How do South Africans experience and respond to HIV stigma?

Cherie Ferreira

Dr Rajohane Matshedisho

Master of Arts' by Coursework and Research Report

Department of Sociology

Humanities

30 November 2020

Word Count: 32 111 (excluding Reference List)

DECLARATION

In terms of Rule G9.8 of the Wits Humanities Rules and Syllabus (2020), I, Cherie Ferreira declare that this Research Report is my own, unaided work. I submit it for the Degree of Master of Arts (Sociology) at the University of the Witwatersrand, Johannesburg. I did not submit it before for any degree or examination at any other University.

Signed ___________________ on this **30th day** of **November 2020** at Krugersdorp, Johannesburg.

Cherie Ferreira

DEDICATION

I dedicate this work to God, our Lord Almighty, my mother and father, Adele and Gideon Ferreira, and a special thanks to all the social workers (Selina and Simphule) and Ma’am Susan Rammekwa at Tshepang Centre for their tireless assistance during this project.

ACKNOWLEDGEMENTS

Firstly, I would like to express my profound gratitude to the Almighty God and all institutions that contributed in one way or the other in making this dissertation (Masters' of Sociology) possible. These institutions include the University of Witwatersrand, especially the Department of Sociology, the Tshepang Program for vulnerable children and the Princess Informal Settlement in Roodepoort.

Secondly, I give special thanks to my supervisor, Dr. Rajohane Matshediso, who greatly assisted me in the completion of this report. His assistance in the course of doing this work is greatly appreciated.

Thirdly, I would like to say "thank you" to the social workers at the Tshepang program for vulnerable children, who assisted me in the study. This research work would not have been achievable without their participation.

Fourthly, my appreciation goes to my family, especially my wonderful mother for her psychological and spiritual support and father for his silently supportive presence.

Furthermore, I am greatly indebted to other individuals whose names are not mentioned here but contributed in one way or the other towards the success of this work.

Finally, I will recognise the efforts of those great lecturers, who handled the different modules during my undergraduate and postgraduate studies before the commencement of my research. They all did their jobs well.

ABSTRACT

Background: HIV (Human Immunodeficiency Virus) is a global pandemic that negatively effects a person's physical and social health. The stigma and discrimination related to HIV has been well documented in previous research (Aggleton et al., 2004; Gilbert, 2016; Gilbert & Walker, 2010; Kimera et al., 2020; Link & Phelan, 2014; Parker & Aggleton, 2003; Scambler, 2009; Zuch & Lurie, 2012). Education has been one of the main tools used to combat the stigma related to HIV, as ignorance is viewed to be the main driver behind people's stigmatizing attitudes towards people living with HIV (PLHVs). The discriminatory behaviour that has been informed by stigmatizing attitudes have also been well documented in previous research (Goffman, 1959, 1963; Hatzenbuehler et al., 2013; Link et al., 2004; Link & Phelan, 2014, 2001; Mill et al., 2013), however, stigma still exists (Mahamboro et al., 2020). Therefore, this research project set out to understand how South African PLHVs experienced and responded to HIV - related stigma.

Purpose: The purpose of this research project was to understand how South African PLHVs experienced and responded to HIV-related stigma.

Methods: To achieve the stated purpose, a qualitative research methodology was utilized that saw to the usage of one – on – one semi – structured interviews. The interviews were conducted with four HIV - positive women from the Princess Informal Settlement in Roodepoort. Ethical clearance was obtained from the Research Ethics Committee of the University of Witwatersrand. Verbal consent was obtained from all participants before the commencement of interviews. All interviews were audio recorded and manually transcribed in semi - verbatim. A thematic analysis was conducted on the transcripts in line with Braun and Clarke's (2018) prescriptions.

Results: In response to experienced stigma, this research project found that PLHVs employed impression management and self – isolation tactics. Additionally, it was also concluded that the education efforts within the community did address the issues of internalized stigma and acceptance among PLHVs close family members. Although the existing efforts did not address the stigmatizing attitudes that were prevalent within the wider community.

Recommendations: The recommendations of this research report are that a more extensive, multitier education approach is needed to address the prevalent stigma within the community at large. Additionally, to address the issues of loneliness and shame among PLHVs, a pride march is recommended to assist PLHVs in building up their self-esteem and community solidarity. Finally, community solidarity would also be duly strengthened through the re-establishment of PLHV support groups within the P.I.S. community.

Keywords: Stigma, HIV Stigma, Impression Management, HIV Education

LIST OF ABBREVIATIONS

HIV	Human Immunodeficiency Virus
AIDS	Acquired Immunodeficiency Syndrome
UNAIDS	Joint United Nations Programme on HIV and AIDS
PLHV	People Living with HIV
ART	Antiretroviral Therapy
AZT	Azidothymidine - an antiretroviral medication
USAID	United States Agency for International Development
UNDP	United Nations Development Programme
NGO	Non-governmental Organizations
P.I.S.	Princess Informal Settlement
TB	Tuberculosis
MSM	Men who have Sex with other Men
TW	Transgender Women
PWID	People Who Inject Drugs
SW	Sex Workers
EEA	Employment Equity Act
LRA	Labour Relations Act

Table of Contents

List of Figures

Chapter 1: Introduction

1. 1 **Introduction:**

Stigma is a social problem that has detrimental consequences for a person's physical and psychological health within their community (Link & Phelan, 2014). Stigma is defined as a social process whereby people that appear to be different in some way or another, are sanctioned (i.e. stigmatized) by their community because of that difference (Dores Cruz et al., 2019). These sanctions vary in the physical, social or psychological manifestations that they can take within a community. Research (Dores Cruz et al., 2019; Goffman, 1959, 1963; Hatzenbuehler et al., 2013; Link & Phelan, 2001, 2014) has demonstrated that stigmatized people often experience discrimination in the form of job loss, excommunication or physical abuse within their communities. The Human Immunodeficiency Virus (HIV) is a predominately sexually transmitted disease that ultimately leads to a person's death. Due to the high mortality rate and spread of the disease, it is highly stigmatized and often associated with sexual deviance and sin (AVERT, 2015, 2020b; Klaas et al., 2018; Mbonu et al., 2009). As such, people that contract the disease, are stigmatized as sexual deviants and sinners.

Due to the stigmatization and consequent discrimination associated with the HIV virus, many people that live with HIV (i.e. PLHVs) do not want to be identified as HIV - positive (Gilbert, 2016; Wolf et al., 2014). Being identified as HIV positive within a community, may leave a person vulnerable to discrimination within that community. Consequently, PLHVs often live in secrecy and do not access the necessary services to medically prolong their lives (Sullivan et al., 2020). Accessing medical treatment, is imperative as antiretroviral therapy, helps a person living with HIV to become virally suppressed and is unable to pass on the virus to their partners or other people. Becoming virally suppressed can help PLHVs to lead normal and healthy lives, however, due to the stigma associated with being identified as HIV - positive PLHVs do not access these necessary services which leaves them capable of passing on the virus to other people. Therefore, a causal link exists between HIV – related stigma and PLHVs refusal to access the necessary services, to enable them to obtain viral suppression and live healthy lives. So long as PLHVs continue to avoid imperative medical services, South Africa will never be able to completely halt the spread of HIV within its borders (UNAIDS, 2014b). The South African government needs to adequately address the problem of HIV – related stigma, if it wishes to address the problem of HIV efficiently.

In relation to the problem of addressing HIV – related stigma, the purpose of this research project was to describe and understand how South African PLHVs experienced and responded to HIV – related stigma. In the first chapter of this report on HIV – related stigma the focus was, on describing the background of the research problem, what the research problem is and the objectives of it. Why the research problem is significant, will also be explained in more depth, along with an explanation of the conceptual framework, used to define the concepts that were used to explain the phenomena under examination in this research project. The methodology that was utilized in the data collection and analysis portions of this research, will also be laid out. An overview of the structure of the report will be the penultimate section of this initial chapter. The section that follows, will provide the background to the social phenomena under examination in this research project, namely HIV – related stigma.

1. 2 Background of the Research Problem:

Any disease that is shrouded in mystery and secrecy is always accompanied by stigma and HIV or the Human Immunodeficiency Virus, is no exception (Link & Phelan, 2014; Scambler, 2009, Hatzenbuehler et al., 2013). Stigma has been related to the HIV disease since it was first discovered in a group of men who had sex with other men in New York during the 1980s (AVERT, 2020; Scambler, 2009). Stigma can be defined as physical or social deviance that contradicts accepted norms and values, therefore giving the affected person, a deeply discrediting social image that decreases their standing in society and their self – confidence (Link & Phelan, 2014; Parker & Aggleton, 2003).

The four main forms of stigmatization, according to previous research (Gilbert, 2016; Gilbert & Walker, 2010; Hatzenbuehler et al., 2013; Link & Phelan, 2001, 2014; Scambler, 2009; Zuch & Lurie, 2012), are perceived stigma, enacted stigma, internalized stigma and stigma by association. Unlike enacted stigma, which are actual experiences of stigma, perceived stigma are the negative attitudes that a person with a stigma, believes to be present in the community around them (Goffman, 1963; Link & Phelan, 2014; Sullivan et al., 2020). Internalized stigma are negative feelings of blame and shame, that an effected person imposes on themselves while stigma by association is when a person is stigmatized because they associate with a person that has a stigma (Goffman, 1963; Link & Phelan, 2001, 2014).

Research (Andersson et al., 2020; Gilbert, 2016; Misir, 2015; Sullivan et al., 2020) has shown that stigma leads to discriminatory behaviour like physical abuse, abandonment from friends and family, social exclusion and even murder. Further research (Feyissa et al., 2012; Klaas et al., 2018) has also shown that a lack of academic education, wealth and knowledge about HIV, increases stigma amongst people. Although, Link and Phelan (2014) demonstrates that stigma is also used as a tool for enforcing social order within society. As a tool of social order, stigma is used to establish a social hierarchy within a group of people, and therefore stigma is not just a product of ignorance, but also a conscious act to elevate one group of people over another (Hatzenbuehler et al., 2013; Link & Phelan, 2001, 2014). Additionally, in support of Link and Phelan (2014), Deacon et al. (2005) also demonstrates that stigma operates along social fault lines and that people who are already stigmatized, like women and homosexuals, tend to be more easily stigmatized than others. Research by Klaas et al. (2018) and Mbonu et al. (2009) demonstrates that women are actually more stigmatized for having HIV, than their male counterparts. In South Africa, women are viewed as the source of the disease's transmission during heterosexual intercourse, despite research showing that the disease is actually brought into the relationship by the man, due to his polygamous sexual activity (Klaas et al., 2018; Tong & Botts, 2018; Wathuta, 2016; WHO, 2013).

Gender inequalities aside, the stigma associated with the disease, whether it is warranted or not, is so detrimental to a person's social, physical and psychological health that it has led people, both men and woman, to abstain from accessing the necessary testing and treatment, that is necessary to maintain their health, by becoming virally suppressed (Batchelder et al., 2020; Friedland et al., 2020; Gilbert, 2016; Link & Phelan, 2014; Mbonu et al., 2009; Parker & Aggleton, 2003; Rankin et al., 2005; Sullivan et al., 2020; Wouters et al., 2020; Yuvaraj et al., 2020). PLHVs avoiding the necessary health care services (i.e. testing and antiretroviral therapy) are one of the constituting factors that has contributed to the perpetuation of the spread of the HIV pandemic in South Africa, and around the world (Gilbert & Walker, 2010; Li et al., 2020).

Given the health risks that these responses (i.e. medical avoidance) to stigma hold for the PLHVs themselves and the community at large, as well as influential health agencies like the Joint United Nations Programme on HIV/AIDS (UNAIDS) have strongly suggested in their guideline notes that every HIV response program around the world, should include an arm that deals exclusively with the stigma related to HIV (Andersson et al., 2020; UNAIDS, 2014b). In response to medical impact of the HIV disease the South African government launched an extensive HIV response program, which includes free universal testing, treatment, pre and post-test counselling, education and condom distribution. It is one of the world's most extensive, self – funded programs (AVERT, 2020; Klaas et al., 2018; Nkosi, 2016; UNAIDS, 2017).

Despite the government's extensive efforts, recent research (Azia et al., 2016; Camacho et al., 2020; Dahab et al., 2011; Dlamini et al., 2009; Kagee et al., 2011; Mathibe et al., 2015; Mokwele & Strydom, 2017; Tumwikirize et al., 2015; Zuch & Lurie, 2012) into ART adherence has shown, stigma and discrimination, are among the serious motivations for PLHVs to not take their medication as prescribed, leaving them without a suppressed viral load and capability of transmitting the disease to others, within their community. Stigma also leads to non-disclosure of status among PLHVs that perceive stigma within their communities (Anakwa et al., 2020). Which means that they are less likely to tell close family members about their HIV status and more likely to avoid any services or treatments that could indirectly disclose their HIV status to others (Anakwa et al., 2020; Andersson et al., 2020; Denis, 2014; Greeff et al., 2008; Kimera et al., 2020; Sullivan et al., 2020). Therefore, these avoidance behaviours demonstrates that even though the necessary medical services are available, they are not being utilized, because they are not addressing the social factor that is keeping PLHVs from accessing these services in the first place, namely stigma. More targeted interventions are needed to address the effects of stigma (Bagchi & Holzemer, 2020; Camacho et al., 2020; Friedland et al., 2020; Jones, 2020; Li et al., 2020; Link & Phelan, 2014; Parcesepe et al., 2020; Yuvaraj et al., 2020).

Stigma is a barrier to care and contributes to the spread of the HIV virus. More targeted interventions are necessary to address the problem of stigma as people, suspected of being infected with HIV are too afraid to get tested, too afraid to suggest the usage of condoms to their sexual partners, and too afraid of continuously taking their medication. These three actions are so fear inspiring as it could expose them to the stigma related to HIV, even though they might not actually be HIV positive (Gilbert & Walker, 2010; UNAIDS, 2014b). The problem therefore is, that HIV - related stigma effects the health care seeking behaviour of people living with HIV, despite ongoing efforts by the South African government to combat the pandemic. More work is urgently needed to understand how existing efforts to combat HIV – related stigma can be improved to ultimately improve the quality of life of PLHVs in South Africa. By improving anti – stigma interventions, research can contribute to improving the quality of life of PLHVs. It is within this avoidance of care, due to fear of HIV – related stigma context, that the study was conduct in an effort to understand how South Africans experienced and responded to HIV – related stigma.

1. 3 Statement of the Research Problem:

Some recent research (Bagchi & Holzemer, 2020; Friedland et al., 2020; Hatzenbuehler et al., 2013; Li et al., 2020; Link & Phelan, 2001, 2014) has shown the existence of HIV – related stigma and the discriminatory consequences of these attitudes. A consequence of HIV – related enacted stigma is that PLHVs engage in behaviour that negatively influences their health and can eventually lead to their death. Therefore, it is imperative that the persistence of stigma be addressed, so that the quality of PLHVs lives can be improved (Andersson et al., 2020; Geibel et al., 2020; Kimera et al., 2020; Parcesepe et al., 2020). In doing so, the research will indirectly be contributing in reducing the spread of HIV, in South Africa.

