

FACULTY OF HEALTH SCIENCES

UNIVERSITY OF CAPE TOWN



**AN ASSESSMENT OF EXTERNAL HIV-RELATED STIGMA IN SOUTH AFRICA:
IMPLICATIONS FOR INTERVENTIONS**

BY

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I dedicate this thesis to all South Africans who are either directly or indirectly affected by external HIV-related stigma. I hope this thesis will make a contribution to the development of more effective policies and intervention strategies to reduce the prevalence of external HIV-related stigma in South Africa. I wish to acknowledge and express my sincere thanks to Prof Leickness Simbayi, Prof John Joska and Prof Peter Nyasulu, my academic supervisors, for their invaluable guidance and mentorship. In compiling this thesis, I acknowledge with special appreciation their dedicated efforts and academic advice they gave me throughout the process. The data used in the study was originally collected by the Human Sciences Research Council (HSRC) team, and would like to give a special thanks to HSRC for giving me permission to use their data sets. Special thanks goes to my family, my two sons Liqhayiya and Aqhamile as well as my mother, Nomaphelo Klaas. They too contributed in one way or another to the successful completion of this thesis.

PLAGIARISM DECLARATION

I, the undersigned, Vuyelwa Eullicia Mehlomakulu, declare that the work presented in this thesis document is my own original work, and that I have not previously, either in its entirety or in part, submitted it to any university for degree purposes.

Signature: _____

Signed by candidate

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Date: 14 August 2020

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LIST OF ABBREVIATIONS

AIDS:	Acquired Immune Deficiency Syndrome
ART:	Antiretroviral Treatment
ARV:	Antiretroviral
CDC:	Centres for Disease Control
DBS:	Dry Blood Spot
DOH:	Department of Health
EAs:	Enumeration areas
HIV:	Human Immunodeficiency Virus
HSRC:	Human Sciences Research Council
HREC:	Human Research Ethics Committee
HTC:	HIV Testing and Counselling
LAMIC:	Low and Middle income Countries
NACOSA:	National AIDS Convention of South Africa
NDoH:	National Department of Health
NGO:	Non-governmental organization
NLD:	Negative labelling devaluation
NSP:	National Strategic Plan
PLHIV:	People Living with HIV
PLWHA:	People living with HIV/AIDS
QES:	Quarterly Employment Surveys
SASSA:	Stigma Assessment Study in South Africa
SEM:	Structural Equation Modelling
SCT:	Social Cognitive Theory
SANAC:	South Africa National AIDS Council
SoE:	Social Exclusion
SSA:	Sub Saharan Africa
STATA:	Statistical Analysis Software
STI:	Sexually Transmitted Infections
TB:	Tuberculosis
UNAIDS:	Joint United Nations Programme on HIV/AIDS
UTT	Universal Test and Treat
USA	United States of America
WHO	World Health Organization

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ABSTRACT

Background

Globally, external HIV-related stigma is a major threat to all HIV prevention, care and treatment interventions including the recently launched Universal Test and Treat (UTT) strategy in South Africa and the 90-90-90 targets set by UNAIDS for the global response by 2020. The 90-90-90 targets are put in place to track the progression from HIV testing to durable viral load suppression among people living with HIV. The targets guide HIV programmes to achieve 90% known HIV status, to access 90% antiretroviral therapy and to suppress 90% viral loads (UNAIDS, 2017). Achievement of the 90-90-90 targets has since become a part of South Africa's National Strategic Plan for HIV, TB and STIs 2017-2022. External HIV-related stigma in this study was defined as the presence of one or more of the following attitudes and behaviours: rejection, avoidance, intolerance, stereotyping, discrimination, and physical violence towards people living or perceived as having HIV. There have not been many efforts to attenuate HIV-related stigma in South Africa, as it continues to exist. There has been a scale up of other HIV responses, such as HIV Counselling and Testing (HCT) and treatment, with the argument made that in scaling up these biomedical approaches, stigma would disappear. Furthermore, its exact magnitude, trends over the years and correlates have not been explored fully at national level, hence the present study known as Stigma Assessment Study in South Africa (SASSA).

SASSA is based on the Institutional Social Construction theory framework. It explores the external HIV-related stigma magnitude and its trends between 2005 and 2012, as well as the associated factors which influence its prevalence in South Africa at a national level. The study further explores the mediating and moderating factors of external HIV-related stigma and tries to explore external HIV-related stigma by viewing individuals with HIV living in families,

societies and structures, with the hope of contributing to the development of new systematic HIV-related stigma interventions in South Africa as well as, strengthening existing ones.

Methodology

The project used secondary data obtained from three South African national population HIV surveys which were conducted in 2005, 2008 and 2012 by a research consortium led by the Human Sciences Research Council. Sub-samples of the original surveys consisting of respondents aged 15 years and older who had responded to the stigma questions in the three surveys were extracted and included in the SASSA analysis. A nationally representative sample of a total of 16 140 individual respondents from the 2005 survey, 13 134 from the 2008 survey and 30 748 from the 2012 survey was used in the study. Two different measures of external HIV stigma are used in this analysis, one is a summary measure from the latest survey data, i.e. 2012, which was used to do a regression analysis. The summary measure was regarded as reliable to use for the regression analysis as it provides crude effect of the exposure factors on external HIV stigma. However, this summary measure was not included in the previous surveys, i.e. 2005 and 2008, and therefore could not be used for trends analysis. We therefore used 4 individual stigma items for the trends analysis as these were included in all 3 surveys. The use of 4 individual stigma items was important because when data from a variety of sources or categories have been joined together, the meaning of the data can be difficult to see. It was therefore considered ideal to assess the performance of the individual constructs on their individual contribution to the impact on HIV external stigma. Furthermore, analysis using individual constructs provided an opportunity to see specific patterns which could have remained obscure in crude analysis.

The first measure of external HIV-related stigma used in the regression analysis was measured by five individual items which elicited attitudes towards people living with HIV (PLHIV). The five items were based on a 9-item scale that was originally developed and tested in a South

African population, and the 9-item scale was found to be internally consistent ($\alpha = 0.75$) and reliable ($r = 0.67$). The 5 items were (1) People who have AIDS are dirty; (2) People who have AIDS are cursed; (3) People who have AIDS should be ashamed; (4) People with AIDS must expect some restrictions on their freedom; (5) A person with AIDS must have done something wrong and deserves to be punished. As explained above, the specific external HIV stigma patterns second measure, which was utilized to explore stigma trends over the years 2005, 2008 and 2012, consists of four individual stigma items which elicited attitudes towards PLHIV. The four individual stigma items included: (1) If you knew that a shopkeeper or food seller had HIV, would you buy food from them? (2) Would you be willing to care for a family member with AIDS? (3) Is it a waste of money to train or give a promotion to someone with HIV/AIDS? (4) Would you want to keep the HIV positive status of a family member a secret?

Findings

Overall, external HIV-related stigma was found to exist among 38.3% of adult South Africans in 2012. Multiple regression analysis showed that predictors of external HIV-related stigma were race, sex, education level, self-perceived risk of HIV infection and HIV knowledge ($p < 0.05$). Those who are White, Coloured and Indian/Asian were more likely to report some external HIV-stigma than those who are Black Africans (aAORs = 2.14, 1.35 and 1.21 respectively, all $ps < 0.01$). Females were less likely to report external HIV-stigma than males (AOR = 0.9, $P < 0.05$). Those with primary education were more likely to report some stigma than those with secondary, Matric, and post-Matric education (aAORs = 0.76, 0.59 and 0.46 respectively, all $ps < 0.001$). Those who perceived themselves to be at high risk of HIV infection were less likely to display some stigma than those who believed they were at low risk (AOR = 0.89, $p < 0.05$). Those displaying incorrect HIV knowledge were also more likely to report some stigma than those who displayed correct HIV knowledge (AOR = 0.63, $p < 0.01$).

The study did not find any significant associations between HIV testing or awareness of HIV status, with external HIV-related stigma in this study.

Looking at the individual external HIV stigma items used to measure trends, the study reveals a slight decrease in the reporting of stigma over the three time periods (2005 vs 2008 vs 2012) on responses for two of the stigma items (Q1: If you knew that a shopkeeper or food seller had HIV, would you buy food from them, and Q2: Would you be willing to care for a family member with AIDS). While an increase was observed in the reporting of stigma over the three years on responses for two of the stigma items (Q3: Is it a waste of money to train or give a promotion to someone with HIV/AIDS, and Q4: Would you want to keep the HIV positive status of a family member a secret).

The structural equation modelling (SEM) showed likelihood ratio test results with a p-value greater than 0.05, a root mean square error of approximation (RMSE) of 0.008 and Tucker–Lewis index (TLI) value of 0.985. The model fit assessment results allow us to accept that an hypothesized model of the study is not far from a perfect model. The SEM results also showed a direct effect of sex on HIV knowledge statistically significant at $p < 0.001$, with race having an effect of 3.3% and education a direct effect of 9.5%, and both of these showed a statistically significant effect ($p < 0.001$) respectively. HIV knowledge showed to have a statistically significant inverse relationship on external HIV stigma of -10.4% (95% CI: -12.3-0.09) $p < 0.001$. Awareness of HIV status had the highest positive direct effect on external stigma of 10% (95% CI: 4.41-15.67%) $p < 0.001$. With regard to indirect effects, sex, race, and education had minimal negative indirect effects on external stigma, which was statistically significant for all the three covariates. With the said effects of external HIV-related stigma, it was found that HIV knowledge independently mediates the relationship between Level of Education, Awareness of HIV status, Race, HIV testing history, and Sex, with External HIV-related stigma.

Conclusion

External HIV-related stigma still exists in South Africa despite previous success in massive ART rollout, HTC campaigns, and most recently test-and-treat programmes, which were arguably thought to have a parallel effect in the decrease of HIV related stigma. The focus on individualistic health structural approaches that do not generally have stigma-reduction as a specific aim, as discussed, is likely to undermine the successes achieved in the fight against HIV thus far. There is a need to develop innovative holistic interventions which are specifically intended for HIV stigma reduction. These should be inclusive of both social institutional elements and health structural elements to address the challenge of external HIV-related stigma.

CHAPTER 1

INTRODUCTION

1.1 Background

The Global and National Response to HIV/AIDS

Globally there were 36.7 million people living with HIV (PLHIV) at the end of 2016 and more than 1.8 million new infections, mainly in low and middle-income countries (UNAIDS, 2017). Southern Africa is the epicentre of HIV/AIDS as its prevalence rates are highest in the world. South Africa continues to have the largest numbers of PLHIV (SANAC, 2017; Shisana et al., 2014; UNAIDS, 2017). At the end of 2016, there were 7 100 000 PLHIV, 270 000 new infections and 110 000 AIDS-related deaths (UNAIDS, 2017). The world has been fighting HIV/AIDS for close to four decades. In South Africa, the government has implemented a number of strategies to curb the disease, including the execution of comprehensive national guidelines for the initiation of HIV care and treatment (NDoH, 2013), the adoption of the UNAIDS 90-90-90 targets and the implementation of the new HIV guideline: Universal Test and Treat (UTT) (SANAC, 2018). Consequently, South Africa has the largest antiretroviral (ART) programme in the world. The response to the HIV epidemic in South Africa now also includes the national strategic plans to reduce HIV/AIDS-related stigma (SANAC, 2018).

HIV-related stigma policies in South Africa

In the late 1987, regulations around HIV by the then government were introduced. These regulations included a mandatory 14-day quarantine for individuals suffering, or suspected of suffering, from AIDS, and more days for those confirmed (South African History Online, 2018). In that era, HIV stigmatising attitudes were often displayed by leaders in higher authority in the parliament where utterances were publicly made that ‘promiscuity’ of gays and Black African South Africans was the reason for the higher numbers of HIV positive individuals seen

in these two populations (Avert, 2011; Fassin & Schneider, 2003). Furthermore, stigmatizing behaviours were witnessed in that era when chemical and biological weapons were used as contraceptive methods to induce sterility in the Black African population (Fassin & Schneider, 2003). The pre-1994 government's response to HIV/AIDS was therefore characterized by very stigmatising attitudes towards PLHIV (Wouters, Van Rensburg & Meulemans, 2010).

Despite the newly elected democratic government in 1994, the focus of the HIV policies and the response to HIV was initially never on combating HIV-related stigma. The National AIDS Plan for South Africa launched in 1994 by the then National Advisory Group (NACOSA) focussed on prevention of HIV, reducing transmission of HIV and HIV treatment (NACOSA, 1994; Wouters et.al., 2010). Only in late 1997, was a slight shift seen in the response to HIV, when HIV-related stigma began to be one of the important components in the fight against HIV. The South African National Department of Health developed a new plan called "The National AIDS Control Programme" which emphasized the objectives of behavioural change, mass media education and community support, but also, more importantly, human rights' protection of people living with HIV (Avert, 2011), which meant protection against stigmatization as well. Despite this progress through a focus on the human rights of those living with HIV, the years 2000-2008 were marked with confusion because of the denialism statements made by former President Mbeki (Achmat and Simcock, 2007; Wouters et.al., 2010). In 2000 the South African National AIDS Council (SANAC) was formed, and progress was seen in the HIV/AIDS policies where some focus was also put into combating HIV/AIDS-related stigma. With the formation of SANAC, the South African National Strategic Plan (NSP) on HIV/AIDS and STD was also developed with a 5-year vision. To date, South Africa has had four NSPs, namely, NSP 2000-2005 (DOH, 2000); NSP 2007-2011 (DOH, 2007); NSP 2012-2016 which also included TB (SANAC, 2012); and NSP2017-2022 (SANAC, 2017). The NSP2017-2022 human rights goal seeks to "Halve stigma related to HIV and TB" (SANAC,

2018). According to Health System Trust, the NSP intends that stigma, discrimination and human rights violations related to HIV would be addressed through:

”1. Monitoring and responding to human rights abuses. Among other measures community-centred legal literacy programmes are envisaged and access to legal services will be scaled up so that there is effective recourse to the courts for purposes of enforcement and redress.

2. Social and behaviour change communication programmes to address some of the known roots of stigmatising behaviour – for example, moral judgment, irrational fear of infection, ignorance of the impact of stigma, and gender-based discrimination.

3. Training and sensitisation of healthcare workers about their rights to a safe working environment and protection from the risk of infection and patients’ rights to informed consent for treatment, confidentiality and treatment that does not discriminate” (nsp summary, 2017,

<https://www.hst.org.za/publications/NonHST%20Publications/NSP%202017->

SUMMARY.pdf)

Gaps in the policies

Gaps exist with all the policies that have been developed to fight external HIV-related stigma in South Africa. The gaps include the following:

1. Currently HIV/AIDS interventions and programmes in South Africa are focused more on the test and treat cascade to reach the 90-90-90 targets with little being done to put more efforts on external HIV-related stigma.
2. Whilst there have been many national and provincial level surveys to monitor HIV prevalence and determinants, monitoring efforts for external HIV-related stigma are almost non-existent (Shisana et al., 2005, 2009, 2014). Existing surveys on HIV-related stigma focus on PLHIV in South Africa (SANAC, 2014). This poses challenges as HIV-related stigma is a complex phenomenon. In order to be able to understand the elements of HIV-related stigma in South Africa, a population approach is also needed. Individuals

with HIV live in families, in societies and structures, with interventions needed at all levels.

3. Changes in stigma over time have been observed in South Africa. (Mall et al., 2013; Visser, 2018). While these studies have contributed a great deal of information on HIV-related stigma in South Africa, they only included small samples and were also limited to a few communities.
4. Lastly, there are contradicting findings from the small HIV-related stigma studies done as to whether HIV-related stigma in South Africa is decreasing or increasing (Forsyth et al., 2008; Mall et al., 2013; Maughan-Brown, 2010). These differences could be related to the fact that these were done in small and very different communities in South Africa. This gap demands clarification, ideally from larger, more general surveys.

1.2 Statement of the problem

Despite significant progress made in the fight against HIV/AIDS in South Africa with the 90-90-90 targets currently at 85-71-86 (HSRC 2018), HIV/AIDS-related stigma continues to be a driver of the epidemic and a challenge to HIV prevention, treatment and care efforts (UNAIDS, 2017). The scaling up of antiretroviral treatment (ART) especially, the implementation of universal test-and-treat (UTT) strategy has restored hope in the lives of PLHIV. Achieving the first 90 (HIV testing) is the initial key to achieving the 90-90-90 targets but evidence shows that external HIV-related stigma poses challenges to this outcome across the globe (Golub & Gamarel, 2013; Mohlabane, Musheke et al., 2013; Njau et al., 2014; Ti & Kerr, 2013; Tutshana, Peltzer, 2016; UNAIDS, 2017). In particular, external HIV-related stigma discourages people from accessing health-care services for HIV testing in order to know their HIV status, and subsequently to enrolling in antiretroviral (ARV) treatment and adherence programmes (Musheke et al., 2013; Rueda et al., 2016; UNAIDS, 2017). In order to address this major public health concern, a greater understanding of the determinants of external HIV-related stigma and

its trends is needed. Recently a stigma index survey was done amongst HIV-positive individuals in South Africa, in which it was found that 36% of the respondents experienced some external stigma (SANAC, 2014). It is estimated that one in eight people living with HIV in South Africa report being denied health services due to their HIV status (SANAC, 2014) and one in nine are denied employment because of their HIV positive status, while 6% report experiencing physical assault (SANAC, 2014).

Women, in particular are vulnerable to HIV related stigma. As a result of external HIV related stigma, married women living with HIV in South Africa experience verbal and physical abuse because their husbands fear that they will contract the disease and lose control over the woman's reproductive processes (Sofolahan and Airhihenbuwa, 2013; Woodard, 2014). Woodard (2014) refers to issues wherein a woman's HIV positive status suggests a man's loss of control in reproduction. The loss of man's control over the woman's reproductive processes introduces elements of external HIV-related stigma in the form of verbal confrontations on the woman's sexuality, labelling her as promiscuous and immoral.

Understanding and working towards the reduction of external HIV-related stigma may lead to a decrease in other forms of HIV stigma. In cases where external HIV-related stigma is experienced, other forms of HIV-related stigma, such as felt stigma, can be created and can be seen in the state of psychosocial health outcomes and behaviour, such as fear of status loss, fear of discrimination and failure to use health services (Deacon, 2006). Felt stigma is defined as self-shame and expectation of discrimination assumed by those with a stigmatized element (Gray 2002). Therefore, better understanding of external HIV-related stigma and how we can reduce it might lead to the reduction of other forms of HIV-related stigma such as felt stigma – a phenomenon which further impacts on access to all HIV/AIDS interventions.

1.3 Study Justification

Leaning on the definition of external stigma as attitudes or actions aimed at those living with HIV, including issues such as rejection, avoidance, intolerance, stereotyping, discrimination, and physical violence (Florom-Smith & De Santis, 2012; Mbonu et al., 2009), in this thesis external HIV-related stigma is defined as attitudes, actions and negative perceptions aimed at those living with HIV. Although previous prevalence studies done in South Africa (Mall, 2013; Maughan-Brown, 2010; Visser, 2018) have contributed to our understanding of external HIV-related stigma, most have been limited by small samples conducted in specific communities and populations. However, it remains unclear what the level of external HIV-related stigma is and what its determinants are at population level. It is also not clear from the studies, whether or not HIV-related stigma in South Africa is decreasing, increasing or staying the same. The reason may not only be related to the small sample sizes but to the nature and methodology of these studies. Larger, more general surveys are needed with the view of providing better evidence-based planning of HIV interventions. As external HIV-related stigma is a complex phenomenon, national representative surveys assessing this form of HIV-related stigma on a continuous basis are also needed in order to monitor, channel and properly align intervention at a national level.

In spite of the developments taking place in the HIV field, it is not known how external HIV-related stigma has changed over the years 2005-2012 at the population level in South Africa, as no trend analyses have been done to date. Furthermore, understanding the causal association of external HIV-related stigma is crucial in the development of interventions to decrease HIV-related stigma in South Africa. For example, HIV knowledge has been reported by other researchers to be associated with external HIV stigma (Du, Chi, & Lic, 2017; Ekstrand, 2013; Mall et al., 2013; Mihan et al., 2016; Mukolo et al., 2013; Okumu et al., 2017; Vorasane, 2017; Ugarte et al., 2013; Wong, 2013). However, the role that HIV related knowledge plays in the

relationship between race, education, regular HIV testing, awareness of HIV status and external HIV-related stigma has not been examined in South Africa.

A greater proportion of females than males are living with HIV in Sub-Saharan Africa and there is disparity in HIV infection by sex (Shisana et al., 2014). Similarly, the manifestation of HIV-related stigma differs by sex (Hargreaves et al., 2018; Mugoya & Ernst, 2014). These differences in the manifestation of external HIV-related stigma could be explained by the gendered roles which are “socially constructed”. Our conception of what women and men are and how they are supposed to behave is produced by the society and communities in which we live. Gender inequality, different gender roles enforced on to males and females, a lack of power in decision-making, and sexual coercion have long been cited as primary reasons for this (Harrison et al., 2000; Kayaa et al., 2002; Mba, 2003). While others affirmed that this is due to biological vulnerabilities, low socio-economic status, dominant sexual practice of males and epidemiological factors (Campbell, 1999; De Bruyn, 1992; Pratt, 1998). Hence it is important to further explore the relationship between sex and external HIV-related stigma especially with regards to the different cultures we have in South Africa.

1.4 Significance of the Study

HIV-related stigma is a universal phenomenon and a major obstacle to any effective HIV response (UNAIDS, 2013b; Grossman & Stangl, 2013). This is both at global and at national levels. Understanding the prevalence and correlates of HIV related stigma on a national scale will inform the development of more effective programmatic initiatives towards the elimination of stigma and discrimination (UNAIDS, 2012). Reducing HIV-related stigma is especially important for African countries like South Africa which carry a huge burden of HIV (Chan, Tsai, Siedner, 2015; Mukolo, Blevins, Victor, Vaz, Sidat & Vergara, 2013). This implies that if no measures are taken to understand and address external HIV-related stigma, South Africa will

face continuing challenges in public health measures to fight the HIV and AIDS epidemic including the increased emotional and psychological burden caused by stigmatizing attitudes and behaviours towards PLHIV.

1.5 The Research question

With the hope that the data from this thesis can inform the design of stigma-reduction interventions and the integration of stigma-reduction into biomedical approaches like Universal Test and Treat (UTT), the research question for this study was: “What is the magnitude and trends over time of external HIV-related stigma at national level and how might the factors which influence its prevalence inform the success or failure of the UTT approach and the 90-90-90 UNAIDS targets in South Africa?”

1.6 The Aim and specific objectives of the study

The aim of the study is to investigate the trends and magnitude of external HIV-related stigma and the factors which influence its prevalence at a national level. The study tries to understand the concept of external HIV-related stigma by looking at individuals with HIV living in families, societies and structures, so that holistic HIV-related interventions can be developed or improved. The specific objectives of this study were:

- To conduct a narrative literature review on external HIV-related stigma in low- and middle-income countries (LAMIC), with a view to report on methods of assessment, prevalence, associated factors and consequences.
- To determine the prevalence and determinants of external HIV-related stigma in the South African population in 2012.
- To investigate trends of HIV-related stigma in South Africa over the past decade using data from three different points in time, 2005, 2008 and 2012.

- To examine whether HIV knowledge mediates the relationship between Level of Education, Knowing HIV status, Race, Awareness, and Sex, and external HIV related stigma.

CHAPTER 2

LITERATURE REVIEW

2.0 Introduction

UNAIDS has established clear goals to move towards eradication of HIV known as the 90-90-90 goals. These “90-90-90” goals propose that 90% of those living with HIV be tested, 90% of those tested be enrolled onto ART, and 90% of those on ART should be virologically undetectable by 2020 (UNAIDS, 2017). Despite every effort to scale up universal test and treat programmes, HIV-related stigma, both external and internalized, remains a major barrier to each goal of HIV care (Blick & Wraight, 2017).

HIV-related stigma has been noted to be one of the drivers of the epidemic in that it is directly linked to public health challenges in HIV care and treatment such as a) lower uptake of maternity services by women, b) less provision of health care workers’ services, c) non-disclosure of HIV-positive status, d) implications for spread of HIV/AIDS, e) non-adherence to ART, f) public denial of HIV/AIDS, g) implications for mental health issues, h) the affect of access to social support and i) the hampering of HIV prevention and promotional efforts (Mbonu et al., 2009). Some of these challenges are driven by the stigmatising attitudes and actions (external HIV-related stigma) which people living with HIV face in their daily lives. Furthermore, external HIV-related stigma’s effect manifests itself into other forms of HIV stigma such as internalized (or felt) stigma, stigma by association, and public stigma (Nemabaka et al. 2014).

In order to understand the extent of the challenge, we conducted a narrative systemic literature review on external HIV-related stigma in low- and middle-income countries (LAMIC), with a focus on South Africa because of the concentration of the epidemic in the country. LAMIC are

defined as “countries with a gross national income (GNI) per capita between \$1,026 and \$3,995” (<https://www.worldbank.org/>).

