV and accepts them as applicable to themselves (Pantelic et al. 2015). It evokes strong feelings of shame and worthlessness (Pantelic et al. 2015), and can compromise use of evidence-based HIV prevention, testing and treatment services (Katz et al. 2013; Earnshaw et al. 2014; Ng and Tsai 2017; Treveskagan et al. 2017; Moshabela et al. 2016). As such, internalised HIV stigma can pose a serious threat to the long-term survival of HIV-positive adolescents (Gross et al. 2006; Lima et al. 2009; Reynolds et al. 2012). Eighty five percent of the world's HIV-positive adolescents live in Sub-Saharan Africa (WHO 2014), but there are no quantitative studies on the prevalence or drivers of internalised HIV stigma in this group (Pantelic et al. 2015). In order to identify points for intervention for these adolescents, it is essential to understand mechanisms of risk for internalised HIV stigma in this population.

In addition to internalised stigma, enacted and anticipated HIV stigma comprise the core, distinct psychosocial processes through which people living with HIV experience stigma (Earnshaw and Chaudoir 2009; Earnshaw et al. 2013). Enacted HIV stigma occurs at an interpersonal level, when people living with HIV experience discrimination, or are treated differently based on their HIV status (Holzemer et al. 2007). Anticipated HIV stigma occurs at an intrapersonal level, when an HIV-positive

individual anticipates negative public attitudes or differential treatment related to their HIV status (Earnshaw and Chaudoir 2009).

Evidence from the US suggests that internalised HIV stigma is correlated with anticipated and enacted HIV stigma (Earnshaw et al. 2013; Earnshaw and Quinn 2012) but there is limited research on this from Sub-Saharan Africa. Most Sub-Saharan African studies that tested associations between internalised HIV stigma and other stigma mechanisms did this using simple bivariate correlations to assess validity of multidimensional HIV stigma scales (Pantelic et al. 2015). They found weak to moderate associations between enacted and internalised HIV stigma (Holzemer et al. 2007; Kalichman et al. 2009; Simbayi et al. 2007), and anticipated and internalised HIV stigma (Visser and Sipsma 2013; Pantelic et al. 2016). But these analyses were intended for psychometric scale assessments and hence did not take into account any potential confounding pathways or variables. More research is needed to better understand whether and how the different HIV stigma mechanisms contribute to internalization of stigma, particularly because the vast majority of available anti-stigma interventions focus on reducing enacted stigma (Stangl et al. 2013).

There is also a dearth of research on other factors associated with internalised HIV stigma in Sub-Saharan Africa – perhaps a reason for the lack of well-established programs to address it (Stangl et al. 2013). A recent systematic review identified individual-level risk factors for internalised HIV stigma in adult samples: poor HIV-related health and depression appeared to predict increased internalised HIV stigma longitudinally (Pantelic et al. 2015). However, interpersonal risk factors were not assessed, and none of the studies focused on children or adolescents.

PROPOSED MODEL FOR INTERNALISED HIV STIGMA AMONG HIV-POSITIVE ADOLESCENTS

This study draws on modified labelling and socio-ecological theory to apply a ‘post-individualistic approach’ (Scambler 2009) to the problem theory of internalised HIV stigma among HIV-positive adolescents. This approach was deemed necessary for ethical, contextual and scientific reasons.

Firstly, from an ethics point of view, it could be argued that individual-level interventions rely on a victim-centric approach to a public health problem (McLeroy et al. 1988). Whilst these individual-level models do not dismiss the existence of inter-personal factors contributing to stigma, they situate the onus of change on the stigmatized. Two of only three known interventions aiming to reduce internalised HIV stigma in Sub-Saharan Africa focus on individual-level factors such as self-esteem and cognition among people living with HIV (Stangl et al. 2013; Tshabalala and Visser 2011; Uys et al. 2009). Such interventions may be able to reduce internalised HIV stigma at the individual level (Uys et al. 2009; Tshabalala and Visser 2011), but they are not equipped to affect its sources at the social level (Abadía-Barrero and Castro 2006; Castro and Farmer 2005). Hence, ‘the burden of adjustment falls on stigmatized individuals – with their responses conceptualized in terms of their individual abilities to adapt to the stress of stigma’ (Campbell and Deacon 2007).

Secondly, a socio-ecological model is highly relevant in the context of South African townships and remote rural areas, where adolescents and young people are exposed to multiple and inter-related social and psychological vulnerabilities (Bronfenbrenner

1979). Ethnographic data from Brazil, South Africa, Zambia and Zimbabwe suggest that the lived experiences of HIV-positive youth and their internalization of HIV stigma are inextricably tied to the violence permeating their households and communities (Abadía-Barrero and Castro 2006; Castro and Farmer 2005). Moreover, adolescents' psychological development is likely to be affected by complex social and biological transitions (Wigfield et al. 1991).

Modified labelling theory expands on the socio-ecological perspective (Mcleroy et al. 1988; Bronfenbrenner 1979) to highlight that stigma is 'dependent on social, economic, and political power' (Link, Cullen, Struening, Shrout, and Dohrenwend 1989). Here, stigma is defined as a co-occurrence of 'labelling, stereotyping, separation, status loss, and discrimination' within 'a power situation that allows them to unfold' (Link and Phelan 1999). This is particularly relevant to adolescents living with HIV, whose lived experiences are embedded within inter-personal dynamics and power-imbalanced environments (Bond 2006; Abadía-Barrero and Castro 2006; Clay, Bond, and Nyblade 2003; Strode and Grant 2001; Mahati et al. 2006). Relationships between adolescents, particularly those living with HIV, and older members of their households and communities are characterized by age, wealth and other power disparities (Abadía-Barrero and Castro 2006). HIV-positive adolescents rely on elders to access important resources such as housing and school fees, as well as life-saving treatment and healthcare. Research suggests that some caregivers, teachers, healthcare providers and community members exercise and maintain their authority through abuse, neglect, suppression, and control over access to information and services (Abadía-Barrero and Castro 2006; Cluver et al.

2011; Meinck, Cluver, Boyes, and Mhlongo 2015). It is therefore essential to assess whether and how these power imbalances, maltreatment and reproduction of social and physical disadvantages affect internalised HIV stigma among adolescents living with HIV (Abadía-Barrero and Castro 2006).

Data from HIV-endemic contexts support modified labelling theory, suggesting pathways from markers of HIV (i.e. poor HIV-related health) to internalised HIV stigma via both inter-personal labelling and psychological risks. First, AIDS-affected adolescents (who may be labelled as such due to association to AIDS-ill or deceased parents) are at higher risk of violence victimization than non-affected adolescents (Cluver et al. 2011; Meinck et al. 2015). The maltreatment of AIDS-affected adolescents is not always exhibited as HIV-specific enacted stigma, but is nonetheless often implicitly tied to the children's health and HIV status (Abadía-Barrero and Castro 2006). For example, ethnographic data from Brazil, South Africa, Zambia and Zimbabwe suggest that child abuse of AIDS-affected youth was linked to other household members' fear of HIV infection, and the perceived added burden of caring for ill children within a context of poverty (Bond 2006; Abadía-Barrero and Castro 2006; Clay, Bond, and Nyblade 2003; Strode and Grant 2001; Mahati et al. 2006). AIDS-affected youths' experiences of abuse victimization were thus inextricably tied to their HIV-related health, and their perceptions of HIV stigma further shaped by abuse victimization. Therefore, the established longitudinal link between poor HIV-related health and internalised HIV stigma (Pantelic et al. 2015), may be accounted for by abuse victimization and enacted HIV stigma (Bond 2006; Abadía-Barrero and Castro 2006; Clay, Bond, and Nyblade 2003; Strode and Grant

2001; Mahati et al. 2006; Meinck, Cluver, Boyes, and Mhlongo 2015; Cluver et al. 2011). However these hypothesized pathways have not yet been tested quantitatively.