Although, more research into how PLHVs are responding to their experiences of enacted stigma are needed if existing efforts are going to be improved to help encourage PLHVs to engage in more activities that promotes their physical and social health, instead of harming themselves. There have been many efforts to educate people on the negative impacts of stigma and discrimination, however, stigma continues to persist (Andersson et al., 2020; Geibel et al., 2020; Sullivan et al., 2020). Stigma is known to exist within the communities of PLHVs because PLHVs have been documented engaging in coping mechanisms, like avoidance and social withdrawal, which are indicators that there is something to be feared within their social existence (Hatzenbuehler et al., 2013; Link & Phelan, 2001, 2014). This something, is stigma and it needs to be addressed. Consequently, this study endeavoured to answer the main question of "How do South Africans experience and respond to HIV stigma?" The research that has been conducted, can contribute to the improvement of existing efforts to combat HIV – related stigma and thus, improve the quality of life of PLHVs.

1. 4 The Purpose and Objectives of the study:

The purpose of this study was to gain an understanding of how South Africans experienced and responded to HIV - related stigma. To achieve this purpose, the researcher had to first demonstrate that HIV – related stigma has continued to persist within a South African community, despite years of HIV education that has tried to address the key drivers of stigma, namely, lack of knowledge of HIV, formal education and poverty (Klaas et al., 2018). Once the researcher has demonstrated that HIV – related stigma has continued to persist within a South African community, then they can move on to trying to describe how South African PLHVs have responded to the stigma they have experienced within their community. After that, once a description had been made, the researcher can then move on to recommending a few changes to the existing intervention efforts that could improve the quality of PLHVs lives within their community.

Therefore, the objectives of this research project was to:

1. To demonstrate the persistence of HIV – related stigma.
2. To describe how PLHVs responded to experienced stigma.
3. And to suggest alternative interventions that can improve the quality of PLHVs lives.

1. 5 Significance of the study:

Research (Anakwa et al., 2020; Camacho et al., 2020; Friedland et al., 2020; Misir, 2015) has shown that PLHVs actively engage in tactics to avoid suspicion from their fellow community members. These avoidance tactics leads them to engage in actions that can severely impact their health and the health of others. These avoidance tactics are in response to experienced or perceived stigma and it can lead PLHVs to defaulting on their medication (Azia et al., 2016; Camacho et al., 2020), not getting tested, or reporting for treatment in the first place (Campbell et al., 2007; Gilbert, 2016; Gilbert & Walker, 2010; Sullivan et al., 2020). All of these avoidance tactics can lead to PLHVs knowingly or unknowingly transmitting HIV to other people, which is a severe health risk. Consequently, it is imperative that one gains an understanding of the stigma that PLHVs are experiencing and how it is effecting them, so that one can improve existing anti-stigma and HIV education interventions. By improving existing anti – stigma and HIV education interventions one can improve the quality of life that PLHVs have (Parcesepe et al., 2020). As well as curb the spread of HIV in South Africa (UNAIDS, 2014b).

The research that has been conducted here, contributes to the existing work surrounding HIV – related stigma and can be used to inform local and national policies regarding the South African response to the HIV pandemic and the social issues (i.e. stigma and discrimination) surrounding it. Existing efforts by the government are aimed at testing and treating people that live with HIV but, is not aimed at dealing with the reason why people are not getting tested or, treated in the first place (Sullivan et al., 2020). The government's existing efforts recognizes the problem of HIV - related stigma but, it does not go far enough to address the stigma that is prevalent within society at large. As such, the government has been unable to reach its 90 – 90 - 90 goals, which dictates that South Africa needs to test 90% of its PLHV population, initiate 90% of its diagnosed PLHV population on ART, and achieve a 90% viral suppression rate of those PLHVs diagnosed and treated (Sullivan et al., 2020). As of 2017, South Africa had only tested 76% of its PLHV population, initiated 79% of those PLHVs diagnosed with HIV on ART, and achieved an 83% viral suppression rate of those PLHVs that were diagnosed and initiated onto ART treatment (Sullivan et al., 2020). Which means that there are still 24% of PLHVs that are walking around South Africa untested, untreated and unprotected.

The South African government's existing efforts are failing and the research presented here, contributes to an understanding of why the government's efforts have not been enough to combat the reason of why these efforts have been failing. It does not adequately address the issue of HIV – related stigma within South African communities. As long as the government does not adequately address the issue of HIV – related stigma, interventions aimed at combatting HIV in South Africa will not succeed. Next, in the section that follows, definitions will be provided for the key terms to be used throughout the work represented here, before moving on to a discussion about the conceptual framework that underpins the work conducted, namely the Goffman – Link and Phelan conceptual framework.

1. 6 Definitions of Key terms:

Stigma and Discrimination - Stigma is defined as negative sentiments or attitudes that a person holds against other people (Goffman, 1959, 1963; Hatzenbuehler et al., 2013; Link & Phelan, 2001, 2014). Stigma is the negative attitude that leads to discriminatory behaviour (Link & Phelan, 2014).

Impression Management - Impression Management, as defined by Goffman (1959), is the social process in which people, consciously or unconsciously, alter their behaviour to conform to an external ideal about themselves. Link and Phelan (2014) refer to these efforts as coping mechanisms that people engage in to remain 'in' a group and avoid the stigma associated with being 'outside' of the group.

Self – Isolation – Refers to an emotional and physical seclusion that can lead to a loss of social support and access to vital resources within a community (Goffman, 1959, 1963; Link & Phelan, 2001, 2014).

Education – Refers to anti – stigma and HIV education regimes, consisting of sex education in schools, that which is taught by Life orientation teachers, according to the state curriculum, anti-stigma rallies and campaigns (e.g. pre and post-test counselling at clinics) that are hosted and advocated for by the South African government and various other NGOs (Non-governmental organizations), to promote a consciousness of the negative effects that stigma has on people's lives and to debunk any misunderstands regarding HIV and its transmission (AVERT, 2015, 2020b; dos Santos et al., 2014; Kimera et al., 2020; Sullivan et al., 2020). Additionally, the sensitivity training that health care workers, law enforcement officers and social workers receive as part of their training for dealing with PLHVs (Duby et al., 2019; Engelbrecht, 2006; Ferreira & Ferreira, 2015; Kleingeld, 2004; Marks, 1995; NASTAD, 2020; Newham et al., 2006; Retief & Green, 2015; Shokane & Masoga, 2018; University of Pretoria, 2020).

People living with HIV – refers to people who are HIV - positive.

1. 7 Conceptual Framework:

The conceptual framework that was utilized in this research report, was a combination of Erving Goffman's conceptualization of stigma, as laid out in his two books, *the presentation of the self in everyday life* (1959) and *Stigma: Notes on the management of spoiled identity* (1963), and the expansion Link and Phelan did, during the work they did in their three journal articles, *Conceptualizing Stigma* (2001), *Stigma as a Fundamental Cause of Population Health Inequalities* [in collaboration with Hatzenbeuhler] (2013), and *Stigma Power* (2014). The Goffman – Link & Phelan conceptual framework, is the framework that has informed the theoretical understanding of the concept of stigma in this research report. As the foundation, Goffman conceptualized stigma, as a deeply discrediting trait that a person possesses which makes them socially undesirable (e.g. mental illness or a criminal record). For Goffman, there were three types of stigma, namely stigma of the body (i.e. a scar on your face), the stigma of the character (i.e. Mental Illness) and stigma of the social community one was associated with (i.e. having a criminal record).

Subsequent research by Gilbert and Walker (2010) and Parker and Aggleton (2003a) have expanded on Goffman's original work by defining four more types of stigma, namely perceived stigma, enacted stigma, internalized stigma and stigma by association. Perceived stigma, is the negative attitudes and views that people with a stigma thinks other people have of them (Sullivan et al., 2020). An enacted stigma is, where a negative attitude is acted on with discriminatory behaviour (i.e. physical abuse) (Gilbert, 2016). Internalized stigma are feelings of shame and blame that a person with a stigma has of themselves (Gottert et al., 2020; Link & Phelan, 2014). Stigma by association refers to a person being stigmatized for being associated to a person, group or institution (Gilbert, 2016; Gilbert & Walker, 2010). Alongside the work of Gilbert and Walker (2010) and Parker and Aggleton (2003a), Link and Phelan (2001) expanded on Goffman's work by extending the scope of the concept of stigma to include a structural component. The structural component highlighted in Link and Phelan's (2001) work, expanded the concept of stigma from an interpersonal issue, to a form of social control that is exercised by people in positions of power, to oppress those with less power and social standing than themselves.

The power play that was mentioned above, is a form of social control that is being exercised, according to Link and Phelan (2001), to maintain the accepted social hierarchy between different people and/or groups. According to Link and Phelan's (2014) conceptualization, people stigmatize others to ensure social order within, and between groups of people, by keeping members 'in' through the fear of stigmatization, and keeping non-members 'out' and 'away' with stigmatization. According to Link and Phelan (2001; 2014), stigmatizing non - members ensures the maintenance of the group's prestige and resources. Link and Phelan's (2001; 2014) expansion of Goffman's original concept explains why, despites years of HIV education to the contrary, people still stigmatize people living with HIV within their communities.

For Link and Phelan (2001; 2014), stigma is both an interpersonal and a structural social mechanism, that operates with agency between people and institutions and therefore, their expansion on Goffman's work is very important and must be remembered, when conducting work on stigma. Link and Phelan's work is important, because it demonstrates that work on stigma cannot be conducted by solely focusing on the individual, there must be a focus on the structural elements that contribute to the situation at hand.

Moving on from here, the persistence with Goffman's work in this research project is because of his in depth work on, the concept of Impression Management. In Link and Phelan's (2001; 2014) work they touch on coping mechanisms but they do not go into the matter as deeply as Goffman did, and therefore, this project relies heavily on Goffman's conceptualization of Impression Management. This research into HIV – related stigma is twofold, in that it seeks to understand (1) how PLHVs experience stigma and (2) how they respond to it. Link and Phelan's work assists one in understanding the workings of the former, but only Goffman's conceptualization of impression management clearly explains, the researcher feels, the process PLHVs use to adapt and blend into their communities. That is why Goffman's original work was utilized in this research project.

Goffman believed that people respond to stigmatization by utilizing impression management to mitigate the impact of enacted stigma on their lives. Impression management, as defined by Goffman (1959), is the social process in which people, consciously or unconsciously, change their behaviour to conform to an external ideal about themselves. Goffman (1963) held that people have two identities, an actual one and a virtual one. The actual identity is who a person really is and the virtual one is who people expect them to be. Now, for Goffman, the rub lies in the moment a person acquires a spoiled identity, an identity that contradicts or conflicts with their virtual identity (e.g. when a person has a criminal record or mental illness). When a person acquires a spoiled identity, according to Goffman, people start to stigmatize that person, and as previously stated, stigma leads to discrimination.

To avoid the stigmatization, people engage in impression management to turn, as much as they possibly can, their actual spoiled identity into their virtual identity. Making the stigmatized individual socially acceptable to others. As is evident from the above, the wider community plays a major role in shaping the forces that impact an individual's behaviour, as the utilization of impression management tactics is a response to external experiences. As such, Goffman's work on impression management aligns perfectly with Link and Phelan's (2001; 2014) expansion, which greatly emphasizes the role external forces play in the process of stigmatization. External structural forces do play a major role in the experiences that people have during their lives, however, individual choice also plays a role in how people choose to respond to the stigma they have experienced. Not all HIV positive individuals react to enacted stigma by withdrawing from their community, some choose to be very open about their status and way of life (Gerbert et al., 1991; McNeil, 1998; Misir, 2015).

Individual preference brings the conversation to the topic of self – isolation. For Goffman (1963), and Link and Phelan (2001; 2014), self – isolation would be an impression management tactic. Where one removes oneself, emotionally and/or physically, from a society in order to avoid disclosure of a stigmatizing characteristic that could lead to discrimination from others. Self – isolation can have very negative effects on the quality of life of an individual which contributes to their already lowered self – confidence and standard of living (Link & Phelan, 2001, 2014).

Goffman and Link and Phelan's work is supported by previous research (Andersson et al., 2020; Gilbert, 2016; Parcesepe et al., 2020; Parker & Aggleton, 2003a; Zuch & Lurie, 2012) which has found that the three main forms of stigma, that Goffman identified, was still present in the experiences of PLHVs today. Additionally, other HIV stigma research (Gilbert, 2016; Gilbert & Walker, 2010; Kimera et al., 2020; Zuch & Lurie, 2012) has also documented efforts by PLHVs to consciously avoid any stigma they might receive, if they were to be identified as HIV positive by a fellow community member. Therefore, existing HIV – related stigma research has shown that PLHVs do experience stigma and that they consciously engage in actions that helps them avoid the stigma associated with HIV. The above argument makes it possible to conclude, that there is supporting literature for the utilization of the Goffman – Link & Phelan framework.