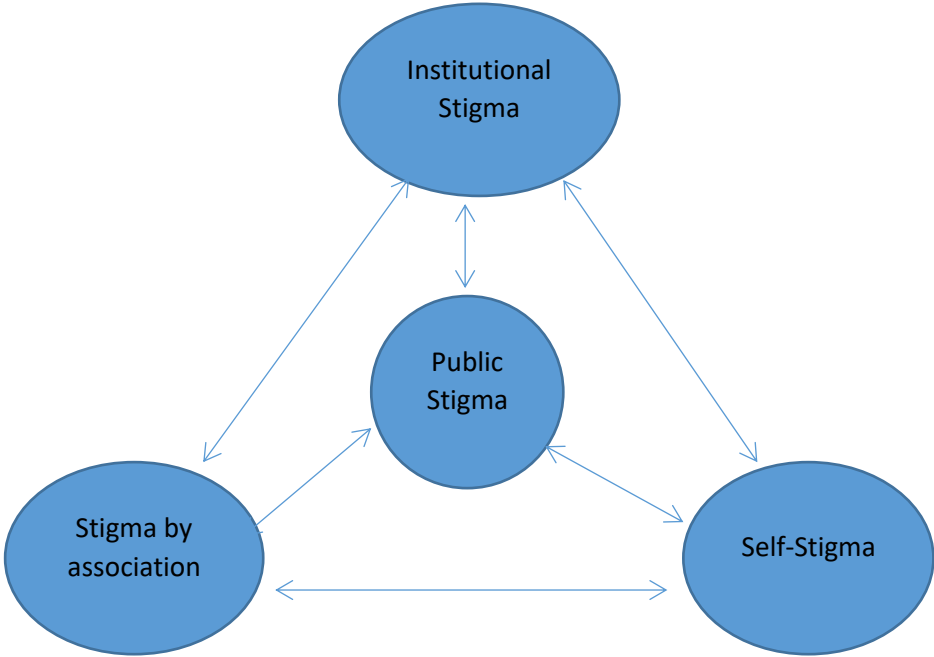
2.1 Stigma generally defined

Historically, the word “stigma” was used by Greeks to refer to bodily signs such as a tattoo or mark designed to expose something unusual and bad about the moral status of the stigmatized individual (Goffman, 1963). The body marks were signals of being a slave, a criminal or a traitor (Stuenkel & Wong, 2009). Goffman then articulated the concept of stigma in the 1960s. He defined stigma as a process of devaluation that ‘significantly discredits’ an individual in the eyes of others (Goffman, 1963). Similarly, Jones and colleagues echoed that stigma is a sign that differentiates a person and connects the marked person to unfavorable characteristics (Jones et al., 1984). Since then, the stigma concept has shifted from being defined only at an individual level, to encompass broader social, cultural, political, and economic forces that may influence stigma (Kleinman & Hall-Clifford, 2009; Parker & Aggleton, 2003; Pryor, Reeder, Landau, 1999).

Parker and Aggleton (2003) further define stigma by including social, cultural, political, and economic forces that inform and shape stigma. As a social and cultural phenomenon, stigma is linked to the actions of whole groups of people with an emphasis of stigmatization as a process of competition for power and the legitimization of social hierarchy and inequality (Parker and Aggleton, 2003). Parker and Aggleton (2003) denote that it is imperative to consider stigma as a social and cultural phenomenon interconnected to actions of whole groups of people where bonds and commitments to families, village, neighbourhood, and community thrive. Link and Phelan (2001) emphasize the presence of social, economic, or political power, which enables a community to collectively identify an undesirable attribute, construct stereotypes, and to act on the negative stereotype by portraying stigmatizing attitudes and behaviours towards the stigmatized.

To further clarify the concept of stigma, Pryor, Reeder, and Landau (1999) grouped stigma into four categories that are shown in Figure 2.1 as follows: a) public stigma, b) self-stigma c) stigma by association and d) institutional stigma. Public stigma entails psychosocial elements imposed on individuals with stigmatised features. It can be looked through the same lens as external stigma already discussed above in its origin, with the elements of “us vs. them” discourse. The components of public stigma include cognitive (stereotypes), affective (prejudice), and behavioural (discrimination) components. Secondly, the self-stigma entails psychosocial bearing on those who are stigmatized. It can be explained as fear and internalization of the negative beliefs and feelings linked with the stigmatized condition (Bond, Chase & Aggleton, 2002). Thirdly, stigma-by-association (commonly termed secondary stigma), which is stigma as conceptualized by Goffman (1963), refers to the psychosocial reactions towards individuals in relation with the stigmatized one, including family and friends (Pryor et al., 1999). Lastly, institutional stigma, which is closely linked to the recent developments of understanding stigma, can be defined as the broader social, cultural, political, and economic forces that structure stigma (Parker & Aggleton, 2003).

Figure 2.1: Four types of stigma. (Source: Pryor, Reeder & Landau, 1999)



It is important to note that stigmatization is likely to be high in conditions that are contagious, serious, considered due to personal responsibility, and norm-violating advanced emotions such as fear, anger, and (lack of) pity (Bos, Schaalma & Pryor 2008).

Several types of HIV-related stigma are reported in the literature reviewed. The interest of this review was on external HIV-related stigma, which are *attitudes or actions aimed at those living with HIV, and these include issues such as rejection, avoidance, intolerance, stereotyping, discrimination, and physical violence* (Florom-Smith & De Santis, 2012; Mbonu et al., 2009).

2.2 Narrative systematic review of literature methodology

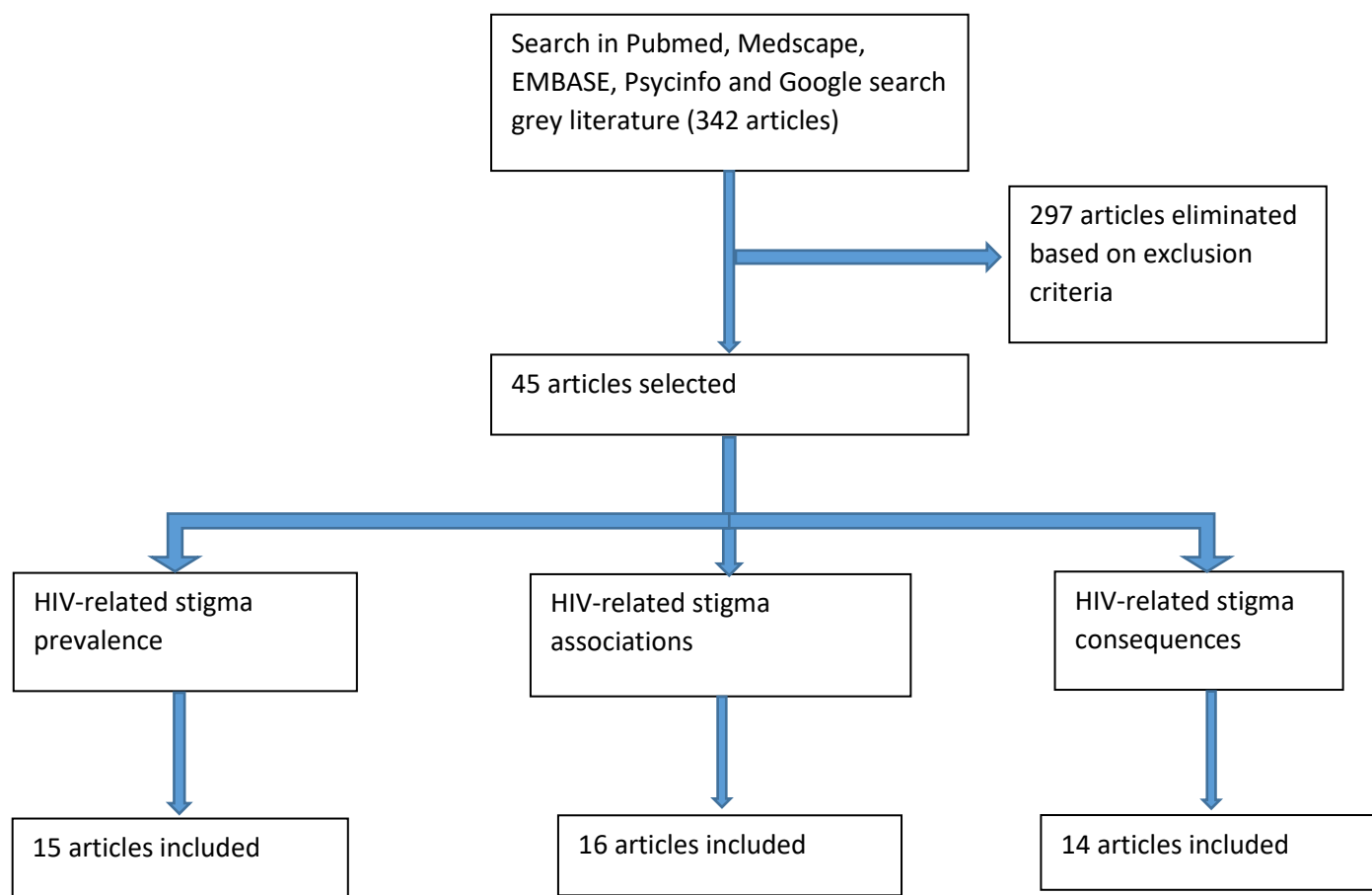
The overall aim of the review was to report on (a) the methods of assessment of external HIV-related stigma, (b) its prevalence, (c) consequences and associated factors, as well as (d) highlighting major findings and identifying key remaining research gaps. Because external HIV-related stigma is reported variably, with many different components, narrative methods were chosen, as these offer the advantage of being able to synthesize both quantitative and qualitative studies, and can be used when the studies included in a systematic review are not sufficiently homogeneous for a meta-analysis to be appropriate (Mays et al. 2005a). Papers for this review were drawn from a very wide literature, with significantly different approaches and findings.

Literature on HIV and AIDS and stigma was systematically searched in Pubmed, Medscape, EMBASE and Psycinfo. The review also included grey literature retrieved from Google search engine. In some instances, ancestry literature search was performed wherein references cited by relevant sources were tracked down. The key terms used for the search were HIV/AIDS, stigma, discrimination, attitudes, people living with HIV/AIDS. These generic key terms allowed for a wide search without restrictions. The inclusion criteria was 1) Studies done in

LAMIC, 2) Studies measuring External HIV-related stigma, and stigma attitudes and actions towards PLHIV, 3) Studies looking at the prevalence, associations and consequences of external HIV-related stigma. Three hundred and forty-two studies were retrieved, and 297 articles were eliminated based on exclusion criteria. All those articles which were not conducted in LAMIC and which focused on other types of stigma (other than external HIV stigma as defined in this review) such as internalised HIV stigma, were excluded from the search.

Forty-five (45) studies looking at prevalence, associations and consequences of external HIV-related stigma were selected for the review. Specifically, only articles with external HIV stigma towards PLHIV as a key objective of study, done in LAMIC, employing qualitative and/or quantitative methods, published in English language, between the years 2010 and 2018 were included. The 8-year time frame was chosen in order to focus on the time period in which the ART roll-out was initiated and scaled up in LAMIC; the data analysed in the study also falls within this time frame. For the purpose of this review these forty-five (45) articles were classified into three broad categories: stigma prevalence articles, stigma associations, and stigma consequences. Figure 2.2 below shows the systematic review flow chart

Figure 2.2 *Flow chart of the systematic review*



2.3 Results

Tables 2.1, 2.2 and 2.3 below show the 45 studies which were included in the review grouped into 3 categories 1) Prevalence of External HIV-related stigma in LAMIC, 2) Associations of External HIV-related stigma in LAMIC and 3) Consequence of external HIV related stigma.

2.3.1 Prevalence of external HIV-related stigma in LAMIC

Broadly, UNAIDS (2017) shows the existence of external HIV-related stigma in LAMIC based on population-based surveys, wherein some countries including Egypt, and Yemen reported high external HIV-related stigma prevalence ranging between 75-100%, while other countries such as Kenya, Lesotho reported lower stigma prevalence between 0-24% (UNAIDS, 2017).

Several studies done in LAMIC, including South African communities, have revealed the existence of HIV/AIDS-related stigma as shown in Table 2 (Akullian et al, 2014; dos Santos, 2014; Hargreaves, 2018; Kelly et al., 2017; Li, Murray, Suwanteerangkul, Wiwatanadate, 2014; Malavéa, et al., 2014; Mall et al., 2013; Masquillier, Wouters, Mortelmans, le Roux & Booyen, 2015; Maughan-Brown, 2010; SANAC, 2014; sedos Santos, 2014; Smith et al., 2014; Visser, 2018).

Li and colleagues conducted a survey in Thailand amongst people living with HIV, looking at HIV-related stigma including their experiences of public attitudes towards them (Li, Murray, Suwanteerangkul, Wiwatanadate, 2014). With an overall HIV-related stigma mean score of 21.4 out of a maximum score of 40. As this review is also interested on external HIV-related stigma experienced by PLHIV, public attitudes in that study accounted for a mean score of 4.37 out of a maximum score of 8. In Sierra Leone, a crossed sectional study based on a population data also revealed an existence of external HIV-related stigma (Kelly et al., 2017). The study measured HIV-related stigma using a three-item scale. The items were 1) “are not willing to care for a family member with the AIDS virus in the respondent’s home,” 2) “would not buy fresh vegetables from shopkeeper who has the AIDS virus,” and/or 3) “say that a teacher with the AIDS virus and is not sick should not be allowed to continue teaching.”. The study found high prevalence of stigmatising attitudes towards PLHIV in the community as more than half of the participants (66%) endorsed at least one item of the HIV stigmatising attitudes scale (Kelly et al., 2017).

Similarly, in the period beyond 2010, evidence showed high prevalence of external HIV-related stigma in South Africa. In South Africa it is estimated that one in eight PLHIV report being denied health services due to their HIV status (UNAIDS, 2014). It is further reported that one in nine are denied employment because of their HIV status, while 6% reported experiencing

physical assault (UNAIDS, 2014). A study done in four provinces; Gauteng; North West; Mpumalanga and Limpopo showed that PLHIV experienced high levels of external HIV-related stigma, with some forms as high as 52.3% (see table 2) (dos Santos et al., 2014). While a recent study by Hargreaves and colleagues showed high prevalence of external HIV-related stigma, with stigma experienced in the community being 22.1% (Hargreaves, 2018). The stigma index national study also revealed 36% of PLHIV experience external HIV stigma (SANAC, 2014)

Qualitative studies have documented participants' views regarding external HIV-related stigma (Aransiola, 2014; Colombini et al., 2014; Hua, 2014; Kulane, 2017; Kumar et al., 2015). In Kenya a study exploring the experiences of stigma of HIV-positive women revealed that some of the women were abandoned by their husbands and experienced negative verbal outbursts and carried the blame of bringing HIV to their homes (Colombini et al., 2014). In a study exploring whether stigma is still a significant problem for people living with HIV in Nigeria, one participant was captured saying: *“There is a lot of stigmatization and discrimination in the society. Once people know your status, you become the subject of discussion around. People will begin to give you space. They may stop dealing with you in any way. You may not be able to do good business because people are very careful that you will not infect them and this is discouraging and killing. You are technically ostracized. (PLHIV, Female, 29 years, Civil servant)* (Aransiola, 2014). Similar findings are documented in qualitative studies done in South India, Somali, and China (Hua, 2014; Kulane, 2017; Kumar et al., 2015).

Longitudinal studies have also been conducted to see prevalence change over time. Mall and colleagues conducted two surveys in one of the townships in the Western Cape between 2004 and 2008 (Mall et al., 2013). The results revealed existence of HIV -related stigma with an increase in the percentage of those who reported no stigma attitudes and a reduction in composite stigma score between the two surveys (median score 2 vs. 3, respectively; $p < 0.001$).

(Mall et al., 2013). While Visser (2018) explored changes in stigma between 2004 and 2016, in a study conducted in one of the townships in Tshwane. In this study personal stigma, which was defined as perceptions of and reactions towards PLWH, decreased over time, while perceived stigma, defined as stigma respondents attributed to most people in their community, remained high. Perceived community stigma remained high in both surveys (Visser, 2018).

While the above surveys show a decrease in external HIV-related stigma within the populations that were selected between 2004 and 2016, one of the studies done in the same period show an increase or distinctively high rates of HIV-related stigma in similar communities in South Africa. In the period between 2005 and 2010 Maughan-Brown's (2010) study done in Cape Town saw an increase in HIV-related stigma as five of the eight stigma questions asked showed a significant increase. The survey was done in a similar geographical area as the Mall 2013 study discussed above, as both studies were conducted in the Western Cape, South Africa, but the population differed in terms of the age of the respondents. Maughan-Brown's study focused on youth adults between the ages 14 and 22 years, while in Mall's study participants were aged 14 years and above. In Maughan-Brown's study, for example, to the question "Imagine that you find out that one of your friends is HIV infected. Would you still be friends with them?" stigma results significantly increased by 11% from 2% in 2003 to 13% in 2006 (Maughan-Brown, 2010). And to the question "Would you drink from the same bottle of water as an HIV infected friend?" Stigma results increased from 21% in 2003 to 43% in 2006, which is a 22% increase in stigma (Maughan-Brown, 2010).

Table 2.1 External HIV-related stigma prevalence studies done in LAMIC

Author/s	Methods	Type of stigma measured	Measures used	Location	Prevalence
Akullian et al, 2014	<ul style="list-style-type: none"> - Community survey - n = 405 - Population: General women 	External HIV/AIDS stigma	Four items HIV is a punishment from God, HIV/AIDS is a punishment for bad behaviour, Women prostitutes spread HIV in the community, People with HIV are promiscuous	Western Kenya	336 (89.4%) reported some indication of externalized stigma
dos Santos, M.M.L., Kruger, P., Mellors, S.E., Wolvaardt, G., and Van der Ryst, E. (2014)	<ul style="list-style-type: none"> - Community survey - n = 486 - Population: PLHIV 	External HIV/AIDS stigma	Stigma and discrimination experienced by PLHIV	South Africa (Gauteng; North West; Mpumalanga and Limpopo)	<p>% of PLHIV experiencing HIV stigma</p> <ul style="list-style-type: none"> - Being gossiped about = (52.3) - Verbally insulted/harassed, threatened = 21.3% - Sexual rejection = 20.8% - Excluded from social gatherings = 18.8% - Physically assaulted = 16.1%
Hargreaves, et.al, (2018)	<ul style="list-style-type: none"> - Cohort study - n = 5088 - Population: General population 	External HIV/AIDS stigma	Stigma experienced in the community	Zambia and South Africa	<p>% of individuals who reported stigmatizing PLHIV</p> <p>Total = 22.1%</p> <p>South Africa = 18.8%</p> <p>Zambia = 24.7%</p>
Hua, 2014	<ul style="list-style-type: none"> - Qualitative study - n = 41 - Population: 23 PLHIV, 14 public health personnel and 4 community workers 	Enacted stigma	emergent stigma-related themes	China	PLHIV experienced enacted stigma

Kelly et al., 2017	<ul style="list-style-type: none"> - cross-sectional study - n = 24,030 - Population: General population 	Community stigma	A 3-item scale measured HIV stigmatizing attitudes	Sierra Leone	<ul style="list-style-type: none"> - 66% endorsed at least one item of the HIV stigmatizing attitudes scale - mean score on the HIV stigmatizing attitudes scale across all study participants was 1.23
Kulane, et al., 2017	<ul style="list-style-type: none"> - Qualitative study - n = 7 - Population: PLHIV 	External HIV-related stigma	Stigma experienced of people diagnosed with HIV	Somali	External HIV stigma impacted their access to care.
Kumar et al., 2015	<ul style="list-style-type: none"> - Qualitative study - n= 15 IDIs - Focus groups participants = 35 - Population: PLHIV 	HIV-related stigma	Feelings of shame, worthlessness, fear of ostracism, rejection	South India	Avoiding associating with PLHA provided the context of HIV-related stigma
Li, Murray, Suwanteerangkul, Wiwatanadate, 2014	<ul style="list-style-type: none"> - Community clinic survey - n = 128 - Population: ? 	Public attitudes	Thai translation of the condensed Berger Stigma Scale	Chiang Mai, Thailand	Mean score of public attitudes = 4.37
Malavéa, Ramakrishnab, Heylena, Bharatc, Ekstrand, 2014	<ul style="list-style-type: none"> - Community survey - n = 313 - Population: Men and Women living with HIV 	Enacted HIV/AIDS stigma	Ten items measured participants' experiences of HIV-related discrimination, e.g., having been forced to move out of one's home, evicted, refused medical care or denied hospital services	Bengaluru, India	<p>mean levels of Enacted Stigma</p> <ul style="list-style-type: none"> -men: M = 1.30, SD= 1.69 -women: M = 2.10, SD = 2.17
Mall, S., Middelkoop, K., Mark, D., Wood, R., Bekker, L. (2013)	<ul style="list-style-type: none"> - Cross-sectional community surveys - 2004 (n= 640) - 2008 (n=1281) - Population: General population 	External HIV/AIDS stigma	Behavioural intentions towards PLHIV	South Africa (Western Cape)	<p>Composite stigma median score</p> <ul style="list-style-type: none"> 2008=2 2004 =3

Maughan-Brown, B. (2010)	<ul style="list-style-type: none"> - Longitudinal community survey - 2003 (n=1371) - 2006 (n= 1075) - Population: General population 	Instrumental and symbolic stigma	Behavioural intentions towards PLHIV	South Africa (Cape Town)	<p>Significant stigma increases:</p> <ul style="list-style-type: none"> - Imagine that you find out that one of your friends is HIV infected. Would you still be friends with them? = 11% - Would you drink from the same bottle of water as an HIV infected friend? = 22% - Would you rather not touch someone with HIV/AIDS because you are scared of infection? = 14% - Do you think HIV/AIDS is a punishment for sleeping around? = 24%
SANAC, 2014	<ul style="list-style-type: none"> - Cross-sectional community surveys - n = 10 473 - Population: PLHIV 	External HIV-related stigma	Stigma experienced by people living with HIV	South Africa (national)	36% of the respondents experienced some external stigma.
Visser, M. (2018)	<ul style="list-style-type: none"> - Cross-sectional community surveys - 2004 (n=901) - 2016 (n=1431) - Population: General population 	<ul style="list-style-type: none"> - Personal stigma - Perceived community stigma 	Moral judgement and interpersonal distancing	South Africa (Tshwane)	<p><i>Personal stigma mean scores</i> 2016=2.14 v.s 2004=1.93</p> <p><i>Perceived community stigma</i> 2016=1.29 v.s 2004=1.31</p>

2.3.2 Associations of external HIV-related stigma in LAMIC

Researchers, in LAMIC including South Africa have identified several variables, among others: gender, HIV transmission knowledge, economic status, education, HIV testing and knowing someone with HIV, as associated with HIV-related stigma (Du, Chi & Li, 2017; Ekstrand et al., 2013; Mall et al., 2013; Mukolo et al., 2013; Okumu, 2017; Paudel & Bara, 2015; Srithanaviboonchai et al., 2017; Vorasane et al., 2017; Wong, 2013). Below the variables are discussed.

HIV-related stigma patterns amongst males and females

HIV in its origin has been a gendered disease, with a greater proportion of females than males living with HIV in Sub-Saharan Africa (Shisana et al., 2014). Globally, out of 36.2 million adults living with HIV in 2018, 18.8 million were women, (UNAIDS, 2019). Of the 800 000 people who acquired HIV in eastern and southern Africa in 2018, 26% were young women between the ages of 15–24 years. While in South Africa specifically, of the 240 000 new HIV infections in 2018, 140 000 of those were women compared to 86 000 males (UNAIDS, 2019). The number of women living with HIV in South Africa is double the number of men living with HIV (4 700 000 vs 2 800 000) (UNAIDS, 2019).

Gender inequality, different gender roles enforced on males and females, a lack of power in decision-making, and sexual coercion have long been cited as primary reasons for this (Harrison et al., 2000; Kayaa et al., 2002; Mba, 2003). While others affirmed that this is due to biological vulnerabilities, low socio-economic status, dominant sexual practice of males and epidemiological factors (Campbell, 199; De Bruyn, 1992; Pratt, 1998). Hence, it is important to review what is currently documented on gender and HIV-related stigma. Several studies have looked at the association between HIV related stigma and gender (see Table 2.3). A survey done in India amongst men and women living with HIV and enacted stigma, reported high

scores in this aspect, with women presenting higher mean scores compared to men (Malavé et al., 2014) (see Table 2.2). A cross-sectional survey done amongst women of childbearing age from western Kenya revealed a very high percentage (89.4%) of these women held a sense of externalized stigma (blame) towards PLHIV (Akullian et al., 2014).