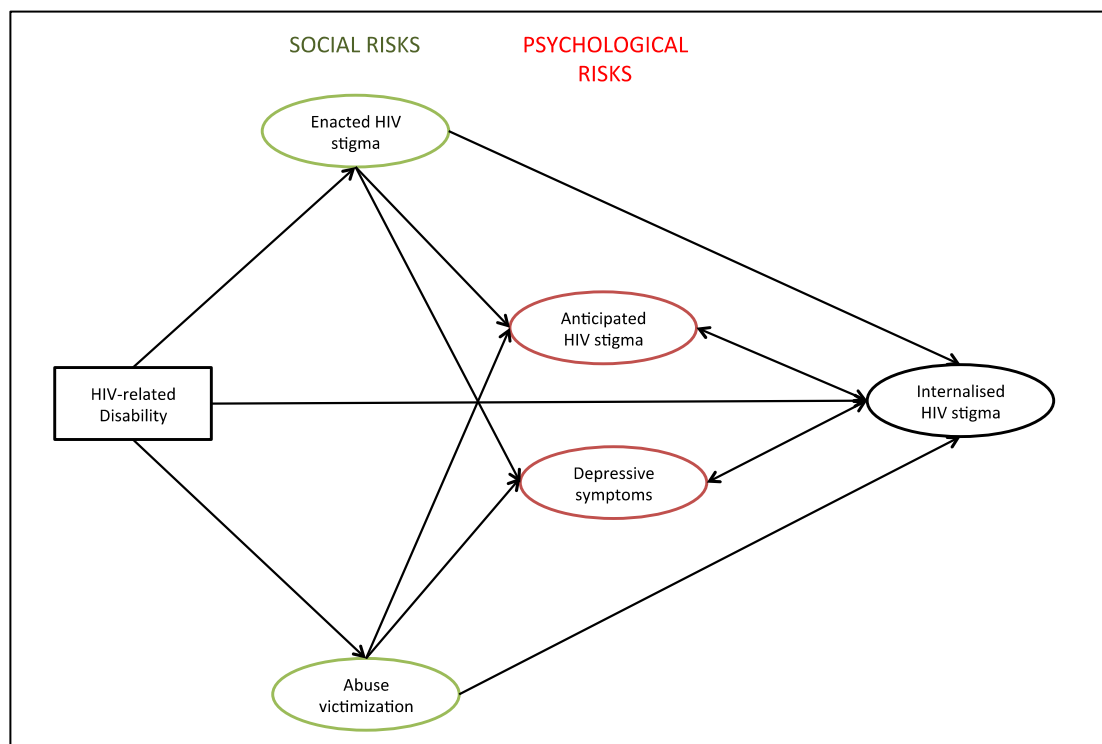
Second, the literature on violence victimization and developmental psychology suggests that child maltreatment may also be a key driver of internalised HIV stigma via reduced psychological wellbeing. Longitudinal data consistently suggest that over time, violence victimization in the form of physical, sexual, emotional abuse and bullying leads to increases in depressive symptoms (Chen et al., 2010; Hillberg et al., 2011; Maniglio, 2009; Norman et al., 2012; Pacheco, Irigaray, Memoriam, Nunes, & Argimon, 2014). Similarly, enacted HIV stigma and bullying victimization have been shown to have enduring negative impacts on depressive symptoms among AIDS-affected youth (Boyes and Cluver 2015; Boyes and Cluver 2013; Cluver and Orkin 2009). Third, longitudinal research with HIV-positive adults suggests that depressive symptoms drive increases in internalised HIV stigma (Pantelic et al. 2015; Tsai, Bangsberg, Bwana, et al. 2013) but this has not yet been assessed among adolescents (Pantelic et al. 2015).

Taken together, a growing body of longitudinal research and in-depth ethnographies suggests likely pathways from poor AIDS-related health (label) to internalised HIV stigma (outcome) via inter-personal maltreatment (violence victimization and enacted HIV stigma) and intrapersonal difficulties (depressive symptoms and anticipated stigma) (Figure 17). However, these potential pathways have not been tested in models, and the associations have not been explored among adolescents

living with HIV. Following from modified labelling theory and supporting evidence, five hypotheses were derived:

- i) HIV-related disability is directly associated with internalised HIV stigma.
- ii) The association between HIV-related disability and internalised HIV-stigma is mediated by inter-personal risks.
- iii) Inter-personal risks are directly associated with internalised HIV stigma.
- iv) The associations between inter-personal risks and internalised HIV stigma are also mediated by intra-personal risks.
- v) Intrapersonal risks are correlated with internalised HIV stigma.

Figure 17 Hypothesized risk pathways from HIV-related disability to internalised HIV stigma



METHODS

From 2013 – 2015, a survey of HIV-positive adolescents was administered in the Eastern Cape, South Africa. First, all state healthcare facilities in two health districts were mapped. Facilities providing treatment for 5 or more HIV-positive adolescents

were included in the study (n=53). Second, all adolescents (ages 10-19) who had ever initiated ART in the selected health facilities were sampled using clinic paper files and electronic databases. These adolescents (n=1,176) were traced in their communities so as to ensure inclusion of HIV-positive adolescents who were not actively engaged in the healthcare system. One-on-one interviews (n=1060) were conducted in participants' homes, clinics or other places identified as safe and comfortable by the participants. Interviews lasted for about 90 minutes, were carried out on tablets and remuneration was not provided except for certificates, refreshments, and a basic toiletry pack. Full details on the study procedures have been reported elsewhere (Pantelic et al. 2016).

Voluntary informed consent was obtained from caregivers and adolescents. Confidentiality was maintained, except in cases of significant harm or when participants requested assistance. Where participants reported recent abuse, rape, suicidal attempt or other risk of significant harm, referrals were made to child protection and health services. Children could send free 'Please call me' text messages to the research team in the event of an emergency. A total of 66 referrals for HIV-positive adolescents were made. Ethical clearance for this study was provided by the University of Oxford, University of Cape Town, South African National Departments of Health, Basic Education and Social Development as well as the Eastern Cape Departments of Health, Basic Education and Social Development.

Measures

Age, gender and rural household location were recorded for descriptive purposes and for inclusion in the model as covariates.

HIV stigma mechanisms were measured via the 10-item HIV stigma scale for adolescents living with HIV (ALHIV-SS). The ALHIV-SS was developed in collaboration with HIV-positive adolescents in South Africa and has been shown to have strong psychometric properties (Pantelic et al. 2016). Enacted, anticipated and internalised HIV stigma were assessed via 3, 2 and 5 items, with Cronbach's α levels of .57, .70 and .75 respectively. Latent variables of enacted, anticipated and internalised HIV stigma were used with individual items loaded onto them.

HIV-related disability was measured via a two-item scale asking about physical and cognitive disability adapted from The International Classification of Functioning, Disability and Health (ICF). The scale displayed good reliability (Cronbach's $\alpha = .60$) (WHO 2001). Items were recoded into a dichotomous variable to capture any report of disability (0: no disability; 1: 1 or more disability).

Violence victimization was a latent measure with loaded factor scores for physical, emotional and sexual abuse, and bullying victimization. *Physical abuse* (2 items) and *emotional abuse* (10 items) were measured using items from the UNICEF Measures for National-level Monitoring of Orphans and Other Vulnerable Children (Snider & Dawes, 2006). These measures have displayed acceptable reliability ($\alpha=.70$) in previous studies of HIV/AIDS affected adolescents in South Africa (Meinck, Cluver, and Boyes 2015) as well as the present sample ($\alpha=.77$). Response options for all

physical abuse and emotional abuse items were offered on a 5-point scale (0: never; 1: has happened, but not in the last year; 2: at least once this year; 3: monthly; 4: weekly). Items on physical abuse asked about being hit with hard items and being slapped, punched or hit by adults. Items capturing emotional abuse include threats to be abandoned, sent away or kicked out of the house and being called names. *Contact sexual abuse* was measured using three items from the Juvenile Victimization Questionnaire (JVQ) (Finkelhor et al. 2005), also used in previous studies in South Africa (Meinck, Cluver, and Boyes 2015). Items included being forced to touch others' or their own private parts; forced sex; being touched or kissed in an uncomfortable way. *Bullying victimization* was measured with the 9-item 'Social and Health Assessment Peer Victimization Scale', used in previous studies with AIDS-affected children (Boyes and Cluver 2015; Cluver, Bowes, and Gardner 2010a; Cluver and Orkin 2009a). This scale was adapted from the Multidimensional Peer Victimization Scale, which was validated in the US (Mynard and Joseph 2000). Items included being called names, being hit or threatened and having possessions broken or stolen. It demonstrated good internal consistency ($\alpha=.79$) in the present sample.

Depressive symptoms were measured via the Child Depression Inventory short form (CDI-S), which has comparable results with the full CDI (Kovacs 1995). CDI-S has been used with AIDS-affected adolescents in South Africa, displaying acceptable internal consistency ($\alpha=.67-.69$) (Cluver et al. 2012). CDI-S also demonstrated acceptable internal consistency in the present sample ($\alpha=.62$). A latent variable was used in the present study, with individual items loading onto the depressive symptoms factor.

ANALYSIS

Analyses were conducted in SPSS and Mplus7. The analysis was conducted in three stages. First, to estimate the extent of bias in the sample, socio-demographic characteristics of eligible HIV-positive adolescents who were not reached were compared to the socio-demographic characteristics of HIV-positive adolescents who were interviewed, using SPSS. Mean age between the included and excluded HIV-positive adolescents was compared using z-scores. Gender and rurality frequencies between the included and excluded HIV-positive adolescents were compared using *Chi*².

Second, prevalence rates of enacted, anticipated and internalised HIV stigma, HIV-related disability, different types of violence victimization were calculated in SPSS. Dichotomous variables for different stigma mechanisms were defined to capture reports of any enacted, anticipated and internalised HIV stigma. Similarly a dichotomous variable for any type of HIV-related disability was calculated. A dichotomous variable was created for *frequent emotional abuse* (0: once this year or less; 1: monthly or more often) and similarly for *frequent physical abuse* (0: once this year or less; 1: monthly or more often). Categorisations of frequent physical and emotional abuse were chosen based on previous studies with vulnerable children in South Africa, which aimed to clearly distinguish abuse from harsh parenting (Meinck, Cluver, Boyes, and Ndhlovu 2015). *Lifetime prevalence of contact sexual abuse* was also assessed (0: never sexually abused; 1: sexually abused). A dichotomous variable for *any* type of bullying victimization reported was calculated. These dichotomies were used solely for descriptive purposes, and scales were retained for the structural

equation model. Mean scores for depressive symptoms were also calculated due to a lack of a validated clinical cutoff for the South African context.