The working of stigma is illustrated in Figure 1 below:

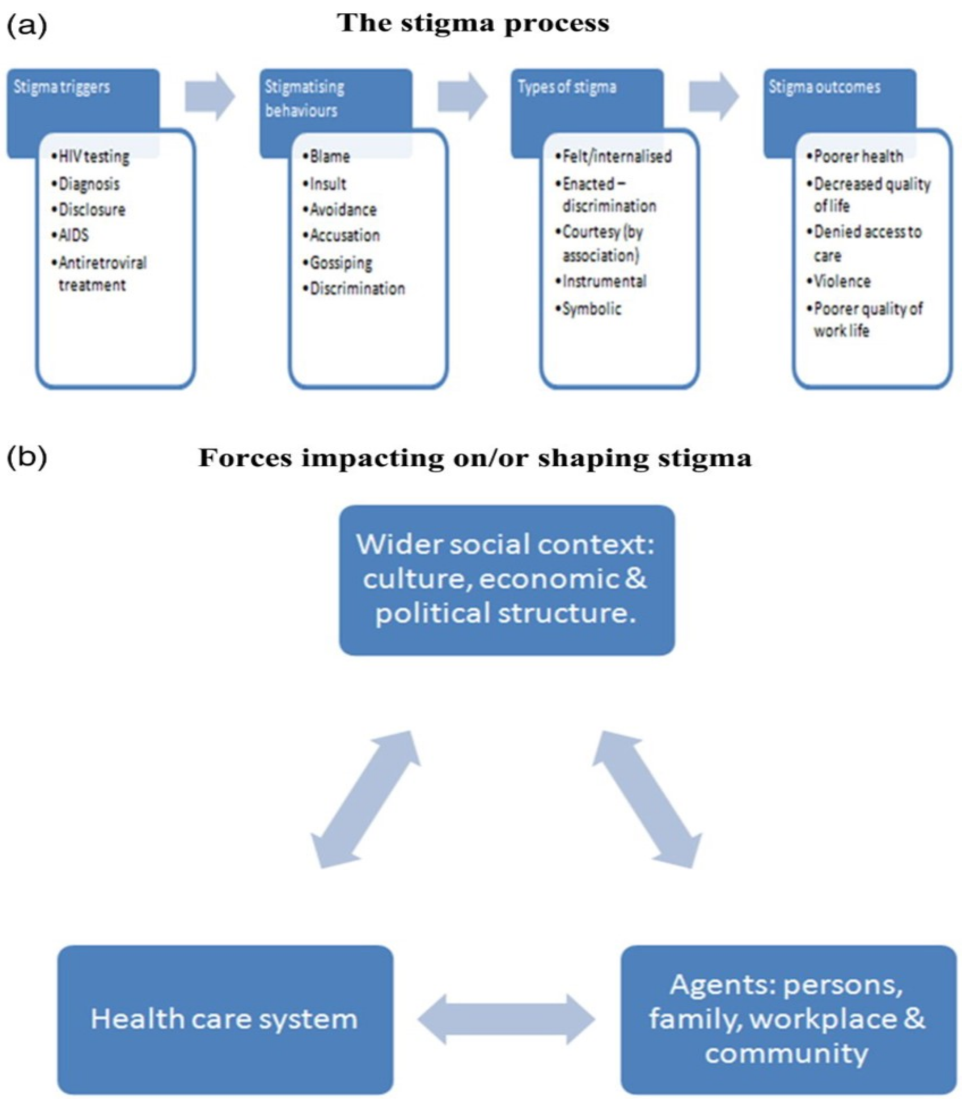

Figure 1: Model of the framework (Source: Gilbert (2016, p. 12))

What is being demonstrated neatly in Figure 1 is the social process of stigmatization and the outcome it leads to, according to the Goffman – Link and Phelan conceptual framework. The process starts with the acquisition of a stigmatized trait and then as the discrediting trait becomes known, judgement is passed and blame and shame is allocated according to the accepted social norms and values of the community. After being stigmatized, a person becomes susceptible to various forms of stigma informed discrimination (e.g. gossiping and/or physical abuse). The discrimination a stigmatized individual face, can range from one on one physical abuse, to institutional discrimination in the form of, police harassment or, refusal of care in hospitals. These forms of discrimination, directly or indirectly, contribute to the decreased social, physical and psychological health of a stigmatized person or group.

Additionally, Figure 1 demonstrates, firstly, that the acquisition of a stigmatizing trait, is directly linked to the experience of enacted stigma, which negatively impacts the social, emotional and physical health of the stigmatized individual (Parcesepe et al., 2020). Secondly, Figure 1 illustrates the impact various social actors have on the movement of stigma within society. Stigma is both an individual and structural process that influences people's quality of life. There exists an interplay between individual and structural forces and the interplay between these forces determines the manifestations of daily enacted stigma (Gilbert, 2016; Gottert et al., 2020; Link & Phelan, 2001, 2014). Therefore, stigma is a multi – layered problem that needs a multi-layered approach to counter act (Hatzenbuehler et al., 2013; Link & Phelan, 2001, 2014). Stigma needs to be addressed on both the individual and structural levels if interventions aimed at combating HIV – related stigma, are to be successful.

Figure 1 is a fine visual representation of the Goffman – Link and Phelan conceptual framework, that has underpinned the work presented in this research project. In the section that follows the focus will shift to an overview of the research methodology utilized in this report, before finally concluding with an overview of the structure of the report to follow.

1. 8 Overview of the research method:

This research was conducted using a qualitative research methodology, with one – on – one semi – structured interviews, as the primary data collection method. Interviews were transcribed in semi – verbatim and thematically analysed according to Braun and Clarke (2018) prescriptions. Convenience sampling was utilized to select participants from the Princess Informal Settlement (P.I.S.) in Roodepoort. Ethical clearance was obtained from the Research Ethics Committee of the University of Witwatersrand. All ethical requirements were adhered to during the project. A discussion of the data collection, analysis and ethical considerations will be done in **Chapter 3**.

1. 9 Structure of the report:

The report consists of five chapters, a references list and appendixes. The first chapter describes the context of the study. The second chapter discusses the relevant literature on HIV - related stigma, with special attention given to explain the concepts of impression management and self-isolation. The third chapter explains the methodology used during the project. The fourth chapter presents and discusses the results of the study, and the fifth chapter, presents the conclusions and recommendations of the study.

1.10 Conclusion:

In this chapter the background of the research was presented. The key terms that will be used in this report, was also defined and the purpose and objectives of the study was stated clearly. The conceptual framework that underpins this research report, has also been presented and justified in this chapter. In the chapter that follows, a literature review will be conducted that focuses on the theoretical and physical history of HIV – related stigma, the social and institutional responses to it and its existence in South Africa.

Chapter 2: Literature Review

2. 1 Introduction:

To understand the situation of HIV – related stigma within South African communities, a literature review was done that focused on seven key areas, namely the context of the area of study, an overview of the physical literature around HIV-related stigma, the history of theory surrounding stigma, the history of responses to stigma, the populations that are most at risk of being stigmatized, and why it is all important. It is necessary to know the history of HIV – related stigma and the responses to it, if one wishes to improve the quality of life of PLHVs, within South African communities. PLHVs quality of life are improved by improving existing interventions aimed at combating the stigma that negatively influences their quality of life.

Accordingly, these seven areas are important to review, as it presents the academic and social work that has already been done to address the problem of stigma, not just in South Africa, but also around the world. Furthermore, to understand what is going on now, one needs to understand where it all began, therefore, one has to look at the history of HIV and the stigma related to it. And then finally, because stigma is a social hierarchy tool, the researcher needs to know who is most likely to be stigmatized for being HIV positive, not only because it can aid the sampling process, but because it can also assist the development of context specific interventions that addresses the issues of the people that are most likely to suffer under the problem of stigma. Focusing resources in the sections of society that needs it the most, ensures a more effective and efficient use of the limited resources (Link & Phelan, 2001, 2014) that are available within South Africa. The South African government's response to HIV and the stigma related to it, will also be discussed in the literature review that follows, along with those population groups that are most in need of the government's resources.

Before discussing the history of research into HIV, let the discussion begin with a look at the history of the area that was the focus for the research, namely the Princess Informal Settlement (P.I.S.) in Roodepoort. Describing the community, that was the area of focus for the research, will assist in creating an understanding of the community that the researcher operated in. Understanding the conditions of the community will help readers understand, why the P.I.S. community was chosen.

2. 2 Princess Informal Settlement (P.I.S.) Context:

Created in 1994 to house homeless workers, after the factories that had employed and housed them closed, the Princess Informal Settlement (P.I.S.) is home to between 3500 and 4000 households (Claybrick, n.d.; South African Government, 2015). The P.I.S. is one of four hundred and eighty nine such shanty towns that existed in Gauteng alone, in 2010 (Moeng, 2010). In 2012, there were six hundred and twenty five informal settlements in Gauteng (HDA, 2013) and in 2016 there was a 51% increase in informal dwellings in the province, according to the Gauteng City-Region observatory (Hamann et al., 2018).

Nationally, there are about two thousand seven hundred informal settlement in South Africa, however, only seven hundred and twenty one of these settlements, have been identified for formalization (Moeng, 2010). Despite being one of the few selected settlements (South African Government, 2015), the P.I.S. community, still suffers from unsanitary living conditions, no service delivery and high levels of unemployment, crime, disease and fires (Makatile, 2018; Moeng, 2010; Ndimande, 2018; South African Government, 2015). In fact the only highlight of the settlement is that there is a public clinic just behind it. A highlight that heavily benefits the significant population of HIV positive individuals in the settlement (Makatile, 2018).

In Gauteng, between 20% and 25% of all the citizens live in shanty towns (HDA, 2013, p. 15; Moeng, 2010), which are characterised by high levels of HIV prevalence, and as such they are ideal sample populations for conducting HIV research. In these shanty towns, people live in very close proximity to each other which means that the sample is not spatially separated and they more or less have the same lived in experiences, which theoretically creates an uniform sample from which to draw participants and eases time and travel constraints during field work. Therefore, conducting the research in the P.I.S. community, like many other similar communities (Cornellius, 2016), that has a high level of HIV prevalence was advantageous. This aspect of the community, that it is one of many such communities in South Africa, also improved the transferability of the findings, which will be discussed in more depth in **Chapter 3**.

Despite the community having many rural characteristics, the people that have lived in these shanty towns are not rural people. The people that live in these informal communities are urban settlers, however, their communities do exhibit a lot of rural community traits, namely high rates of vigilantism, crime, lack of education and employment (Bloem, 2020; Makatile, 2018). Additionally, the community does not have access to a lot of municipal services, due to the high crime rate and lack of infrastructure within the area. The lack of service delivery has made the community very self-reliant as they police and provide for themselves in an area that is highlighted by low levels of sanitation and high levels of crime (Makatile, 2018). The self-policing that is a hallmark of communities like P.I.S., is a major problem for local law enforcement, as the self-policing that occurs in these communities, have often resulted in drastic action being taken against perceived criminals. Instances of perceived thieves or rapists being killed during outbursts of mob justice, are frequent examples of the justice that forms part of the P.I.S community's self – policing (Chabalala, 2017a; Corrospondent, 2017; Nyoka, 2017).

According to research that has been conducted on the stressors that feed into the utilization of stigma, it is clear that people who are unemployed, lesser educated and poor, often exhibit more stigmatising attitudes than those who are employed, higher educated and well off (Ekstrand et al., 2013; Klaas et al., 2018; Nyblade et al., 2019; Pulerwitz et al., 2010; Shisana & Simbayi, 2002; Stadler, 2003; Stangl et al., 2019; Visser et al., 2009; Volks, 2003). Additionally, Mbonu et al. (2009) states that cultures with a strong communal life, as is present within the informal settlements, are more likely to stigmatize people in order to protect the resources of the group from individuals that might drain them. PLHVs are viewed as burdens on community resources, as they are unable to work and contribute when sick. When on ART treatment, PLHVs are able to contribute to the resources of the community through work, however, the view that they only take the community's resources continues to exist. Being stigmatized within such a culture, that has a strong emphasis on communal life, usually amounts to being excommunicated from the group. Which has proven to be very detrimental for people from such cultures, as the resources of the community are shared and if one becomes ostracized from the community, one losses access to the resources of the group, physically, socially and psychologically, which can be seen to be as devastating as death itself.

Furthermore, community members in these shanty towns, for various previously discussed reasons, seem inclined to take passing judgement on others into their own hands.

> *"After witnessing a crowd kill a* ***suspected*** [emphasis added] *thief outside her home, a woman living in the Princess Informal Settlement, in Roodepoort, says she is living in fear for her life"* Jeannette Chabalala (2017a) reported for News24.

> *"one man was murdered by an angry mob,* ***allegedly*** [emphasis added] *for being a 'well-known criminal'",* according to a senior Roodepoort police officer (Antonie, 2017)

These quotes from the local News24- and The Citizen news outlets, demonstrate that these shanty towns sometimes have their own judicial system that operate outside the law of the land. Even though enacted stigma is considered illegal in South Africa (Afrika, 2016; Modise & Mahomed, 2011), it does not mean that discrimination is not happening in these communities. Therefore, the P.I.S. community appeared to be ideal for possibly finding answers to the research question, and its objectives. The community, theoretically, presented with all the necessary features to enable the researcher to conduct productive research in it.

To summarise, the P.I.S. is a poor informal settlement in Roodepoort, with a population of more than 3500 households. The living conditions within the settlement were highlighted by high and chronic levels of unemployment, crime, disease, and lack of service delivery (e.g. mainly policing and refuse removal). The communal lifestyle of the community and its poor and underserviced qualities made the P.I.S., theoretically, ideal for the researcher to conduct productive research, in as the community seemed to present with all the necessary characteristics for enabling the researcher to find answers to the research question, and its objectives. Therefore, the P.I.S. was selected as the area of focus for conducting the research in.

2. 3 History of research into HIV:

Looking up the timeline of HIV literature, one sees that academic interest into the disease started in America during the 1970s when men who had sex with other men started presenting at hospitals for treatment of the related symptoms of HIV (e.g. Kaposi's sarcoma) (AVERT, 2020a; Hymes et al., 1981). Although, academic interest in Africa, only officially started in 1982 with the Ugandan publication of the occurrence of the 'slim disease' in the country (AVERT, 2020a; Serwadda et al., 1985). 'Slim disease' was the local term used to refer to HIV at that time as people who presented with the disease lost a lot of weight (AVERT, 2020a). From there interest in the disease, mainly focused on identifying what the disease was really about and then it transitioned into a search for a cure or treatment of the symptoms (AIDS.gov, n.d.; AVERT, 2020a). Unfortunately, the stigma related to HIV only really became a matter of academic thought during the early 2010s when scholars started primarily researching the social effects of the pandemic (Mbonu et al., 2009; UNAIDS, 2014b). If a researcher traced the timeline of international action against HIV, they would see that HIV-related stigma only officially became a global concern in 2015, when the UNAIDS added an anti-stigma component to their HIV advocacy campaigns and guideline notes (AVERT, 2015; UNAIDS, 2014b).

Before HIV – related stigma was made a global issue by the UNAIDS, stigma and its consequential discriminatory effects (e.g. an immigration ban on HIV-positive individuals in the USA, was only official removed in 2009 by President Barak Obama (Preston, 2009)) was known and people advocated against it (e.g. NGOs boycotted the 6th International AIDS conference because of the US immigration policy) but it was never really part of the central focus of the global HIV response until 2015 (AVERT, 2020a; UNAIDS, 2015). Therefore, while research into the physical effects of HIV have been ongoing for the last four decades, the social effects have only been seriously pursued in the last decade (AVERT, 2020a).

The lag in academic interest and effort, can explain why the response to the stigma related to HIV (e.g. in 2015, UNAIDS released their 2016 – 2021 strategy which called for the achievement of zero discrimination in the HIV response) has also lagged behind the pharmaceutical progress (e.g. in 1987, the FDA approved the usage of Zidovudine (AZT) for the treatment of HIV) that had been made (Andersson et al., 2020; AVERT, 2020b; Duffy, 2005; MacQuarrie et al., 2009; Mbonu et al., 2009; Parker & Aggleton, 2003a; Stangl & Grossman, 2013; Sullivan et al., 2020). The academic lag also explains why people are still dealing with the effects and persistence of HIV – related stigma, while doctors have effectively reversed the geographical and anatomical spread of the disease.