Table 2.2 Studies which assessed the associations of HIV-related stigma towards PLWH done in LAMIC

Author/s	Methods	Type of stigma	Measures	Location	Associations reported	Results																
Gender																						
Malavé et al., 2014	- community survey n - n = 313 - Population: General population	- Enacted stigma	Ten items measured participants' experiences of HIV-related discrimination, e.g., having been forced to move out of one's home, evicted, refused medical care or denied hospital services	India	Gender	Mean scores Men = 1.30 Women = 2.10																
Mugoya & Ernst, 2014	- cross-sectional study - n = 11818 - Population: General population	HIV stigma	acceptance of individuals with HIV	Kenya	Gender	<table border="0"> <tr> <td></td> <td>Men</td> <td>vs.</td> <td>Women</td> </tr> <tr> <td>Low</td> <td>23.1</td> <td></td> <td>23.0</td> </tr> <tr> <td>Medium</td> <td>11.1</td> <td></td> <td>15.6</td> </tr> <tr> <td>High</td> <td>2.7</td> <td></td> <td>4.9</td> </tr> </table>		Men	vs.	Women	Low	23.1		23.0	Medium	11.1		15.6	High	2.7		4.9
	Men	vs.	Women																			
Low	23.1		23.0																			
Medium	11.1		15.6																			
High	2.7		4.9																			

<p>Srithanaviboonchai et al., 2017</p>	<p>- General population Survey, - n= 10,522 - Population: General population</p>	<p>-Social judgment, - Experienced stigma, - Discrimination</p>	<p>- Do you agree with this sentence?: "I would be ashamed if someone in my family had HIV or AIDS" - You feel too disgusted to buy fresh food or ready-to-eat food from a shopkeeper or vendor whom you know has HIV or AIDS. - You think that children living with HIV or AIDS should not attend the same classroom with other children.</p>	<p>Thailand, Southeast Asia</p>	<p>Gender</p>	<p>- Overall Men had lower stigma scores than Women (56.7%/ 60.4%; p<0.001). Men vs. Women stigma item % - Social judgement=42.0/ 34.7 - Experienced=49.5/ 54.6 - Discrimination = 24.3/23.2</p>
<p>Pannetier, Lelièvre & Le Coeur, 2016</p>	<p>- community survey - n = 500 (General population) = n = 513 (PLHIV) - Population: General population and PLHIV</p>	<p>- Enacted stigma - Instrumental stigma</p>	<p>discrimination, exclusion or reject and attitudes.</p>	<p>Thailand</p>	<p>Gender</p>	<p>Women vs. Men Enacted 51% vs 30% Instrumental: Reluctance to eat or share a meal prepared by a PLHIV 8.7 vs. 5.5</p>
<p>Race</p>						
<p>Brown, 2016</p>	<p>- Qualitative - Population: Student teachers</p>	<p>HIV stigma</p>	<p>The use of drawing and narratives as a critical pedagogical tool to shift student teachers' narrow, racialized and gendered perceptions of HIV</p>	<p>South Africa</p>	<p>Race</p>	<p>Students perceived HIV as a disease of the "other", and the "other" referring to the Black race</p>

			towards a more nuanced and intersectional (Watkins-Hayes 2014) understanding of the pandemic			
Petros et al., 2006	-Qualitative study - 39 FGDs -28 IDIs - Population: General population	HIV-related self-stigma	PEN-3 Model	South Africa	Race	Othering by race reported
Wong, 2013	- Cross-sectional national survey - n=2271 - Population: General population	-HIV-related self-stigma, -public stigma	-Family and self-stigmatization attitudes, and describes the stigma surrounding personal HIV i stasis or a family member's HIV status - Social discriminatory attitudes towards PLHIV, discriminatory attitudes related to interactions with PLHIV	Malaysia	Race	Indian compared to others β scores P<0.001 Malay= -0.359 Chinese= -0.260
HIV knowledge						

Du, Chi, & Li, 2017	<ul style="list-style-type: none"> - Database study - Study 2 (n=122 countries) - Population: General population 	HIV stigma	Discriminatory attitudes toward PLHIV	<p>Two international data sets :</p> <ul style="list-style-type: none"> -UNAIDS 2009 HIV epidemiological Report -the World Values Survey 	HIV knowledge	<p>As potential mediator, HIV knowledge, negatively predicted HIV stigma. HIV prevalence had a significant indirect effect on HIV stigma, through HIV knowledge $-\beta = -0.18, p = .006,$ -95% confidence interval = [-0.31 – -0.05]</p>
Mukolo, et al., 2013	<ul style="list-style-type: none"> - Household survey of – n=3749 - Population: randomly sampled female heads of households 	Negative labelling and devaluation (NLD) and social exclusion (SoE).	Labels and stereotypes that devalue and reduce a person with HIV to a tainted and socially undesirable status	Zambezia Province, Mozambique	HIV knowledge	<p>-NLD was significantly (p,0.01) and inversely related to HIV knowledge $\beta = -4.06$ 95%CI= -6.20; -1.91 - SoE was significantly (p,0.01) and inversely related to knowledge $\beta = -3.52$ 95%CI= -5.89; -1.15</p>
Vorasane et al., 2017.	<ul style="list-style-type: none"> - A cross-sectional study - 558 - Population: Health care workers 	HIV-related stigma	Discriminatory intent at work, prejudiced attitudes, internalized shame, fear of PLWHA, and opinion about healthcare for clients living with HIV	Vientiane, Lao PDR	HIV knowledge	<p>Lower levels of HIV/AIDS knowledge were associated with higher levels of stigmatizing attitudes towards people living with HIV/AIDS. Coef. = - 0.69, 95% CI:-1.34 – -0.04, p = 0.036 respectively).</p>
Knowing someone living with HIV						

Du, Chi, & Li, 2017	- Database study - Study one (n=58,275) - Population: doctors, nurses, ward staff	HIV stigma	Intention to avoid contact with PLHIV	Two international data sets -UNAIDS 2009 HIV Epidemiological Report -the World Values Survey	Knowing someone living with HIV	Higher HIV prevalence was associated with less HIV stigma (coefficient = -0.91, p = .006),
Ekstrand, et al., 2013	- Cross-sectional study - n= 305 doctors, 369 nurses and 346 ward staff - Population: Health care workers	-Stigma manifestations	-Intent to discriminate against PLHIV in professional situations -Intent to discriminate against PLHIV in non-professional contexts -Endorsement of coercive policies	Bengaluru and Mumbai, two Indian cities	Knowing someone living with HIV	Doctors with less frequent professional contact with PLHIV AOR=1.35; 95% CI=1.08-1.70
Mall et al., 2013	- Cross-sectional community surveys - 2004 (n= 640) - 2008 (n=1281) - Population: General population	external HIV-related stigma	behavioural intentions towards PLHIV	South Africa (Western Cape)	Knowing someone living with HIV	Composite stigma score median (IQR) P<0.001 2004 = 3 (2-5) 2008 = 2 (1-2)
Mukolo, et al., 2013	- Household survey of – n=3749 - Population: randomly sampled female heads of households	Negative labelling and devaluation (NLD) and social exclusion (SoE).	labels and stereotypes that devalue and reduce a person with HIV to a tainted and socially undesirable status	Zambezia Province, Mozambique	Knowing someone living with HIV	$\beta = 26.94$; p,0.001
Vorasane et al., 2017.	- A cross-sectional study - 558 - Population: Health care workers	HIV-related stigma	Discriminatory intent at work, prejudiced attitudes, internalized shame, fear of PLWHA, and opinion about healthcare for clients living with HIV	Vientiane, Lao PDR	Knowing someone living with HIV	Provided care to PLHIV for a longer period Doctors - (Coef.= -0.09, 95% CI:-0.17 – -0.02, p = 0.013

						Nurses - (Coef. = -0.11, 95% CI:-0.18 – -0.04, p = 0.001),
Education						
Akullian et al, (2014)	- Community-based survey - n= 405 - Population: General population (women)	Externalized stigma (blame)	- HIV is a punishment from God - HIV/AIDS is a punishment for bad behavior - Women prostitutes spread HIV in the community - People with HIV are promiscuous	Western Kenya	Education	Individuals reporting externalized stigma had lower levels of education (P=0.01)
Bekalu, Eggermont, Ramanadhan, Viswanath, (2014)	- Population surveys (2006–2011) - n= 204,343 - Population: General population	HIV-related stigma	1) if they would care for a relative who is sick of AIDS in their own households, 2) if they would want to keep a family member's HIV positive status secret, 3) if they would be willing to buy fresh vegetables from a market vendor who is HIV positive, and 4) if they thought a female teacher who is HIV positive but not sick of AIDS should be allowed to continue teaching.	Sub-Saharan Africa	Education	HIV-related stigma tends to be higher among individuals with low levels of education

Corno and de Walque (2013)	- General population Survey, - n= 20,833 -Population: General population	HIV stigma	Attitudes toward people living with HIV	Lesotho	Education	The proportion of individuals who report stigmatizing ideas decreases with education attainment
Tsai and Venkataramani, (2015).	Community-based survey - n= 7100 - Population: General population	Negative attitudes toward persons with HIV	- "If a member of your family got infected with the AIDS virus, would you want it to remain a secret or not?" - "Would you buy fresh vegetables from a shopkeeper or vendor if you knew that this person had the AIDS virus?" - "If a member of your family became sick with AIDS, would you be willing to care for her or him in your own household?" - "In your opinion, if a female teacher has the AIDS virus but is not sick, should she be allowed to continue teaching in the school?"	Uganda	Education	statistically significant, negative association between years of schooling and HIV stigma (each P < 0.001, with t-statistics ranging from 4.9 to 14.7).

A study using 2008-2009 Kenya Demographic and Health Survey data looked at gender differences in HIV-related stigma in Kenya and revealed gender variations in this aspect (Mugoya & Ernst, 2014). The study showed that women were more likely to express higher stigmatising attitudes towards PLHIV compared to men. Malavé and colleagues conducted a study on the differences in testing, stigma, and perceived consequences of stigmatization among heterosexual men and women living with HIV in India (Malavé et al., 2014). They measured participants' experiences of HIV-related discrimination, using items such as having been forced to move out of one's home, evicted, refused medical care or denied hospital services. In this study women had higher mean scores of experienced stigma compared to men (men: $M = 1.30$, $SD = 1.69$; women: $M = 2.10$, $SD = 2.17$; $t = 3.61$; $df = 288.922$; $p < 0.001$) (Malavé et al., 2014).

Pannetier and colleagues assessed the relationship between gender and HIV-related stigma in Thailand measuring experienced stigma by PLHIV ($n = 513$) and stigma attitudes towards PLHIV by the general population ($n = 500$) (Pannetier, Lelièvre & Le Coeur, 2016). Amongst the PLHIV sample, results showed that women experienced more external HIV-related stigma than men. Stereotypes such as "blameworthy" were prevalent among the general population, with more women than men reporting instrumental stigma, which was measured by reluctance to eat or share a meal prepared by a PLHIV or misgivings about PLHIV attending community events. Similarly, in a study done by Srithanaviboonchai and colleagues in the general population of Thailand, women showed more HIV stigma on the (Fear of HIV infection) item measured by "Do you fear that you could contract HIV if you come into contact with the saliva of a person living with HIV?" and also on (Experienced Stigma) item measured by "Do you feel too disgusted to buy fresh food or ready-to-eat food from a shopkeeper or vendor whom you know has HIV or AIDS?" (Srithanaviboonchai et al., 2017).

The gender differences on the experience of HIV stigma amongst PLHIV as well as the gender difference on the attitudes towards PLHIV could be explained by the different social constructed roles assigned to men and women. Women are more likely to attend health care facilities than men (Yeatman, Chamberlin, Dovel, 2018; WHO; 2017; WHO, 2018) which could mean that women receive more exposure to HIV-related education, which could then translate to women expressing less stigma attitudes towards PLHIV. This difference can also be related to other factors such as the level of education between men and women, employment status and financial situation, women's social role in the community and low control in decision making (Family Health International-Nepal, 2009; Leasure, Seidemen, Pascussi, 2009; Paudel and Baral, 2015; Wagner et. al., 2010)

HIV-related stigma, ethnicity and race

Other studies have alluded to the importance of socio-demographic factors such as race and ethnicity in understanding HIV-related stigma (Shisana et al., 2008; Shisana et al., 2012; Wong, 2013; Brown, 2016; Petros et al., 2006). Ethnicity has been documented as one of the strong correlates of HIV-related stigma (Wong, 2013). For example, a study done amongst 2271 Malaysian adults looking at prevalence and factors associated with HIV -related stigma and discriminatory attitudes showed that the ethnic group was significantly correlated with the social discriminatory score (see Table 2.3) (Wong, 2013). Specifically, the results revealed that ethnicity significantly correlated with HIV-related stigma in the form of interactions with PLHIV (Wong, 2013). Some studies done in South Africa have suggested that HIV stigma in South Africa cannot be separated from the equally stigmatised construct of race (Brown, 2016; Petros et al., 2006). His study based on strategies to shift epistemologies around race, class and HIV with first year Life Orientation Teacher Education students at one university in South Africa, revealed that students from that university saw HIV and AIDS as a “Black” race disease

(Brown, 2016). He further stipulates that the students perceived HIV as a disease of the “other”, and the “other” referred to the Black race in South Africa.

HIV-related stigma and knowing someone living with HIV

Evidence points towards a relationship of lower HIV-related stigma amongst those knowing someone with HIV (Ekstrand et al., 2013; Mukolo et al., 2013; Vorasane, 2017). A survey done in Cape Town, South Africa, also reported that lower composite stigma score was associated with knowing someone who was living with HIV, as well as knowing someone who had died from AIDS related illnesses (Mall et al., 2013). The composite stigma score in both surveys was much lower if the person living with HIV was a family member, a friend, or a sexual partner.

The relationship between knowing someone living with HIV and stigma has also been reported in a study done in Vientiane in Laos (Vorasane et al., 2017). In their study doctors and nurses who had more contact with clients living with HIV had lower external HIV-related stigma attitudes. Their multiple linear regression results showed a significant, negative direction of association between HIV stigmatizing attitudes and doctors who had provided care to HIV patients for a longer duration. While in a study conducted in India investigating the drivers of stigma and discrimination, high levels of stigma were also shown amongst all the health workers (Ekstrand et al., 2013). Significant, negative direction of association was reported between external HIV-related stigma and reduced professional contact with PLHIV. These studies, though done amongst health care workers rather than general community population, strongly add to the evidence of the association between knowing someone living with HIV and HIV-related stigma.

It is worth noting a study which yielded some interesting results in relation to knowing someone

living with HIV and stigma. The study drew on a relationship between high numbers of those who live with HIV and lower HIV-related stigma. The results of this cross-national investigation revealed that high HIV prevalence predicts less HIV-related stigma (Du, Chi, & Lic, 2017). From the two international data sets used in the study (the UNAIDS 2009 HIV Epidemiological Report and the World Values Survey), the results suggest that in countries with higher HIV prevalence, individuals were less likely to stigmatize PLHIV (Du et al., 2017). Though the researchers were not sure what mechanisms underlie the effect of HIV prevalence on HIV stigma, they deduced that the association could be explained by the contact-stigma reduction hypothesis. Using this hypothesis, one could deduce that when there is high prevalence of HIV in a community where people are living with PLHIV, it is likely that they will portray less stigmatizing attitudes towards PLHIV.

HIV-related stigma and HIV knowledge

Knowledge about HIV transmission has been documented as one of the major correlates of HIV-related stigma (see Du et al., 2017; Ekstrand, 2013; Wong, 2013; Mukolo et al., 2013; Okumu et al., 2017; Vorasane, 2017). In their study looking at the correlates of HIV-related stigma in a rural setting in Mozambique, Mukolo and colleagues found that HIV transmission route knowledge had a negative correlation with both the dimensions of stigma reported (i.e. negative labeling and devaluation [NLD] and social exclusion [SoE]) (Mukolo et al., 2013). A cross-sectional study done in León, Nicaragua, revealed similar results. Those reported to have insufficient HIV-related transmission knowledge showed higher stigmatizing attitudes and higher discriminatory actions towards people living with HIV (Ugarte et al., 2013). Similarly, a study done on HIV-related stigma among African, Caribbean, and Black youth in Windsor, Ontario, showed higher levels of stigma associated with lower knowledge amongst African-Muslim and male participants (Mihan et al., 2016).

Du and colleagues reported that HIV knowledge mediates the relationships between HIV-related stigma, HIV testing and HIV country prevalence. Their study looking at whether and how HIV prevalence is associated with individual and country-level HIV stigma, also found that HIV knowledge mediated the relationship between HIV prevalence and stigma (Du et al., 2017). Their study results showed that in countries with higher HIV prevalence people were more knowledgeable about HIV transmission, and reflected lower stigmatizing attitudes, hence they concluded that the relationship between high HIV prevalence and low stigma was partially explained by HIV knowledge (Du et al., 2017)

HIV-related stigma and Education

Some studies have found a relationship between HIV stigma and level of education (Ajong et al., 2018; Akullian et al, 2014; Bekalu, Eggermont, Ramanadhan, Viswanath, 2014; Corno and de Walque, 2013; Tsai and Venkataramani, 2015; Wagner et al., 2010). A study done using the 2004 and 2009 Demographic and Health Surveys conducted in Lesotho measured socioeconomic associations of stigmatising attitudes toward PLHIV. In this study Corno and deWalque (2013) found a negative association between stigmatizing attitudes and education. In a community based study done in the general population of Kenya, results showed that those reporting externalized stigma had lower levels of education ($P=0.01$) (Akullian et al, 2014). While a study done in Cameroon amongst PLHIV showed that in this sample those with a level of education below tertiary experienced high levels of HIV-related stigma (Ajong et al., 2018). A study done using population-based data from the 2011 Uganda Demographic and Health Survey and the 2011 Uganda AIDS Indicator Survey suggests a statistically significant, negative association between years of schooling and HIV stigma (Tsai and Venkataramani, 2015). Bekalu and colleagues did a study based on cross-sectional data pooled from the 2006–2011 Demographic and Health Surveys of 11 sub-Saharan African countries (Bekalu, Eggermont, Ramanadhan, Viswanath, 2014). Their results show that HIV-related stigma tends

to be higher among individuals with low levels of education (Bekalu, Eggermont, Ramanadhan, Viswanath, 2014). These studies show that level of education is one of the important factors in trying to understand external HIV-related stigma as experienced by PLHIV and as portrayed by the general populations towards PLHIV.

2.3.3 Consequences of external HIV-related stigma in LAMIC

HIV-related stigma, health outcomes and 90-90-90 targets

HIV-related stigma has been seen to induce anxiety, depression, and lower self-esteem mental states, while clinically it impacts on physical health outcomes, and is associated with higher viral loads amongst those living with HIV (Chambers et al., 2015). The other consequence of HIV stigma is treatment adherence which can then lead to difficulties in achieving the 90-90-90 targets. In a study done in Haiti exploring factors affecting treatment adherence, significant negative correlations were reported between treatment adherence and total perceived stigma ($p < 0.05$) (Rubens et al., 2018). While in a qualitative study done in Malawi in which content analysis was conducted, HIV-related stigma was reported as one of the barriers to treatment adherence (Elwell, 2016).

HIV-related stigma, psychological health and social care

Other studies have reported on psychological health and social care consequences of HIV stigma (Onyebuchi-Iwudibia & Brown, 2014; Rueda et al., 2016). A study done in Eastern Nigeria examining the association between depression and HIV-related stigma among people living with HIV, revealed that a higher HIV-related stigma score was associated with higher levels of depression with significant correlations with HIV stigma ($p < 0.001$) (Onyebuchi-Iwudibia & Brown, 2014). Similar findings are reiterated in a meta-analysis of 64 studies on the association between HIV-related stigma and general health among PLHIV (Rueda et al., 2016). Once again, the study showed evidence that there was an association between HIV-related stigma and higher rates of depression.

Table 2.3. Studies documenting consequence of external HIV related stigma

Author/s	HIV- related stigma Consequences documented	Location
1. Chambers et al., 2015	Impacts on physical health outcomes Associated with higher viral loads	qualitative meta-summary of 55 studies
2. Elwell, 2016	Barrier to treatment adherence	Malawi
3. Flax et al., 2017	Non-disclosure	Malawi and Uganda
4. Govender, Bowen, Edwards, and Cattell, 2016	Affects HIV testing attitudes	South Africa
5. Katz et al 2013	Affects mental outcomes HIV-related stigma undermined ART adherence	Meta-analysis (75 studies, 32 countries)
6. Onyebuchi-Iwudibia & Brown, 2014	higher levels of depression	Eastern Nigeria
7. Parcesepe et al., 2018	Affects mental outcomes	Ethiopia
8. Rubens et al., 2018	Barrier to treatment adherence	Haiti
9. Rueda et al., 2016	Higher levels of depression	Meta-analysis (64 studies)
10. Seth et al., 2014	Affects mental outcomes	Tanzania

Many other studies have shown the concerning association between HIV-related stigma and mental health outcomes amongst those living with HIV (Katz et al 2013; Parcesepe et al.,2018; Rubens et al., 2018; Seth et al., 2014)

Studies done in LAMIC, including South Africa, have reported on some of the social consequences of HIV stigma experienced by PLHIV, such as lack of emotional support from family and friends, non-disclosure of HIV status, the negative influence of gender, and discriminative cultural beliefs which have been reported to be associated with HIV-related stigma (Flax et al., 2017; Govender, Bowen, Edwards, and Cattell, 2016). For example, a study done in Malawi and Uganda reported that HIV stigmatising behaviour such as lack of support from husbands, lack of economic support and being divorced were some of the reasons for not disclosing their HIV status (Flax et al., 2017).

2.4 Summary

The review revealed that HIV-related stigma studies are mostly limited by the use of small samples and conducted in specific communities and sub-populations in South Africa and other LAMIC. It also showed that there are limited HIV-related stigma studies done at a population level. This gap demands clarification, ideally from larger, more general surveys, with a view to planning interventions in South Africa. The review also revealed that HIV-related stigma is still highly prevalent in LAMIC, and associated with race, knowing someone with HIV, HIV knowledge, level of education and sex. Lastly the review showed that HIV-related stigma has negative consequences on those living with HIV such as the impact on physical health outcomes, higher viral loads, barrier to treatment adherence, non-disclosure, and affects mental health outcomes.

CHAPTER 3

THEORETICAL FRAMEWORK

3.1 Introduction

HIV-related stigma is a complex phenomenon which limits the ability of public health programmes to develop effective interventions to reduce it (Visser, Makin, Vandormael, Sikkema, Forsyth, 2014). Scientists have tried to understand why stigmatizing attitudes and behaviour towards people living with HIV arise. Consequently, several frameworks that conceptualize HIV-related stigma have been developed. These frameworks have been used to deconstruct the phenomenon, with a view to formulating interventions to address HIV-related stigma. This chapter will expand on the social cognitive theory frameworks with particular emphasis on the Institutional Social Construction framework that has been adopted for this study.

3.2 Social cognitive theory frameworks

Social Cognitive Theory (SCT), pioneered by Albert Bandura in the 1960's posits that people learn by observing the actions of others and the rewards of those actions, then cognitively take a decision to act the same way to attain similar rewards (Bandura, A., 1977; Harinie et al., 2017). It describes how an individual thinks about and responds to his/her social environment (Harinie et al., 2017). The literature to date has drawn on social cognition theory frameworks to understand the concept of HIV-related stigma, with a view to develop interventions. Social scientists such as Herek and Capitano (1998), Kraft and Rise (1995), Price and Hsu (1992) and Pryor, Reeder and Landau (1999) have used a social cognitive theoretical framework referred to as the Two-Factor-Theory which conceptualises HIV-related stigma as an outcome of two processes.

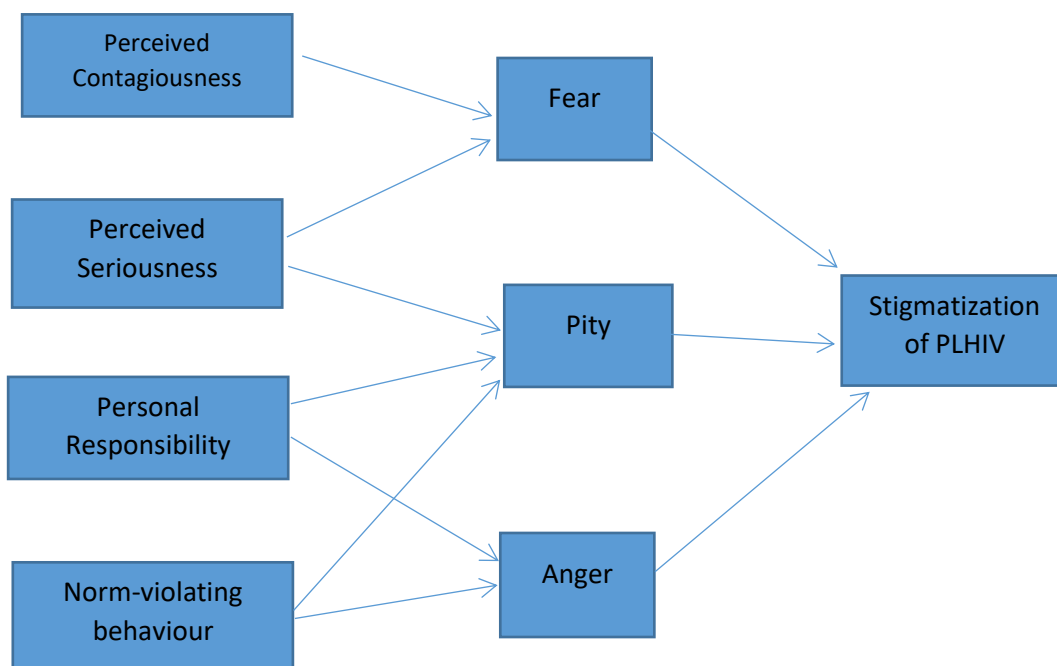
Firstly, they conceptualise HIV-related stigma as a result of instrumental fear which is a cognitive process where people would weigh the pros and cons of socializing with an HIV positive individual, based on their beliefs about transmission (Pryor, Reeder & Landau, 1999). For example, people from different societies or communities will view HIV transmission differently, based on how HIV presents itself in that particular community. Pryor and colleagues make a comparison between United States and sub-Saharan Africa (Pryor, Reeder & Landau, 1999). They state that individuals from these different environments are likely to have different HIV transmission beliefs, due to what they have observed in their communities. When the unfavourable factors out-weigh the favourable factors during the cognitive process, then fear of contracting HIV casual contact becomes prevalent (Pryor, Reeder & Landau, 1999).