Third, the structural equation model consisted of (1) a confirmatory factor analysis to confirm latent constructs and (2) a pathway model to assess a hypothesized theoretical model of internalised HIV stigma risks (Figure 17). All included variables were latent constructs except for child disability, which was an observed variable. The structural equation model controlled for age, gender and rural household location. Model fit was assessed with: Comparative Fit Index (CFI) (>.90 indicates adequate fit), Tucker Lewis Index (TLI) (> .95 indicates adequate/good fit) (Li-tze Hu and Bentler 1995; Bentler 1990; Li-tze Hu and Bentler 1999), and Root Mean Square Error of Approximation (RMSEA) (< .05 indicated good model fit) (Bowen and Guo 2012). χ^2 is not recommended for assessing goodness-of-fit in large samples as it is sensitive to sample size and is prone to Type 2 error (Schermeleeh-Engel, K. Moosbrugger and Müller 2003; Vandenberg 2006). χ^2 was therefore noted but not used to estimate model fit.

RESULTS

A total of 90.1% (n=1060) of the eligible HIV-positive adolescents were interviewed. 4.1% of HIV-positive adolescents refused to participate (either caregiver or adolescent), 3.7% could not be traced, 0.9% were excluded due to severe cognitive delays and 1.2% were excluded due to other reasons such as emergency referrals, unsafe communities, and having moved out of study catchment area. As reported in the methodology chapter of this thesis, a comparison of the included and excluded

eligible samples based on known information: age, gender and rural/ urban residential location identified no statistically significant differences between the interviewed and excluded samples (Table 6 in Chapter IV).

Table 14 summarizes characteristics of the study sample. The mean age of respondents was 13.8; 55.2% (587) of them were girls and 21.4% (228) lived in rural locations. Prevalence of enacted, anticipated and internalised HIV stigma was 7.4%, 29.9%, and 26.5% respectively. Lifetime prevalence of contact sexual abuse victimisation among HIV-positive adolescents was six percent. Five percent of HIV-positive adolescents reported being physically abused at least monthly, and eight percent of HIV-positive adolescents reported being emotionally abused at least monthly in the past year. 59% of respondents reported any instances of bullying victimization in the past year. 40.8% of respondents reported having an HIV-related disability. The mean (SD) score for depressive symptoms was 1.25 (1.98), with values ranging between 0 and 15.

Table 14 Sample characteristics (n=1060 adolescents living with HIV)

	n, %
Sociodemographics	
Age (mean, SD)	13.8, 2.834
Female	587, 55.2%
Rural	228, 21.4%
Intra-personal risks	
Any anticipated stigma	314, 29.9%
Any internalized stigma	281, 26.5%
HIV-related disability	432, 40.8%
Depressive symptoms (mean, SD)	1.25 (1.98)
Inter-personal risks	
Any enacted stigma	78, 7.4%
Lifetime prevalence of contact sexual abuse	64, 6.0%
Monthly physical abuse victimization in the past year	53, 5.0%
Monthly emotional abuse victimization in the past year	85, 8.0%
Past year bullying victimization	625, 59.0%

MEASUREMENT MODEL

The measurement model confirmed distinct latent constructs for enacted HIV stigma, violence victimization, anticipated HIV stigma, depression and internalised HIV stigma. Table 15 summarizes factor loadings of each indicator onto latent constructs of abuse victimization, enacted HIV stigma, anticipated HIV stigma, depression and internalised HIV stigma. The measurement model statistics indicated excellent model fit: RMSEA=.04; CFI=.984; TLI=.982; WRMR=.873; $\chi^2(df) = 297.935$ (242).

Table 15 Factor loadings for latent constructs

	Standardized estimate
Abuse victimization	
Physical abuse	.458***
Emotional abuse	.659***
Sexual abuse	.407***
Bullying victimization	.648***
Enacted HIV stigma	
Stopped spending time with friends	.769***
Lost friends because of HIV	.674***
Teased because of HIV status	.990***
Anticipated HIV stigma	
People think that HIV-positive people are disgusting	.994***
People think that HIV is a punishment	.729***
Depression	
Personal outlook	.550***
Frequency of sadness	.695***
Feelings about appearance	.599***
Feelings toward self	.768***
Frequency of loneliness	.529***
Self-evaluation	.456***
Friends	.387***
Frequency of crying	.662***
Feelings of love	.623***
Bothered frequency	.769***
Internalised HIV stigma	
Does not feel as good as others because of their HIV status	.766***
Would rather die than live with HIV	.817***
Feels like a bad person for living with HIV	.833***
Feels ashamed of their HIV status	.780***
Feels dirty/contaminated inside because of HIV	.852***

*** indicates $p < .001$

STRUCTURAL EQUATION MODEL

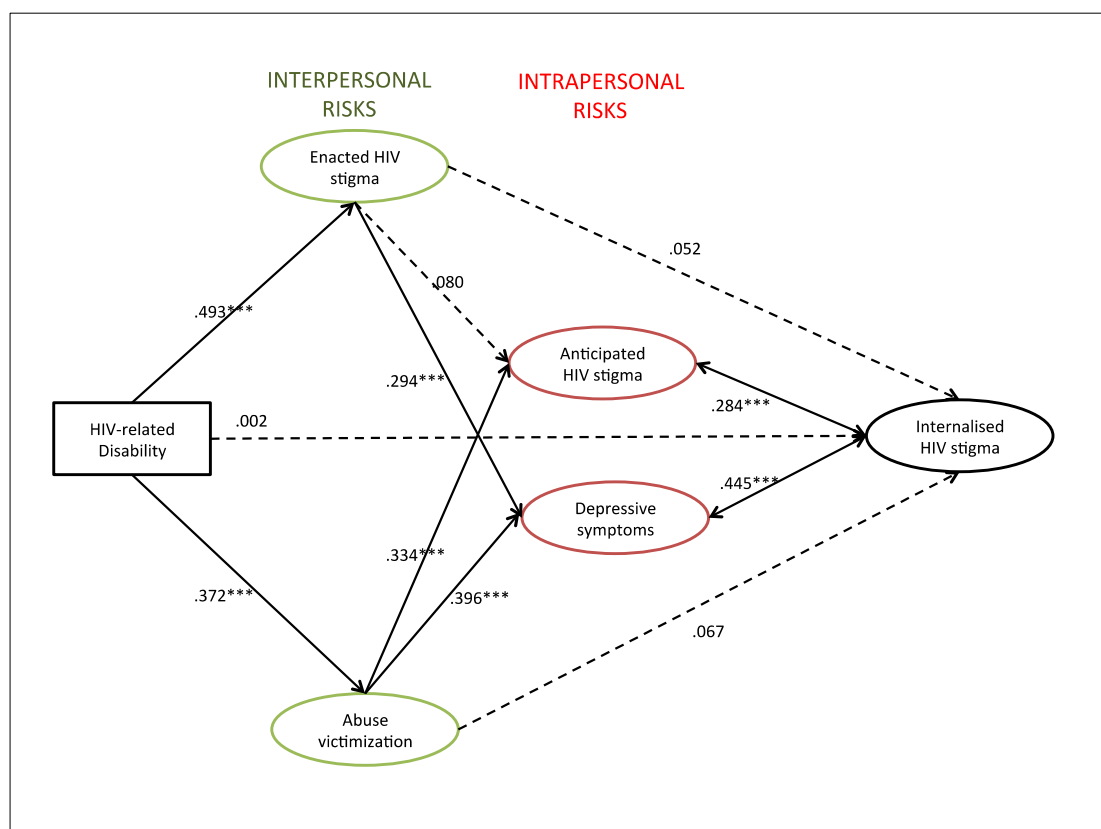
The results of the structural equation model are summarized in Figure 18. The model controlled for age, gender and rural household location. Rectangular shapes signify observed variables whereas ovals mark latent variables. Values indicate standardized β weights. Full lines indicate pathways that were significant at the $p < .001$ level (***). Dotted lines indicate hypothesized pathways that were non-significant. Child disability was hypothesized to have a direct effect on enacted HIV stigma, abuse victimization and internalised HIV stigma. Child disability was hypothesized to predict enacted HIV stigma, abuse victimization and internalised HIV stigma. Enacted HIV stigma and abuse victimization were both hypothesized to be associated with depression, anticipated HIV stigma and internalised HIV stigma. Bidirectional associations between internalised HIV stigma and anticipated HIV stigma and depression were also hypothesized. Of these hypothesized associations, four were non-significant: (1) the direct association between HIV-related disability and internalised HIV stigma, (2) the direct association between abuse victimization and internalised HIV stigma, (3) the direct association between enacted HIV stigma and internalised HIV stigma and (4) the association between enacted HIV stigma and anticipated HIV stigma.

Internalised HIV stigma was directly associated with anticipated HIV stigma ($\beta = .284$, $p < .001$), depressive symptoms ($\beta = .445$, $p < .001$) and urban household location ($\beta = -.014$, $p < .001$). Gender ($\beta = .017$, $p = .196$) and age ($\beta = -.011$, $p = .583$) were not significantly associated with internalised HIV stigma. In addition, the following pathways were identified. HIV-related disability was associated with more enacted

HIV stigma ($\beta=.493, p<.001$) and more abuse victimization ($\beta=.372, p<.001$). Enacted HIV stigma was associated with more depressive symptoms ($\beta=.294, p<.001$) but not with anticipated HIV stigma. Abuse victimization was associated with more anticipated HIV stigma ($\beta=.334, p<.001$) and more depressive symptoms ($\beta=.396, p<.001$). Indirect effects of HIV-related disability on higher depression scores via more abuse victimization ($\beta=.147, p<.001$) and more enacted HIV stigma ($\beta=.145, p<.001$) were observed. HIV-related disability was also indirectly associated with more anticipated HIV stigma via more abuse victimization ($\beta=.124, p<.001$).