While there is a way to suppress HIV (i.e. through the uptake of ART treatment), it has been a daunting challenge to minimise the stigma thereof. The latest research of interest into HIV – related stigma (Andersson et al., 2020; Geibel et al., 2020; Kimera et al., 2020; Parcesepe et al., 2020) has been focused on how HIV – related stigma impacts the quality of PLHVs lives. According to most recent research HIV – related stigma negatively impacts PLHVs quality of live and therefore it needs to be addressed with interventions that are aimed at improving the quality of PLHVs lives. This is in line with the earlier work of Link and Phelan (2014) that demonstrated that stigma negatively impacted people's life chances, by relegating them to a lower social status in society. Other recent research (Anakwa et al., 2020; Bagchi & Holzemer, 2020; Friedland et al., 2020) does still focus on the impact of HIV – related stigma on subjects, like ART adherence and avoidance or resistance behaviour in PLHVs, but this focus on the quality of life that PLHVs live, is somewhat related to the work that is being done in this research report. The quality of life of PLHVs seems to be an issue of rising importance within the field of research into the effects of HIV – related stigma.

2. 4 The theoretical history of Stigma:

To begin any conversation on stigma, one must inevitably refer to the work Goffman did in his two books, *the presentation of the self in everyday life* (1959) and *Stigma: Notes on the management of spoiled identity* (1963). In them, he defined stigma as a quality that is highly damaging to the person that possesses it (i.e. a scar on the face, a criminal record or mental illness). Consequently, people engaged in impression management to hide their damaging quality from other people in society. Impression management is a process where people with damaging qualities try to make their actual identities (i.e. who they really are) match up with their virtual identities (i.e. who people expect them to be) by engaging in stereotypical behaviour like hyper masculinity or excessive plastic surgery (Goffman, 1959; Link & Phelan, 2001, 2014). Goffman (1959, 1963) states that people try to align their actual identity with their virtual one because they do not want to face the stigma that is associated with their discrediting quality, which usually involves social rejection, humiliation and/or physical abuse.

It has been well documented that HIV-positive people engage in a process of impression management to hide the fact of their illness (Anakwa et al., 2020; Andersson et al., 2020; Camacho et al., 2020; Gilbert & Walker, 2010). Research (Bagchi & Holzemer, 2020; Batchelder et al., 2020; Gilbert, 2016; Hatzenbuehler et al., 2013; Link & Phelan, 2001, 2014; Mbonu et al., 2009; Sullivan et al., 2020; UNAIDS, 2014; Yuvaraj et al., 2020) has also shown that engaging in impression management is to their physical and mental determent as it prevents them from accessing live prolonging treatment (i.e. antiretroviral therapy (ART)). Even more dangerous than the individual risk, is the risk impression management holds for the community at large. Despite nationwide rollout of ART South Africa still experiences 240 000 new infections every year (AIDSinfo, 2018).

The high national new infections number is partly due to HIV-positive people that infect other people unknowingly, because they did not know they needed to be tested yet, or knowingly, because they suspected that they were infected but they refused to get tested, or commit to continuous ART treatment. PLHVs refusal to get tested or commit to continuous treatment can be due to a fear of HIV-related stigma (AVERT, 2015; Sullivan et al., 2020; UNAIDS, 2014b, 2014a). Many researchers attribute PLHVs' fear of HIV - related stigma to the reason why HIV/AIDS is still such a serious epidemic in the world (Feyissa et al., 2012; Friedland et al., 2020; Gilbert, 2016; Gilbert & Walker, 2010; UN News, 2017; UNAIDS, 2014b).

Now, as for the three examples (i.e. scar on the body, mental illness and a criminal record) that was used to demonstrate possible discrediting qualities in the introduction of this section, it is evident that they constitute three different kinds of qualities. Firstly, a scar on the body is a physical stigma, while, secondly, having a mental illness such as Bipolar is a psychological stigma. Thirdly, having a criminal record is a social stigma by association, as having a criminal record automatically puts one in league with other criminals. Applying these three qualities to Goffman's work, would mean that a scar on the body would be a stigma of the body, and having a mental illness would be a stigma of the character. While having a criminal record would be a stigma of the social community a person is associated with, as explained above. These three types of stigma carry varying degrees of social sanctioning, with the third being the worst.

Having a stigma of the body is problematic, but can be mitigated in terms of sympathy as one can be born with a birth defect, or have a disability due to the result of a car accident. A stigma of the character can also be damning in the sense that one is perceived to be weak of character (Hatzenbuehler et al., 2013; Link & Phelan, 2014), however, the perceived weakness of mental illness can also be mitigated in the modern age through sympathy, as a person can develop PTSD as a result of military service. That being said, sympathy is a stigmatic problem on its own and many stigmatized people do not perceive sympathy as a positive experience. The third stigma, stigma by association, is one of the most stigmatized positions a person can have as it is viewed as having been acquired by choice.

Despite evidence to the contrary, many believe that the acquisition of HIV as an illness, is a choice, as a person chooses to be sexually promiscuous, homosexual or a drug user (AVERT, 2015, 2020b; Hartwig et al., 2006; Klaas et al., 2018; Mbonu et al., 2009). Therefore, the reactions to a stigma by association is usually very harsh, hence people actively try and avoid it through Impression Management tactics (Andersson et al., 2020; Camacho et al., 2020; Parcesepe et al., 2020; Sullivan et al., 2020). These Impression Management Tactics include avoidance, lying and self – censorship, which often makes the person look guiltier in the eyes of the observer. Increasing the stigma placed upon them by society, and increasing the negative impact the stigma has on the individual's physical and psychological health (Anakwa et al., 2020; Sullivan et al., 2020).

In recent years social researchers have elaborated on Goffman's work (Gilbert, 2016; Gilbert & Walker, 2010; Parker & Aggleton, 2003) and has distinguished between four more types of stigma, namely perceived stigma, enacted stigma, internalized stigma and stigma by association. Perceived stigma is the stigma that a person perceives to be active within their community (Hatzenbuehler et al., 2013; Link & Phelan, 2001, 2014). These perceptions are usually informed by observations of interactions between community members and similarly stigmatized individuals. Therefore, perceived stigma is what a person thinks will happen to them if they make their discrediting quality known to others (Sullivan et al., 2020). Enacted stigma are actual experiences of discrimination that a stigmatized individual has experienced during their lives (Kimera et al., 2020, p. 14). Internalized stigma are negative perceptions that stigmatized people have about themselves (Link & Phelan, 2014).

These perceptions are informed by the cultural norms and values that are socialized to individuals during their youth and daily experiences (Hatzenbuehler et al., 2013; Link & Phelan, 2001, 2014). Gender norms (i.e. what is expect of good little boys and girls) and the general understanding of those (i.e. Gays and Whores) that do not conform to those norms are an excellent example of this process of education (Klaas et al., 2018; Mbonu et al., 2009). And then finally, there is stigma by association, which usually affects people that are family of or associated with a person that is deeply stigmatized. Interest into stigma by association is primarily the research (Kimera et al., 2020; Oke et al., 2019) that shows how PLHVs are shunned or rejected by their families or friends. Their families and friends have shunned or rejected them because they did not want to be stigmatized and discriminated against as well (Gilbert, 2016; Mbonu et al., 2009).

In terms of human rights, South Africa has a well set out legal system that strongly condemns discrimination of any kind in the Bill of Rights in the constitution of 1996, the Employment Equity Act (EEA) 55 of 1998 and Labour Relations Act (LRA) 66 of 1995. Legally, there is no reason why people should be afraid of stigma, but as Sullivan et al. (2020) and Gilbert and Walker's (2010) work shows people are afraid, so afraid that they are willing to rather die than receive the stigma associated with HIV and its treatment. Due to findings such as these, further research into the problem has come to realize that stigma is not a solely individual process and it is not going away through education alone (Hatzenbuehler et al., 2013; Kimera et al., 2020; Link et al., 2004; Link & Phelan, 2001, 2014; Oke et al., 2019).

Stigma is a structural process as well (Hatzenbuehler et al., 2013; Link & Phelan, 2001, 2014). Recent research discovered that stigma operates according to social fault lines in a community (Gilbert & Walker, 2010; Gottert et al., 2020; Link & Phelan, 2014). According to Link and Phelan (2014), if a person belonged to an already stigmatized social group (e.g. the LGBTi community or women) they were more likely to be stigmatized than someone from a less stigmatized group (e.g. Heteronormative individuals or men). Furthermore, they realized that people did not stigmatize because they were ignorant, they stigmatize because it benefits them to stigmatize others (Deacon et al., 2005; Hatzenbuehler et al., 2013; Link & Phelan, 2001, 2014; Parker & Aggleton, 2003; Scambler, 2009).

Link and Phelan's (2001, 2014) work demonstrates that people stigmatize each other, because it is a very effective and advantageous social tool for establishing and maintaining a social hierarchy within society, that benefits one group of people over another (Hatzenbuehler et al., 2013; Link & Phelan, 2001, 2014; Mbonu et al., 2009). Patriarchy is a very good example of how stigma is used to maintain a social hierarchy within society. Link and Phelan's work explains why people who might not fit the stereotypical example of masculinity (i.e. physically weak men) might still perpetuate gender stereotypes that benefit men over women in society (Klaas et al., 2018; Mbonu et al., 2009; Tong & Botts, 2018). They perpetuate patriarchy, and the stigmatizing attitudes that accommodate it, because the regime benefits them, directly or indirectly. Gender stereotypes help average men maintain male supremacy over women and that is why they consciously perpetuate it. The point that Link and Phelan's work proves, is that people know what they are doing when they stigmatize others. Stigma is an individual and a structural process and it cannot be viewed in isolation, it needs to be viewed in combination. As individual and structural forces combine behind stigma to exploit an individual to the benefit of others.

Link and Phelan's work partially refutes other research (Aggleton et al., 2004; Cloete et al., 2008; Parker & Aggleton, 2003a) that has found that ignorance and the individual were at fault for the maintenance of stigma within society. Link and Phelan's work does not reject previous research as incorrect, the individual does play a part in the perpetuation of stigma. Although, the role of the individual has been redefined by recent research. Recent research, like that conducted by Link and Phelan (2014), have found that individuals are not passive in the stigmatizing process and they do not stigmatize out of ignorance, they consciously stigmatize others because it benefits them. Mbonu et al. (2009) and Klaas et al. (2018) work corresponds with Link and Phelan's work as it has shown that men perpetuate gender inequalities through the social institution of patriarchy, to maintain and improve their own social standing in South African communities.

Considering the structural element of stigma that Link and Phelan (2001; 2014) brings to the table, it also further emphasizes the importance of context (Blacklock et al., 2016; Gilbert, 2016; Gilbert & Walker, 2010; Laher et al., 2019; Mbonu et al., 2009; Naidu & Sliep, 2011; Parker & Aggleton, 2003a). The state of structural forces and the history and societal dynamics that influence the shape of the structural forces that are at work within a specific society varies from community to community. Additionally, Link and Phelan's (2014) work also demonstrates that people in the same context, can experience those structural forces very differently. Meaning, that some people benefit from them and others are exploited by them, as illustrated earlier (Klaas et al., 2018). The point here is that context is very important when one seeks to understand why people experience and respond to those structural forces in the way that they do. Context cannot be ignored because doing so will limit the researcher's ability to correctly interpret a participant's experiences (Edwards & Holland, 2013; Hatzenbuehler et al., 2013; Nilsen & Bernhardsson, 2019; Ryan et al., 2009).

Additionally, it also curbs a researcher's ability to understand the entire scope of the individual and structural forces that impact a person's daily life. This limitation is very important for Link and Phelan (2001; 2014) as effective interventions cannot be launched without an effective understanding of the full scope of stigma's operations within society. According to Link and Phelan (2014), to stop stigma, one must attempt to understand the entirety of the mechanisms of stigma. The word 'attempt' is being used here because no one researcher can reveal and understand the entirety of the mechanisms that stigma uses to operate within a specific society, as Link and Phelan's (2014) own work shows, stigma is an evolving process and much of it has not yet been discovered. Therefore, one can only try to be as inclusive and open minded as possible, but including the entire scope of what might be possible, just is not possible within this research report. Link and Phelan (2014) do advocate for a synthesis of existing work on the subject of stigma, however, such a summary falls outside the purpose of this research report. Please refer to Sullivan et al (2020), Andersson et al (2020) and Mbonu et al (2009) for examples of attempts at Link and Phelan's (2014) request.

Returning to the argument regarding the importance of context that Link and Phelan's (2001, 2014) work brought forward, it is worth talking about why considering context is so important here in Africa. The denial of the role context plays has been a major problem in the field of research, especially here in Africa, as previously used models were moved around from one country to the next without a regard for the social context that informed them, and thus the results produced proved ineffective (Shokane & Masoga, 2018). Recent work, especially on the development of the UNAIDS' PLHV stigma Index (Bandeira, 2015; dos Santos et al., 2014; Gottert et al., 2020; Misir, 2015; Simbayi et al., 2015; UNAIDS, 2014b), has sought to address the problem of contextualization. Although, despite the UNAIDS efforts, it is a constant issue that needs to be continuously addressed, especially here in Africa. Given Africa's long history of pulling on the shortest end when it came to Eurocentric testing and research (Link & Phelan, 2014). Furthermore, one cannot arbitrarily transplant the findings of a Ugandan study to the context of South Africa just because Uganda happens to be an African country as well. The vice versa is also true.

Although, an emphasis on context does not mean that there are no lessons that can be learnt from research conducted in/by different countries, but the contexts cannot be assumed to be the same just because the two countries are on the same continent. The factors that influence the contexts of these countries, namely history, language, culture, etc., are different and therefore the experiences and meanings attached to these occurrences are likely to be different. The importance of context and legacy needs to be acknowledged and accounted for. Proving the vital role context plays in the validity of research findings.

So far in this literature review, it has become clear that stigma is a social process that operates on both the individual and structural levels of society. It has also become clear that people do not stigmatize out of ignorance, they stigmatize others because it benefits them socially, physically and emotionally to do so. Exploiting some to the benefit of others is not a new social process, it is a process that is as old as humanity itself and can be found in the work of scholars like Frantz Fanon and Edward Said. These two distinguished writers, note the usage of discrimination during the peak of its utilization, namely colonialism. In Fanon's book, *Black Skins, White Masks* (1952), he demonstrates how colonialists used the processes of othering and stigma to justify their exploitation of Africans during colonialism. By stigmatizing Africans as inferior and degenerative, colonialists justified their subjugation and exploitation in the eyes of the masses in the mother land and it enabled them to commit atrocities, for excessive profits, against Africans with little to no repercussions. The same processes can be found to be at work in Edward Said's book, *Orientalism* (1978), about the subjugation of the Orientals to Colonialist rule.