Secondly, the social cognitive theoretical framework conceptualises HIV-related stigma as an outcome which arises from the connection of HIV to negatively evaluated social aspects (symbols) such as homosexual promiscuity, drug injecting, promiscuous sex, sex with sex workers, death and the wrath of God for moral transgressions (Herek & Capitano, 1998; Kraft & Rise, 1995; Price & Hsu, 1992). The framework posits that when people stigmatize PLHIV, it may be an indication of how they feel about the symbol (the negatively evaluated social aspects), (Pryor et al., 1999). For an example, Price and Hsu (1992) found that homophobic attitudes (symbolic cognitive process) independently predicted stigmatizing reactions towards PLHIV (Price & Hsu, 1992). In this way, HIV-related stigma is induced as a result of symbolic cognitive processes (Herek, 1999).

Bos, Schaalma, and Pryor (2008) have since added to the features of social cognitive theory frameworks that lead to a condition being stigmatized. In their Cognitive-Emotional framework of HIV-related stigmatization (see Figure 3.1), they state that HIV has long been perceived as contagious and serious. It is further stated that people hold perceptions that those infected are

'responsible' for being HIV positive and that those infected have been involved in norm-violating behaviours (Bos et al., 2008). One might need to relook at the elements of this framework with developments in HIV programmes such as “test and treat”, in which HIV might no longer be perceived as the most contagious and serious disease. With the widespread ARV treatment through the public health sector, PLHIV now have a longer lifespan. Therefore, HIV might no longer be seen as a “serious” medical condition but rather a manageable one.

Figure 3.1: Cognitive-Emotional of HIV-related stigmatization (Source: Bos et al., 2008)



Following the social cognitive theory frameworks, social contact theory framework has been adopted to understand why people have stigmatizing attitudes towards PLHIV (Attell, 2013). The Contact Hypothesis Theory framework posits that one’s opinions about AIDS and health care are a result of whom one knows and where one lives (Attell, 2013). Emerging from Allport’s work, the social contact theory framework work articulates that “various types of social contacts such as casual contacts, acquaintances, residential contacts, occupational contacts, and goodwill contacts have an influence in either reducing or increasing prejudice held towards out-group members” (Allport, 1958:250-266). When applied in the case of HIV-

related stigma, it can be understood as various types of social contacts with HIV positive individuals, be it as family, friends, work colleagues, or doing HIV advocacy work, that can influence how one decides to act and behave towards PLHIV.

The social contact theory framework has been utilized across different groups, situations and societies with different research methods and procedures (Pettigrew & Tropp, 2006). Gerbert and colleagues conducted a study where they were looking at the impact of who you know and where you live, on opinions about AIDS and health care. The study revealed that those who had contact with PLHIV: “1) endorsed less employment restrictions on PLHIVs, 2) were less likely to say that they would switch from an HIV-infected health care provider or a provider who treated HIV-infected patients, and 3) were less likely to overestimate the likelihood of HIV infection in a variety of low-risk situations” (Gerbert et al., 1991:678). Similarly, in a cross-sectional study of variables impacting on AIDS-related knowledge, attitudes, and behaviors among employees of a Minnesota teaching hospital, knowledge about AIDS, attitudes toward PLHIVs, and intentions to avoid PLHIVs among staff members, were found to be associated with contact with PLHIV (Henry, Campbell, & Willenbring, 1990). While in a study looking at attitudes of teenagers who knew someone with AIDS, those who reported knowing a person with HIV were more willing to interact with people who have AIDS than were matched controls (Zimet, 1992). The studies show the cognitive processes involved when individuals are socially presented with, or frequently exposed to, certain stimuli (i.e. PLHIV). In essence, individuals who are in social contact with PLHIV eventually accept them as part of “us” rather than “them”.

3.3 The South African Approach to HIV-related stigma

South Africa has not necessarily implemented specific stigma-reduction interventions. Although one of the NSP 2007-2011 key priority areas refers to Human Rights and Access to Justice, there have been no activities directed to specific HIV-related stigma reduction in national health programmes. There are activities and policies aimed at the reduction of HIV infections that are hoped to/assumed to reduce stigma. The approach to HIV-related stigma by key institutions in public health has largely followed the individualistic framework approaches to conceptualise HIV-related stigma (National Department of Health (DoH), 2015). HIV stigma reduction related activities have been aimed at the acquiring of coping skills by those living with HIV. For example, HIV counselling and testing (HCT) has been found to be associated with reduced HIV-related stigma in South Africa (NDoH, 2015). Previous studies in South Africa have shown that members of the public who had undergone HCT had lower scores of HIV stigmatizing attitudes than those who had not (Mall et al., 2013; Kalichman & Simbayi, 2003). The idea posits that if someone goes for HCT, they get some education on HIV transmission information and that being HIV positive is not a death sentence, which provides a better platform to accept PLHIV. Therefore, with this association it is not surprising that HCT would be one of the responses or interventions to curb HIV incidence and, additionally, to curb HIV-related stigma. In 2010, the South African Government initiated a massive HCT campaign as part of a scaling up of the national HIV response. The national HCT campaign was intended to mobilise all South Africans to be tested for HIV and to ensure that every South African knew their HIV status, with the hope that the campaign would also address the issues around HIV-related stigma (SANAC, 2010).

The national HCT campaign in South Africa has been lauded by UNAIDS (2013) as a game changer in the fight against HIV and AIDS and its success has also been largely credited for the success in enrolling over 3.7 million people onto ARV treatment in the country to date (UNAIDS, 2017). As previous studies suggest, there is an association between HCT and lower

stigmatizing attitudes in South Africa (Mall et al., 2013; Kalichman & Simbayi, 2003). It is therefore not farfetched to expect that as more South Africans volunteer to do HCT, a reduction in HIV-related stigma towards PLHIV will be seen. Nevertheless, as discussed in the previous chapter, the relatively high existence of HIV-related stigma is still a challenge which we face in public health. In South Africa, an increase in access to ART as well as the implementation of HIV - policies raises hope that these interventions will have a significant impact on the reduction of HIV -related stigma. However, current evidence suggests that this is not the case, as a very slow decline in HIV-related stigma is seen, and progress has been uneven across different communities and provinces in South Africa, with some forms of HIV-related stigma still very high.

3.4 Why do we need an alternative way of thinking?

The social cognitive theory frameworks have to some extent been useful in understanding and developing interventions to reduce HIV-related stigma, but they present with some limitations. As Parker and Aggleton (2003) have noted, these theoretical frameworks have played a big role and have provided useful insights into HIV-related stigma issues. Nevertheless, as discussed in the previous chapter, HIV-related stigma is still a challenge and continues to be a barrier to the achievement of effective HIV treatment and care programmes; the reason probably being that the concept of HIV-related stigma is complex because it involves the intersection of cross-cultural, structural inequalities, institutional and social differences. The social cognitive theoretical frameworks used to date have utilised a very individualistic approach. Kleinman and Hall-Clifford (2009) have argued that these frameworks have heavily focussed on the processes by which stigma is internalized and how it shapes individual behaviour. These individualistic approaches then limit the reduction of HIV- related stigma, as stigma in itself is a social process. More so, given the unique contextual background and many political changes in South Africa,

as well as many social and cultural diversities. Therefore, interventions that address stigma as a social process tied to power relations and the reproduction of social inequalities are needed.

3.5 The study theoretical framework – Institutional Social Construction

3.5.1 Defining Social Construction framework

Social construction theoretical frameworks explain people's beliefs and behaviour as created within the social context in which they live (Cheung, 1997). It is further suggested that people's knowledge, as a social phenomenon, develops within social interactions (Cheung, 1997). Social construction framework is removed from the individualistic cognitive processes that accompany knowledge; its lens is more a social rather than an individual focus (Young & Colin, 2004). As mentioned before, the South African context is formed by diverse cultural communities and traditional patriarchal societies (Airhihenbuwa et al., 2009; Iwelunmor, Zungu, & Airhihenbuwa, 2010), it is therefore important to understand the unique social and cultural context of HIV-related stigma in South Africa. "Stigma as an expression of belonging and relationships conveys institutional and familial values that influence groups' perceptions and interpretations of meanings and of acceptance and rejection as they relate to a disease such as HIV/AIDS." (Airhihenbuwa, et al., 2012, p. 410)

South Africa's apartheid regime has seen South Africans being classified according to race (White, Black and Coloured.), where certain race groups were oppressed based on the colour of their skin. This regime saw certain groups receiving better access to "education" and "health". As Airhihenbuwa and colleagues state, in a post-apartheid South Africa the location of power along lines of racial, class, and gender identities is relevant with respect to group acceptance and rejection, and hence relevant to HIV related stigma. They further state that "stigma as an expression of belonging and relationships conveys institutional and familial

values that influence groups' perceptions and interpretations of meanings and of acceptance and rejection as they relate to a disease such as HIV/AIDS, thus culture enables us to negotiate and develop strategies that could help us to understand the complex nature of stigma and ensure that appropriate interventions are developed for HIV reduction and possible elimination” (Airhihenbuwa et al., 2012, p. 410).

3.5.2 Applying Institutional Social Construction framework

Institutional social construction framework is used in this study to conceptualise external HIV-related stigma. As stipulated before, much literature and research alludes to social cognition theory frameworks in order to understand the concept of HIV-related stigma and the development of interventions. There is sparse evidence seen in the area of combating HIV-related stigma using the Institutional Social Construction frameworks. As Martin states “Institutions are profoundly social; they are characteristic of groups. Institutions are constituted by a collection of people who associate with each other extensively and, through interaction; develop recursive practices and associated meanings” (Martin, 2004, pg. 1256). Therefore, in trying to address a social challenge such as external HIV-related stigma in the unique South African context, one cannot ignore elements such as gender, race, and education. One could argue that these social institution elements have a direct impact on external HIV-related stigma as they generally inform how individuals behave, specifically towards PLHIV, while the health structural elements (the entry points to either the HIV prevention continuum or the HIV care continuum, which in this study include HIV testing, HIV knowledge, Knowing HIV status) have an indirect impact to the same.

3.5.3 Social institution elements in the study framework

Gender: In the field of HIV stigma gender has been mostly analysed at an individual level with the biological framework of males and females. It is important to also look into gender as a “socially constructed” phenomenon, as our conception of what males and females are and what they are supposed to be is produced by the society in which we live. Hence in the South African diverse context with mostly patriarchal rooted communities, gender would play a distinctive role in how stigma towards PLHIV is constructed and therefore manifested. For an example some studies show that women are less likely to stigmatise PLHIV compared to men. This has to be understood beyond the biological differences between males and females, but rather at how gender as an institution influences such results. We need to understand HIV stigma and how it can be influenced by gender norms which affect how women and men act towards PLHIV. For example, gender norms construct women as caregivers, mothers and nurturers (Iwelunmor et al., 2010), therefore it is understandable that they would portray less stigmatising attitudes towards PLHIV than men. Epidemiologically, more women than men live with HIV, at least in the Sub-Saharan Africa. This then means they are more exposed to HIV education as they access health care services more than men. The lack of / less HIV knowledge which men have might then also explain the fact that more men than women would stigmatise PLHIV. Therefore, if we want to curb external HIV related stigma, our interventions frameworks should include gender as an institutional element.

Race: Just like gender, race is a form of ‘group identity’ and is socially constructed. In South Africa we experience an uneven distribution of HIV amongst racial groups (Shisana et al. 2008, 2012). This is mainly rooted in the structural inequalities shaped by pre- 1994 government systems which provided the White race with first class health care compared to third class care rendered to the Black race (Forsyth, Vandormael, Kershaw, Grobbelaar, 2008). In South Africa Black and Coloured racial groups have a higher likelihood to be HIV-positive than the White

racial group (Shisana et al. 2008, 2012). Loutfy et al. (2012) state that since the early detections of HIV, racist blaming utterances have been embedded within constructions of HIV as a disease. This has been true for South Africa as well, where the Black race has been blamed for the spread of the virus (Cloete et al. 2010). Cloete and colleagues further state that racist stereotypes fuel the stigmatisation of PLHIV (Cloete et al. 2010). Therefore, external HIV related stigma interventions are more likely if they include race as an institutional element in their frameworks.

Education: Education is also a social institutional element. Different education levels form certain societal groups (i.e. university students, certain socioeconomic sub-groups, certain work cadres and others) which share similar values and norms. Education level has also been linked with external HIV-related stigma (Rivera, 2015). Furthermore Herek, Widaman and Capitano (2005), state that external HIV-related stigma is more prevalent amongst the low socioeconomic sub-population as they are more likely to have inaccurate knowledge of how HIV is transmitted. Other studies have also alluded to the fact that low education levels are associated with HIV stigma (Darrow, Montanea, & Gladwin, 2009; Lentine et al., 2000). In South Africa, due to the apartheid system, we still have many less well-educated sub-populations, and therefore it becomes important to include education as an institutional element in external HIV related interventions

3.5.4 Health structural elements in the study framework

This study also takes into consideration “health structural elements” which I define in this study as the entry points to either the HIV prevention continuum or the HIV care continuum, which in this study include HIV test history, HIV knowledge, and Awareness HIV status. These three elements are defined in this study as follow:

HIV Knowledge. HSRC12 utilised 5 items to measure this variable. The HSRC12 team used a composite measure of precise knowledge based on responses to three prompted questions related to HIV prevention, namely: ‘To prevent HIV infection, a condom must be used for

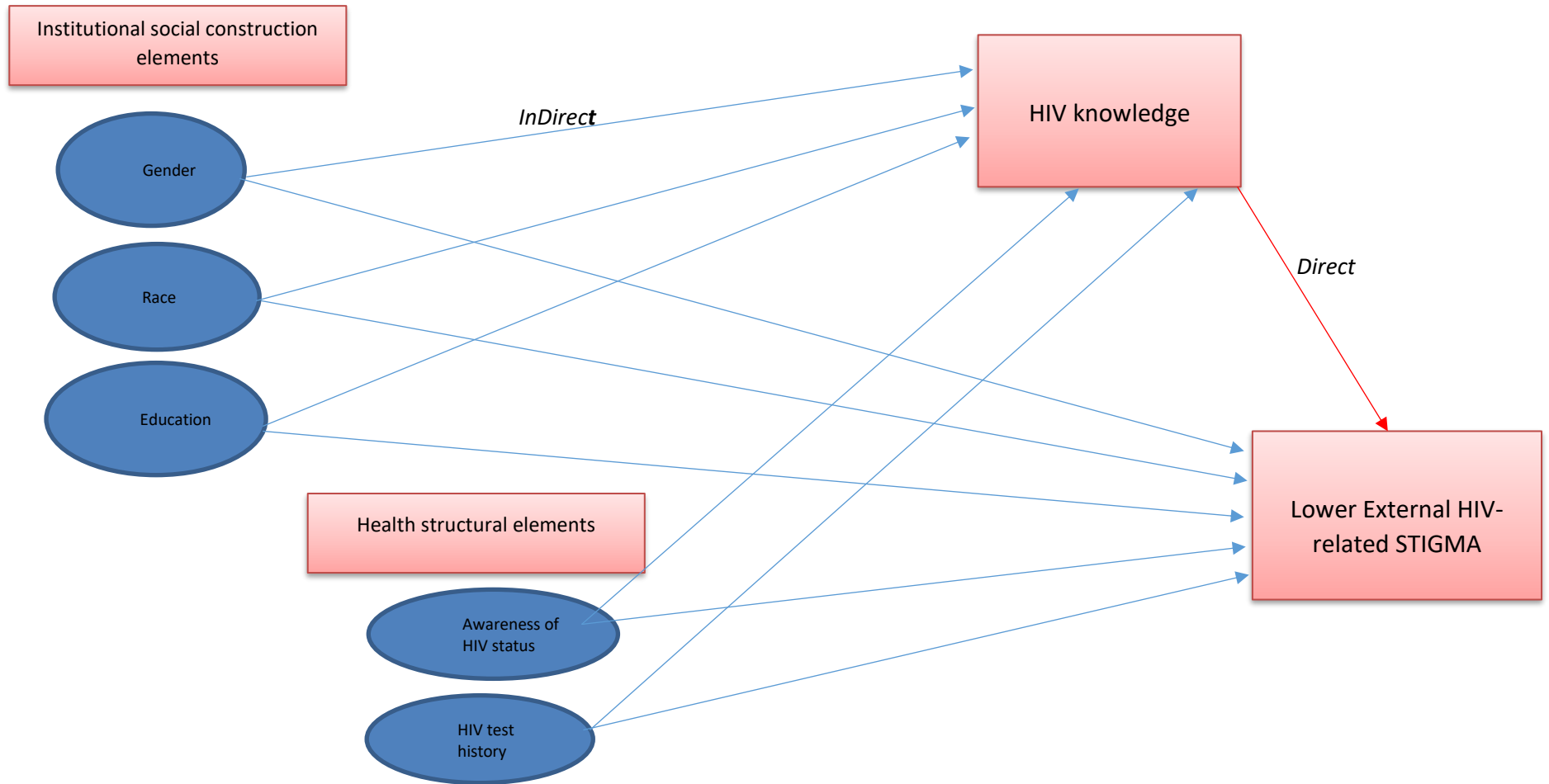
every round of sex’, ‘One can reduce the risk of HIV by having fewer sexual partners’ and ‘Can a healthy-looking person have HIV’, together with two items related to myths and misconceptions about the disease namely: ‘Can AIDS be cured?’ and ‘Can a person get HIV by sharing food with someone who is infected?’ (Shisana et al., 2014). The HSRC team scored these items as recommended by UNAIDS (Shisana et al., 2014) as three correct facts and two myths.

Awareness of HIV status. This variable was based on whether participants had ever gone for an HIV test, and were then asked, “Have you been told/informed of the result of your most recent test?”. HSRC12 classified those who had never tested for HIV as not being aware of their HIV status.

HIV test history. This variable was based on a self-reported measure on whether respondents who had ever tested for HIV had their most recent HIV test either “Less than a year ago” or “More than a year ago”.

One does not take for granted the importance of health structural elements in fighting external HIV related stigma. These are elements which contribute to the awareness of HIV as a disease and therefore positively impact on how individuals conceptualise both HIV and those who are living with HIV. These elements therefore have some association in decreasing external HIV-related stigma. One could argue that having a holistic approach which takes into consideration both social institutional elements and health structural elements could help in developing successful interventions to reduce external HIV-related stigma. Figure 3.2 presents the study’s theoretical framework model.

Figure 3.2: Study Framework showing inter-relationships among various variables and HIV-related stigma

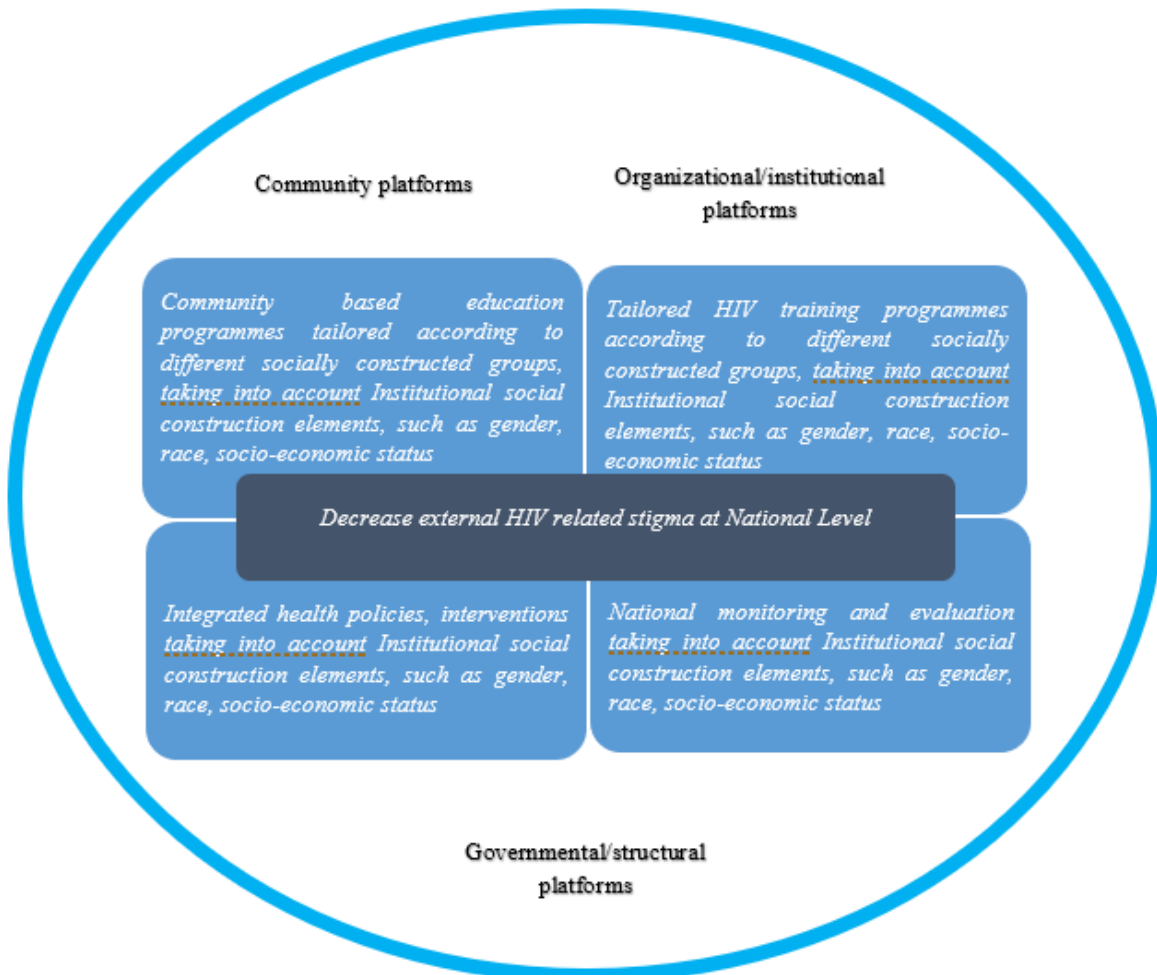


3.6 Using Institutional Social Construction as a macro-level intervention to decrease external HIV related stigma

As Patterson (2008) states, one way people respond to problems in their surroundings depends on how that problem is socially constructed. One could argue that in South Africa external HIV-related stigma is socially constructed within social institutional elements such as gender, race, and education. A structural equation modelling to support my statement will be carried out in chapter 7 of this thesis. These socially constructed understandings are used to develop practices and associated meanings around PLHIV. With this argument in mind, I deduce that developing macro level interventions, which will be framed around social institutional elements such as race, education and gender in South Africa, will decrease external HIV-related stigma in the general national population.

Figure 3.3 below shows how the dialogue on the reduction of external HIV-related stigma can be changed to form interventions which are tailored to take into account institutional social construction elements as previously stated. Taking into account that HIV-related stigma is a socially constructed phenomenon, this approach will build on the individualistic approaches that are currently utilised in South Africa. A holistic approach, in which interventions could be introduced to community, organisational/institutional and governmental/structural platforms (see figure 3.3) in South Africa, is needed in order to curb external HIV-related stigma. I therefore argue that social dynamics related to race, gender and education need to be fundamentally changed in order to effectively decrease HIV-related stigma.

Figure 3.3: Suggested Institutional social construction macro-level intervention for the decrease in HIV-related stigma in South Africa



CHAPTER 4

METHODOLOGY

4.1 Introduction

This chapter lays out the “general” methodology of the thesis, while the detailed methodologies for each study objective will be individually covered in each of the following Chapters 5, 6, and 7. The thesis is based on archived datasets of three national household surveys that have been conducted in all the nine provinces of South Africa. The surveys were conducted by the Human Sciences Research Council (HSRC) at three different times in years 2005, 2008 and 2012 (see Shisana et al., 2005, 2009, 2014). The three original surveys, whose databases were used in this thesis reported in Shisana et al. (2005, 2009, 2014), are henceforth referred to as HSRC05, HSRC08 and HSRC12. HSRC05 refers to the survey done by HSRC in 2005, HSRC08 refers to the survey done by HSRC in 2008, while HSRC12 refers to the survey done by HSRC in 2012. In instances where I refer to all of them, they will be labelled as HSRC050812. This current thesis will henceforth be referred to simply as the Stigma Assessment Study in South Africa (SASSA).

4.2 Study design

This is an archival study which used secondary data obtained from HSRC05, HSRC08 and HSRC12 (see <http://datacuration.hsrc.ac.za/search/keyword/HEALTH>). The HSRC050812 surveys were all cross-sectional community household-based surveys that included laboratory testing for HIV infection and exposure to antiretroviral (ARV) drugs using dry blood spots (DBS) specimens. The surveys also used questionnaires on knowledge, attitudes and behaviours related to HIV (see Shisana et.al, 2005, 2009, and 2014). SASSA is therefore an archival study which used secondary data obtained from HSRC050812.