The fit of the final model was RMSEA=.023; CFI=.94; TLI=.95; WRMR=1.070; χ^2 (df)= 3857.655 (372). All fit statistics were excellent according to the pre-specified criteria.

Figure 18 Final structural equation model results.



DISCUSSION

This paper aimed to test a theoretical model of hypothesized risk pathways to internalised HIV stigma among adolescents living with HIV in South Africa. As hypothesized, significant associations between internalised stigma and anticipated stigma, as well as depression were obtained. Unexpectedly, HIV-related disability, victimization, and enacted stigma were not directly associated with internalised stigma. These findings highlight the complicated nature of internalised HIV stigma. Whilst it is seemingly a psychological process, indirect pathways suggest multi-level mechanisms leading to internalised HIV stigma.

The present study expands on findings from longitudinal studies with HIV-positive adults in the region, which found visible markers of HIV (poor HIV-related health) to be predictive of increases in internalised HIV stigma (Pantelic et al. 2015). However, our findings suggest that this relationship is mediated by social and psychological risks. Namely, HIV-related disability was associated with internalised HIV stigma only indirectly, via social risks (enacted HIV stigma and abuse victimization) and psychological risks (anticipated HIV stigma and depressive symptoms). This suggests that multi-level approaches to internalised HIV stigma are likely to be needed.

Meta-analytic evidence has established that internalised HIV stigma is a key risk factor for non-adherence to ART (Katz et al. 2013), which increases the likelihood of onward HIV transmission and death. Yet, the vast majority of anti-stigma interventions target enacted HIV stigma (Stangl et al. 2013). Two of the three tested interventions that target internalised HIV stigma in Sub-Saharan Africa focused on

psychological and cognitive factors, (Uys et al. 2009; Tshabalala and Visser 2011). They were delivered in clinic settings to small groups (n=7-10) of HIV-positive adults (Uys et al. 2009; Tshabalala and Visser 2011). The only other known intervention offered year-long food assistance on a monthly basis, and was embedded in an HIV care program within a non-governmental clinic (Maluccio et al. 2016). In light of present findings, a more holistic approach to addressing internalised HIV stigma may be required for adolescents. Our findings suggest that addressing individual-level risks – such as anticipated HIV stigma and depression – and HIV treatment and care will be essential to reduce internalised HIV stigma among adolescents living with HIV. However they also suggest that tackling discrimination against adolescents living with HIV and violence victimization in homes, schools and communities may also help by producing indirect effects against internalised HIV stigma. Hence family, peer and community interventions outside of clinic settings may be needed.

Of note is that enacted HIV stigma was *not* associated with anticipated HIV stigma, which was one of the correlates of internalised HIV stigma. This is contrary to adult-focused studies, which used simple bivariate correlations (Pantelic et al. 2015). Our findings suggest that HIV-related disability and/or violence victimization predict anticipated HIV stigma over and above enacted HIV stigma. Moreover, our findings suggest that enacted HIV stigma is associated with internalised HIV stigma only indirectly, via higher levels of depressive symptoms. More foundational and intervention research on the various HIV stigma mechanisms is urgently needed.

This study has four important limitations that should be noted. First, the cross-sectional data limit inferences about order of effects. More foundational,

longitudinal research is needed to understand the mechanisms and their temporal sequencing. Second, stigma is culturally embedded and socially constructed (Goffman 1968; Kleinman and Hall-Clifford), and therefore the manifestation of HIV stigma mechanisms is dependent on the context. The present study reports on data from HIV-positive adolescents in the Eastern Cape, South Africa and this may limit generalizability of findings. Third, only adolescents who had ever initiated ART were sampled. This may have limited reach of the most stigmatized adolescents who have not yet tested or initiated ART. However, unlike previous studies on internalised HIV stigma (Pantelic et al. 2015), this study community-traced adolescents in an attempt to reach adolescents who had dropped out of treatment. Hence, adolescents who were missing clinic visits, defaulting or were lost to follow up were included in the study.

Fourth, many of the adolescents living with HIV in this study were unaware of their status, and it remains unclear whether and how this could have impacted their internalisation of HIV stigma. To avoid inadvertent disclosure of status to the adolescents, we were not able to ask them directly about their knowledge of HIV status. Rather, we were only able to record whether or not the adolescent disclosed their status to the research team. Our sample also included adolescents who have been told they are HIV-positive but have not yet come to terms with their status and we were unable to explore these nuances so as to avoid inadvertent disclosure of adolescents' status to them or their families. Future research on whether and how knowledge of one's HIV status – as well as the varying degrees of understanding of HIV seropositivity – impact internalised HIV stigma is clearly needed.

This study also has a number of strengths. First, to our knowledge, this is the first study on internalised HIV stigma among HIV-positive adolescents in Africa. Second, the structural equation model allowed us to take into account multiple inter-related risks such as the various HIV-stigma mechanisms, violence victimization, depressive symptoms and HIV-related disability. This enabled a more nuanced picture of how HIV-related disability – a key risk factor which had already been detected in previous research (Pantelic et al. 2015) – leads to internalised HIV stigma. Lastly, the inclusion of all three HIV stigma mechanisms enabled the analysis to test associations between them. These associations had previously been assumed from simple bivariate analyses. However previous epidemiological (Pantelic et al. 2015) and intervention research (Stangl et al. 2013) on internalised HIV stigma did not always account for other HIV stigma mechanisms. Understanding whether and how enacted, anticipated and internalised HIV stigma are related is essential to informing policy and programming.

Conclusions

This study identified multiple pathways of risk to internalised HIV stigma. Findings suggest that internalised HIV stigma may be addressed by acting on multiple levels. Namely, reducing HIV-related health problems, tackling maltreatment of adolescents living with HIV as well as child abuse, and mental health support could play important roles in stigma reduction strategies. Hence, anti-stigma interventions might benefit from incorporating components of ART adherence interventions to improve the physical health of adolescents living with HIV. However more research is needed on how to best support HIV-positive adolescents' adherence (Chaiyachati et

al. 2014). Cognitive-behavioural therapy and exercise, which have been shown to effectively reduce depression among adolescents (Das et al. 2016), might also help adolescents living with HIV and have flow on protective effects against internalised HIV stigma. Lastly, interventions that do not necessarily target HIV-positive adolescents but are sensitive to their needs such as parenting programmes (Mikton and Butchart 2009) and school-based anti-bullying programmes (Cantone et al. 2015) to reduce violence victimization might help reduce internalised HIV stigma.

REFERENCES

To avoid repetition, citations used in this paper are listed in the joint references section at the end of this thesis.

CHAPTER VIII. DISCUSSION

OVERVIEW

The main aim of this thesis was to contribute to the problem theory of internalised HIV stigma among adolescents living with HIV in Sub-Saharan Africa. As the first epidemiological study on internalised HIV stigma in this population, the DPhil had three specific objectives, each resulting in a stand-alone peer-reviewed paper:

Objective 1/ Paper 1: To systematically review the literature on prevalence and predictors of internalised HIV stigma among people living with HIV in Sub-Saharan Africa;

Objective 2/ Paper 2: To develop a culturally relevant and age-appropriate tool for measuring HIV stigma among HIV-positive adolescents in the region; and

Objective 3/ Paper 3: To test a theoretical model of risk pathways to internalised HIV stigma within the world's largest known sample of HIV-positive adolescents.

This DPhil has contributed to knowledge and methodology for future research on HIV stigma. Papers 1 and 3, the systematic review and the empirical paper, contributed to knowledge on prevalence and correlates of internalised HIV stigma, and identified potential points of intervention. Modified labelling theory and the socio-ecological model of human development informed the interpretation of systematic review findings and generated hypotheses for the primary study.

Although previous adult-focused studies focused on individual-level predictors of internalised HIV stigma, findings from this thesis suggest that post-individualistic models such as modified labelling theory are relevant to studying internalised HIV stigma among adolescents. This thesis has also made a methodological contribution to the field through its sampling methodology and by developing the first scale for measuring HIV stigma among adolescents living with HIV in Southern Africa (Paper 2). The scale is fully accessible through an online open-access journal (*Child Indicators Research*).

The following sections provide a discussion on each of the overall DPhil findings, categorized into the following themes: prevalence of internalised HIV stigma, factors associated with internalised HIV stigma and methodological contributions. Next, the DPhil limitations and strengths are discussed. The penultimate section reflects on implications for policy and future research. The chapter ends with a summary of dissemination strategies employed as part of this DPhil.

PREVALENCE OF INTERNALISED HIV STIGMA

Prevalence of any report of internalised stigma in the study sample of adolescents living with HIV was 26.5%. The systematic review found that, within adult samples in Sub-Saharan Africa, reports of any internalised HIV stigma ranged between 26.9% and 66%. These differences are a likely reflection of key differences between the primary studies in the systematic review and the primary study of this DPhil. First, the characteristics of the samples included in the systematic review have limited relevance to the present sample of South African adolescents living with HIV. The six

studies from the systematic review that reported on prevalence of internalised HIV stigma focused on different target populations: one focused on men who have sex with men (Cloete et al. 2008), two focused on pregnant women (Cuca et al. 2012; Visser and Sipsma 2013) and all focused on adults living with HIV (Kingori et al. 2013; Neuman and Obermeyer 2013; Sorsdahl et al. 2011). Moreover, these samples came from a wide variety of countries. Even within the same study, Neuman and Obermeyer (2013) found stark differences in prevalence rates between countries: ranging from 9.6% in Malawi to 45% in Burkina Faso⁴.