The process of othering and then stigmatizing to justify exploitation, which was identified by Fanon (1952) and Said (1978), is still present in society today. If one looks at how people talk about HIV/AIDS, people always talk as if the disease is something that other people get, not them. With straight people HIV is a gay plague, with White people HIV is a disease only African people get and with religious people HIV is the punishment of immoral sinners (AVERT, 2020b; Mantell et al., 2011). The process of othering and then stigmatizing that Fanon (1952) and Said (1978) had identified has been concisely laid out in a four step model by Link and Phelan (2001). According to Link and Phelan (2001), the process of stigmatization proceeds according to four steps, namely (1) the problem that is threatening the stability of the society, (2) Identifying of the target population that can easily be blamed for the problem (i.e. scapegoated), (3) Applying the stigma to the target population through the reinforcement of cultural norms and practices, and then finally (4) The Outcome is the maintenance of the established order within the community. Applying these four steps to the process of the stigmatization of women in South Africa, for the purpose of maintaining patriarchy, proceeds as follows according to Link and Phelan (2001):

Step1: The problem which is threatening the stability of the community

The problem that is threatening the stability of the community is the spread of HIV/AIDS through heterosexual sex in South Africa. The status quo in South African communities are that women, due to African cultural gender norms, are expected to be monogamous while men are expected to be polygamous in their sexual affairs. Therefore, a woman, despite being monogamous, can still contract the disease from her polygamous male partner (Klaas et al., 2018; Mbonu et al., 2009). There is a belief in African cultures that women are the vectors of HIV despite research (Klaas et al., 2018) that points to the male, due to his polygamous sexual activity, as the one that usually introduces HIV into the relationship. Given the problem of the heterosexual transmission of HIV in South Africa, due to the above mentioned situation, the accepted status quo is under threat and needs to be protected. Which brings the process of stigmatization, as theorised by Link and Phelan (2001), to its next step.

Step 2: Identifying the target population that can easily be blamed for the problem (i.e. scapegoated)

To protect the accepted social order, namely patriarchy, any person or group that threatens it must be removed from the community to ensure the continued stability of the established social order. Patriarchy is a social hierarchy that has been built on the exploitation of women to the benefit of men, as such if women start challenging the accepted hierarchy it threatens the stability of the community, and as therefore it cannot be tolerated. Independent women that can provide for themselves, threaten the existing gender power relations within South African communities (Klaas et al., 2018; Mbonu et al., 2009). Independent women threaten the existing status quo because most women in Sub-Saharan Africa are dependent on their husbands for their food, shelter and clothing. As such, if women start working and becoming intellectually and economically independent, the existing status quo will be threatened by women demanding more power and resources for themselves (Klaas et al., 2018; Mbonu et al., 2009). Which undermines the power position of men in their communities.

Therefore, independent women are a problem for African patriarchy and processes have been put in place to keep women in their place. These processes involve socially constructed cultural and gender norms that make it culturally frowned upon for a woman to enquire about reproductive health from a third party, or to insist on the usage of reproductive resources with her partner during sexual relations (Klaas et al., 2018; Mbonu et al., 2009). With these norms in place rules have been created that regulate women's behaviour and ensures their submissive position within the community. Once rules and norms have been created all that is left is to give people a reason to follow them. Which moves the process to its third step, namely the application of stigma to the target population.

Step 3: Applying the stigma to the target population through the reinforcement of cultural norms and practices.

With rules and regulations in place independent women, who threaten the accepted status quo of patriarchy, are brought back into line with a simple ultimatum of you either conform or you are out. Stigma is applied to independent women who refuse to conform to the accepted gender norms under patriarchy and as such they are stigmatized by the men in their community as punishment for their non – conformity. Stigma is applied to women in subtle ways that involves gossip within the community which aim is to ruin the women's reputations among their colleagues, friends and family (Dores Cruz et al., 2019). Once the stigma has been applied and the target's life has been ruined, the outcome becomes clear which brings the process of stigmatization to its final step, namely the maintenance of the establish order.

Step 4: The Outcome is the maintenance of the established order within the community.

With her reputation ruined within the community, a woman has two choices presented to her by her community, either conform and maintain your own oppression, or do not conform and ensure your own suppression within the community. Either way it does not matter, the overall aim of the process of stigmatization will be achieved. Male supremacy through the practice of patriarchy will be maintained within the community.

The process of stigmatization is an indirect process, but a very efficient one, as it enables its instigator to always meet its goals. For the maintenance of male superiority stigma ensures the inferiority of women, whether it be by their own hand or that of others, it does not matter. All that matters is the maintenance of the established social order. The maintenance of the established social order is the overarching aim of the process of stigmatization for social control. Link and Phelan (2014) digs deeper into the process of stigmatization as they attempt to demonstrate the fundamental ways in which stigmatization is used as a form of social control.

For Link and Phelan (2014), these four steps serve three purposes, to keep a person who can, or might have violated the group's social norms in, away or/and down. As is evident from the layout above, to stay 'in' the group, women must maintain their own ignorance and subjugation while going 'out' of the group can constitute a social, psychological and physical death. Because when one is 'out', the group will try its very best to keep the individual 'down' as well, due to the need for the group to ensure its own cohesion and to discourage any more mutineers. To maintain its cohesion, the group must demonstrate that life outside the group is detrimental to one's quality of life and to demonstrate the individual's dependence on the group, the group utilizes a combination of individual and structural forms of discrimination to demonstrate to its members that life is better within the group than outside of it. Therefore, they stigmatize members that have left the group.

The forms of discrimination that can come to bare on individuals that have left the group can vary from structural discrimination, to one on one physical discrimination (Link and Phelan, 2014). As such, the discrimination can vary from police harassment (as was the case with the LGBTQ+ community and the African majority during Apartheid) to physical abuse from a spouse or fellow community member (as was the case with the HIV activist Gugu Dlamini, who was beaten to death by her fellow community members ("Aids Activist 'Attacked Twice" 2001; Masuku, 2015; McNeil, 1998)). When it comes to HIV the process of othering does not exclusively occur between men and women, as per the illustration above. Upon looking deeper one will quickly notice that HIV has always been projected onto one group elevating itself over another (Link & Phelan, 2001, 2014), i.e. the heterosexuals above the homosexuals, the white people over the Africans and the Christians over the sinners (Mbonu et al., 2009).

All of these examples are daily realities for most South Africans which is why Link and Phelan (2001, 2014) advocated that if researchers wanted to see concrete changes in society, they needed to change the individual and structural components in society that was allowing these heinous acts to occur in the first place. For Link and Phelan (2001, 2014), most research only focused on one outcome of stigma (i.e. non-utilization of available HIV preventative resources (Klaas et al., 2018) and this idiosyncratic approach has not been enough, as stated above in this chapter. If a researcher only focused on one aspect, they could never be able to grasp the entire scope of the stigma process, and therefore it would be pointless. As such, they called for sociological research to expand its scope to illuminate the intersectional workings of stigma. Which would assist in developing a multi-level approach that would either eliminate the stigma, or empower the stigmatized not to be controlled by the stigma (Hatzenbuehler et al., 2013; Link & Phelan, 2014).

By asking South African PLHVs about their experiences of stigma in their daily lives, it enables this researcher to understand their experiences of individual and structural discrimination, as Link and Phelan (2001, 2014) suggested. Asking PLHVs about the individual and structural forces within the community, is possible because the PLHVs interact with these individual and structural forces in their daily lives. They have to navigate their interpersonal relationships with their fellow community members and the attitudes of the police officers, social workers and health care workers that they depend on for survival. As stated earlier, the P. I. S. is a very interdependent community with a communal culture which means that the PLHVs that live within the community, cannot exist in physical and social isolation. They have to navigate the various attitudes and stigmas that exist within the community if they want to survive, because they are dependent on the community's resources for their survival (Klaas et al., 2018; Mbonu et al., 2009). Thus, they will have a pretty good understanding of the individual and structural forces that are complicating their lives as PLHVs because of their daily interactions with these forces. PLHVs are the best suited to know what the problems are that PLHVs face in society (Hodgson et al., 2012; Power et al., 2018).

In support of alternative knowledge, Parker and Aggleton (2003a) flagged a problem within the existing research, which problematized the fact that experts tended to go into communities with an all - knowing attitude. Parker and Aggleton (2003a) encouraged experts to adopt the attitude that only members of a community truly knows what goes on within that community. The need for the researcher to have the ability to give a voice to alternative knowledge, lends support to the utilization of one-on-one semi – structured interviews in this research project.

One-on-one interviews can be guided by the interviewer, but it also allows for the participant to lead the researcher to an understanding about their reality and desires (Bolderston, 2012; Edwards & Holland, 2013; Knapik, 2006; Ryan et al., 2009). One – on – one semi – structured interview is the ideal data collection tool for encouraging the voicing of alternative knowledge, while also enabling the researcher to maintain a sense of control over the conversation, as to avoid getting bobbed down by unnecessary distractions. The one – on – one semi – structured interview enables the researcher and the participants to work together on a more mutually beneficial footing, which allows the researcher to capitalize on the imbedded knowledge that the participants might have about the internal workings of their community.

The fact that members of a community has intimate knowledge of its internal workings is particularly true for PLHVs, as Link and Phelan (2001, 2014), Misir (2015) as well as Gottert et al (2020) demonstrates, those that stigmatize and those that are stigmatized are not passive beings. People know what they are doing (i.e. in the case of the stigmatizing) and they know what is going on (i.e. in the case of stigmatized). Consequently they are the best people to ask about their experiences. Although, it is true, lay persons might not refer to their experiences as the product of stigma, they do know there are elements in their daily lives that are disadvantaging them to the benefit of others.

The very fact that people employ stigma mitigating strategies, like Impression Management, is evidence enough to let researchers know t there is something at work within that community, to make people employ them and only those affected, who live under stigmatising circumstances every day, can tell a researcher what it is. They are the most reliable sources, and it would be ideal for the researcher of this research report to approach them. Aside from the PLHVs being best suited to provide the researcher with the necessary information, it is also important to consider the sensitive nature of HIV. Historically, interviews have been the preferred method of data collection in most previous research (Dahab et al., 2011; Govender et al., 2015; Mokwele & Strydom, 2017), as the data collection method is able to provide the participants with a level of confidentiality, while also enabling the researcher to interact with the participants in a one – on - one manner. Which is beneficial when discussing a topic as sensitive in nature as HIV.

Along with a sensitivity to alternative knowledge, Parker and Aggleton (2003a) also advocated for the need to consider the political climate of a country if one wishes to understand the crisis it is in. It is important to understand how people interpret their environment however, it is also important to understand how people are the products of their environment. The context of a person's life is shaped by the people and institutions that they interact with on a daily basis, and these people and institutions are shaped by a community's history. Therefore, to understand the meaning people attach to f their lives, one must also understand the context within which they exist. Context plays a very important role in determining the validity of the findings of a research report, as it influences how people interpret their environments. Context cannot be ignored and it must always be incorporated if, one's research is to be valid and reliable.

When conducting research, context is very important, however, that does not mean that one cannot learn lessons from work conducted in other contexts (i.e. Asia and South America). An example of research work that can be learnt from is, interventions that have been conducted on the effectiveness and durability of HIV education programs, in addressing institutional stigma (Jones, 2020; Shah et al., 2020; Yang et al., 2020). The findings about institutional discrimination from these studies, can be usefully incorporated into research conducted here, in South Africa, however, this work should not be the corner stone, as the contexts are different and therefore the results might be different as well (Gilbert, 2016; Gottert et al., 2020). The cornerstone of research into HIV – related stigma in South Africa, should be work done in South Africa.

Parker and Aggleton's (2003a) work highlights the importance of alternative knowledge and context, however, there is a point of weakness in their work. They recommend that any intervention in treating HIV-related stigma needs to be individual and structural, which this researcher agrees with, as it is in alignment with Link and Phelan's (2001, 2014) work, but then, in their conclusion they state that it should be made clear that stigma is intolerable through education campaigns. Gilbert and Walker (2010), in alignment with Link and Phelan's (2014) work, demonstrates that due to the education campaigns, people know that stigma is unacceptable but, they keep doing it anyway. People that stigmatize others just keep on operating in a covert manner, through spreading rumours and social distancing (Dores Cruz et al., 2019; Gilbert & Walker, 2010, p. 145; Hatzenbuehler et al., 2013; Link & Phelan, 2001, 2014; Mbonu et al., 2009; Misir, 2015; Rankin et al., 2005; Stadler, 2003). Therefore, simple education is not enough to effect the eradication of stigma in society. More multi-level interventions are needed to effect change (Hatzenbuehler et al., 2013; L. Li et al., 2020; Link & Phelan, 2001, 2014; Mbonu et al., 2009).

Multi-level interventions are needed to address stigma at the individual, group, community and national levels (Cloete et al., 2008; Koodibetse, 2015). These interventions need to run in parallel, as only focussing on a national campaign, would neglect the individual and vice versa would not be sufficient (Hatzenbuehler et al., 2013; Link & Phelan, 2001, 2014). To eradicate stigma a society needs consensus and to gain consensus one needs the individual, hence no one intervention can operate in isolation, as is the case currently (Link & Phelan, 2014; Parker & Aggleton, 2003).

2. 5 The social effects of stigma on PLHVs:

The preceding section on the theoretical history of the concept of stigma, has given a layout of how the mechanisms of stigma operate once a person's spoiled identity becomes known to their peers in the wider community. Although, it should be noted that different people may face a different combination of forces if their status was to become known. As stated before, different people experience similar things differently. Research (Hatzenbuehler et al., 2013; Link & Phelan, 2014) has shown that context plays a big part in how people experience and respond to occurrences in their lives. The experience of HIV – related stigma is no different. Different people could experience it differently. With the possibility of difference noted, it must be said, that there are a few general trends that has been highlighted in previous research (AVERT, 2015, 2020b; Chambers et al., 2015; Gilbert, 2016; Gilbert & Walker, 2010; Link & Phelan, 2014; Oke et al., 2019; Parker & Aggleton, 2003b; Ulasi et al., 2009; UNAIDS, 2014b). These trends are best encapsulated in a quote from the 1993 film, *Philadelphia*, in which Andrew Beckett, who is HIV positive, said the following about the social effect of the HIV disease,

> *"Subsequent decisions* [from the US Supreme Court] *have held that AIDS is protected as a handicap under law, not only because of the physical limitations it imposes, but because the prejudice surrounding AIDS exacts a social death which precede... which precedes the actual physical one*" (Demme, 1993).