4.3 Sampling and Sample Size

HSRC050812 used a multi-stage disproportionate, stratified sampling approach at the national level and in all nine provinces (Shisana et al., 2005, 2009, 2014). Persons of all ages living in South African households and hostels found in both townships and mines were allowed to participate, while excluding those living in educational institutions, old-age homes, hospitals, correctional facilities and uniformed-service barracks, as well as, homeless persons (Shisana et al., 2005, 2009, 2014). From a database of 86 000 enumeration areas (EAs) of the population census, a total of 1 000 were randomly selected and stratified by province, locality type and race (Shisana et al., 2005, 2009, 2014). In each sampled EA, a random selection of 15 households was done (Shisana et al., 2005, 2009, 2014). For both HSRC05 and HSRC08 (Shisana et al., 2005, 2009) a maximum of 4 individuals per selected household were sampled within each household, one from each of the following four age groups: 0-2 years, 2-14 years, 15-24 years, and 25 years and older. For HSRC12, all members of selected households participated in the survey, meaning that every single household member was interviewed, which is partly seen in the very large sample compared to the other two earlier surveys (Shisana et al., 2014). Overall, a total of 10,584 individuals participated in HSRC05 (Shisana et al., 2005), 20,826 individuals participated in HSRC08 (Shisana et al., 2009), and 38,431 individuals participated in HSRC12 (Shisana et al., 2014).

A sub-population of participants 15 years and older data was extracted from the HSRC050812 datasets. A total of 16 140 from HSRC05, 13134 from HSRC08 and 26 528 from HSRC12 participants' data who completed the same four stigma items was included in the SASSA study. In addition, a sub-population consisting of 30,748 participants aged 15 years and older data from HSRC12 who completed a 6-item scale on HIV/AIDS-related stigma was included in the SASSA study. The noted difference in sample size for the HSRC12 data for the four items vs

the six items is due to the fact that not all participants who answered the six items responded to the four items.

Weighting of the sample for HSRC12

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

Weighting of the sample for HSRC08

“Weighting of the sample by age, race group, and province was applied to ensure that the estimates of HIV prevalence and incidence are representative of the general population.” (Shisana, et al., 2014: page xvi)

Weighting of the sample for HSRC05

“Due to the Sampling design of the survey, some individuals have a lesser or greater probability of selection than others. To correct this problem, sample weights were introduced to correct for bias at EA, household and individual levels and also to adjust for non-response. This process produced a final sample representative of the population in South Africa for gender, age, race, locality type and province.” (Shisana, et al., 2005: page xxi)

4.4 SASSA Variables and measures

The use of different measures for external HIV-related stigma and different variables for each analysis (i.e. trends, regression and structural equation modelling) might bring about some confusion. To avoid this confusion to the reader, a clearer explanation of each variable and measures will be included in each of the following results Chapters 5, 6 and 7. From the HSRC05, HSRC08 and HSRC12 datasets, relevant variables to the objectives of the SASSA study were included for analysis as follow:

External HIV-related stigma: (the scale): This is the outcome variable used when the regression analysis was conducted. To measure external HIV-related stigma, HSRC12 utilised six individual items which elicited attitudes towards PLWHA. The items were chosen for this analysis as they were based on a 9-item scale that was originally developed by Kalichman et al. (2005) with good consistency and reliability. The original scale was tested in a South African population and was found to be internally consistent, $\alpha = 0.75$ and stable over 3 months, $r = 0.67$, with reliability in English, Xhosa, and Afrikaans languages (Kalichman et al., 2005). The six items included in HSRC12 were: (1) People who have AIDS are dirty; (2) People who have AIDS are cursed; (3) People who have AIDS should be ashamed; (4) It is safe for people who have AIDS to work with children; (5) People with AIDS must expect some restrictions on their freedom; (6) A person with AIDS must have done something wrong and deserves to be punished. For the regression analysis, the internal consistency test for the 6 items was done and found to be 0.66. Item 4 was reverse-scored and produced ambivalent findings and therefore removed from the scale. The internal consistency test for the remaining 5 items increased to 0.72 which was reliable. Consequently, it was decided to use the remaining 5-item scale for the analysis presented in this the SASSA study. Participants could either respond “Agree”, “Not sure” or “Do not agree” to the statements.

External HIV-related stigma (trends analysis). For the trends analysis I could not use the same 6 stigma items which were used for the regression analysis. The reason for this was that the 6 stigma items were only used for the first time in the HSRC12 survey, and therefore would not be able to answer one of the SASSA objectives which was to look at the stigma trends between 2005 and 2012. Therefore, four individual stigma items which were used in all three surveys (i.e. HSRC050812) were then used for the SASSA external HIV-related stigma trends analysis as follows:

1. If you knew that a shopkeeper or food seller had HIV, would you buy food from them?
2. Would you be willing to care for a family member with AIDS?
3. Is it a waste of money to train or give a promotion to someone with HIV/AIDS?
4. Would you want to keep the HIV positive status of a family member a secret?

The independent variables used for the analyses of the SASSA study included:

Demographic characteristics. The following demographic variables from all three databases were included in the SASSA study: race, age, sex, education level, marital status and employment status.

HIV Knowledge. HSRC12 utilised 5 items to measure this variable. The HSRC12 team used a composite measure of precise knowledge based on responses to three prompted questions related to HIV prevention, namely: ‘To prevent HIV infection, a condom must be used for every round of sex’, ‘One can reduce the risk of HIV by having fewer sexual partners’ and ‘Can a healthy-looking person have HIV’, together with two items related to myths and misconceptions about the disease namely: ‘Can AIDS be cured?’ and ‘Can a person get HIV by sharing food with someone who is infected?’ (Shisana et al., 2014). The HSRC team scored these items as recommended by UNAIDS (Shisana et al., 2014) as three correct facts and two myths.

Self-perception of risk of HIV Infection. This variable was selected for the regression analysis. For this variable, participants were asked “How would you rate yourself in terms of risk of becoming infected with HIV?”. Participants could choose one of the four responses as follows: “I will definitely not get infected with HIV”; “I probably won’t get infected”; “I am probably going to get infected”; and “I am definitely going to get infected with HIV”. During analysis, HSRC12 grouped items 1 and 2 together and 3 and 4 together to create a binary measure scored as low risk and high risk (Shisana et al., 2014).

Awareness of HIV status. This variable was based on whether participants had ever gone for an HIV test, and were then asked “Have you been told/informed of the result of your most recent test?”. HSRC12 classified those who had never tested for HIV as not being aware of their HIV status.

HIV test history. This variable was based on a self-reported measure on whether respondents who had ever tested for HIV had their most recent HIV test either “Less than a year ago” or “More than a year ago”.

Sexual partners. This variable included in the SASSA study was based on a number of sexual partners had during the past 12 months (for sexually active respondents)? HSRC12 categorised participants into two groups, those who have had one partner and those who have had more than one partner (i.e., two or more).

Condom use. This was based on a self-report by participants on whether they have used condoms or not for most recent sex (for sexually active respondents). Responses were “Yes” or “No”

HIV status: This variable included in the trend analysis distinguished between participants who are HIV positive and those who are HIV negative and whether stigma questions varied

significantly by whether a person tested positive or not for HIV. DBS specimen collection was used in HSRC050812 to determine participants' HIV status.

4.5 Data collection

Data for the SASSA study was obtained from the archived databases of the three surveys (see <http://datacuration.hsrc.ac.za/search/keyword/HEALTH>). These surveys as described above used a questionnaire to collect data that aimed at soliciting information related to knowledge, attitudes and behaviours related to HIV/AIDS including HIV/AIDS-related stigma (Shisana et al., 2005, 2009, 2014). Specific data related to variables of interest for this study were extracted from the main population-based household surveys database.

4.6 Data management

HSRC12 dataset was used for the regression and stigma trends analysis for the SASSA study while both HSRC05 and HSRC08 datasets were only used for the SASSA stigma trends analysis. HSRC050812 datasets were extracted from the HSRC data archives (see <http://datacuration.hsrc.ac.za/search/keyword/HEALTH>). A process of data cleaning was undertaken using Stata statistical software (STATA). This led to three new datasets which were used for the SASSA study analysis. From the HSRC12 a new dataset was formed by using the “keep” command from STATA, where selected variables relevant to the SASSA study were kept, while all the other variables used for the HSRC12 were dropped. The same procedure was followed for the HSRC05 and HSRC08 datasets. Therefore, SASSA had four datasets (i.e., SASSA05, SASSA08, SASSA12 and SASSA050812).

In the SASSA datasets a recoding technique was used to allow the combination or grouping of two or more categories of a variable together in order to simplify the process of analysis. Recoding was also done to help create tables that are easier to read and identify patterns in responses. The following variables were recoded:

- HSRC12 sample included participant younger than 15 years. Given the fact that the SASSA study sample consisted of participants older than 15 years old, I recoded the “Age” variable into three categories (15-24yrs, 25-49yrs, and 50+ yrs) so that one would be able to see if there are stigma variations amongst youth (15-24), economically active young adults (25-49yrs) and older generation (50+ yrs), dropping all participants younger than 15 years. The “Age” variable was then given a new label in the SASSA dataset “age_grp1”.
- In HSRC12 “Education” variable was categorised into 5 (Grades 0 to 7, Grades 8 to 11 , Grade 12 , Some post school studies, and Further degrees completed). To identify better the patterns in responses, I decided to collapse “Some post school studies” and “Further degrees completed” categories into one category namely “Tertiary”. The “Education” variable was then given a new label in the SASSA dataset “educ_nw”.
- The “External HIV stigma” variable measured by the 5-item stigma scale was recoded into a binary variable in the SASSA study. Cases who agreed with the items and those who were not sure were collapsed into one category defined as “some stigma”. While those who disagreed with the items were grouped into another group defined as “no stigma”. The “External HIV stigma” variable was then given a new label in the SASSA dataset “stig2_gp”

To ensure data safety, backup was done every time a change was done on the datasets.

4.7 Data analyses

As stated in this chapter’s introduction, detailed methodologies will be reported in each of the chapters covering the objectives of the SASSA study. The detailed methodologies will include the data analysis procedures undertaken for each study objective. In general data analysis was conducted using STATA 15 software. The study analysis included data exploration, descriptive

analysis, linear regression analysis, multiple regression analysis, trends analysis and structural equation modelling analysis.

4.8 Ethical considerations

For this type of study formal consent is not required. The survey protocol for the original study was approved by the HSRC's Research Ethics Committee (REC: 5/17/11/10) as well as by the Associate Director of Science of the National Center for HIV and AIDS, Viral Hepatitis, STD and TB Prevention at the Centers for Disease Control and Prevention (CDC) in Atlanta, USA. Ethical clearance for this study was also obtained from the University of Cape Town, Faculty of Health Sciences Human Research Ethics Committee (HREC REF 627/2013).

CHAPTER 5

**PREVALENCE OF EXTERNAL HIV -RELATED STIGMA AND
CORRELATES THEREOF IN THE GENERAL POPULATION OF
SOUTH AFRICA**

While in the previous chapter (Chapter 4), I provide the methodologies followed in the study, this chapter is the first of the three results chapters. The chapter seeks to achieve objective two of the study, which is to determine the prevalence and associations of external HIV-related stigma in the South African population in 2012. The methods, analyses and results are therefore presented.

5.1 Methodology

5.1.1 Study design

This analysis is based on a cross sectional design using secondary data collected by Human Sciences Research Council (HSRC) during a South African national population household survey conducted in 2012 (Shisana et al., 2014). The details of the survey have already been reported in chapter 4, page 50.

5.1.2 Sampling and Sample Size

The HSRC survey used a multi-stage, disproportionate, stratified sampling approach at the national level and in all nine provinces (Shisana et al., 2014). A total of 38,431 individuals participated in HSRC12 (Shisana et al., 2014). For the analysis of this SASSA objective, data was used from a sub-population of participants 15 years and older. A total of 30,748 participants' data from the HSRC survey who completed a 5-item scale on external HIV -related stigma were included in this analysis. Further details of the sampling and sample size methodology are provided in Chapter 4 page 51.

5.1.3 Selected variables

The choice of variables selected from the HSRC12 survey dataset was informed by the literature review and insights into how they were related to HIV stigma and therefore how they would be useful to this analysis. In addition, the variables were selected based on the objectives of the study. The outcome and explanatory variables are listed in Table 5.1. Definitions of these variables are elaborated in Chapter 4, pages 52-55.

5.1.4 Data extraction and data management

The HSRC12 survey dataset was extracted from the HSRC data archives. A process of data cleaning was undertaken using Stata statistical software (STATA) to formulate the SASSA12 dataset for this specific analysis. From the HSRC12 a new SASSA dataset was formed by using the “keep” command from STATA, where selected variables relevant to achieve the objectives of this SASSA12 chapter (see Table 5.1) were retained, while all the other variables used for the HSRC12 survey that are irrelevant to this thesis were dropped.

During the cleaning process of the SASSA12 dataset the recoding technique was used to allow the combination or grouping of two or more categories of certain variables together in order to rationalize the process of analysis. Recoding was also done to better enable the identification of patterns in responses.

- HSRC12 sample included participants younger than 15 years. Given the fact that the sample consisted of participants older than 15 years old, I recoded the “Age” variable into three categories (15-24yrs, 25-49yrs, and 50+ yrs) so that it is possible to see if there are stigma variations amongst youth (15-24), economically active young adults (25-49yrs) and older generation (50+ yrs), dropping all participants younger than 15 years. The “Age” variable was then given a new label in the SASSA12 dataset “age_grp1”.

Table 5.1: SASSA external HIV-related stigma regression analysis variables

Outcome variable		Explanatory variables	
Overall outcome variable	Individual five items	Demographics	Behavioural
External HIV-related stigma	People who have AIDS are dirty	Age	Correct knowledge
	People who have AIDS are cursed	Sex	Self-perception of risk of HIV infection
	People who have AIDS should be ashamed	Education level	Awareness of HIV status
	People with AIDS must expect some restrictions on their freedom	Marital status	HIV test history
	A person with AIDS must have done something wrong and deserves to be punished	Employment status	Sexual partners
			Condom use

- In HSRC12, the “Education” variable was categorised into 5 groups (Grades 0 to 7, Grades 8 to 11, Grade 12, Some post school studies, and Further degrees completed). To identify better the patterns in responses, the categories “Some post school studies” and “Further degrees completed” were collapsed into one category namely “Tertiary”. The “Education” variable was then given a new label in the SASSA12 dataset “educ_nw” with four categories (Grades 0 to 7, Grades 8 to 11, Grade 12, Tertiary).
- The “External HIV stigma” variable measured by the 5-item stigma scale was recoded into a binary variable in the SASSA study. Cases who agreed with at least one of the five items and those who were not sure were collapsed into one category defined as “some stigma”. The decision was taken to include the participants who responded “not sure” in this category because of issues related to social desirability bias; that is, respondents may have provided the answers they thought were socially acceptable or did not want to be seen as stigmatisers, and therefore chose not to give a true response. While those who disagreed with all five items were grouped into another group defined as “no stigma”. The “External HIV stigma” variable was then given a new label in the SASSA dataset “stig2_gp”

5.1.5 Data analyses

SASSA12 data analysis was conducted using STATA 15 software. Descriptive statistical analysis was done to describe the sample characteristics. As discussed above in the data analysis section, external HIV-related stigma was divided into “some stigma” and “no stigma”. Chi-Square test of independence was employed to determine if there is a relationship between external HIV-related stigma and the categorical independent variables. Frequency of external HIV-related stigma was compared across the categories of the independent variables. The null hypothesis for the Chi-Square test was that there is no relationship between

external HIV-related stigma and the study independent variables, while the alternative hypothesis was that there is a relationship between external HIV-related stigma and the study independent variables. Logistic regressions were conducted to identify associations of external HIV-related stigma. This approach was chosen as it allowed analyses of more than two explanatory variables simultaneously. Using the regression analyses, external HIV-related stigma was modelled based on individual characteristics of the participants. Backward elimination stepwise logistic regression was conducted to identify predictor variables related to external HIV-related stigma. Variables with $p < 0.01$ were then added into a multivariate logistic regression model to identify independent predictors of external HIV-related stigma. Variables with $p < 0.05$ in the multivariate model were considered significant predictors of stigma.

5.2 RESULTS

5.2.1 Description of Study Population

Table 5.2 shows the demographic characteristics of the sample used in this study. A total of 30,758 participants who responded to the five items related to external HIV-related stigma were included in this analysis. The table shows that the largest proportions of respondents were aged 25-49 years (44.8%), female (45.4%), African (55.9%), had secondary school education (40.5%), and were employed (41.1%).

Overall, the magnitude of those displaying some external HIV-related stigma in the general population of South Africa was nearly two fifths of the sample (38.3%, 95% CI: 37.4-39.1).

Table 5.2: Demographic characteristics of respondents aged 15 years and older and their association to external HIV-related stigma level, South Africa 2012 (N=30,758)

Demographic characteristics	n	%
Sex		
Males	13,951	54.6
Females	16,807	45.4
Age group		
15-24	8,221	26.7
25-49	13,768	44.8
50+	8,758	28.5
Marital status		
Married/Civil union	9,532	35.9
Living together	7,550	28.4
Single	6,321	23.8
Divorced	906	3.5
Widower/widow	2,229	8.4
Race		
African	17,126	55.9
White	3,511	11.5
Coloured	5,943	19.4
Indian/Asian	4,047	13.2
Education		
Gr 0-7	5,038	18.9
Gr 8-11	10,811	40.5
Gr 12	8,027	30.1
Tertiary	2,816	10.5
Employment		
Employed formal/ informal	9,993	41.1
Unemployed not looking	9,692	39.9
Student	3,774	15.5
Unable to work	858	3.5

5.2.2 Associations of external HIV-related stigma in the South African Population

The unadjusted analysis results (Table 5.3) showed that factors significantly associated with some external HIV-related stigma attitudes were aged older than 50 years (45.5%, $p < 0.01$), widowed (50.9%, $p < 0.01$), Whites (41.7%, $p < 0.01$), had primary education (44%, $p < 0.001$), those who were unemployed (45%, $p < 0.05$), those who were not aware of their HIV status (46%, $p < 0.001$), those who perceived themselves as not at risk of HIV-infection (45%, $p < 0.001$), those who reported no condom use at last sex (39.9%, $p < 0.05$), those who reported inaccurate knowledge about HIV transmission and prevention (40%, $p < 0.001$).

The results from the multivariable regression analysis of the associations of external HIV-related stigma in the South African population show that race, sex, education level, self-perceived risk of HIV infection and HIV knowledge were significant predictors of external HIV/AIDS-related stigma attitudes in the present study. Those who are White, Coloured and Indian/Asian were more likely to report some external HIV-stigma than those who are Black Africans (aAORs = 2.14, 1.35 and 1.21 respectively, all $ps < 0.01$). Females were 10.0% less likely to report external HIV-stigma than males (AOR = 0.9, $P < 0.05$). Those with primary education or less were 24.0%, 41.0% and 54.0% more likely to report some stigma than those with secondary, matric, and post-matric education (aAORs = 0.76, 0.59 and 0.46 respectively, all $ps < 0.001$). Those who perceived themselves to be at high risk of HIV infection were 11.0% less likely to display some stigma than those who believed they were at low risk (AOR = 0.89, $p < 0.05$). Those displaying incorrect HIV knowledge were 37.0% more likely to report some stigma than those who displayed correct HIV knowledge (aAOR = 0.63, $p < 0.01$).

Table 5.3 Associations of external HIV/AIDS-related stigma by demographic and behavioural characteristics, South Africa 2012

Sample characteristics	Some stigma n/N (%)	UOR (95% CI)	p-Value	AOR (95% CI)	p-Value
Sex					
Males	5,210/13,951 (37.3)	1.00	1.00		
Females	6,591/16,807 (39.2)	1.01 [0.9 -1.01]	0.76	0.90 [0.83 – 0.98]	0.02
Age group					
15-24	3,148/8,221 (38.3)	1.00	1.00		
25-49	4,739/13,768 (34.4)	0.85 [0.79-0.89]	0.001	0.91 [0.82 – 1.01]	0.07
50+	3,911/8,758 (45.5)	1.3 [1.2-1.38]	0.001	1.04 [0.92 – 1.18]	0.05
Marital status					
Married/Civil union	4,198 /9,532 (44)	1.00			
Going steady/living together	3,198/7,550 (42.1)	0.93 [0.87-0.99]	0.03	-	-
Single	2,671/6,321 (42.1)	0.92 [0.87-0.99]	0.03	-	-
Divorced	393/906 (43.4)	0.97 [0.85-1.12]	0.71	-	-
Widower/widow	1,134/2,229 (50.9)	1.32 [1.19-1.44]	0.001	-	-
Race					
African	6,505 /17,126 (37.9)	1.00		1.00	
White	1,467/3,511 (41.7)	1.17 [1.09-1.26]	0.001	2.14 [1.87 – 2.45]	0.001
Coloured	2,318/5,943 (39.0)	1.04 [0.98-1.11]	0.16	1.35 [1.28 - 1.49]	0.001
Indian/Asian	1,486 /4,047 (36.7)	0.95 [0.88-1.02]	0.136	1.21 [1.07 - 1.37]	0.002
Education					
Gr 0-7	2,199/ 5,038 (44)	1.00			
Gr 8-11	4,248/10,811 (39.2)	0.76 [0.68 – 0.86]	0.001	0.76 [0.68 – 0.86]	0.00
Gr 12	2,655/8,027 (33.1)	0.59 [0.52 – 0.67]	0.001	0.59 [0.52 – 0.67]	0.00

Tertiary	813/2,816 (29)	0.46 [0.38 – 0.55]	0.001	0.46 [0.38 – 0.55]	0.00
Employment					
Employed formal/ informal	4,115 /9,993 (41.1)	1.00			
Unemployed not looking	4,338 /9,692 (45)	1.16 [1.09-1.22]	0.001	-	-
Student	1,624 /3,774 (43)	1.08 [1.00-1.16]	0.049	-	-
Unable to work	450 /858 (52.4)	1.58 [1.37-1.81]	0.001	-	-
When did you have HIV test					
Less than a year ago	4,462 /10,681 (41.7)	1.00			
More than a year ago	2,493/ 5,923 (42.1)	1.01 [0.95-1.08]	0.69	-	-
Awareness of HIV status					
Yes	4,167/ 10,075 (41.2)	1.00			
No	7,366/ 16,080 (46)	1.19 [1.14-1.26]	0.001	1.05 [0.96 – 1.15]	0.29
Sexual partners in the last 12 months					
1 partner	5,989/ 14,274 (42)	1.00			
2+ partners	642/ 1,495 (43)	1.04 [0.93-1.16]	0.46	-	-
Self-perception of risk of HIV Infection					
Low risk	9,563/ 21,369 (45)	1.00			
High risk	2,035/ 4,915 (41.4)	0.87 [0.82-0.93]	0.001	0.89 [0.80 – 0.99]	0.04
Condom use at last sex					
Yes	4,654/ 10,732 (43.3)	1.00			
No	1,853/ 4,743 (39.1)	0.84 [0.78-0.89]	0.001	0.99 [0.85 – 1.16]	0.98
Incorrect Knowledge					
Yes	6,214/ 12,679 (49)				
No	5,577/ 13,952 (40)	0.69[0.66-0.73]	0.001	0.63 [0.58 – 0.69]	0.001

UOR =
Unadjusted Odds
Ratio;
AOR = Adjusted
Odds Ratio; 95%
CI= Confidence
interval

5.3 Summary

In this analysis we found that over one third of the South African population displays external HIV-related stigma. We further were able to ascertain that those who were 50+ years, those who were widowed, Whites, those with only primary education, those who were unemployed, those not aware of their HIV status, those who perceived themselves as not at risk of HIV-infection, those who reported no condom use at last sex, and those who reported inaccurate knowledge about HIV transmission and prevention are the population sub-groups in South Africa which were found to display more external HIV-related stigma attitudes when compared to their counterparts on each of these variables. Finally, the predictors of external HIV-related stigma are race, sex, education level, self-perceived risk of HIV infection and HIV knowledge. I will discuss both these results and their implications in Chapters 8 and 9 of this thesis.

CHAPTER 6

TRENDS OF HIV-RELATED STIGMA ATTITUDES TOWARDS PEOPLE LIVING WITH HIV IN SOUTH AFRICA: CHANGE FROM 2005-2012

In the previous chapter the analyses and results of the prevalence and associations of external HIV-related stigma in the South African population in 2012 were presented. This chapter is the second of the three results chapters and seeks to achieve objective three of the study. The chapter presents the change of HIV-related stigma in South Africa over the past decade using data from three different points in time, 2005, 2008 and 2012. The methods, analyses and results are therefore reported.

6.1 Methodology

6.1.1 Study design

This Stigma Assessment Study in South Africa (SASSA) study used the archival research method by employing secondary data analyses on data extracted from the HSRC 2005, 2008 and 2012 datasets of the South African National HIV Population-based Household Survey.

6.1.2 Sampling and Sample Size

A multi-stage disproportionate, stratified sampling approach was used for all three HSRC surveys. This analysis is based on a sub-population of participants who took part in these three HSRC surveys who were aged 15 years and older, who responded to four individual stigma items. Data from a total of 16 395 individual's data from the 2005 HSRC survey dataset, 13 828 individual's data from the 2008 HSRC survey dataset, and 26 806 individual's data from the 2012 HSRC survey were used.

6.1.3 Selected Variables

Stigma items:

Stigma changes were investigated using stigma items measuring social attitudes. Four items were selected from the three original HSRC surveys as they were consistently asked throughout 2005, 2008 and 2012 surveys. The four items are as follow:

1. *If you knew that, a shopkeeper or food seller had HIV, would you buy food from them?*
2. *Would you be willing to care for a family member with AIDS?*
3. *Is it a waste of money to train or give a promotion to someone with HIV/AIDS?*
4. *Would you want to keep the HIV positive status of a family member a secret?*

Participants could either respond “Yes”, “No” or “Not sure” to these four statements.