Second, major differences in sampling and recruitment between the present study, and the studies included in the systematic review should be noted. Two-thirds of the articles included in the systematic review reported a response or retention rate below 70%, and the majority of the studies (10/18 papers) did not report on response or retention rates at all. Moreover, the majority of the systematic review studies that reported on prevalence rates recruited participants within organizations offering non-medical support to people living with HIV (i.e. support groups, the South African National Association of People Living with HIV, social service providers and gay venues). This is likely to have generated non-representative samples of people living with HIV. Namely, studies recruiting only people who are receiving additional support due to specific needs might be biased due to one or both of the following reasons. Such studies could 1) oversample most at risk people in need of

⁴ For the purposes of the systematic review, these values were pooled into an average to allow reporting per study, rather than subsamples within studies.

additional services, or 2) result in an underestimate of risk due to reaching only people who are receiving beneficial services. Of the studies that recruited participants through health facilities, the vast majority did not report any method for selecting participating health facilities. Within facilities, less than a third of studies (5/18) used total or random sampling of participants. Due to these methodological shortfalls a meta-analysis was not conducted, as it would have rendered biased estimates (Kukull and Ganguli 2012). Conversely, this DPhil used total population sampling of health facilities and community tracing of all adolescents registered within health facilities. For these reasons it is likely that the prevalence estimate generated through the primary study of this DPhil is more generalizable to people living with HIV rather than patients actively engaged in selected health facilities.

It should be noted that there is no known agreed cut-off for measuring prevalence of internalised HIV stigma (Stevelling et al. 2012; McAteer et al. 2016). Therefore, caution is warranted against making firm conclusions about the prevalence of internalised HIV stigma based on the primary study with adolescents living with HIV. The present study followed the same cut-off used in other studies identified in the systematic review: it differentiated between no internalised HIV stigma and any internalised stigma. This 'zero stigma' cut-off is also used in the UNAIDS 'Getting to zero' strategy (UNAIDS 2010a), which put forth policy recommendations for eliminating new HIV infections, AIDS related deaths and HIV-related stigma. The UNAIDS 'zero stigma' target was a key component of this strategy due to anticipated public health benefits. First, the elimination of stigma was envisioned to curb new HIV infections and AIDS-related deaths by strengthening HIV prevention and

treatment access (UNAIDS 2010a; Katz et al. 2013). Second, reaching the ‘zero stigma’ target would promote the advancement of human rights and improve the quality of life of people living with HIV (UNAIDS 2010, Peltzer 2012).. Therefore, measuring the prevalence of ‘any’ stigma reported by people living with HIV is highly relevant for policy and programmatic reasons.

METHODOLOGICAL CONTRIBUTIONS OF THE DPHIL

One of the barriers to conducting research on internalised HIV stigma among HIV-positive adolescents in Africa has been the lack of a culturally-relevant, age appropriate and validated tool for measuring stigma in this population (Earnshaw and Chaudoir 2009; McAteer et al. 2016; Stevelink et al. 2012). Paper 2 sought to make a methodological contribution to the field by cross-culturally adapting and psychometrically assessing an HIV stigma scale for adolescents living with HIV. The resultant scale is the first HIV stigma tool specifically designed for and in collaboration with adolescents living with HIV in the region. This is also the first HIV stigma scale to measure all three HIV stigma mechanisms within an HIV-positive sample in Sub-Saharan Africa. Given the dearth of research on HIV stigma among adolescents living with HIV, this measurement tool will be valuable for future foundational and intervention research in this high-risk group.

The community tracing used in this study is likely to have generated a highly representative sample of adolescents living with HIV. The approaches used to enable research outside of clinic settings have been described in detail in this thesis – including approaches to tracing, consent, data confidentiality, screening of

adolescents' HIV status awareness, and interviews. Previous quantitative studies on internalised HIV stigma recruited participants through healthcare facilities, community organizations or other service providers (Pantelic et al. 2015; Stangl et al. 2013). Such recruitment approaches would have generated biased samples. Studies recruiting through health facilities would exclude adolescents living with HIV who are most at risk for internalised stigma, and whose access to services is likely to be hampered by stigma. Studies recruiting through community based organizations servicing those most in need are likely to result in a different bias, one overestimating risk. The work conducted as part of this DPhil demonstrates that community tracing of adolescents living with HIV is feasible. This approach may have important implications for future research and interventions, as adolescents living with HIV continue to display low levels of engagement with healthcare services. Only 11.8% of the present study's participants were interviewed in healthcare facilities and the rest were traced in communities.

FACTORS ASSOCIATED WITH INTERNALISED HIV STIGMA

This DPhil used modified labelling theory to 1) synthesize the evidence base on predictors of internalised HIV stigma in Sub-Saharan Africa and 2) explore a theoretical model of risk for internalised HIV stigma among South African adolescents living with HIV. Findings from the systematic review (Paper 1) informed the inclusion of specific variables into the structural equation model in the empirical paper (Paper 3). The enacted, anticipated and internalised HIV stigma sub-scales developed in Paper 2 were used.

Paper 1 found few studies using prospective cohort data and, from their findings, the only consistent predictors of internalised HIV stigma identified were individual-level risk factors. Specifically, poor physical health was found to be predictive of increases in internalised HIV stigma in three longitudinal studies, and poor mental health predicted internalised HIV stigma in two longitudinal studies. Inter-personal risk or protective factors were not studied longitudinally despite strong criticisms of HIV stigma research for its omission of the broader social and cultural contexts in which stigma develops (Parker and Aggleton 2003; Link, Cullen, Struening, Shrout, and Dohrenwend 1989).

In line with what Parker and Aggleton have highlighted in their review of HIV stigma research (Parker and Aggleton 2003), few of the primary studies included in the systematic review were grounded in any theoretical perspectives. This thesis used modified labelling theory to expand on the systematic review findings and hypothesize a post-individualistic model of risk for internalised stigma. This framework stresses the importance of inter-personal relationships and power imbalances in the creation and persistence of stigma (Link, Cullen, Struening, Shrout, and Bruce 1989). Through this lens, internalised HIV stigma among adolescents living with HIV can be seen as a product of maltreatment, discrimination and violence victimization within power-unequal relationships (Abadía-Barrero and Castro 2006).

Hence, Paper 3 explored both inter-personal and intrapersonal pathways from HIV-related disability to internalised HIV stigma. As hypothesized, significant associations between internalised stigma and other intrapersonal risks were obtained (anticipated stigma and depressive symptoms). However, unexpectedly, HIV-related

disability and inter-personal risks were not directly associated with internalised stigma. Rather, HIV-related disability was associated with internalised HIV stigma only indirectly, via inter-personal and intra-personal risks. Inter-personal risks were also associated with internalised HIV stigma only indirectly, via intra-personal risks.

Findings suggest that HIV-positive adolescents experience internalised HIV stigma due to enacted stigma, violence victimization and the resultant psychological distress. Adolescents with visible markers of HIV infection seem to be at heightened risk of maltreatment such as teasing, bullying and abuse victimization, which can have follow on effects for psychological distress and internalised HIV stigma. This partly confirms findings from previous studies examining relationships between HIV-related health and internalised HIV stigma in adult samples. These studies found that over time on ART, internalised HIV stigma reduces due to improvements in physical and mental health. However the present study makes an important contribution by suggesting additional inter-personal pathways of risk among adolescents living with HIV. These inter-personal risks occur among peers, family and community members.

Adolescence is a time when self-conceptions develop: early adolescents often see themselves through abstract and occasionally discrepant characterizations, and their self-image becomes more coherent as they approach adulthood (Steinberg and Morris 2001). Difficult physical, psychosocial and intellectual transitions often compromise the self-worth and general self-esteem of adolescents (Wigfield et al. 1991), and HIV adds complexities to each of these developmental transitions (Li et al. 2010). Adolescents who were born with HIV are more likely to experience lower weight and height-for-age compared to their peers (Isanaka, Duggan, and Fawzi

2009). HIV can also affect the nervous system and cause cognitive delays (Sherr, Croome, et al. 2014). With few evidence-based interventions to support these youth and their carers (Sherr et al. 2014), cognitive difficulties often result in poor educational outcomes for young people living with HIV relative to HIV-negative peers (Guo, Li, and Sherr 2012). Findings from this DPhil suggest that adolescents with physical and/or cognitive markers of HIV are at heightened risk of maltreatment and psychological distress, and that this can compromise their self-worth.

In line with previous qualitative studies (Bond 2006; Abadía-Barrero and Castro 2006; Clay, Bond, and Nyblade 2003; Strode and Grant 2001; Mahati et al. 2006), this DPhil found that the maltreatment is not always exhibited as HIV-specific discrimination. Rather, it is often manifested through bullying victimization and physical, emotional or sexual abuse. All of these forms of maltreatment seem to affect internalised HIV-related stigma among adolescents living with HIV. This adds complexity to some of the theoretical models used to explain internalised HIV stigma as a product of enacted and anticipated stigmas (Earnshaw et al. 2013; Earnshaw and Chaudoir 2009). Whilst there is a strong evidence base for interventions aiming to reduce enacted HIV stigma (Stangl et al. 2013), findings from this DPhil suggest that stigma may be more multi-faceted than what is often assumed, and include severe forms of maltreatment and violence victimization.