HIV is an incurable disease, that can only be suppressed not eradicated and as such, when a person is diagnosed with the disease they are confronted with their own mortality. Along with the terrifying realization of one's own mortality, a person also has to deal with the social death that accompanies the illness. This social death is forced upon a person because unlike cancer, which is a disease that can be talked about with one's family and friends, a person living with

HIV cannot talk openly about their struggles with family and friends. HIV is a disease that has been shrouded in secrecy and shame, for much of its known existence (Aggleton et al., 2004; Misir, 2015). As was stated in the previous sections of this literature review, HIV has been believed to be the strict preserve of perverts and sinners. As such, if one presents with the disease, one automatically becomes either a pervert, or a sinner and perverts and sinners are shunned or punished by the community. This is the learnt experiences of people that have been socialized into society (Fanon, 1952; Leerkes et al., 2020).

Consequently, when a person can least afford to lose all of their social and physical support that is exactly what happens to them, when it becomes known that they are HIV positive. Previous research (Chambers et al., 2015; Gilbert, 2016; Gilbert & Walker, 2010; McNeil, 1998; Oke et al., 2019; Parker & Aggleton, 2003a) has demonstrated that PLHVs are thrown out of their homes by their spouses, beaten and abused by their community members, fired from their jobs and abandoned by their families, when it becomes widely known that they are HIV positive. Thus, the literature makes it very clear that they are justified in their fear that they might lose their family, their jobs or their homes if their status was to be revealed (Mbonu et al., 2009; D. McNeil G., 1998; UN News, 2017; UNAIDS, 2014b). It is clear that being identified with this disease, is a very serious matter that has implications for the person's social, physical and psychological health.

To address the problems that research into the issue of HIV – related stigma have highlighted, namely that the problem of stigma is a lack of education amongst the masses, the South African government initiated education campaigns, that were aimed at spreading awareness and normalizing, the disease within communities (Cloete et al., 2014; Parker & Aggleton, 2003; UNAIDS, 2014). In doing so, the South African government, with the help of various international institutions (e.g. UNAIDS, etc.), have tried to spread awareness about HIV-stigma with the 2002, 2003 and 2013 World AIDS Days (the themes of these three years were exclusively focused on the problems of stigma and discrimination) (UNAIDS, 2020b), Sexual education in schools and free pre - and post – test counselling for all at public clinics (AVERT, 2020b). Sensitivity training is also a part of the training of health care workers, social workers and law enforcement officers, who are the people that are most likely to interact with PLHVs on a regular basis (Duby et al., 2019; Ferreira & Ferreira, 2015; Galetz, 2018; Larti et al., 2018; Marks, 1995; NASTAD, 2020; Singh et al., 2017).

Nevertheless, a 2010 study by Gilbert and Walker showed that people were still afraid of the stigma associated with HIV. A more recent study conducted by Wouters et al (2020), a whole 10 years later, corresponds with Gilbert and Walker's (2010) work. The Wouters et al (2020) study looked at the fear people have of being diagnosed with TB (Tuberculosis) because of its well-known co-morbidity with HIV. This fear stems from the fact that, in the minds of most people, if a person gets diagnosed with TB, they have HIV as well and then they are treated as such. This corresponds with previously reported fears, in other research (AVERT, 2020c; Bond et al., 2019; Wolf et al., 2014), of PLHVs being sighted by neighbours at a HIV clinic. People were so afraid of being spotted at a HIV clinic, due to the general assumption of that being sighted at a clinic by a fellow community member, would automatically label that person as HIV positive and they would be treated as such by their community at large, regardless of whether they were positive or not, in the first place.

Being perceived to be HIV positive, has very detrimental consequences for a person's social, emotional and physical wellbeing. As such, people do not want to be associated with the disease, despite South Africa's very thorough legal code (Afrika, 2016; Health4Men, 2015; Modise & Mahomed, 2011), that rigorously tries to stamp out discrimination within the country. People were still losing their jobs, their families and homes because of this stigma and thousands of HIV-positive people may not be getting the treatment they need because of the fear of HIV-related stigma (Friedland et al., 2020; Kagee et al., 2011; Wouters et al., 2020). The individual and structural consequences of being HIV positive were just too much and PLHV people were not accessing the available resources.

This fear induced behaviour, was also evident in the fact that thousands of PLHVs on ART treatment admitted to skipping a dose on a regular basis, because they did not want a co-worker or fellow community member to suspect that they were HIV-positive (Friedland et al., 2020; Kagee et al., 2011). Skipping ART doses leads PLHVs to the risk of becoming ART resistant which means, that PLHVs may no longer be able to obtain viral suppression (Azia et al., 2016). Achieving viral suppression is essential for the suppression of the spread of HIV in South Africa. The negative social impact of HIV-related stigma is clear and it is costing South Africans their lives. As it prevents people from accessing the necessary medical services that could enable them to know their status, receive the necessary treatment and live healthy lives. Without suppressing HIV – related stigma, the South African government will never be able to suppress the spread of HIV.

2. 6 The South African Government's HIV response:

South Africa has the world's biggest self-funded HIV/AIDS program, which annually costs the government R23 billion (Klaas et al., 2018; Nkosi, 2016; UNAIDS, 2017). The South African government focuses their funding in four main areas, namely Testing, Counselling, Prevention and Treatment. In the treatment area, South Africa has a nation-wide rollout of ART for anyone who tests positive, regardless of their CD-4 cell count (AVERT, 2020b). The treatment is completely free at all public health care facilities. In the area of prevention, the biggest effort is being made in condom distribution with over 800 million male condoms having been distributed in 2016 (AVERT, 2020b; "Choice Condoms Go to the Max," 2019).

Though, only 24 million female condoms were distributed in 2016 (AVERT, 2020b), which indicates that there is a major gender disparity in distribution efforts. This discrepancy in the distribution of condoms to men and women, may be representative of a national patriarchal attitude that tends to be opposed to giving women more access to condoms, for fear that it could potentially encourage more promiscuity in women's sexual behaviour (Klaas et al., 2018; Mbonu et al., 2009). This is just another example of the forms of control that cultural forces try to impose upon women to maintain the status quo, as explained in **Section 2.4**.

With the gender discrepancy in condom distribution noted, the condom distribution service is also free and condoms are regularly available at public restrooms, universities, clubs, taverns, etc. This program is aimed at men and women because the main form of HIV transmission in South Africa is through heterosexual sex (AVERT, 2020b). Although, it does seem that the condom distribution program is geared more towards men than women. There is a discrepancy between the amount of female and male condoms and in the levels of availability in the national program's services that are available to men compared to women. Some research also confirms that the majority of people that lack adequate access to services for combating the HIV disease are women (AVERT, 2020b; Klaas et al., 2018; Mbonu et al., 2009).

The fact that women are the population with the lowest level of access to available resources in South Africa, is very problematic due to the fact that women constitute the largest proportion of PLHVs in the world. Along with South African women's lack of access to HIV resources, their problem is also compounded by a double burden of stigma. Research (Sullivan et al., 2020) has shown that women are more likely to be stigmatized than men for being HIV positive. This second burden has led women to avoid services that might unintentionally disclose their status to others. Consequently, women avoid the little services that are available to them. This avoidance of available services are examples of impression management, as female PLHVs actively avoid places that might identify them as HIV positive within the community. It could be the case that there is a little service provision but the fear of the stigma attached to these services are preventing women from accessing them (Klaas et al., 2018; Sullivan et al., 2020; Zuch & Lurie, 2012). For women in South Africa, being HIV positive is a double burden as they lack adequate service provision and the few services that are available to them, are stigmatized and as a consequence they have ended up with more or less no service delivery (Klaas et al., 2018). Which is very problematic for the population that constitutes the biggest group of PLHVs in South Africa.

Another HIV service that the South African government provides is free counselling and is made available to people when they test positive under the HIV testing and counselling (HTC) program (AVERT, 2020b). The government reports that as of 2016, 86% of PLHV are aware of their status (AVERT, 2020b; Johnson et al., 2017). This government statistic should be taken with a pinch of salt, since the statisticians are working with rough estimates and they do not include those that have not been tested yet (UNAIDS, 2014b). As already mentioned, there are many people that might be positive, but do not get tested, due to the fear of enacted stigma. (Andersson et al., 2020; Sullivan et al., 2020). Research has shown that many people fear going to the hospitals for testing, even if they test negative, just their recognized presence at an HIV clinic will label them as HIV-positive in the eyes of their community (Gilbert & Walker, 2010; Wolf et al., 2014).

All of the above demonstrates that the necessary medical services are available, but these services are not addressing the social factor that is keeping PLHVs from accessing these services in the first place, namely stigma. The South African government can fund all the services they want to but if they are not addressing the issue that is keeping people from accessing these services in the first place, it is all just a waste of money. More targeted interventions are needed to address the effects of stigma and the prevalent gender disparity.

2. 7 Population groups that are most at risk of HIV and its related stigma:

The questions in this section are, who is the most at risk of contracting HIV, and how does this impact the research? The South African government recognizes five population groups that are most at risk of contracting the HIV virus, and the stigma that is associated with it. As will become clear, these different groups of people are already stigmatized within society and therefore, as previous research (Deacon et al., 2005; Hatzenbuehler et al., 2013; Link & Phelan, 2001, 2014; Sullivan et al., 2020) demonstrates, they are more vulnerable to the stigma related to HIV.

The 5 population groups that the South African government recognizes as vulnerable are: (a) men that have sex with other men (MSMs): (b) people who inject drugs (PWIDs): (c) sex workers (SWs); (d) transgender women (TWs); and (e) women and children (AVERT, 2020b). Aside from the women and children category, it is obvious that the other four are in themselves stigmatized groups, due to various aspects associated with their lifestyles (i.e. the perceived immorality of homosexuality, drug use and sex work, and the perceived abnormality of transgender individuals).

Research has shown that sex workers are very unlikely to seek out medical help because of the demeaning way in which health care workers and the police interact with them (AVERT, 2020b; Feyissa et al., 2012; Sullivan et al., 2020). Generally, sex workers are not well treated due to the perceived immorality of their occupation. Research has shown that Sex Workers are regularly harassed by police and just having condoms on their person makes them liable for arrest (AVERT, 2015, 2020b; Mbonu et al., 2009). Thus, this behaviour discourages sex workers from taking precaution and seeking out help (Sullivan et al., 2020).

The finding that the negative attitudes of health care workers and the police discourages PLHVs from accessing the necessary preventative services can be used as a measure of stigma within the Princess Informal Settlement. It is indicative of a negative institutional attitude that could be the reason why PLHVs refuse to access the services that are available to them in the first place. As the foot soldiers of the institutions that they represent, it could be indicative of a wider institutional problem if the health care workers and police officers possess stigmatizing attitudes. The probability is pretty high that it will be found to exist within communities as previous research (Gilbert, 2016; Kagee et al., 2011; Mathibe et al., 2015; Mokwele & Strydom, 2017; Zuch & Lurie, 2012) has shown that institutional stigma is pretty prevalent within society as a whole.

Furthermore, the problem of institutional stigma is also indicative of the inadequate impact of the existing HIV education efforts that healthcare workers and police officers have been receiving to help them deal with the needs of the PLHVs that they are most likely to interact with on a daily basis. Research has shown that the effectiveness of the empathetic training that health care workers and police officers receive during their basic training fades over time and needs to be continuously refreshed if it is to remain effective. This recommendation is not being implemented because the very fact that PLHVs continue to have fears of discrimination and lack of confidentiality (Sullivan et al., 2020) when they enter the health care setting in South Africa, shows that the health care workers are not receiving the necessary training and reinforcement of that training to enable them to deal with PLHVs in an empathetic and supportive way. The presence of institutional stigma within the healthcare setting proves Link and Phelan's (2014) point that stigmatized people are usually additionally stigmatized. This vulnerable population is stigmatized for the type of work that they do, the unfortunate consequences of this work leaves them helpless in attempts to ensure their own health and future. The final vulnerable group is the women and children category and they are also particularly vulnerable (AVERT, 2020; Mbonu et al., 2009). Children by their very nature are defenceless in the face of sexual assault but they are also blameless due to the fact that most children contract the HIV virus during birth from their HIV – positive mother. The government has rolled out the Prevention of Mother to Child Transmission (PMTCT) program to address this form of transmission, with a high level of success (Bhardwaj et al., 2014; Sherman et al., 2017). Mother to child transmission rates are nearing elimination thresholds with an annual rate of 4.89% (AIDSinfo, 2018).

When it comes to women on the other hand, women constitute the largest and most stigmatized proportion of South Africa's PLHV population (Klaas et al., 2018; Klaas et al., 2014; Mbonu et al., 2009; Sullivan et al., 2020). In most African cultures women are viewed to be the carriers of the disease, despite factual evidence that point to the men as the super spreaders due to their polygamous sexual activity. Due to this general believe the burden is on the women to prove that they is not HIV positive and therefore, research has shown, that they will engage in activities that can be harmful to their health for the sake of avoiding any suspicion from their male partners. Women are physically and socially unable to ensure their own health due to the restraining effects of HIV – related stigma.

All five of these vulnerable groups are groups of people that are already stigmatized in society for the lifestyles that they pursue and many of them are often viewed as deserving of the virus. As such, it is often very difficult for members of these population groups to seek out assistance, which makes them more vulnerable to exploitation and abuse from institutions like hospitals and law enforcement. Individual abuses are also a major problem as they often go unreported by the victims. Therefore, it is imperative that interventions involve members of these vulnerable groups (Hodgson et al., 2012; Power et al., 2018) so that efforts can be focused on improving their quality of life by reducing the amount of stigma that they are forced to face in their daily lives.

2. 8 Social Factors contributing to the perpetuations of HIV – related stigma:

Clearly, there is a problem in South African society regarding HIV and this stems from various external factors. The UNAIDS (2014) identifies lack of education, awareness and social inequality as the main reasons for the continued stigmatization of HIV. In South Africa there is an additional factor, the ANC's previous history of HIV/AIDS denialism (Burton et al., 2015; Denis, 2014; Geffen, 2016; Gisselquist, 2008; J. McNeil, 2011; Muula, 2008). During the early 2000s, President Mbeki and his government firmly rejected that the HIV epidemic was anything of note, they argued that it was a money making scheme from big pharmaceutical company and that HIV and AIDs was only due to poverty (McNeil, 2011; Visser & Sipsma, 2013). Poverty does play a part in the direction of the spread of HIV to the most vulnerable populations in South African society (AVERT, 2020b; Deacon et al., 2005; Gilbert & Walker, 2010; UN News, 2017; UNAIDS, 2014b) but it is hardly the biological reason for the problem. Due to the government's views regarding HIV, ART was banned from public hospitals and the media propagated the government's denialist views. As such, many South Africans still hold negative views of HIV and the national response to the problem lagged for a couple of years. Recent governments have rolled out education programs and awareness campaigns but the damage to the adult population has been done.