Other variables:

As this thesis aimed to measure the changes in HIV-related stigma from three consecutive surveys, variables had to be chosen which were consistently included throughout the three surveys. Though this was very limiting, the only variables that could be included in the exploration of changes in HIV- related stigma were age, sex, and race.

6.1.4 Data management

The three HSRC survey’s datasets were the source of data for the external HIV -related stigma trends analysis. The origin of these datasets is the Human Sciences Research Council (HSRC) data archives (<http://www.hsrc.ac.za/en/departments/rmdc/data-curation>). Three new SASSA datasets were generated by using the “keep” command in STATA, where selected variables included in this analysis of SASSA trends study were retained, while all the other variables used for the HSRC surveys were censored. SASSA ended up with three datasets namely (SASSA05, SASSA08 and SASSA12). A new SASSA trend dataset was then created by combining SASSA05, SASSA08 and SASSA12. The combined SASSA dataset variables were

re-labeled by inserting SASSA05, SASSA08 and SASSA12 in front of the original labels. This was done to allow for identification of the survey year for each observation. External HIV - related stigma was based on questions and response options consistently worded across all the three HSRC surveys years 2005, 2008 and 2012 included in this trend analysis.

Recoding of the four individual external HIV-related stigma items was done so that they were all in the same direction (0=No stigma; 1=Stigma). Those participants who responded “not sure” to any of the questions were included in the group of participants coded as “1”. Missing data was treated as “No stigma” and therefore coded as “0”.

6.1.5 Data Analysis

Proportions were computed to assess a change in stigma between the three time points (2005, 2008 and 2012) for each stigma item. Significant differences in the proportions of each stigma item were compared using X^2 where $p < 0.05$ was considered significant. A graphic display was constructed to show trends of stigma by different stigma items e.g. sex. A statistically significant increase or decrease in stigma during this period was considered present where $p < 0.05$.

6.2 RESULTS

Table 6.1 displays the demographics data used in the SASSA in this analysis. Generally, the sample had more females (10057 in 2005, 8327 in 2008 and 15202 in 2012) than males (6338 in 2005, 5501 in 2008, and 11603 in 2012). The sample had a higher number of Black African individuals across all three surveys, followed by Coloured, while a smaller percentage of White and Indian responded. The sample also had a higher number of those in the age group 25-49 compared to other age groups across all three surveys.

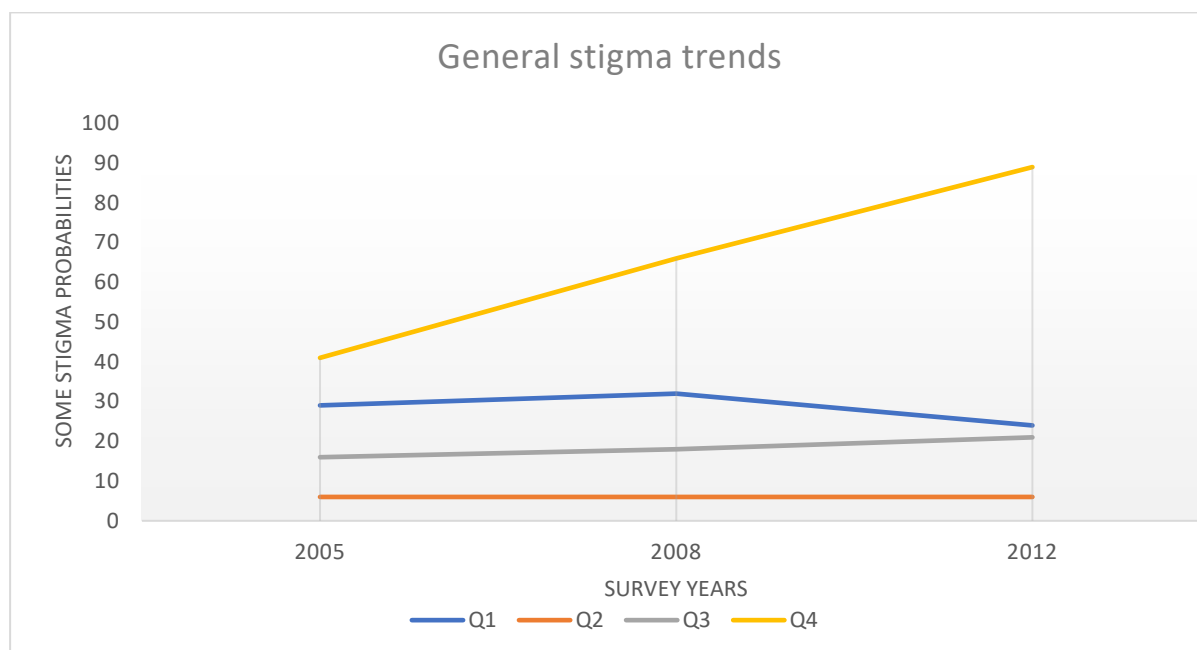
Table 6.1: Demographic characteristics of respondents aged 15 years and older who responded to individual statements about people living with HIV and AIDS, South Africa

Demographic characteristics	2005		2008		2012	
	n	%	n	%	n	%
Age						
15 to 24	5708	30.7	4580	30.1	7220	27.5
25 to 49	6892	48.2	5818	48.6	11745	50.6
50+	3795	21.1	3430	21.3	7841	21.9
Sex						
Male	6338	46.1	5501	47	11603	48.1
Female	10057	53.9	8327	53	15202	51.9
Race						
Black African	9664	77.7	8297	76.5	15387	77.7
White	1913	11.1	1645	11.1	2900	10.3
Coloured	3013	8.6	2506	9.4	4979	9.3
Indian/Asian	1772	2.6	1352	2.8	3467	2.8

Figures 6.1 and 6.2 as well as Table 6.2 show the trends in reported external stigma in South Africa over the period 2005-2012, measured by the four individual external stigma items (Q1: *If you knew that a shopkeeper or food seller had HIV, would you buy food from them?*; Q2: *Would you be willing to care for a family member with AIDS*; Q3: *Is it a waste of money to train or give a promotion to someone with HIV/AIDS?*; Q4: *Would you want to keep the HIV positive status of a family member a secret?*).

Figure 6.1 shows trends proportions of those individuals who reported “some stigma” on each of the four items, in each of the three surveys. Figure 6.1 shows that the trend indicates a decrease in stigma amongst those who responded to Q1 between years 2008 and 2012, while no change is observed in the stigma trends amongst those who responded to Q2 over the years. A significant increase in stigma trends is observed amongst those who responded to Q4. This trend is seen to be increasing with each year.

Figure 6.1: General stigma trends



*Q1: If you knew that a shopkeeper or food seller had HIV, would you buy food from them? Q2: Would you be willing to care for a family member with AIDS? Q3: Is it a waste of money to train or give a promotion to someone with HIV? Q4: Would you want to keep the HIV positive status of a family member a secret?

Q1: If you knew that a shopkeeper or food seller had HIV, would you buy food from them?:

There was change in reporting stigma showing a steady decrease from 2005 and 2008 as well as from 2008 to 2012. This observed change was statistically significant (28% in 2005, 31% in 2008, and 24% in 2012) ($P < 0.001$).

Q2: Would you be willing to care for a family member with AIDS?:

A non-significant trend was observed, with reporting stigma remaining similar throughout 2005, 2008 and 2012 for Q2 (5%, 6%, 5% respectively) ($P = 0.5866$).

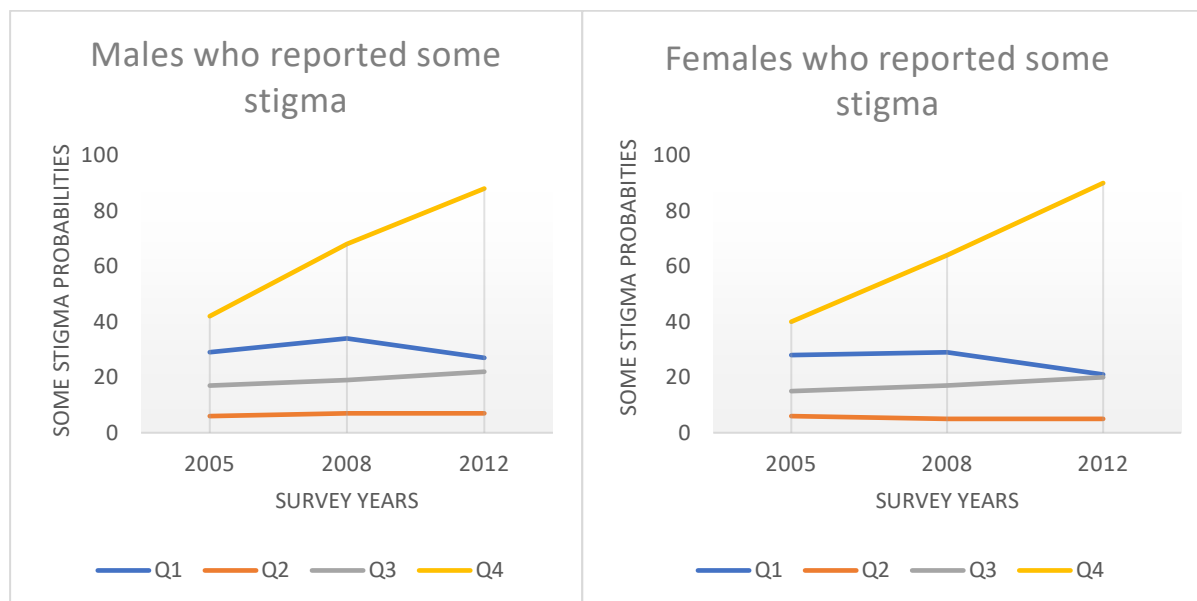
Q3: Is it a waste of money to train or give a promotion to someone with HIV/AIDS?:

There was a significant linear trend with an increase in the reporting of stigma throughout 2005, 2008 and 2012 (0.16%, 0.18%, and 0.21% respectively) ($p < 0.001$).

Q4: Would you want to keep the HIV positive status of a family member a secret?:

Similarly, a significant linear trend with an increase in the reporting of stigma in the three points in time: 2005, 2008 and 2012 was observed (0.41%, 0.66%, and 0.89% respectively) ($P < 0.001$).

Figure 6.2: Stigma trends of males and female



*Q1: If you knew that a shopkeeper or food seller had HIV, would you buy food from them? Q2: Would you be willing to care for a family member with AIDS? Q3: Is it a waste of money to train or give a promotion to someone with HIV? Q4: Would you want to keep the HIV positive status of a family member a secret?

Figure 6.2 shows a decrease in stigma trends in Q1 between years 2008 and 2012, while no change is observed in the stigma trends amongst those who responded to Q2 over the years. A significant increase in stigma trends is observed in Q3 and Q4, with quite a steep increase in Q4 for both males and females. This trend is seen to be increasing more with each year.

Table 6.2 shows stigma trends amongst those who responded to the 4 items by race and age. Similar trends are observed amongst Black African, Coloured and White races. Table 6.2 shows that, amongst these three races, stigma trends decreased between years 2008 and 2012 in those who responded to Q1, while no change is observed in the stigma trends amongst those who responded to Q2 over the years. A significant increase in stigma trends is observed in those who responded to Q3 and Q4. An important observation is amongst Indian/Asian race. In this race a significant increase is observed in stigma trends for all four stigma items over the three points in time: 2005, 2008 and 2012.

Table 6.2 also shows similar trends amongst all three age groups. Stigma trends decreased between years 2008 and 2012 amongst those who responded in Q1, while no change is observed in the stigma trends amongst those who responded to Q2 over the years in all three age groups. A significant increase in stigma trends is once again observed in those who responded to Q3 and Q4 for all age groups.

6.3 Summary

Looking at the general stigma trend, a slight decrease is observed in the reporting of stigma over the three years on responses to two of the stigma items (*Q1: If you knew that a shopkeeper or food seller had HIV, would you buy food from them?*, and *Q2: Would you be willing to care for a family member with AIDS?*). While we observe some increase in the reporting of stigma over the three years on responses to two of the stigma items (*Q3: Is it a waste of money to train or give a promotion to someone with HIV/AIDS?*, and *Q4: Would you want to keep the HIV positive status of a family member a secret?*).

It is good to see some decrease in stigma on responses to the two stigma items (Q1 and Q2). However, it is concerning that within the responses to individual stigma items, an increasing trend of stigmatising attitudes towards PLHIV in the South African population between 2005 and 2012 is indicated. Responses to Q3 and Q4, seem to be important catalysts of HIV/AIDS stigma. Respecting the equality of individuals irrespective of their HIV status (Q3) and SHAME, stigma by association and disclosure (Q4), seem to be factors fuelling HIV stigma in South Africa. One will also need to take into account the results of responses for Q4 because it has since been identified to be ambiguous, as non-disclosure can also be seen as a family wanting to protect their loved one from stigma and discrimination in the community. This point is further looked at in the discussion chapter. This suggests that more needs to be done to change the status core where these factors are concerned.

Table 6.2 Trends of HIV-related stigma in the general population of South Africa (individual items)

Race	2005 *n/N (%)	2008 *n/N (%)	2012 *n/N (%)	p-value
African				
Q1	2223/7314(30)	1826/6298(28)	2561/14115(18)	<0.001
Q2	565/8967 (6)	426/7674(5)	806/15855(5)	<0.001
Q3	1359/8138(16)	1293/6806(18)	2983/13674(21)	<0.001
Q4	2799/6718(41)	3437/4645(73)	7732/8877 (87)	<0.001
Whites				
Q1	342/1538(22)	420/1132(37)	685/2303(29)	<0.001
Q2	134/1744(7)	125/1426(8)	274/2711(10)	<0.01
Q3	245/1627(15)	251/1299(19)	477/2508(19)	<0.01
Q4	507/1367(37)	588/959(61)	1188/1791(66)	<0.01
Coloureds				
Q1	734/2215(33)	666/1778(37)	1197/4146(28)	<0.002
Q2	189/2760(6)	133/2311(5)	302/5035(5)	0.2093
Q3	376/2563(14)	367/2073(17)	1000/4333(23)	<0.001
Q4	871/2077(41)	810/1633(49)	2023/3301(61)	<0.001
Indians/Asians				
Q1	311/1428(21)	317/998(31)	1083/2576(42)	<0.001
Q2	74/1663(4)	56/1260(4)	280/3376(8)	<0.001
Q3	235/1491(15)	195/1120(17)	593/3063(19)	<0.01
Q4	512/1225(41)	494/814(60)	1423/2228(63)	<0.001
Age group				
15 to 24				
Q1	1153/4466(25)	768/3195(24)	1133/6042(18)	<0.0001
Q2	310/5308(5)	170/3788(4)	348/6822(5)	0.1121
Q3	682/4915(13)	549/3404(16)	1203/5961(20)	<0.0001
Q4	1759/3847(45)	1685/2259(74)	3480/3673 (95)	<0.0001

25 to 49				
Q1	1437/5338(26)	1082/4108(26)	1881/9771(19)	<0.0001
Q2	365/6401(5)	233/4949(4)	545/11096(4)	0.0472
Q3	947/5803(16)	770/4407(17)	2014/9621(20)	<0.0001
Q4	1956/4807(40)	1997/3172(62)	5451/6149(88)	<0.0001
50 plus				
Q1	1024/2719(37)	1020/2079(49)	1914/5868(32)	<0.0001
Q2	289/3454(8)	237/2855(8)	571/7204(7)	0.4403
Q3	590/3128(18)	608/2487(24)	1481/6297(23)	0.0002
Q4	985/2754(35)	1106/1984(55)	3289/4467(73)	<0.0001

n: number of individuals who reported some stigma; Q1: If you knew that a shopkeeper or food seller had HIV, would you buy food from them? Q2: Would you be willing to care for a family member with AIDS? Q3: Is it a waste of money to train or give a promotion to someone with HIV? Q4: Would you want to keep the HIV positive status of a family member a secret?

CHAPTER 7

RELATIONSHIP BETWEEN HIV-RELATED STIGMA AND ITS PREDICTORS:

A structural equation modelling

This chapter is the last of the three results chapters and seeks to achieve objective 4 of the thesis. In the previous chapter results were presented that showed the trends of HIV-related stigma in South Africa over the past decade using data from three different points in time, namely, 2005, 2008 and 2012. This chapter explores the relationships between the endogenous and exogenous variables using structural equation modelling (SEM) to assess whether HIV-related knowledge mediates these relationships. Therefore, the aims of this chapter are:

- a) to explore whether the proposed study model was sufficient;
- b) to explore whether HIV knowledge independently mediates the relationship between education, gender, race, awareness of HIV status, and HIV testing;
- c) to explore the direct and indirect effects of the exogenous variables on external stigma.

7.1 Methodology

7.1.1 Sampling Data

HSRC12 survey data was used. The sample consisted of a sub-sample of participants who were ≥ 15 years of age, and responded to the 5-items of external HIV/AIDS-related stigma.

7.1.2 Variables

Endogenous variables

In the model, external HIV stigma was the observed endogenous variable. The focus was to explore the direct and indirect relationships of key variables with external HIV stigma. External HIV stigma was constructed from the five external stigma items. External HIV stigma was dichotomised to “some stigma” and “no stigma”. Those who agreed with at least one of the five

items and those who were not sure were collapsed into one category defined as “some stigma”. The participants who responded “not sure” in this category were included because of issues related to social desirability bias; that is, respondents may have provided the answers they thought were socially acceptable or not want to be seen as having stigmatizing attitudes, and therefore chose not to give a true response. While those who disagreed with all five items were grouped into another group defined as “no stigma”.

Exogenous variables

The selected exogenous variables included in the SEM were: level of education, race, gender, HIV testing history, awareness of HIV status. These variables were already defined in Chapter 4 on page 64. These exogenous variables were chosen based on the grounds of theoretical plausibility (see Chapter 3) and empiric outcomes, wherein it is argued that in South Africa external HIV-related stigma is socially constructed within social institutional elements such as gender, race, and education as well as health structural elements such as HIV testing history and awareness of HIV status. These variables may be grouped into the demographic constructs of gender, race and education which in the model are presented as social institutional elements and the health structural variables constructs of HIV testing history and awareness of HIV status. All the selected exogenous variables were found to be significantly associated with HIV-related stigma (see Chapter 5). The aim was also to see if the significant associations found in Chapter 5 are mediated by HIV knowledge

Mediator variable

A mediator is a hypothetical variable that is included in a mediation model to help explain the observed relationship between an independent variable and a dependent variable (MacKinnon, 2011). In this SEM, HIV knowledge was included as a mediating variable. It was hypothesized that HIV knowledge would mediate the effects of the sets of demographic and health structural variables on external HIV stigma. This hypothesis is based on the theoretical model, in which

external HIV-related stigma is socially constructed within social institutional elements such as gender, race, and education as well as health structural elements such as HIV testing and awareness of HIV status. The hypothesis is also based on the correlation between HIV knowledge, gender, race, level of education, HIV testing and awareness, and external HIV-related stigma. In Chapter 3.I, the mediation model was used to explore whether the relationship between these independent variables could be explained by HIV knowledge.

7.1.3 Study model

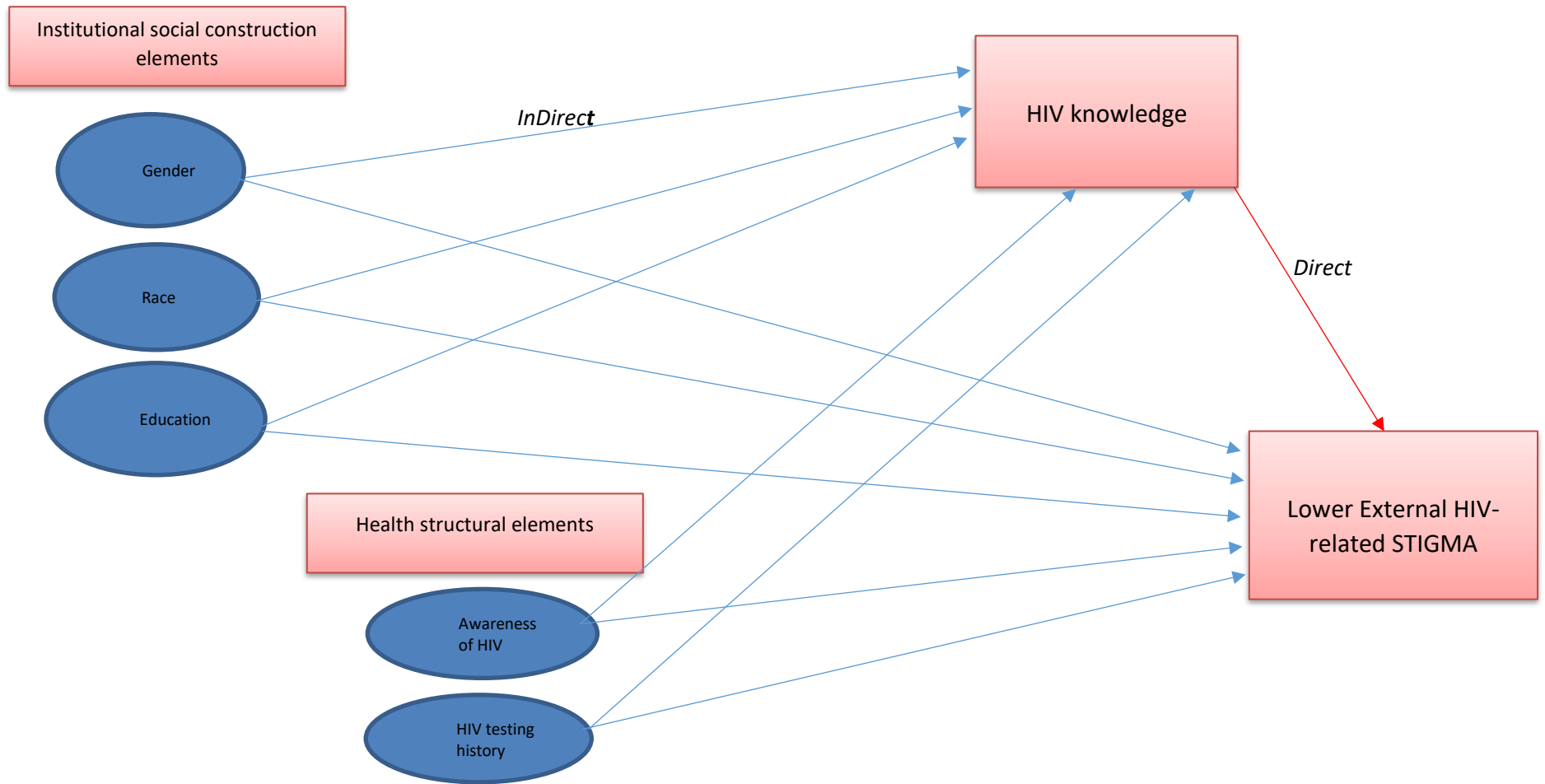
The proposed model is presented in Figure 7.1. The model, following the Institutional Social Construction theory framework, hypothesises that social institution elements such as gender, race, and education have an impact on external HIV-related stigma, the reason being that they generally inform how individuals behave, specifically towards PLHIV, while the health structural elements have some impact to the same (Cloete et al. 2010; Iwelunmor et al., 2010; Loutfy et al., 2012). While these relationships exist, we also hypothesise that HIV knowledge acts as a mediator in the make-up of these relationships. Gender, race and education are socially constructed phenomenon that should be of importance when dealing with HIV-related stigma. As stated in Chapter 3, HIV stigma has mostly been analysed at an individual level with the biological framework, but the suggested study model looks at HIV- related stigma holistically from the point of view of applying institutional social construction theory. For an example, the model includes gender as having an impact on external HIV-related stigma. Gender is a “socially constructed” phenomenon, as our conception of what males and females are and what they are supposed to be is produced by the society in which we live, and therefore how males and females portray HIV- related stigma would differ. The model also includes race. Just like gender, race is a form of ‘group identity’ and is socially constructed. In South Africa we experience an uneven distribution of HIV amongst racial groups (Shisana et al., 2008, 2012), therefore how HIV-related stigma is portrayed in these different groups could be different and

it is therefore important to explore these relationships. Similarly, with education. This also is a social institutional element as different educational levels form certain societal groups (i.e. university students, certain socioeconomic sub-groups, certain work cadres and others) which share similar values and norms. Educational level has also been linked with external HIV-related stigma (Rivera, 2015). The model also includes health structural elements such as HIV testing history and awareness of HIV status. These were found to be significantly associated with external HIV-related stigma in Chapter 5. As reiterated previously, for a holistic approach which includes both institutional social construction elements and health structural elements in HIV-related stigma, it was important to include these variables in the model as well.

7.1.4 Analysis

I performed statistical analysis using the statistical analysis software STATA version 15. The suggested model (see Fig. 7.1) was tested by structural equation modeling (SEM)-path analysis. SEM is useful for identifying both direct and indirect effects and for measuring the overall model fit (Hox, 1999; Xia & Yang, 2019). SEM path analysis approach was conducted because it is able to include relationships among variables that serve as predictors in one single model (Hox, 1999; Xia & Yang, 2019). Mediation analysis for each variable was performed. A final path analysis including the goodness of fit was conducted. Model fit was assessed with multiple times, using the goodness-of-fit chi square test, root mean square error of approximation (RMSEA), Tucker–Lewis index (TLI), and comparative fit index (CFI).