In light of these findings, internalised HIV stigma may be addressed by interrupting interpersonal risks in addition to intrapersonal ones, which has not yet been done (Stangl et al. 2013). The implications for programming, directions for future research

and limitations of this DPhil are discussed in more detail within the following sections of this chapter.

IMPLICATIONS FOR POLICY AND PROGRAMMING

This DPhil focused on inter-personal and intra-personal risks associated with internalised HIV stigma, and consisted of a systematic review and a primary study. The systematic review identified only a limited number of longitudinal studies on predictors of internalised stigma and these were all based on adult samples. Moreover, the primary study conducted as part of this DPhil used cross-sectional data, which precludes the determination of casual risk factors. However, findings from the primary study are aligned with data from longitudinal adult-focused studies in Sub-Saharan Africa (Pantelic et al. 2015), and supported by evidence from the US (Lee, Kochman, and Sikkema 2002). Taken together, there is a reasonable amount of evidence to generate hypotheses about interventions that may help reduce internalised HIV stigma among HIV-positive adolescents. Rigorous programme and process evaluations are warranted to test the effectiveness and applicability of these interventions before firm conclusions can be made (Fraser et al. 2009).

1. Internalised HIV stigma is common among adolescents living with HIV and warrants more programmatic attention. Prevalence of any report of internalised stigma was 26.5% in this sample. By contrast, only three interventions targeting internalised stigma have been evaluated in Sub-Saharan Africa, and none are available for adolescents. Interventions should aim to address correlates of

internalised stigma identified by this DPhil and in future studies, and be evaluated ideally through randomized control trials.

2. Family- and community-level interventions might be suitable for tackling internalised stigma among HIV-positive adolescents through protection from violence victimization and child abuse.

Interventions targeting internalised HIV stigma in sub-Saharan Africa were investigated only within healthcare facilities (Uys et al. 2009; Tshabalala and Visser 2011; Maluccio et al. 2016). However this thesis found that violence victimization and enacted stigma are associated with higher levels of internalised HIV stigma via higher levels of depressive symptoms and anticipated stigma. Whilst these findings are cross-sectional, they are in line with longitudinal studies on adult internalised HIV stigma, violence victimization and adolescent mental health (Cluver and Orkin 2009b; Boyes and Cluver 2015). For example, longitudinal findings from multiple systematic reviews consistently suggest that over time, child abuse victimization in the form of physical, sexual, emotional abuse and bullying leads to increases in depressive symptoms (Chen et al. 2010; Hillberg, Hamilton-Giachritsis, and Dixon 2011; Maniglio 2009; Norman et al. 2012; Pacheco et al. 2014; Ttofi et al. 2011). Similarly, enacted HIV stigma and bullying have been shown to have enduring negative impacts on depressive symptoms among AIDS-affected youth (Boyes and Cluver 2015). Longitudinal research with HIV-positive adults suggests that depressive symptoms drive increases in internalised HIV stigma (Pantelic et al. 2015; Tsai, Bangsberg, Bwana, et al. 2013). Taken together, this growing body of longitudinal research supports our findings of likely pathways from violence victimization and enacted HIV stigma to internalised HIV stigma via

depressive symptoms. Therefore, broad violence prevention programmes within communities, schools and homes might help reduce internalised HIV stigma among adolescents living with HIV.

For example, interventions that do not necessarily target HIV-positive adolescents but are sensitive to their needs such as parenting programmes (Mikton and Butchart 2009) and school-based anti-bullying programmes (Cantone et al. 2015) to reduce violence victimization might help reduce internalised HIV stigma. Parenting interventions specifically adapted for resource-limited settings are currently being tested in South Africa and are showing promising results (Cluver, Meinck, Shenderovich, et al. 2016; Cluver, Meinck, Yakubovich, et al. 2016; Jordans et al. 2013). Youth violence exposure in one environment may impact involvement and/or victimization within another (Bowes et al. 2009). Therefore, violence prevention programmes simultaneously targeting adolescents' local communities, homes and schools might be particularly beneficial.

But without a precedent, it is unclear how violence prevention programmes that are administered at the community, school and/or home level would measure their effects on internalised HIV stigma. Including measures of internalised stigma as an additional outcome measure in these trials could empirically test whether reducing violence exposure is associated with reductions in internalised stigma. However, careful consideration of adolescents' privacy and confidentiality is warranted in the design and implementation of such evaluations. The HIV stigma measurement developed as part of this DPhil might be of use as it offers two options – one with HIV-specific wording used for adolescents who disclose their HIV-positive status, and

another with general mentions of illness rather than HIV for status unknown adolescents (Pantelic et al. 2016).

3. Translating ART use into optimal adherence and clinical outcomes for adolescents living with HIV may have follow-on protective effects against internalised HIV stigma.

The systematic review found that higher HIV symptom burden and poorer physical health were consistently associated with increases in internalised stigma in adult samples. The primary study found indirect pathways from HIV-related disability and internalised HIV stigma via higher levels of violence victimization, enacted stigma, depression and anticipated stigma. This suggests that manifestations of health problems contribute to HIV-related shame through indirect social and psychological mechanisms. One of the most rigorous studies identified by the systematic review partially confirms this – here, reductions in internalised stigma over time on ART were driven by improvements in HIV-related health and mental health (Tsai, Bangsberg, Bwana, et al. 2013). In light of these findings, enhancing ART adherence and retention in care might also help reduce internalised stigma. However, as part of this, more research is needed on how to best support HIV-positive adolescents' adherence (Chaiyachati et al. 2014).

4. ART initiation is no doubt a necessary first step for sustaining the health and wellbeing of HIV-positive adolescents, but findings from this DPhil suggest that ART provision alone will not be sufficient to reduce internalised HIV stigma among youth.

For example, the systematic review found that ART use alone was not associated with reductions in internalised stigma when compared to non-use. The

empirical study consisted of adolescents who had at some point initiated ART yet 26.5% of them reported experienced some level of internalised HIV stigma.

5. There is an important need for psychological support for adolescents living with

HIV. Both the systematic review and the primary study pointed to associations between poor mental health and internalised HIV stigma. These observations suggest that internalised HIV stigma occurs within a syndemic of psychological challenges, highlighting the need for psychological support for adolescents living with HIV. Systematic review-level evidence suggests that school-based group interventions, cognitive-behavioural therapy, community-based creative activities and exercise may help reduce depression and psychological distress among general populations of adolescents (Das et al. 2016). There is some evidence of internet-based prevention and treatment programs for anxiety and depression among adolescents (Das et al. 2016) and this may be particularly beneficial for adolescents living with HIV who wish to remain anonymous. However more research on this is needed particularly in Sub-Saharan Africa. Evidence from low and middle income countries highlights the potential for school- and community-based interventions (Barry et al. 2013). School-based life skills and resilience interventions may improve young people's self-esteem but the effects for adolescents living with HIV remain unknown. In South Africa, community-based interventions incorporating some form of economic strengthening or support have also been shown to improve self-esteem and reduce depression among young people (Barry et al. 2013). However caution is warranted as there is no evidence of how these interventions would work for

adolescents living with HIV, and whether they would have follow on protective effects against internalised HIV stigma.

DIRECTIONS FOR FUTURE RESEARCH

This section summarizes implications for future research arising from each of the DPhil papers.

The systematic review found no studies on adolescents, and this gap was directly addressed through this DPhil, which was the first epidemiological study of internalised HIV stigma among adolescents living with HIV in Sub-Saharan Africa. The cross-cultural adaptation and psychometric assessment of the HIV stigma scale for adolescents provided a methodological contribution, alleviating a major roadblock to research in this field. However, the systematic review also found few longitudinal studies and this gap could not be addressed by the present DPhil. Hypothesised causal pathways remain therefore largely untested. More foundational research to inform the epidemiology of internalised HIV stigma among HIV-positive adolescents and program theory is urgently needed. In particular longitudinal studies can contribute to this field by utilizing analyses of change and accounting for planned, literature-informed confounds (Fraser et al. 2009).

The systematic review also found that, of the longitudinal studies available, only individual-level factors were studied. This DPhil partly addressed this gap by testing a theoretical model of risk, which examined inter-personal risk factors in tandem with individual-level risk factors. However, structural risk factors were not the subject of this thesis, and future studies exploring this would be essential for informing

legislation and national-level policies. For example, Castro and Farmer (2005) hypothesize that, in addition to social differentials, economic and political inequalities drive stigma. They suggest that structural risks determine access to quality health care and, in doing so, increase the likelihood of AIDS-related stigma (Castro and Farmer 2005). Quantitative data from Uganda offer support for this hypothesis by suggesting that, over time, ART access decreases internalised HIV stigma in HIV-positive adults (Tsai, Bangsberg, Bwana, et al. 2013). However, ethnographic studies with HIV-positive youth suggest a more complex story. For example, although access to ART can help reduce internalised HIV stigma via reductions in AIDS-related symptoms (Tsai, Bangsberg, Bwana, et al. 2013), adolescents continue to experience challenges with respect to the quality of care received (Abadía-Barrero and Castro 2006). During adolescence, young people living with HIV also transition from paediatric to adult HIV care and it is unclear whether and how this affects their experiences of HIV-related stigma. It is therefore essential to assess whether and how different forms of healthcare provision influence internalised HIV stigma among adolescents.