HIV is transmitted from an infected individual through the exchange of bodily fluids (e.g. blood, semen, etc.) and the only effective treatment to suppress the disease is antiretroviral therapy (ART) ((AVERT, 2020b). Not beet root or a simple shower like many ANC figureheads have propagated to the masses (Geffen, 2016). The HIV epidemic and the stigma related it has been perpetuated due to misinformation from the government, citizens' lack of education, social inequalities and the prejudices in society that have also been perpetuated by religious, traditional and political institutions (Dahab et al., 2011; Gisselquist, 2008; Hartwig et al., 2006; Link & Phelan, 2014; Mbonu et al., 2009; Sullivan et al., 2020).

Now, the question is if stigmatization is so obvious and governments and NGOs are actively campaigning against the enactment of stigma within communities, why is it still so prevalent? Research suggests that it is due to the active campaigning of NGOs and the government that people have learnt that stigma is frowned upon by the law and have now switched their behaviour to more covert methods of stigmatization (Misir, 2015; Rankin et al., 2005; Sullivan et al., 2020). Examples of these methods are gossiping (Dores Cruz et al., 2019; Misir, 2015; Stadler, 2003), social distancing (Mbonu et al., 2009; Sullivan et al., 2020) and total excommunication from the community (Sullivan et al., 2020).

Given that most close knit communities, like informal settlements and rural villages, are very interdependent, being excommunicated from the community is effectively a death sentence (Klaas et al., 2018; Mbonu et al., 2009; Rankin et al., 2005). As such, given the social sanctions associated with being stigmatized, it is not surprising that more people would rather live in silent oppression than try to fight the system (Link & Phelan, 2014). The deterrents are innumerable, e.g.:

- young women being shunned from their communities for being raped (Snodgrass, 2018),
- women getting thrown out by their husbands for being HIV-positive (Sullivan et al., 2020),
- people being mocked at police stations while trying to lay a rape complaint (Mgolozeli & Duma, 2020),
- homosexuals being corrective raped or sodomized (Du Toit, 2014),
- prostitutes being harassed by police for carrying condoms (AVERT, 2020b),
- and etc.

Stigmatization is a constantly evolving social process that adapts to ensure that its goals are always met when it is confronted with opposition. As such, it is a very difficult process to combat as it comes in many different shapes and sizes, often determined by the context in which it operates.

2. 9 Institutional responses:

Making the healthcare, social work and police services more sensitive to the plights of their communities have been an ongoing process, however, the process has been unequal in how the institutions have sought to sensitize their employees. In the healthcare service, sensitivity has been encouraged when dealing with the various vulnerable populations that exist in South Africa, namely transgender people, men who have sex with other men and people who inject drugs (Duby et al., 2019; NASTAD, 2020). As the first point of contact, along with the police, this training is imperative to improve service delivery to PLHVs (University of Pretoria, 2020). To the point of helping PLHVs, the police service has also introduced sensitivity training to cater for the emotional needs of their officers, as well as the people they come into contact with on a daily basis (Kleingeld, 2004; Marks, 1995; Newham et al., 2006; University of Pretoria, 2020). Although, for social workers the service seems more interested in encouraging cultural sensitivity in their employees, than empathetic understanding (Engelbrecht, 2006; Retief & Green, 2015; Shokane & Masoga, 2018).

Ferreira and Ferreira's (2015) work suggests that the service is more interested in dealing with its' 'clients' in an equal and objective manner than an empathic one. The emphasis social workers put on impartiality is problematic, because not all people have equal needs and sometimes some people need more help than others, firstly, and secondly, one cannot deal with emotional issues through impartiality and logic, there must be some humanity when dealing with people who have seen the worse of humanity. Additionally, there is also a problem with the sensitivity training that healthcare workers and police officers receive. It is not continuous, the work of Singh et al (2017) and Galetz (2018) has demonstrated that after a period of time, people's empathy for others fades. and therefore, this training must be routine to constantly reinforce the ideals of empathetic interactions with others, in the minds of the workers (Retief & Green, 2015).

In general overview of the existing sensitivity training that frontliners have been receiving, it is not enough, these training programs do not address the stigma that PLHVs face outside of the clinical or judicial system, in their daily lives (AVERT, 2020b). The training these officials are receiving needs to be constant, and so does the educational efforts in the wider community. Research (Duby et al., 2019; Kimera et al., 2020) has shown that the stigma and discrimination that PLHVs face in their own communities are just as detrimental to their continued health as that which they face within the institutional setting.

2. 10 Impression Management and Self – Isolation:

Recent work done by Gottert et al (2020) has corresponded with Link and Phelan's (2001, 2014) work that different people respond differently to enacted stigma. Some people give in to the pressure put upon them by their community through enacted stigma (Feinberg et al., 2012; Melwani, 2012), while others respond with resistance. Resistance to stigma can take many shapes, but mostly the shape of resistance is determined by a person's context. Gottert et al (2020) work demonstrates that factors such as level of human rights violations, experiences of enacted stigma and access to resources and legal knowledge, all determine the level of resistance people have against stigma. Gottert et al (2020) conducted the UNAIDS' people living with HIV stigma index in three different countries, namely Cambodia, the

Dominican Republic and Uganda. In Uganda, (the African representative in the study), it was found that PLHVs reported the most experiences of enacted stigma, the lowest awareness of legal rights, and the lowest level of access to resources such as housing and food. Accordingly, PLHVs in Uganda had a very low level of resistance to enacted stigma.

Resistance to stigma and having an improved quality of life, are intrinsically linked for PLHVs, which means that by improving PLHVs quality of life, interventions will also indirectly increase their resistance to stigma. Empowering victims of stigma to help themselves is one of the main recommendations of Link and Phelan's (Hatzenbuehler et al., 2013; Link & Phelan, 2001, 2014) work. To achieve Link and Phelan's recommendation a multi-level approach is needed to empower PLHVs both individually and institutionally.

All of the above being said, the question that is being asked in this research is, how do South African PLHVs experience and respond to HIV-related stigma. Two of the main ways in which people respond to perceived and enacted stigma, according to the research (Andersson et al., 2020; Hatzenbuehler et al., 2013; Link & Phelan, 2014; Misir, 2015; Sullivan et al., 2020), are Impression Management and Self – Isolation. Impression management as, defined by Goffman (1959), is a conscious practice of regulating one's behaviour to meet a certain socially accepted standard. This is especially done when a person possesses a characteristic that is socially undesirable, and which can lead to social exclusion. Therefore, there is a need to adjust one's appearance to avoid social sanctioning.

Self – Isolation, as defined by the Merriam – Webster dictionary (2020), are feelings of shame that leads to self-isolating behaviour in order to hide characteristics, usually undesirable, which can result in loss of social support. This self-isolation can be seen in PLHVs refusal to disclose their HIV statuses to their family and friends or, to commit to long term and continuous ART treatment (Anakwa et al., 2020; Zuch & Lurie, 2012). This refusal is motivated by a fear of the stigma associated to the disease that has seen many PLHVs being excommunicated from their families and communities (Gilbert, 2016; Gilbert & Walker, 2010; Sullivan et al., 2020). Thus, negatively influencing their quality of life (Andersson et al., 2020; Geibel et al., 2020; Kimera et al., 2020; Link & Phelan, 2014; Parcesepe et al., 2020).

2. 11 Conclusion:

In an attempt to understand the situation of HIV – related stigma within South African communities, a literature review was done. The literature review focused on the following areas of interest, namely the context of the area of study, the literature around HIV-related stigma, the history of theory surrounding HIV - related stigma, the history of responses to HIV – related stigma, and the populations that are most at risk of being stigmatized for being HIV positive. It was necessary to focus on these areas of interest, because knowing about the history of HIV – related stigma, the responses to it, and the people that are most likely to suffer from it assisted the researcher in understanding and interpreting the experiences of the PLHV's that participated in this research project. An improved understanding also enabled the researcher to make recommendations that can improve existing efforts aimed at improving the quality of life of PLHVs within South Africa. The Goffman – Link and Phelan conceptual framework argued that improving PLHVs quality of life, will indirectly improve PLHVs ability to combat the effects of the stigma associated with HIV. Combatting the stigma related to HIV, will also assist the government in combating the spread of HIV within the country.

Chapter 3: Methodology

3. 1 Introduction:

In this chapter on Methodology, a thick description of the qualitative research methodology that was utilized in this research project will be provided for the readers. The qualitative research methodology was best suited for conducting this research, due to its need for information rich data that could illuminate the lived experiences of the four HIV – positive women that participated in this study. One – on – one semi - structured interviews were the data collection method of choice, it was supported by a thematic analysis that was conducted on the semi - verbatim transcribed interviews. The semi – structured nature of the interviews enabled the researcher to obtain information rich examples from the participants that aided the researcher’s understanding of the participants’ experiences. The aim of the research was to gain an understanding of PLHVs lived experiences with HIV – related stigma and that was achieved with the methodology as it is laid out in this chapter.

In this chapter the discussion will start with an introduction to the research paradigm that was utilized to inform the data collection and analysis practices of this project. This discussion will be followed by a discussion of the weaknesses of the practices utilized before moving on to looking at the data collection tool, namely the one – on- one semi - structured interviews, that were conducted with four HIV – positive women from the P.I.S. During the discussion the aspects of note will be, why the specific data collection tool was selected, how it was utilized, as well as the weaknesses of the tool. Before repeating the process with the data analysis tool that was utilized, a discussion of the ethical concerns related to the research and the limits that were imposed upon the process, will be conducted. However, firstly, a discussion of the chosen research methodological orientation will follow.

3. 2 Research Approach:

Due to the serious ethical need for confidentiality when dealing with PLHVs, and given the high potential for social harm, it was decided that the qualitative methodology was best suited for conducting this research. As the qualitative methodology possessed the necessary data collection and analysis tools that would enable the researcher to collect information rich data from a relatively small sample (Rahman, 2016). Additionally, due to the documented history of reluctance to admit to a HIV – positive diagnosis within general society (Bond et al., 2019; Wolf et al., 2014), the expectation was that a smaller sample size would have to suffice.

The qualitative methodology provided the researcher with the necessary data collection and analysis tools (i.e. one on one, semi - structured interviews and thematic analysis) that would enable them to conduct fruitful research despite a relatively small sample of participants. Additionally, the researcher felt that the data collection and analysis tools that the qualitative methodology provided, would enable them to engage with the emotional and social experiences of the participants regarding their lived experiences as PLHVs in the P.I.S. (Edwards & Holland, 2013; Rahman, 2016; Ryan et al., 2009).

3. 3 Sample and Sampling Technique:

3.3.1 Sample:

The sample existed out of 4 convenience sampled HIV- positive women, who all resided within the Princess Informal Settlement (P.I.S.). All of the participants spoke Setswana, their ages ranged between 25 and 50 years old. All of the participants were unmarried with more than one child in their direct care. As per their employment statuses, 75% of the participants were unemployed, and a 100% of them were actively receiving child support grants from the government that amounted to R440 per month, per child (Kelly & Groundup, 2017; South African Government, 2014). For 75% of the participants, this child grant was their only source of income. Finally, all of the participants were actively receiving ART treatment from the local clinic and was an acquaintance of the Key Informant (i.e. the social worker), who helped recruit all the participants to the study.

The selection criteria for participation in this study were:

1.) Participants had to be older than 18 years of age.
2.) Participants had to have previously disclosed their status to a third party (i.e. the KI).
3.) Participants had to be HIV positive.
4.) And finally, Participants had to be a resident of the Princess informal settlement.

As is evident from the criteria above, selection did not consciously discriminate on the basis of gender, employment, race or marital status. It was never the intent to select a gender homogenous sample, however, the fact that the sample ended up being gender homogenous has turned out to be advantageous for the transferability of this study. However, the gender homogenous nature of the sample does leave the findings open to bias, as no male voice was represented within the process. That being said, since female PLHVs are the biggest constituting population of South Africa's PLHV community (Klaas et al., 2018; Mbonu et al., 2009) it is not such a big problem (Jager et al., 2017). Why it is not such a big problem will be discussed in section **3.3.2 Sampling Technique** Finally, in relation to the problem of the small size of the sample, a small sample is generally a problem, however, given the qualitative approach of this research it was not that big of a problem as a qualitative research approach enables one to obtain a high quality of data from a relatively smaller sample. Thus, making the size of the sample was more or less irrelevant (Jager et al., 2017; Moser & Korstjens, 2018; Rahman, 2016).

3.3.2 Sampling Technique:

In this section on the sampling technique, a description of the sampling frame and technique that was utilized in this research will be given. Afterwards, a discussion will be conducted to demonstrate that the small and homogenous nature of the sample is actually an advantage of the study and not an impediment. To start things off, a description of the sampling frame will be given before presenting a description of the motivating factors that led to the utilization of the convenience sampling strategy.

The temporary and illegal nature of informal settlements has made obtaining accurate and relevant demographic information regarding the general population almost impossible. New shacks go up daily in and around the Princess Informal Settlement (P.I.S.) and therefore, one can only rely on rough estimates. As previously stated in this report, the Princess Informal Settlement is one of the few informal settlements slated for modernization by the Gauteng government (Claybrick, n.d.; Moeng, 2010; Ndimande, 2019; South African Government, 2015). For the purpose of modernization, the municipality created RDP (Government subsidy housing) housing units for 4 000 families, in the hopes of eradicating the shacks by 2016 (South African Government, 2015). As such, it can be said that there are four thousand families in the Princess Informal Settlement. Although, that number is problematic because it only accounts for the families that have been allocated RDP housing.

Now, these are the new RDP housing apartments that were supposed to house the informal settlers in 2016, as shown in **Figure 2**.

Figure 2: RDP Housing next Princess Informal Settlement, in Roodepoort (Source: Claybrick, n.d.)

Despite the RDP development, this is how the informal settlement looks today, in 2020, please refer to **Figure 3**. The settlement is still there, right next to the new RDP houses, and housing new residents, as is shown in **Figure 3**.

Figure 3: the Shacks next to the RDP housing apartments – the RDPs are on the left and everything right of the line are the shacks Source: *Google Maps (2020)*

The point of it all is, that the settlement is growing (South African Government, 2015) and there is no way of obtaining accurate and relevant demographic information. All that is known is that the people that live there are majority African, poor, and unemployed (Antonie, 2017; Makatile, 2018). Additionally, the researcher's own observations are that the people of the P.I.S. are also living in unhygienic, unsafe and unsustainable conditions, as presented in **Figures 4** and **5** below.

Figure 4: Refuse dumps behind some shacks.
Source*: Nhlanhla Phillips* (Makatile, 2018) and *Tshidi Madia* (Nkonki, 2012)

Figure 5: Shacks in the Princess Informal Settlement. & A child walking on a flimsy handmade bridge over refuse.
Source: Nhlanhla Phillips (Makatile, 2018) & *Nigel Sibanda* ("Princess Plot Housing Project to Start in Feb," 2014)

Consequently, the sample collected here (i.e. Four African, HIV-positive female residents of the Princess informal settlement) was loosely representative of the general population within the settlement in relation to the fact that they were all unemployed (except for a single participant), poor, African squatters living in an informal settlement.