Figure 7.1: Proposed study model



RMSEA is an absolute fit index, which assesses how far a hypothesized model is from a perfect model, while CFI and TLI assess the fit of a hypothesized model with that of a baseline model (Hu and Bentler, 1999; Schumaker and Lomax,2016; Xia & Yang, 2019). An RMSEA value of < .05 indicated a “close fit,” while < .08 indicated a reasonable model–data fit, and a TLI > .90 indicates an acceptable fit (Xia & Yang, 2019).

7.2 RESULTS

7.2.1 Mediator effects

Mediation was explored using Baron and Kenny’s causal steps (Baron & Kenny, 1986), whereby mediation is established when:

- (a) there is a significant relationship between the independent and mediating variable;
- (b) the independent and dependent variables are significantly related;
- (c) the mediator and dependent variable must be significantly related; and
- (d) the relationship between the independent variable and dependent variable should be non-significant or weaker when the mediator is introduced.

Table 7.1 How the independent variables influence external HIV-related stigma (Step 1 in establishing mediation)

Structural External Stigma	Coef.	Std. Err.	z	P> z 	[95% Conf. Interval]
Sex	-.0232132	.0084594	-2.74	0.006	-.0397933 -.0066331
Race	.0098803	.0037773	2.62	0.009	.0024769 .0172837
Awareness of HIV status	.1012523	.0287524	3.52	0.000	.0448986 .1576061
HIV testing history	-.0898019	.0290977	-3.09	0.002	-.1468322 -.0327715
Education	-.0602831	.0059501	-10.13	0.000	-.071945 -.0486212

Step 1. In Table 7.1, the independent variables were shown to significantly influence the dependent variable in the first regression equation. From the table above, all the independent variables significantly influenced external stigma.

Table 7.2 How the independent variables influence the mediator variable (Step 2 in establishing mediation)

Structural Knowledge	Coef.	Std. Err.	z	P> z 	[95% Conf. Interval]
Sex	.0176459	.0074978	2.35	0.019	.0029505 .0323413
Race	.0328589	.0033465	9.82	0.000	.0262999 .0394178
Awareness of HIV status	-.0420069	.0255301	-1.65	0.100	-.0920451 .0080313
HIV testing history	.0491868	.0258354	1.90	0.057	-.0014496 .0998233
Education	.095385	.0052727	18.09	0.000	.0850506 .1057193

Step 2. In Table 7.2, the independent variables were shown to significantly influence the mediator except for HIV testing and Awareness

Table 7.3 How the mediator variable influences external HIV-related stigma (Step 3 in establishing mediation)

Structural External Stigma	Coef.	Std. Err.	z	P> z 	[95% Conf. Interval]
HIV Knowledge	-.1040258	.0094738	-10.98	0.000	-.1225941 -.0854576
Sex	-.0213452	.008439	-2.53	0.011	-.0378853 -.0048052
Race	.0091666	.0037817	2.42	0.015	.0017547 .0165786
Education	-.0604183	.0059587	-10.14	0.000	-.0720971 -.0487395
Awareness of HIV status	.1003716	.028732	3.49	0.000	.044058 .1566853
HIV testing history	-.0868149	.0290764	-2.99	0.003	-.1438037 -.0298261

Step 3. Mediator must significantly influence the dependent variable in the third equation. In Table 7.3, the independent variable and mediators were entered as predictors. HIV knowledge was significantly related to the independent variables, therefore satisfying condition (a) of the Baron and Kenny mediation steps (Baron, R. M., & Kenny, D. A., 1986). There was a strong association between all independent variables with the dependent variable external HIV-related stigma, therefore satisfying condition (b) of the Baron and Kenny mediation steps. The mediator HIV knowledge was also a strong predictor of external HIV-related stigma therefore satisfying condition (c) of the Baron and Kenny mediation steps. It was also seen that the effect of the independent variables and External HIV-related stigma becomes weaker as soon as the mediation variable HIV knowledge is introduced in the estimation process, therefore satisfying condition (d) of the Baron and Kenny mediation steps (Baron, R. M., & Kenny, D. A., 1986). The exploration therefore confirms that HIV knowledge mediates the effects of dependent variables (sex, race, education, awareness and HIV testing) towards external HIV-related stigma.

7.2.2 Goodness of fit test

Table 7.4 The performance of the three fit statistics (Likelihood ratio, RMSEA TLI, CFI.)

Fit statistic	Value	Description
<i>Likelihood ratio</i>		
chi2_ms(2)	3.964	model vs. saturated
p > chi2	0.138	
chi2_bs(11)	722.838	baseline vs. saturated
p > chi2	<0.001	
<i>Population error</i>		
RMSEA	0.008	Root mean squared error of approximation
90% CI, lower bound	<0.001	
upper bound	0.020	
pclose	1.000	Probability RMSEA <= 0.05
<i>Baseline comparison</i>		
CFI	0.997	Comparative fit index
TLI	0.985	Tucker-Lewis index

From Table 7.4, the likelihood ratio test shows that the p-value is greater than 0.05, which suggests that our model is of good fit. For the population error analysis, we see that our RMSEA is 0.008. According to Xia and Yang (2019), a RMSEA value of <0.05 indicates a “good fit,”, thus our model is show to have a good fit. This was also supported by the p-close value of 1. In the Baseline comparison, our TLI value is 0.985 which is greater than 0.95, and this indicates evidence of acceptance model fit.

7.2.3 Direct and indirect effects on external HIV-related stigma

Table 7.5 Direct and indirect effects of the dependent on external HIV-related stigma

Direct effects					
Structural	Coef.	Std. Err.	z	P> z	[95% Conf. Interval]
<i>HIV Knowledge</i>					
Sex	.0178922	.0074978	2.39	0.017	.0031968 .0325876
Race	.0332105	.0033294	9.97	0.000	.026685 .039736
Education	.0957156	.0052662	18.18	0.000	.0853939 .1060372
<i>External Stigma</i>					
HIV Knowledge	-.1040258	.0094738	-10.98	0.000	-.1225941 -.0854576
Sex	-.0213452	.008439	-2.53	0.011	-.0378853 -.0048052
Race	.0126214	.0037786	3.34	0.001	.0052154 .0200274
Education	-.0504614	.0060019	-8.41	0.000	-.0622248 -.038698
Awareness of HIV status	.1003716	.028732	3.49	0.000	.044058 .1566853
HIV testing history	-.0868149	.0290764	-2.99	0.003	-.1438037 -.0298261
Indirect effects					
Structural	Coef.	Std. Err.	z	P> z	[95% Conf. Interval]
<i>External Stigma</i>					
Sex	-.0018613	.0007982	-2.33	0.020	-.0034256 -.0002969
Race	-.0034547	.0004679	-7.38	0.000	-.0043718 -.0025376
Education	-.0099569	.0010594	-9.40	0.000	-.0120333 -.0078805

As indicated in Table 7.5, the direct effect of sex on HIV knowledge is nearly 2% (95% CI: 0.3-3.2%) and is statistically significant $p < 0.001$. Furthermore, race appeared to have an effect of 3.3% and education a direct effect of 9.5%, and both of these showed that a statistically significant effect ($p < 0.001$) respectively. HIV knowledge is shown to have a statistically significant inverse relationship on External stigma of -10.4% (95% CI: -12.3-0.09) $p < 0.001$. Awareness had the highest positive direct effect on external stigma of 10% (95% CI: 4.41-15.67%) $p < 0.001$. With regards to indirect effects, sex, race, and education had minimal negative indirect effects on External stigma, which was statistically significant for all the three covariates.

7.3 Summary

The SEM applied using the Institutional Social Construction theory framework represents a useful approach to understanding the direct and indirect effects of underlying Institutional social construction elements such as race, gender and education as well as the health institutional elements such as HIV testing history and awareness of HIV status. The model fit assessment results allows us to accept that the hypothesized model of the study is not far from a perfect model. We further conclude that HIV knowledge mediates the relationship between external HIV-stigma and the exogenous factors such as sex, race and education. This is important in informing future HIV-related external stigma interventions.

CHAPTER 8

DISCUSSION

8.0 Introduction

Using secondary data from the HSRC second (2005), third (2008) and fourth (2012) South African National HIV Prevalence, Incidence, Behavior and Communication Surveys, this PhD study focuses on conducting a narrative literature review on external HIV-related stigma in low- and middle-income countries (LAMIC), with a view to report on methods of assessment, prevalence, associated factors and consequences of external HIV-related stigma, examining the magnitude of external HIV related stigma, its trends over the time period between 2005 and 2012 and its correlates in South Africa, and examine whether HIV knowledge mediates the relationship between Level of Education, Awareness HIV status, Race, HIV testing history, and Sex, and external HIV related stigma. It is stated that at least a quarter of those living with HIV have been stigmatised (UNAIDS, 2018). The persistence of stigma may well represent a key hurdle in order to reach the lofty 90-90-90 goals proposed by the WHO (UNAIDS, 2017).

This study applied a variety of methods in order to have a full understanding of external HIV stigma. The Social Cognitive Theory Framework with particular emphasis on the Institutional Social Construction theory framework was adopted. This developed into potential mitigating factors that would be catalyst in controlling the scourge of the spread of new infection in the population. To support the study, a comprehensive systematic review explored the magnitude of stigma, its association and consequences in Low- and Middle-Income Countries (LAMIC), with particular emphasis on studies done in South Africa. To have a better understanding of the status quo of external HIV-related stigma in South Africa, the prevalence and associations of external HIV related stigma in the South African adult population in 2012 was then explored.

To understand whether there are changes with regards to stigmatising attitudes in the country, this SASSA study further analysed the stigma trends in the South African population during the years 2005, 2008 and 2012. Lastly, using structural equation modeling, this study examined whether HIV knowledge mediates the relationship between Level of Education, Awareness of HIV status, Race, HIV testing history, and Sex, and external HIV-related stigma.

8.1. Persistence in external HIV-related stigma

External HIV related stigma continues to be prevalent despite health structural approach interventions. The latest data examined in this study shows that external HIV/AIDS-related stigma existed among 38.3% of the South African adult population in 2012. The study also has shown that between 2005 and 2012, there was a slight decrease in the reporting of stigma over the three years for two of the stigma items (*Q1: If you knew that a shopkeeper or food seller had HIV, would you buy food from them?*, and *Q2: Would you be willing to care for a family member with AIDS?*). While we observe some increase in the reporting of stigma over the three years for two of the stigma items (*Q3: Is it a waste of money to train or give a promotion to someone with HIV/AIDS?*, and *Q4: Would you want to keep the HIV positive status of a family member a secret?*).

The results suggest that overall there is still a substantial proportion of the adult general population in South Africa that hold some external HIV/AIDS-related stigma, which is consistent with other previous research reports (Mall, et al., 2013; Petros et al., 2006; SANAC, 2014; Shisana et al., 2005, 2009, 2014). Though external HIV stigma still exists in South Africa, this study also showed some evidence that over the years there are some changes happening with some negative attitudes towards PLHIV. There is some increase in the acceptance and engaging with PLHV as seen in the percentages in Q1 and Q2 decreasing over the years 2005-2012. The thinking that an HIV positive person's life span is shorter than an

HIV negative person might be an issue as an increasing number of people over the years 2005-2012 thought that there was no need to use resources to increase the skills of PLHIV (Q3). Shame and stigma by association could be an issue as indicated by the increase in the attitude to keep an HIV status of a family member a secret over the years 2005-2012. However, one needs to be cautious with this interpretation because of the ambiguity of this item (Q4) and what it could otherwise be measuring.

The study further shows that indeed these attitudes still remain in spite of the progress that has been achieved by many countries in the East and Southern African region, including South Africa. South Africa, like its neighbours in the region, has committed itself to a rights-based response through their respective national strategic plans on HIV/AIDS (UNAIDS, 2013c). With the objective of the three national strategic plans dated from year 2000 being HIV prevention, treatment, and the fight for the human rights of those living with HIV/AIDS (see SANAC, 2012), the impact should be seen through the declining trends of those portraying HIV/AIDS-related stigma throughout the last decade, but based on these outcomes, this is not evident.

The trends show a slight decrease for one of the stigma items “Q1: If you knew that a shopkeeper or food seller had HIV, would you buy food from them?” between 2008 and 2012, which might be attributed to the progress in people having more access to HCT. Such programmes have some effect in how people perceive HIV infection and those living with it, especially if the person is not part of their immediate circle such as a colleague or a family member. Through HCT, individuals get pre- and post-counselling where they are informed on HIV related matters including transmission. Therefore, with this knowledge acquired through HCT, people would know that HIV is not transmitted through touching or talking to a seller in

the streets. Also, it could be that if PLHIV are not in a person's circle, then the problem is not seen as important or affecting that individual, meaning that having more access to HCT may have reduced social distancing toward PLHIV. Though the increase in two of the stigma items between 2008 and 2012 and the high prevalence in 2012 suggests that the implementation of the NSP goals to curb HIV-related stigma, together with the idea that access to HCT will curb HIV-related stigma, are not entirely effective or no longer have an impact. Beyond that, the two items are related to much closer circles and the problem could be seen to be closer to home.

8.2 Factors associated with external HIV-related stigma

Factors associated with external HIV-related stigma were: 1) 50+ years, 2) widowed, 3) White race, 4) primary education, 5) unemployed, 6) not aware of their HIV status, 7) perceiving oneself as not at risk of HIV-infection, 8) reporting no condom use at last sex, and 9) reporting inaccurate knowledge about HIV transmission and prevention. These nine population sub-groups held more external HIV/AIDS-related stigma attitudes when compared to their counterpart individuals in other sub-groups. Notably, in adjusted analyses the predictors of external HIV-related stigma were race, sex, education level, self-perceived risk of HIV infection and HIV knowledge. Similar results have been reported by smaller studies done in South Africa and elsewhere (Du, Chi & Li, 2017; Ekstrand et al., 2013; Mall et al., 2013; Mukolo et al., 2013; Okumu, 2017; Paudel & Bara, 2015; Srithanaviboonchai et al., 2017; Vorasane et al., 2017; Wong, 2013). It is worth noting that the literature review done in this study revealed that there is limited information or studies done on the associations of external HIV-related stigma in the recent years in LAMIC, specifically in South Africa. This is a concern given the fact that HIV stigma is an important element in the fight against HIV and AIDS.

8.2.1 External HIV-related stigma as a function of low socio-economic status (low education level)

As shown by the results of this study, it is a concern that the LAMIC are still faced with the challenge of external HIV-related stigma, even with more access to HCT in countries such as South Africa, as well as the new test and treat programme which has changed the nature of HIV/AIDS as a disease.

This could be related to a combination of factors. Firstly, it is known that LAMIC carry the highest burden of HIV infection globally (UNAIDS, 2017). Secondly, these are the countries that are faced with poor socio-economic conditions, poor access to health care, and economic or political displacement of communities (Becky et al., 2009; Bonnington et al., 2017).

The study done by Becky and colleagues shows that in settings where there is a lack of health care, there are high levels of HIV-related stigma (Genberg et al., 2008). Similar findings have been reported in another eighteen countries in sub-Saharan Africa (see Chan & Tsa, 2016; Chan et al., 2015). With the lack of and/or inefficient health care comes the faster progression of HIV which could bring about fear of HIV infection, and therefore could produce stigmatising attitudes towards the illness itself and those who are infected. Bonnington et al. (2017) points out the stigmatising attitudes of immorality and blame as the outcomes of fear brought about by how HIV is viewed in these countries.

In this study low education level was associated with external HIV -related stigma. This finding is also in keeping with other previous findings (Ajong et al., 2018; Coleman, 2016). According to Herek et al. (2005), external HIV/AIDS-related stigma is related to socio-economic factors. Low education can be seen as one of the socio-economic factors. Herek et

al. (2005) stated that external HIV/AIDS-related stigma is more prevalent amongst the low socio-economic sub-population as they are more likely to have inaccurate knowledge of how HIV is transmitted. Coleman and colleagues argue that the reason those with lower level of education show more stigmatising attitude towards PLHIV could be that they have less exposure to diverse groups of people (Coleman, 2016). They further argue that having a higher level education develops critical thinking skills and this could help in better HIV/AIDS knowledge. In South Africa, due to the apartheid system, we still have many less well educated (primary education) sub-populations and this could well be one of the reasons why the results of this study show that this socio-economic factor (low education level) is associated with external HIV-related stigma.

The association between external HIV-related stigma and low socio-economic status suggests that, without an improvement in the socio-economic conditions, most importantly health care and more access to education in LAMIC specifically in South Africa, there will be difficulties in eliminating external HIV-related stigma, and therefore we will continue to face challenges in the reduction of HIV infections.

8.2.2 Low external HIV-related stigma among women

This study shows that female sex is associated with low external HIV-related stigma. As per study results, women portray less external HIV-related stigma attitudes compared to men.

In South Africa, given its patriarchal context, these findings are exposing the position of men and women in the South African communities and how this can be related to men portraying more stigmatising attitudes than women (Campbell, 2009; Kasapoğlu, 2008; Visser, 2012;

Woodard, 2014). *I would argue that external HIV/AIDS-related stigma in South Africa could be a phenomenon embedded in the complex socio-cultural gender roles, norms and values.*

Some researchers have concluded that women's greater HIV prevalence, engagement in caregiving and access to health care could explain why women are less likely to portray stigmatising attitudes towards PLHIV (Coates et al., 2014; Salako, 2012; UNAIDS, 2012; UNAIDS, 2013B). While others affirm that the difference in men and women with regards to external HIV-related stigma is due to gender differences in HIV-related knowledge, and personal experiences with PLHIV (McMahon et al., 2017; Russell et al., 2016). Men in South African communities hold more power in everything including sexual relations, therefore for them to have an HIV positive individual in their families or communities could be a reflection of failure in them as "men" and hence the non-accepting reaction to an HIV-positive person. Others refer to the different meaning of being a man and woman, wherein women are more the caregivers than men, hence the difference in the portrayal of external stigma (Srithanaviboonchai et al., 2017; Pannetier, Lelièvre, Le Coeur, 2016). These distinctions of roles according to sex could be the reason why women in South Africa are more accepting of those living with HIV, as in essence they are the ones who take care of PLHIV.

8.2.3 Lower external HIV-related stigma among African population

The exploratory regression results revealed that in South Africa being Black African is associated with less external stigmatising attitudes compared to being White, Coloured or Indian. The higher levels of stigma were found in other race groups especially among Whites

and Indians. The Indian race showed a significant increase in stigma odds trends for all four stigma items over the years 2005, 2008 and 2012.

Firstly, the lower external stigma among African population can be explained by the fact that in South Africa throughout the past decade, HIV has been more prevalent amongst Black Africans followed by Coloureds, while it is very low among both Whites and Indians/Asians (Shisana et al., 2005, 2009, 2014). Secondly the higher levels of stigma found in other race groups especially among Whites and Indians could be explained by the historic background where HIV/AIDS was conceptualised as a Black (African) disease (Brown, 2016).

Prior stigma framework has suggested that personal relationships with PLHIV is associated with lower levels of HIV/AIDS-related stigma (Herek, 1998). Presumably, Black African people in South Africa are more exposed to PLHIV than White, Coloured and Indian people. Also, because of the higher HIV prevalence amongst Black Africans, the results could partly reflect the fact that HIV-related interventions, including stigma related ones, are targeting Black African communities more than they target White, Coloured and Indian communities. This then places Black African South Africans in a position to be more knowledgeable of, and exposed to, HIV and therefore more accepting of those living with the infection.

The higher stigma in other races may be indicative of the era where attitudes were displayed by leaders in higher authority in the parliament and where utterances were publicly made that 'promiscuity' of mainly White gays and Black African South Africans was the reason for higher numbers of HIV positive individuals in these two sub-groups (Avert, 2011; Fassin and Schneider, 2003). It could be that with less HIV intervention programmes in non-black

communities, this conceptualisation of HIV/AIDS has not shifted and has hence encouraged the existence of more external stigma in these racial groups.

Lastly, the increasing stigma trends amongst the Indian race group. One of the reasons for this could be that some of the individuals in this race groups, as said above, have not changed their mindset from the old era of pre-1994 wherein HIV was seen as a disease for only White gays and Black South Africans (Fassin & Schneider, 2003; Avert, 2011). This means that HIV is still seen by some in this race group as a Black African disease only. This could also be embedded in the cultural practices which mould these individuals and the HIV meaning in this particular race group. It is worth noting that the reasons for the increasing trend in external stigma in 2005, 2008 and 2012 amongst the Indian race group are not readily obvious.

8.2.4 HIV knowledge, a key to external HIV-related stigma reduction

The study found that those portraying correct knowledge and rejection of myths were less likely to show external HIV-related stigma compared to those who reported incorrect knowledge and rejection of myths. Furthermore, the outcomes of this study also revealed the fact that HIV knowledge mediates the causal effects of race, sex, level of education, regular HIV testing, and awareness of HIV status with external HIV-related stigma.

In South Africa the significant association between lower external HIV/AIDS-related stigma and those having more HIV knowledge can be explained by previous frameworks which argue that as HIV knowledge increases, HIV-related fear decreases (Herek et al., 2002; Ogden & Nyblade, 2005). Low HIV knowledge, which is associated with external HIV-related stigma, could be the result of how HIV is perceived in the South African complex, socio-cultural context, wherein individuals tend to distance themselves from anything that is related to HIV

because they do not want to be seen as “other” in their communities or to lose the roles and responsibilities they hold within the cultural settings.

The association between HIV knowledge and external HIV-related stigma is in line with that obtained from previous research (Barker et al., 2012; Chao et al., 2010; Du, Chi, & Lic, 2017; Ekstrand, 2013; Wong, 2013; Mukolo et al., 2013; Okumu et al., 2017; Vorasane, 2017). As it is argued in other previous frameworks that, with an increase in HIV knowledge, HIV related fear decreases (Herek et al., 2002; Ogden & Nyblade, 2005).

On the other hand, relationship between external HIV-related stigma and lack of HIV knowledge in South Africa could be embedded in the socialisations of the specific roles women and men lay in the communities. For example, women may not want to lose their status as “child bearers” and might therefore turn away or distant themselves from any information session related to HIV. Men, on the other hand, might not want to be seen as not in control of their sexual relations by accepting HIV-positive individuals, and therefore may also turn away from any educational programme related to HIV. This then highlights the need for tailored HIV educational interventions which will take into account this rather unique gender context that is not only found in South Africa but throughout most of Sub-Saharan Africa. We need to realise that in South Africa HIV education programmes are increasingly available through social media, in health settings as well as in NGOs in the communities. Therefore, the challenges do not lie in the availability of the information, but rather in the factors which impede the accessing of these educational programmes, such as gender related issues within the communities. Also, to note that HIV information can be readily available to individuals but this might not translate to more HIV knowledge. Wen et al. (2015) states that by providing

HIV information or education does not mean people will be curious or interested in HIV/AIDS knowledge (Wen et al., 2015).

It would be advantageous to relook into the current HIV-knowledge programmes and their content as well as the targeted populations. For example, we cannot rely on a “one glove fits all” HIV-knowledge programme in the hope that it will have an impact on the reduction of external HIV-related stigma. An important realisation from this study is that there are various predictors of external HIV stigma, and therefore provision and dissemination of knowledge regarding HIV must address all factors in some way in order to achieve the broadest possible effects. For example, the racial differences on the levels of external HIV-related stigma discussed above will not be adequately addressed by programmes focussed mainly on general HIV transmission.

The mediation effect of HIV knowledge found in this study is important. The comprehensive literature search which supported this study revealed no other studies which explored such an effect at a population level in South Africa. Mugoya et al. (2016), in their study done using 2013 Nigeria Demographic Health Survey, alluded to the fact that the mediating effect of HIV knowledge has important implications for interventions. This could also be true for the South African case, where HIV knowledge programmes take a step further to acknowledge other factors that would be helpful to consider, such as race and gender as discussed above.

8.3 External HIV-related stigma by association and family shame on the rise

As discussed above, there seems to be a strong need to keep the HIV positive status of a family member a secret in the South African communities. This raises other elements of external stigma that need some attention.

While noting the limitation of the item used (Q4) which can be interpreted in different ways, the understanding in this study is that the non-disclosure of the HIV status of a family member could firstly be referenced with the “stigma by association”. Secondly, this secrecy also plays to what the family member’s HIV status brings to the family. The secrecy and non-disclosure could also be explained by shame.

As said above, the non-disclosure of the HIV status of the family member could explain a high prevalence of “stigma by association” in the South African communities. Individuals could be afraid of being associated with PLHIV, and hence the reluctance to disclose the HIV status of family members. Stigma by association has been defined in many ways as including what is known as ‘courtesy stigma’ or ‘HIV/AIDS ‘secondary stigma’ and or ‘associated stigma’ (Goffman 1963; Bond et al. 2003; Holzemer et al. 2007). Some research has noted the possibility of an associated stigma attached to the family members, care givers or colleagues of those living with HIV (Holzemer et al. 2007; Bond et al. 2003; Siyamkela, 2003; Poindexter & Linsk 1999, Wight et al. 2000). It is noted though that limited research has been done on HIV association stigma in sub-Saharan Africa (Haber, Roby, High-George, 2011). Despite the fact that some individuals in the general population may not be living with HIV themselves, they have the propensity to suffer negative effects of “associative stigma” wherein they may be targets of HIV-related prejudice and discrimination by virtue of being related to an HIV positive person. Hence, we are seeing the gradual increase over the past years in the reluctance to disclose the HIV status of a family member living with HIV.