A number of other inter-personal and environmental factors should be studied in relation to internalised HIV stigma. Self-perception of adolescents living with HIV might be threatened by difficulties around HIV status disclosure to peers (Wiener and Battles 2006), the shame associated with young people's sexuality (Campbell, Nair, and Maimane 2007), parental AIDS illness and death (Battles and Wiener 2002; Cluver et al. 2012), and the resultant poverty. Given that HIV transmission in sub-Saharan Africa is driven by heterosexual intercourse and vertical transmission

(UNAIDS 2010b), research is needed to assess potentially differing pathways to internalised stigma among perinatally versus postnatally-infected child and adolescent populations. These areas of research were beyond the scope of this DPhil but could help further inform the problem theory of internalised HIV stigma among adolescents living with HIV.

It is essential for more studies to reach HIV-positive individuals who are not actively engaged in the healthcare system. Prior to this study, all observational studies on internalised HIV stigma recruited participants through clinics (Pantelic et al. 2015). Moreover, the only three available interventions aiming to reduce internalised HIV stigma were delivered within through clinics (Uys et al. 2009; Tshabalala and Visser 2011; Maluccio et al. 2016; Stangl et al. 2013). The difficulties around conducting HIV stigma research outside of the clinic context should not be underestimated. This thesis highlighted a number of methodological difficulties and ethical entanglements arising from community tracing of HIV-positive adolescents. Nonetheless, more community-based research will be necessary to collect representative data and reach youth who are not using healthcare services or adhering to ART. Active engagement of adolescents living with HIV throughout the research design and implementation was crucial for this type of research.

DPHIL STRENGTHS AND LIMITATIONS

This DPhil is part of the world's largest study of HIV-positive adolescents, and is the first quantitative study on internalised HIV stigma in this under-studied population. The strong theoretical underpinning and structural equation modelling allowed me

to simultaneously explore social and psychological pathways of risk to internalised HIV stigma. The resulting findings suggest that HIV-related disability may lead to internalised HIV stigma not just via psychological distress as earlier studies had suggested (Pantelic et al. 2015) but also via inter-personal maltreatment. Methodological contributions include the development of a new stigma scale for Southern African adolescents living with HIV, as well as the community-based approach to internalised HIV stigma.

Nonetheless, several important limitations should be noted and taken into consideration when drawing inferences from this DPhil.

SYSTEMATIC REVIEW LIMITATIONS

1. Due to resource constraints, I was only able to search records written in English.

This could have resulted in oversight of potentially relevant papers (Shenderovich et al. 2016).

2. Lack of a validated cut-off for measuring prevalence of internalised HIV stigma.

Based on other primary studies on internalised HIV stigma identified through the systematic review, this DPhil assessed prevalence as any report of internalised HIV stigma. However, as the peer-reviewers of the systematic review rightfully pointed out, it was essential not to label these statistics as 'prevalence' due to a lack of a validated cut-off. This DPhil therefore consistently used the term 'prevalence of any report of internalised HIV stigma'.

3. A meta-analysis was not conducted. Heterogeneity between studies and largely cross-sectional findings would have limited inferences about causality and strength of effect.

PRIMARY STUDY LIMITATIONS

1. Findings from the primary study are based on cross-sectional data. The gold standard for a study like this would be one that uses longitudinal data and analysis of change (Murray, Farrington, and Eisner 2009), as cross-sectional data limit inferences about causality or directionality. Throughout the DPhil and publications, careful attention was paid to avoid using language suggestive of causality. The explored pathways of risk for internalised HIV stigma aimed to inform theories of change for future longitudinal and intervention research.

2. Although the consistency of internalised and anticipated stigma subscales were good, the enacted stigma subscale displayed an alpha of 0.57, which is considered poor reliability. Whilst this could have been prevented by adding items to the scale, shorter questionnaires are essential for reducing burden for HIV-positive youth, many of whom are cognitively delayed (Sherr, Croome, et al. 2014). Scale reliability also depends on the inter-correlations between items. However, inter-item-correlation is often low for measurements of inter-personal maltreatment (i.e. Vivolo-Kantor et al. 2014) because the items aim to capture behaviours and perceptions of multiple individuals.

3. The multidimensional HIV stigma scale developed as part of this DPhil might have limited generalizability to other populations. This scale was developed with

and for HIV-positive adolescents in the Eastern Cape, South Africa, who were predominantly Xhosa-speaking. Future research may find this scale helpful as a starting point for additional cross-cultural adaptation and validation.

4. Risk of measurement and conceptual overlap bias between depression and internalised HIV stigma variables. Given that internalising mental health problems and internalised HIV stigma are often characterised by similar symptoms, it is difficult to differentiate between the two constructs. For example, depressive symptoms might produce feelings of worthlessness, self-hatred and loneliness (Helsel and Matson 1984), which are all features of internalised HIV stigma as well. Moreover, given that the measures used in this DPhil relied on self-report, there is high risk of measurement overlap bias between variables. The systematic review conducted as part of this DPhil uncovered the same problems with all primary studies assessing both depression and internalised HIV stigma. Unfortunately, none of these studies addressed or discussed these risks.

Some of the literature on mental health-related internalised stigma acknowledges these shortfalls when interpreting findings but no methodological responses have been proposed. Having found consistent links between mental health-related internalised stigma and other psychological variables in their systematic review, Livingston and Boyd acknowledge the “conceptually intersecting and experientially intertwined” nature of the two constructs. They add that “perhaps the difficulty of compartmentalising psychosocial variables [including internalised stigma] into neat categories reflects the messy and entangled nature of people’s lived experiences” (Livingston and Boyd 2010). This DPhil attempted to assess the risk of measurement

and conceptual overlap between internalised stigma and depression by using factor analysis. The measurement model that preceded the structural equation model resulted in internalised HIV stigma and depression falling into distinct factors, confirming that the two measurements capture separate constructs.

5. Risk of bias due to double use of data. Given that the outcome measure (internalised HIV stigma) was developed as part of this DPhil, I conducted the psychometric assessment of the outcome measure using a subsample of the data used in the final empirical paper. Concurrent criterion validity of the tool was assessed via associations with social support, depression and physical health. However depression was also used to later assess pathways from violence and enacted stigma victimisation to internalised HIV stigma. This reuse of data means that the results on pathways to internalised HIV stigma were correlated with the psychometric assessment data. It is important to note that the psychometric assessment used data from a subset of HIV-positive adolescents who were fully aware of their status (n=721) whereas the structural equation modelling in Paper 3 used the full sample of HIV-positive adolescents, irrespective of their HIV status awareness (n=1060).

ETHICAL CHALLENGES IN HIV STIGMA RESEARCH AND LESSONS LEARNT

The ethical protocol for this study was a product of over a year of teamwork, legislation research and consultations with experts, practitioners and HIV-positive adolescents. Nonetheless, a number of unanticipated entanglements arose throughout data collection.

HIV stigma research with HIV-positive adolescents is filled with ethical complexities. First, there are key challenges that are inherent to any current research with HIV-positive adolescents in Sub-Saharan Africa. This population includes: 1) adolescents who are at risk of dying due to non-access or non-adherence to life-saving treatment; 2) adolescents who know their status but have not disclosed their status at home; and 3) adolescents who do not know their status whilst their family members and healthcare providers do. Each of these intersecting categories of adolescents presented a unique set of challenges and important lessons were learnt along the way. This section aims to transparently report on the challenges and how we resolved them, as well as initiate a discussion on some of the unresolved aspects of conducting this type of research.

1) Adolescents who are at risk of dying due to non-access or non-adherence to life-saving treatment. From an ethical and epidemiological point of view it was essential to include this group of adolescents in the study. According to the pivotal Belmont Report (Office of the Secretary, Ethical Principles and Guidelines for the Protection of Human Subjects of Research, and The National Commission of the Protection of Human Subjects of Biomedical and Behavioral Research 1979), all research involving human participants must guarantee justice. Here, justice entails a reciprocal relationship between the researchers and population of interest, whereby those faced by adversities (such as HIV and stigma) should ultimately benefit from research on these adversities. Interviewing non-adherent HIV-positive adolescents was the only way to adhere to the principle of justice, by ensuring that findings have the potential to produce meaningful policy recommendations for most-at-risk youth.

Given that these adolescents were defaulting from treatment and not engaging with the healthcare system, community-tracing was necessary.

However, community-tracing introduced an additional array of complexities and risks involved, particularly for the following two groups of adolescents.

2) Adolescents who know their status but have not disclosed their status at home.

Inadvertent disclosure of these adolescents' status to their family and peers would have increased the risk of stigma, ostracism and abuse (Norman et al. 2012; Meinck, Cluver, Boyes, and Ndhlovu 2015). Therefore, in order to preserve participants' discretion and safety, the study was presented in communities as an overall study on service access and health among adolescents.

3) Adolescents who do not know their status whilst their family members and healthcare providers do. Working with this subsample was perplexing at times, particularly because, to my knowledge, all research on internalised HIV stigma to date has made explicit reference to HIV and/or AIDS (Stevelling et al. 2012; Pantelic et al. 2015). So as to avoid disclosure of the adolescents' HIV status to them, questions on HIV stigma substituted the word HIV with illness. For example, adolescents who were aware of their status were asked whether they had lost friends due to *having HIV*, whereas adolescents who were unaware of their status were asked whether they had lost friends due to *being ill*.