To explain the element of shame, remember that from the onset, HIV was a dirty and shameful disease, driven by immoral sexual behaviour. It could be that this understanding is still alive

within South African communities, and that an HIV positive status of a family member brings shame to the family at large and hence the secrecy and non-disclosure. According to Li et al. (2008), research has shown that if the status of a PLHIV is disclosed to the community, the family fears losing face and feels shame. They further state that in Thailand the whole family gets stigmatised due to one family member being HIV positive. Many other studies have also alluded to the association of non-disclosure and family shame (Pequegnat et al., 2001; Rotheram-Borus, Flannery, Rice, & Lester, 2005.) Therefore, external stigma in South Africa could be a result of stigma by association and family shame, and further research in this regard is needed to explore these effects at the family level. These elements could be some of the causes that lead to external HIV stigma.

With expanding access to ARV and HCT campaigns in the population between the years 2005-2012, this could have brought about an increased confidence to those who were tested and diagnosed with HIV to actually disclose their HIV status at least to their families (Norman, Chopra, and Kadiyala, 2007). However, this could have then brought about fear and uncertainty amongst the family and hence the increase we are seeing from the results of this study where non-disclosure of family member HIV status is a concern. We must remember that the HCT intervention is an individualistic approach as the pre- and post-test counselling sessions focus on the individual. Therefore, whatever effect it has on the individual might not necessarily carry over to those around him/her, as they did not receive the same intervention. Hence the argument made earlier that individualistic approaches / interventions might not be effective in the reduction of external HIV-related stigma . External HV-related stigma interventions in a holistic model should also target issues relating to close relations such as family.

On the other hand, one could argue that non-disclosure by family members means that the family members are more respectful of the infected individuals and therefore prefer that they personally disclose only when they feel the time is right. It is evident that external HIV-related intervention should be developed with an understanding of the family and community structures rather than remain individualistic.

8.4 Human rights not afforded for PLHIV

A systematic assessment is required regarding understanding the observed slight increase in reported external HIV-related stigma over the past decade among South Africans as measured by the stigma item *“Is it a waste of money to train or give a promotion to someone with HIV/AIDS?”*

It is likely that HIV in South Africa might no longer be associated with death due to the growing access to ART and reduced HIV-related mortality, but this information might not be filtering through to some people.

The rising rate in this stigma item could mean that people still associate HIV with shorter life spans. Therefore, there is a feeling that it is a waste of money to empower and develop an HIV positive individual. With job employment rates on a decrease in South Africa, reported by Statistics South Africa in the Quarterly Employment Statistics (QES) survey, and with some people still associating HIV with shorter life spans, this could explain the rise in external HIV-related stigma in the aspect of human rights. There might be a feeling that PLHIV could become sick and not be able to work, or may die sooner, and that is a loss of a job. Therefore,

there could be reasoning amongst South African people that it is better to promote the “non-infected” people than those infected with HIV.

This could also be linked to stigma by association as discussed above, where individuals do not want to be in the same work place with those who live with HIV because they fear that they may be targets of HIV-related prejudice and discrimination by virtue of being colleagues with HIV positive individuals, and would perhaps prefer not to be in the same workplace. This could be an indication that there is a lack of holistic external interventions penetrating the working places in South Africa.

8.5 Limited external HIV-related stigma research at population level is problematic

Lastly, the scoping review in this study could not find specific studies at a population level in South Africa. Studies done specifically in South Africa, are mostly at a small scale, with small samples, and are conducted in selected communities (Mall et al, 2013; Maughan-Brown, 2010; Visser, 2018). The limited studies at population level done in some of the countries, such as the PLHIV Stigma Index studies, collected data mostly from only convenience samples of HIV positive individuals and not from the general populations. This could explain the other finding of the narrative review, wherein there are contradictory findings as to whether HIV related stigma is decreasing or increasing in LAMIC including in South Africa. These differences could be related to the sample size, nature and methodology of these studies. This can pose challenges in monitoring and evaluation of external HIV-related stigma in the country as they yield results that cannot be generalised to the broader population, be it among the general population or among PLHIV or both. This gap demands clarification, ideally from larger, more general surveys, with view to planning interventions in South Africa, such as this study.

External HIV-related stigma is a complex phenomenon, nationally representative surveys such as this one assessing on a continuous basis are needed in order to monitor, channel and properly align interventions at a population level, this study being the first in that direction in South Africa.

CHAPTER 9

STUDY IMPLICATIONS AND RECOMMENDATIONS

9.1 Rationale of the thesis

This PhD work set out to understand the phenomenon of external HIV-related stigma in South Africa and its correlates. This thesis was able to provide information on external HIV-related stigma which might help to identify elements which impede on any activities towards its reduction in the general population of South Africa. It further provided information on the changes of external HIV-related stigma over a time period of 8 years in the general population, which has not been done before in South Africa except in small selective sampled studies (i.e. Mall et al., 2013). The study was also able to provide information on the pathways of external HIV-related stigma in South Africa.

9.2 Thesis contributions

Firstly, the scoping review on external HIV-related stigma in low- and middle-income countries (LAMIC), including South Africa, provided a better understanding of the methods of assessment that had been used as well as the prevalence, associated factors and consequences of external HIV-related stigma in these countries. The study revealed that HIV-related stigma studies documented are mostly limited by the use of small samples and conducted in specific communities and sub-populations in South Africa and other LAMIC.

Secondly, the analysis conducted in this study revealed that in 2012, over one third of the South African population displayed some degree of external HIV-related stigma (38.3%) with key

predictors being race, sex, education level, self-perceived risk of HIV infection, and HIV knowledge.

Thirdly, I explored trends of external HIV/AIDS-related stigma in South Africa over an 8-year period, which had been measured during 2005, 2008 and 2012. In South Africa, surveys are done at provincial and regional or national levels to monitor HIV prevalence and associations. Similar monitoring efforts for HIV-related stigma are however almost non-existent (Shisana et al., 2005, 2009, 2014). Until this study, it was not known how external HIV-related stigma had changed over the years 2005-2012 at the general population level in South Africa. In this study the trends show that, between 2005 and 2012, there was some increase in the individual stigma items measured in the South African population largely due to the increase in two external HIV-related stigma items namely, “*Is it a waste of money to train or give a promotion to someone with HIV/AIDS? (Q3)*” and “*Would you want to keep the HIV positive status of a family member a secret? (Q4)*”.

Lastly, understanding the direct and indirect effects of other elements on external HIV-related stigma is crucial in the development of interventions to decrease HIV-related stigma in South Africa. I therefore explored the role that HIV-related knowledge plays in the relationship between other predictors of external HIV-related stigma such as race, sex, level of education, regular HIV testing, awareness of HIV status in relation to external HIV-related stigma. The pathway exploration results showed that HIV knowledge mediates the effects of level of education, awareness of HIV status, time to HIV testing, sex and race towards external HIV-related stigma. As suggested by Mugoya et al. (2016), the mediating effect of HIV knowledge has important implications for HIV-related stigma interventions.

9.3 Implications of study results

9.3.1 National external HIV-related stigma studies in the general population

The results of this study can be generalized across the entire South African general population as the results analysed were from household-based population survey data obtained using a nationally representative sample. In other words, these results could inform the development of interventions that could be implemented at national level in all South African settings. To my knowledge, this is the first study to have a closer look into external HIV-related stigma in South Africa at a population/national level. The only other large-scale HIV-stigma survey that was done is the PLHIV index stigma survey (SANAC, 2014). Unlike this survey, which collected data only from HIV positive individuals, my study analyses are based on data collected from South African adults irrespective of their HIV status. To be able to effectively monitor the status core of HIV-related stigma in South Africa we need national population-based studies, which will be done periodically, this being the first in that direction.

9.3.2 External HIV-related stigma interventions in South Africa

In Chapter 3, I have argued that the individualistic approaches such as access to HCT to reduce external HIV-related stigma may not be effective because, as defined by Blick and Wraight (2017), external HIV/AIDS-related stigma refers to prejudice, discounting, discrediting and discrimination directed at persons perceived to have AIDS or HIV, as well as their partners, friends, families and communities. In the context of HIV and AIDS, several factors such as ignorance of how HIV is transmitted, poverty and gender inequality produce social contexts in which external HIV related-stigma is constructed (Deacon, 2016). It is therefore logical to develop interventions which look beyond just the individual who is HIV positive. The results of this study could be a confirmatory point of this argument.

The results in Chapter 5 show that despite efforts such as increased access to ART and HCT mass campaigns done in South Africa, external HIV stigma in some form still exists in one third of the country. While results in Chapter 6 confirm this by showing some increasing trends of external HIV-related stigma comparing results from three points, namely, 2005, 2008 and 2012. These results could inform the development of new effective external HIV-related stigma interventions (discussed in the recommendations below) in South Africa as they show a gap in the current interventions in the country. These results are informative not only for the government or public sector but also for other stakeholders, such HIV-focused non-governmental organizations (NGOs), the private sector and the community structures to relook into their current HIV and stigma-related programmes.

The results of the correlates of HIV-related stigma in Chapter 5 are not far removed from what has been found before (e.g., see Dua et al., 2018; Ekstrand, 2013; Hargreaves, 2018; Kingori et al., 2017; Mukolo et al., 2013; Srithanaviboonchai et al., 2017). But once again this speaks to the fact that, though there is evidence showing similar results of the associations of HIV-related stigma, it is not properly used to inform the development of external HIV-related stigma interventions because we see an increasing pattern in external HIV-related stigma. This tells us the current external HIV-related stigma interventions are not aligned with research evidence, which is a concern. Interestingly, I noted that time to HIV testing is not a predictor of external HIV-related stigma as it was found by other researchers. These results therefore inform once again the point that we need to move away from individualistic approaches, which only focus on improving health structural elements, if we are to win the fight against external HIV-related stigma. We should remember that these might work in other countries but might not be the case in South Africa, given that our epidemic is also driven by other socio-economical elements such as poverty and lower levels of education and in some instances poor access to health care.

Perhaps these approaches worked at some point but currently are no longer effective in the reduction of external HIV-related stigma.

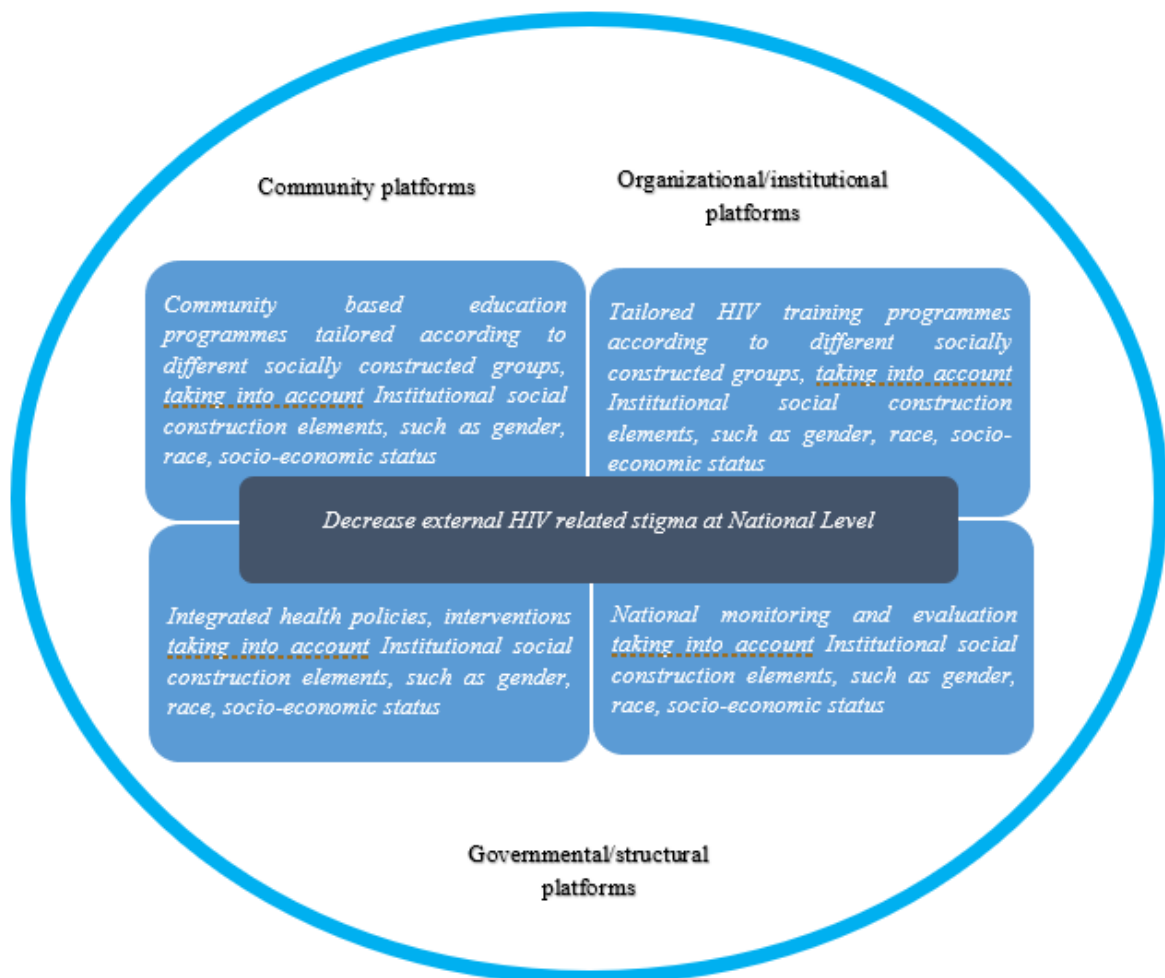
Knowledge emerged as one of the most significant predictors of HIV stigma in Chapter 5, while the results of pathway effects of both social institutional elements and health structural elements in Chapter 7 show that HIV knowledge independently mediates the relationship between level of education, awareness HIV status, HIV testing history, sex and race with external HIV-related stigma. The results are informative in that, perhaps, there is a need to unpack what kind of HIV knowledge is needed by the South African population to reduce external HIV-related stigma. Currently, HIV knowledge programmes focus on transmission and prevention with the hope that when people have this knowledge, they will not stigmatise those living with HIV. But the results of this study allude to the fact that a different kind of HIV knowledge might be needed. For example, in both Chapters 5 and 6 Whites and Indians were found to report more stigmatising attitudes than Black African and Coloureds. We need to unpack this information to ask whether the kind of HIV knowledge needed to be addressed by HIV stigma interventions is not perhaps embedded in the HIV discourse from pre-1994 i.e. that HIV is a “Black” disease as discussed in the previous Chapter 8, or could it perhaps be embedded in cultures and family structures in South Africa. We need to look again at the development of HIV knowledge messages that will be aligned with the predictors of HIV-related stigma as found in this thesis.

9.4 Recommendations

Figure 9.1 below was introduced in Chapter 3 as a suggested intervention framework in the reduction of external HIV-related stigma in South Africa. The figure shows how the programmes on the reduction of external HIV-related stigma can be changed to inform interventions which

are tailored to take into account institutional social construction elements. As HIV-related stigma is a socially constructed phenomenon, this approach will build on the individualistic approaches that are currently utilised in South Africa. An approach, in which interventions could be penetrated in community, organisational/institutional and governmental/structural platforms (see Figure 9.1) in South Africa is needed in to curb external HIV-related stigma. Below are recommendations based on the intervention framework I suggested in Chapter 3 (see Figure 9.1).

Figure 9.1: Institutional social construction macro-level intervention framework



9.4.1 Community platforms

The results of this study call on interventions aligned to the predictors of external HIV-related stigma such as race, sex and HIV knowledge. Therefore, encouraging the government and stakeholders to work with community organisations as follows:

- Expose all the different racial groups that exist in South Africa to a range of HIV-related messages addressing different aspects of stigma such as “othering”, “blame”, “shame” which have been identified in this study;

- Address culture and family identities which might lead to the stigmatisation of individual, family and friends of those living with HIV;
- Provide opportunities to discuss stigma and the factors contributing to it with peers;
- Provide opportunities for community dialogues amongst men and women on gender and cultural related issues around HIV-related stigma.

Therefore, South Africa could benefit in a development of a comprehensive community-based external HIV stigma reduction intervention. Such interventions have been seen to be effective at a smaller scale in some parts of South Africa and elsewhere (Chidrawi, Greeff, Temane, Doak, 2016; Jain, Nuankaew, Mongkholwiboolphol, Banpabuth, Tuvinnun, Ayuthaya, Richter, 2013; Berkley-Patton, Moore, Berman, Simon, Thompson, Schleicher, Hawes, 2013). One intervention included workshops which informed the community members about HIV stigma elements as well as building coping skills. The strength of these interventions is that they did not only include PLHIV, but also those around them, such as spouses/partners, children, family members, friends, spiritual leaders, and neighbours. These are the kind of interventions which could give a platform to discuss issues around gender, race, family/community values and norms which have been found to be predictors of external HIV-related stigma in this study.

9.4.2 Organizational/institutional platforms

The results of this have alluded to the fact that there is still a belief that those who are HIV positive do not deserve human rights such as equal opportunities at the work environment. The trends results showed an increase in those who believe that HIV positive individuals do not deserve to be promoted at work. This therefore calls for the development of effective external HIV-related stigma reduction interventions in the organizational/institutional platforms such as:

- Identifying peers who can influence other workers to drive anti-stigma programmes within the work environment;
- Development of anti-stigma organisational policies which protect the rights of those living with HIV should be considered;
- HIV-related organisational programmes should be inclusive of HIV-related stigma narratives as suggested in this study.

We have seen advocacy groups for the rights of PLHIV such as Treatment Action Campaign (TAC). We need similar advocacy within organisations/workplace. To encourage dialogues on HIV stigma in this platform we need interventions where, for example, external HIV stigma becomes part of the in-house enforced policies. This could include HIV stigma awareness talks during company induction programmes. This could also include the attendance at ongoing HIV stigma seminars forming part of the performance appraisals and key indicators for all employers to attend stigma awareness programmes. One of the few successful interventions in this is reported in (Heijnders & van der Meij, 2006) wherein PLHIV are empowered to be actively involved in the implementation of stigma-reduction interventions in the workplace, such as conducting awareness forums and drawing up policies that will hold employees/employers responsible for providing a stigma-free environment in the workplace.

9.4.3 Governmental/structural platforms

With predictors such as low level of education found by this study, the government policies in sectors such as Education, Social development and Health Ministries should take into account HIV-related interventions aligned with evidence provided in this study. This could include:

- Implementation of a policy to ensure that information aligned with the South African context on HIV and stigma is provided through the school curriculum;

- HIV programmes to integrate HIV stigma related interventions which are aligned with the findings of this study, such as relevant HIV knowledge according to racial groups and gender orientated;
- Social development policies to include empowerment programmes which influence change in the gender related roles created by communities that lead to the stigmatisation of those living with HIV.

Because of the socio-economic elements that drive the HIV epidemic in South Africa which then lead to the stigmatisation of PLHIV as found in this study, we need all governmental sectors to be involved in the fight to reduce external HIV-related stigma. For example, we could benefit from enforced policies which eradicate inequality in health access, employment, gender equality, and access to education. I acknowledge that this would not be easy to implement and might take some time given the political history of the country. This approach has also been suggested by Smith (2002).

9.5 Future research

Based on the outcomes of this study, the following suggested future research studies could be beneficial in the efforts to reduce external HIV-related stigma in South Africa.

1. The results of this study tells us that with the changing HIV scope and narratives, a robust, population-based, external HIV-related stigma monitoring and evaluation framework is needed to enable a development of research questions and or a research agenda.
2. Studies that will specifically unpack the relationship between race and HIV-related stigma in the South African context are needed, given the different stigmatising attitudes among Black, White, Coloured, and Indian race groups.

3. Studies exploring the relationships between family identities, shame and HIV-related stigma are needed, once again related to the different stigmatising attitudes among Black, White, Coloured and Indian race groups.
4. Lastly, studies exploring the development of new HIV knowledge and anti-stigma messages which are aligned with the unique South African context and taking into account the South African history would be beneficial.
5. As this study included data up till 2012, there has been advances made in treatment access, test and treat roll out and prevention approaches (like PrEP) after 2012, therefore continuation of further exploration and research on the status quo of external HIV stigma, using the most current datasets i.e HSRC 2017 survey data, is needed in South Africa.

9.6 Strengths and limitations

1. This study is an archival study that used secondary data obtained from HSRC05, HSRC08 and HSRC12. The use of secondary data brought about limitations in selecting the measures of variables used in this study, for example:
 - The use of different external HIV-related stigma measures for the exploration of stigma trends and the all the other analyses of external HIV-related stigma in the study. The reason for the use of the different measures for the trends analyses is simply that the stigma items used as the measure for trends were included in all the three HSRC survey's (i.e., 2005, 2008 and 2012) data-sets, while the other scale used for the analysis of the external HIV-related stigma prevalence, associations and pathways was only used in the 2012 survey data collection tool. Therefore, it was not possible to explore trends over time using the latter. I selected to use the 5-item stigma scale which was used in 2012 for all the other analyses, as this was the latest survey data-set available

at the time of starting this thesis, meaning one would be able to report on the most recent results. Also this 5-item scale, as indicated in the Methods chapter, was a reliable scale given that the 4-item scale included an item that is no longer recommended as a measure for stigma and which was removed from the DHS many years ago because of the challenges in interpreting what it actually means/is measuring, which is in itself a limitation.

- Also, in the literature review there were interesting studies which reported on the association between external HIV related stigma and knowing someone who is living with HIV. We unfortunately could not add this variable in our analysis as there was no good measure for it in the HSRC survey data sets used in this study.
2. The author acknowledges the limitation and the risk of dichotomising the Stigma and Knowledge variables i.e a person that endorses one stigma item, will be much different from a person that endorses all stigma items
 3. One of the limitations of the study is that the measure for external HIV/AIDS-related stigma attitudes was based on participants' self-responses and these may be affected by social desirability bias; that is, respondents may have provided the answers they thought were socially acceptable.
 4. HIV infection has evolved over time from being a hidden and stigmatizing illness associated with sexual misconduct to being a more open ailment where individuals can talk about it while attending clinics, adherence clubs or even other social gatherings. This has been enabled by active de-campaigning messages through intersectional collaboration and the social political will of the government to make HIV a more manageable ailment. Over the years, we have seen mushrooming organizations working within the area of HIV/AIDS clinical as well as health education. This certainly has had an impact overall on making HIV a more acceptable illness in the society. In my opinion, this has led to the changing

dynamics of perception around HIV/AIDS in the country. I would therefore expect a change or modification of various factors that play a role in mitigating stigma in the society. This in the long run would have a different impact on HIV stigma. The observed findings might certainly have been influenced by differences in these factors and therefore caused a limitation for this study.

5. I also note the limitation that, though there is some overlap between the study data and the time of literature review in chapter 2, the focus is actually on different times: 2005-2012 (study data) and 2010 –2018 (literature review).
6. Lastly, HSRC 12 that was used in this study is currently not the latest HIV survey conducted by the council. There is a later survey done in 2016, but unfortunately, I could not add the data from that survey in my analyses as it had not yet been released to student researchers at the time of embarking on this study. It would have been good to compare external HIV related stigma from 2012 and 2016 using the 5-item scale. It is therefore important to note that conclusions based on data through 2012 may not adequately represent the current level of external HIV stigma and this puts an emphasis on the importance of continuing this research and developing up to date stigma related interventions.

In spite of these limitations, this study poses a strength in that the study results can be generalized across the entire South African general population because the data analysed was from household-based population survey databases obtained using a nationally representative sample. In my knowledge this is the first study to have a closer look into external HIV-related stigma in South Africa at a population/national level. To be able to effectively monitor the status core of HIV-related stigma in South Africa, we need population/national based studies which will be continuously done, this being the first in that direction. The thesis also provides information on the changes of external HIV-related stigma over a time period of eight years in

the general population, which has not been done before in South Africa except in small selective sampled studies. The information therefore helps in determining whether external HIV-related stigma is increasing or decreasing in South Africa and the nature of that change.

9.7 Conclusion

1. External HIV-related stigma still exists in South Africa despite previous success in massive ART rollout, HTC campaigns, and most recently test-and treat-programmes.
2. The focus on individualistic health structural approaches and interventions to reduce external HIV-related stigma as discussed is likely to undermine the successes achieved in the control of HIV and AIDS thus far.
3. There is a need to study and develop innovative holistic interventions which will be inclusive of both social institutional elements and health structural elements, as suggested in my model and intervention framework, to address the challenge of external HIV-related stigma.

In summary, because of the prevalence and the demographic and behavioural factors that are related or predict the existence of external HIV-related stigmatising attitudes, this study shows that in South Africa external HIV-related stigma is embedded with roots that could be tied to the unique social and cultural aspects of the various communities found in the country. This is indeed of great concern given both the scope and age of the epidemic in South Africa. South Africa still has the highest prevalence of HIV/AIDS cases. The focus on access to HCT and ART without appropriate interventions to specifically address HIV-related stigma and its effects is likely to deprive South Africans of the success achieved thus far in the fight against HIV and AIDS.

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