The deception tactics outlined above were necessary to safeguard the well-being and privacy of our participants. The procedures were approved by ethics review boards of Oxford University, University of Cape Town and relevant government

bodies in South Africa. Nonetheless, it could be argued that informed consent was compromised due to the deception involved. The candidate has taken care to transparently reflect and discuss these challenges as part of this thesis, within the publications and dissemination sessions. More inter-sectorial work between ethics committees, academics, practitioners and HIV-positive youth is needed to produce a set of best-practice recommendations for research with adolescents living with HIV.

Tracing difficulties

Fear of stigma was rife in this population and, as a result, we encountered similar difficulties to those faced by service providers: many adolescents living with HIV did not want to be known. They often provided fake addresses and even names when registering at the clinic. It became clear to the research team that we could never be certain whether an adolescent who we were tracing even existed. This made it difficult to decide when to stop searching for a hard-to-reach participant. On the other hand, some of the hard-to-reach participants were found in unexpected villages, schools, homes and healthcare facilities in the course of searching for other participants. This required close communication between the interviewers, clinic liaisons and office-based colleagues, who could check and alter data in most up-to-date rosters. However, our interviewers had the difficult task of trying to build rapport with adolescents and this made prompt WhatsApp messaging impossible at times. As a result, in a few instances the interviewers would WhatsApp the office after having conducted the interview, only to realize that the same adolescent had already been interviewed previously. This only happened when adolescents did not

disclose having participated in the study ($n < 10$). In such instances, data from the first interview was retained.

Research, or rescue?

As described in the methodology chapter of this thesis, referrals were made for the most-at-risk participants. Many of the services were not available within the research site (i.e. psychiatric care). We therefore worked closely with adolescents, their family and social services to find solutions within the under-resourced public service system whenever possible.

This blurred the lines between our roles as researchers and service providers and introduced complexities for both the research team and participants. The research team were, for the most part, not trained social workers or healthcare workers, and we had limited capacity to assist all those in need. For example, only 68 (6.4%) referrals were made within the study sample. However, in reality, 10.6% reported frequent (monthly) physical or emotional abuse and many more reported severe food insecurity or health problems. In some cases, the researchers' safety precluded our ability to facilitate a referral. For example if the participant had symptomatic untreated TB, transportation funds were provided rather than accompaniment to the clinic. At times, our intervention sent conflicting messages to participants. In a few instances, our interviewers received calls for help from adolescents outside of the study, because study participants shared the contact information. In such instances the interviewers made clear that they were unable to help and that they were researchers rather than service providers. Nonetheless, this posed ethical

dilemmas for the research team, particularly as we had not anticipated such calls and did not have a clear script as to what to say in such situations.

DISSEMINATION AND IMPACT

Knowledge exchange and impact have been among the core goals of this DPhil. Throughout the DPhil, great care was taken to ensure that the evidence and methodological contributions stemming from this thesis are made available to researchers, programmers, policy makers and stakeholders. Dissemination of findings from this DPhil has included: publications in peer-reviewed journals; presentations at conferences, roundtables and workshops; and webinars/ talks at universities, advocacy platforms and local/ national organisations.

Three first authored peer-reviewed papers have come out of this DPhil and have been presented in this thesis. The systematic review was referenced eight times in other high impact journals such as *AIDS and Behaviour* and *AIDS Care*. Notably, the DPhil publications also reached non-academics through citations on the Wikipedia page on HIV-related stigma⁵, citations in policy documents such as the UNICEF Working Paper on parenting of adolescents⁶ and features on the UNAIDS 'Science

⁵https://en.wikipedia.org/wiki/Discrimination_against_people_with_HIV/AIDS

⁶https://static1.squarespace.com/static/54e3c4b3e4b02a415877e452/t/58594bd58419c209ff5b27d1/1482247131484/IWP_2016_20-2.pdf

Now' and 'Pills and Policies' blogs^{7,8}. An additional four co-authored papers on the broader Mzantsi Wakho study are currently under review.

The analyses and methodologies used for this thesis were also presented at the following academic seminars, roundtables and conferences (most recent first):

1. 'HIV, violence, blame and shame: Internalised HIV stigma among South African HIV-positive adolescents', *Marija Pantelic, Mark Boyes, Lucie Cluver, Franziska Meinck*, 14 June, Southern African AIDS Conference, Durban, South Africa.
2. Social and psychological pathways of risk to internalised HIV stigma among South African HIV-positive adolescents, *Marija Pantelic, Mark Boyes, Lucie Cluver, Franziska Meinck*, June 2017, Southern African AIDS Conference, Durban, South Africa.
3. 'HIV, blame and shame: Pathways of risk to internalised HIV stigma among South African HIV-positive adolescents', *Marija Pantelic, Mark Boyes, Lucie Cluver, Franziska Meinck*, 17 May 2017, INTEREST Workshop, Lilongwe, Malawi.
4. 'Teen Voice: What do the Sustainable Development Goals mean for HIV-positive adolescents in Southern Africa?', *Hodes, R, Cluver, L. Toska, E. Vale*,

⁷<https://pillsandpolicies.com/2015/12/01/hiv-stigma-is-institutional-simple-raising-awareness-wont-help/>

⁸<https://scienzenow.unaids.org/post/eliminate-stigma-and-discrimination-23>

- B. Pantelic, M. Gittings, L. Doubt, 18 May 2017, INTEREST Workshop, Lilongwe, Malawi.*
5. *Social and psychological pathways of risk to internalised stigma among HIV-positive adolescents: A structural equation model', 23 Feb 2017, CEBI Research Group, Department of Social Policy and Intervention, University of Oxford.*
 6. *'HIV is a punishment for bad behaviour': Blame and shame among South African HIV-positive adolescents. 25 May 2016, Green Templeton College, University of Oxford.*
 7. *How to disseminate DPhil findings to policy makers? 6 May 2016, Department of Social Policy and Intervention, University of Oxford.*
 8. *Violence exposure and internalised HIV stigma among South African adolescents living with HIV. 4 May 2016, CEBI Research Group, Department of Social Policy and Intervention, University of Oxford.*
 9. *HIV stigma in the 21st century - a key barrier to eradication. 26 November 2015. Worcester College, University of Oxford.*
 10. *'They say HIV is a punishment from God or from ancestors': Cross-cultural adaptation of an HIV stigma measurement tool for South African HIV-positive teens. Pantelic, M., Cluver, L., Thabeng, M. June 2015. Poster presentation, 7th South African AIDS Conference, Durban, South Africa.*
 11. *Power to Participants? Participatory methodologies within a large quantitative study of adolescents. 10 June 2015, Oral presentation, 7th South African AIDS Conference, Durban, South Africa.*

This DPhil helped enable much needed quantitative research on internalised HIV stigma among adolescents in Southern Africa. The culturally relevant, age-appropriate and validated HIV stigma scale for use with this understudied population was made available in English and isiXhosa. To my knowledge, this scale has been taken up by two additional on-going studies in the region:

1. Researchers at University of Zimbabwe have translated the scale into chiShona for another study on HIV-positive adolescents.
2. Researchers at the Elizabeth Glaser Paediatrics AIDS Foundation have translated the scale into siSwati for assessing the effects of an adolescent HIV support group in Swaziland.

A critical component of dissemination will involve reporting findings to families; community leaders and local health, education and social service providers. I am currently developing a longer-term local dissemination plan, which will consist of in-person dissemination as well as capacity building with more junior researchers in field to share these findings. Future dissemination plans for this research include presenting to all participating health facilities, and research partners on the ground, which include: Kheth'Impilo, Small Projects Foundation, Beyond Zero and the Keiskamma Trust, South African national, provincial and district departments of Health, Basic Education, and Social Development.

The post-individualistic approach to studying internalised stigma in this thesis has been discussed with the Executive Director of the Global Network of People Living with HIV, Dr. Laurel Sprague. As an established HIV stigma researcher and a person

living with HIV, Dr. Sprague has endorsed this conceptualisation of internalised stigma. This engagement has resulted in a joint opinion piece calling for a shift in focus of internalised HIV stigma research, one that moves beyond psychological frameworks to social and structural conceptualizations of stigma:

Pantelic, M, Sprague, L, Stangl, A. (in press): "It's not 'all in your head': Critical knowledge gaps in internalised HIV stigma and a call for socio-structural conceptualisations", *BMC Infectious Diseases* (IF:2.963)

CONCLUSION

This was the first epidemiological study of internalised HIV stigma among adolescents living with HIV in Sub-Saharan Africa. It consisted of a systematic review and a primary study, which was the largest known social science study on HIV-positive adolescents to date.

Data from this DPhil suggest that more than a quarter of adolescents living with HIV report experiencing internalised stigma. The cross-sectional data generated strong implications for research with more tentative implications for practice. Findings suggest a need to expand programmatic responses to internalised HIV stigma, from individualistic, clinic-based programmes to integrative, community-based approaches. This highlights the potential for interventions that do not necessarily target HIV-positive adolescents but are sensitive to their needs. More foundational research to inform interventions is also urgently needed. In particular, future studies can contribute to this field by grounding hypotheses in theory, utilizing analyses of change and accounting for planned, literature-informed confounds. It is hoped that by developing a psychometrically sound tool for measuring HIV stigma among adolescents, this DPhil will enable further research on this understudied population.

Whilst there were no known epidemiological studies of internalised HIV stigma among adolescents living with HIV prior to this thesis, the broader (adult-focused) corpus of research has overlooked interpersonal risk factors. This thesis highlights the relevance of power inequalities and domination for the study of internalised HIV stigma.

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