Next, a description and discussion of the sampling strategy employed during this research study will be presented. Due to the sensitive and stigmatized nature of HIV, it was decided that a convenience sampling method would be best suited for the recruitment of HIV – positive participants. Convenience sampling was considered as necessary for the researcher due to their need to minimize the possibility of trauma through the indirect disclosure of the participants' confidential information during the study. The usage of more conventional strategies like probability sampling, where participants are selected or approached at random to participate in the study, was too dangerous.

One must remember that the study was conducted in a very communal and closed knit setting, where people routinely take the law into their own hands when perceived crimes have been committed (Antonie, 2017; Bloem, 2020; Chabalala, 2017a; Makatile, 2018; Ndimande, 2019; Pindral, 2018; Van Zyl, 2017). it should be mentioned that the community has a severe lack of service delivery and law enforcement assistance, and as such much of the violence that erupts in the settlement is in relation to their lack of service delivery (Bloem, 2020; Chabalala, 2017b; Pindral, 2018; Tau, 2014; Van Zyl, 2013). It was just too dangerous to approach anyone at random as even the impression that they might be HIV - positive could have been very detrimental to their physical, social and psychological health (Mbonu et al., 2009; D. McNeil, 1998). Therefore, the decision was made that a convenience sample was to be collected through the help of a Key Informant (KI). The Key Informant (KI) routinely interacted with the participants in her capacity as a social worker within the community. As such, her presence with the researcher within the community, was not that out of the ordinary.

Given the KI's embeddedness within the community, it was arranged that she would go into the community by herself initially to approach the participants with an offer to participate in the research. All together eight PLHVs were approached to participate in the study. Although, only four finally agreed to participate. The other four, either said no or due to the temporary nature of life within an Informal Settlement, were too difficult to locate or to contact. Additionally, due to their domestic and child care responsibilities, it was difficult to pin down a date for the interviews to be conducted with the four participants that did agree to participate. Therefore, given the logistical and safety issues related to this research, a non- probability convenience sample was the only option available to the researcher.

The benefits of a convenience sample was that a convenience sampling strategy enabled the researcher to recruit participants that had already disclosed their HIV status to a third party, i.e. the KI, and therefore, the trauma and danger of accidental disclosure was minimized. Although, a convenience sampling strategy does have certain pitfalls. Chief among them was the problem that people that volunteer to participate in a research project, usually have some sort of an agenda. There are specific reasons why people might be eager to speak to the researcher and this leaves the study open to co-option by the participants' political or social desires, as the project could become a mouth piece for their personal causes (Etikan, 2016).

This pitfall is best addressed through the use of an interview schedule, which allows the researcher to guide the conversation so that the process becomes mutually beneficial, as the researcher obtains the information they need, while the participant gains an opportunity to express their opinion. Which can be very therapeutic for a participant, especially in this case. The participants in this study, all come from a community where HIV is something that is not spoken about and as such, the participants might have benefited from a platform on which they could honestly and openly express their feelings and experiences. Although, the researcher must never forget that they are not a therapist, they are a researcher and they should stick to the interview schedule (Etikan, 2016). Lest they come out of the interview empty handed, which makes the whole process pointless. That being said, the interview schedule also serves to keep the researcher on track, as the schedule serves as a constant reminder of what needs to be done. Thus, it keeps both the researcher and the participants focused during the interview.

Another risk of convenience sampling is that the sample is not always representative of the larger community of which claims are being made, which brings problems of transferability to the table (Jager et al., 2017; Korstjens & Moser, 2018). This problem of transferability, however, was addressed in the gender homogenous nature of the sample. According to Jager et al. (2017), transferability, when it comes to qualitative research work, is actually enhanced when one uses a homogenous convenience sample, as opposed to a conventional convenience sample. This enhancement happens as most of the variation within a homogenous sample has been removed, giving the results improved transferability. That being said, Jager at al. (2017) does acknowledge that a homogenous convenience sample does have a narrowed transferability as the results only addresses a smaller subgroup of the wider population. Although, for this research the subgroup being addressed is the largest population of PLHVs in the country. Poor, African women make up the majority of HIV-positive cases within South Africa, as such the subgroup this research addresses is sufficiently wide enough that the findings can be transferred to almost any setting within South Africa.

In South Africa, two thirds of the 270 000 cases of new HIV infections were women in 2018, according to Klaas et al. (2018). Of the 38 million PLHVs in the world (UNAIDS, 2020a), 17, 8 million were women (Klaas et al., 2018). Additionally, in South Africa, the majority of PLHVs live in poor or informal settlements around the country, with between 20% and 25% of Gauteng's population living in informal settlements (HDA, 2013; Moeng, 2010).

Finally, according to Wathuta (2016), WHO (2013), Klaas et al. (2018) and Mbuno et al. (2009) female PLHVs in South Africa are the most dense and stigmatized population of PLHVs in the country. Which makes them the most relevant population when it comes to addressing the effects of HIV-related stigma. The subgroup that is being addressed in this report, is the biggest constituting population group in South Africa and therefore, these findings are very relevant.

Jager et al (2017) argument recasts the problem of the small size into a more positive light. This coupled with the fact that the research is predicated on a qualitative research methodology disarms the problem into a less intimidating speed bump. The reality, though, is that the topic of the research left the researcher in a position of 'beggars can't be choosers' and the sample existed out of people that were willing to participate in the time given. That being said, the strategic advantages of the qualitative method and the rationale provided above which compensates for the small size of this sample, should see to it that it does not remain such an imposing problem anymore, given the disproportionate size of the population of female PLHVs in South Africa. Now onto the problem of the bias that is related to the gender homogenous convenience sample that was utilized during this study. According to Jager et al. (2017), the homogenous nature of the sample, actually decreases the bias and so long as the findings are applied correctly to the appropriate subgroup, that should not be a problem. Again, the fact that this subgroup constitutes the majority, enhances the transferability of the work presented here.

In conclusion, this research project utilized a homogenous convenience sample of four participants from the Princess Informal Settlement (P.I.S.) in Roodepoort. The small sample size is complimented by the homogenous nature of the sample as the homogenous nature also improves the transferability of the findings presented here. Finally, the homogenous nature also decreases the bias of the findings. So long as it is applied correctly, to the appropriate subgroup. Moving on, the focus will shift to the ethical issues related to this project, but first a discussion of the data collection and analysis process will follow.

3. 4 Data Collection:

In this section the focus will be on how the data was collected. To collect the data a semi-structured interview process was utilized which was conducted in a face – to – face manner at the residences of the four participants. A discussion of why one – on – one semi structured interviews were selected for the data collection practice of choice will follow, as well as a layout of the questions and how they were structured to enable the researcher to obtain the necessary data to answer the question posed by this research project.

3.4.1 Data collection process:

The interviews were between 40 to 60 minutes in length and all participants signed the interview sheets at the end of the interview, as a form of consent. Before each interview, each participant was given a short explanation of the project and asked if they would be willing to be interviewed. All participants agreed to be interviewed. Upon receiving verbal consent the interviews commenced, with the entire interview being audio recorded. Verbal Consent was obtained, due to the fact that when willing participants were obtained the research data collection tool had changed from focus groups, to one – on – one interviews. However, the KI, who approached the prospective participants, only had access to the original participant information sheet when they approached the participants. As such, and due to the limited resources of the researcher, it was decided to dispense with the formal participant information sheet. Instead, verbal consent was obtained from the participants before the commencement of the interviews, after a short overview of the study. Additionally, the participants also signed the researcher's interview notes as a way of physically signing their consent. Despite the decision to dispense with the participant information sheet, the participants were briefed about the aims of the research before the interviews were commenced and as such the participants knew what the research was about. Verbal permission was also asked before audio recording commenced, as per the suggestions of Ryan et al. (2009), Thompson (2016), DeFranzo (2014), Opdenakker (2006) and Stofer (2019). The interviews were conducted at the participant's place of residence as per the request of the participants. Thus, all of the participants had informed consent.

3.4.2 One – on- One interview:

With the use of a semi-structured interview schedule the researcher interviewed four female participants from the P.I.S. about their experiences of HIV – related stigma, their responses to their experiences of HIV – related stigma and the support that they received from their families and community. Working from the position, as stated in the literature review, that only the participants know what they are experiencing within their community (Naidu & Sliep, 2011; Shokane & Masoga, 2018), the researcher decided that the semi – structured interview schedule would be best suited for allowing the participants to express their feelings and experiences. The researcher hoped to illicit information rich examples from the participants that would illuminate the problem of HIV – related stigma and help the researcher understand how the participants experienced and responded to the problem.

The semi – structured interview allows participants to talk freely due to its open ended and less structured nature (Moser & Korstjens, 2018; Stofer, 2019; Thompson, 2016). During the semi – structured interview the conversation could flow as the discussion was not led by a rigid interview schedule as one would find in a structured interview. However, the process is not completely informal either, as the relaxed interview schedule helps the interviewer maintain a focus during the discussion. If focus is not maintained, the researcher risked stepping out of the interview with no useful information with which to conduct their research (DeFranzo, 2014; Opdenakker, 2006; Ryan et al., 2009; Stofer, 2019; Thompson, 2016). Additionally, given the convenience sampling that was used in this research the interview schedule also served to mitigate, to an extent, the biases of the researcher and the participants during the data collection process (Etikan, 2016).

With these concerns in mind the researcher stepped into the data collection process with a prepared interview schedule that consisted of 47 questions, divided into 6 groups of questions, as presented in **Appendix B**. Each group of questions were aimed at steering the participants to a response that would illuminate the conditions of their daily lives as PLHVs in a South African community. The first three questions were demographic questions, however, the groups of questions that followed were aimed at probing the participants' experiences of (4 – 5) rejection and perceived stigma, (6) Internalized stigma, (7) enacted stigma and Impression Management, and (8 – 9) community support.

These questions were used to enable the researcher to perceive (1) the existence of HIV – related stigma within the community, (2) how PLHVs responded to their experienced stigma, and (3) the impact this has on their quality of life. The results of the interviews will be discussed in depth in the **Discussion section** to follow this chapter. The most important aspect of this discussion is that the aim of the interviews are to explore people's understanding and interpretations of the experiences they have in their lives and one cannot have this if the voice of the participant is silenced in a mass of predetermined questions. Additionally, the power relations between the researcher and their participants are always an important factor to consider when interacting with people that are socially placed in a lower power position.

It is important to consider the impact the researcher's presence can have on the participants, however, the impact the participants can have on the researcher also needs to be considered.

Participants are not passive beings and they can heavily influence the findings of a research project, which reemphasizes the need for an interview schedule which can level the playing ground between researcher and participants. That being said, if the researcher wanted the participants to open up to them, they needed to empower them by providing them with a platform for airing their opinions without fear of judgment or rejection.

It was imperative that the researcher toe the middle line in the relationship between the researcher and the participants, so that the relationship could be mutually beneficial for both of the participants in the process. Ideally, the researcher obtains the information they needed, while the participant got the opportunity to air their feelings and experiences in a confidential setting. This freedom was especially important given the emotional and social isolation that PLHVs operate under in their daily lives. However, the researcher must also always remember that the interview setting is not a therapy session. It is important to empower people by allowing them to freely express their opinions, which has been found to be therapeutic for participants, but the overarching goal of the process must never be forgotten (DeFranzo, 2014; Opdenakker, 2006; Ryan et al., 2009; Stofer, 2019; Thompson, 2016).

The middle line was achieved through the usage of a semi – structured interview which allowed the participants to lead the conversation and express themselves freely while the interview schedule was used to guide the conversation so that there was space for expression but the conversation did not get bobbed down by venturing off of topic (Stofer, 2019). Another way the middle line was maintained was through the participation of a social worker (i.e. the KI). The KI provided emotional support to the participants when needed during the interviews and they were also vital for the protection of the participant from misunderstandings or influence from the researcher. As the translator during the interviews the KI was able to translate the interview questions to the participants and explain them during instances of confusion, as was the case during section 6 of the interview that dealt with internalized stigma and the allocation of blame.

At first the participants responded with offense or defence at the questions being asked but the KI was able to quickly explain and address any issues that arouse during this section of questioning. As previously stated, all the participants spoke Setswana and therefore the interview relied heavily on the translations of the KI to avoid offense or misunderstandings between the researcher and participants. In preforming their duties as translator, the KI was also able to provide emotional support to the participants during tough sections of questioning about enacted and perceived stigma. Thus, also addressing the ethical issue of doing no harm to one's participants. The need for researchers to do no harm to their participants will be discussed in more detail in the appropriate ethics section below.

The thick description of the data collection process enables other researchers to replicate the process if they so wish in the future (Korstjens & Moser, 2018). The usage of an interview schedule also allows for a small amount of standardization, which will also assist replication efforts in the future. However, at every point during the interview, the order and approach to the questions were determined by the ebb and flow of the conversation. It was not a linear process, instead the conversation moved back and forth as the questions became relevant.

In summary, this research depended on one – on – one, semi – structured interview process for its data collection method. Interviews lasted between 40 to 60 minutes, and was conducted with an interview schedule that existed out of 47 questions. The questions were divided into nine sections that attempted to measure, (1 – 3) demographics, (4 -5) rejection and perceived stigma, (6) internalized stigma, (7) enacted stigma and impression management, and (8 – 9) community support. Additionally, the interviews were conducted at the participants' residences, as per their requests. The interviews were also conducted with the assistance of a Key Informant, who acted as the official translator for the researcher and participants. The KI also provided emotional support for the participants during the interviews. This thick description could possibly aid future repetition efforts. In the section that follows, the limitations of the research process will be discussed.

3.4.3 Limitations:

The discussion that follows will be dealing with the possible weaknesses in this research process. The possible weaknesses of this process can negatively impact the relevance and quality of the research findings. The possible weaknesses of the project are limitations that are external obstacles that can restrict the transferability or credibility of the research findings. As such, the limitations need to be addressed to strengthen the credibility and transferability of the project and its findings. How these limitations were addressed, will be discussed in the section that follows.

The utilization of a non – probability convenience sampling technique in this research project has compromised the project's ability to be representative of the wider community. However, due to the secretiveness surrounding HIV (Wolf et al., 2014) it was extremely difficult to gather people living with HIV to participate in the study. Additionally, cost and time constraints also limited the researcher's ability to gather a larger sample. That being said, the researcher believes that the homogenous nature of the convenience sample (Jager et al., 2017) will actually be beneficial to the transferability of the sample as women PLHVs are the largest constituting population of South Africa's PLHV community.

The fact that there are no male voices within the sample is a problem. It biases the findings and makes it almost impossible to relate the findings to the experiences of male PLHVs in South Africa. The sample was not intentionally selected with a gender bias, the sample existed out PLHVs that were willing to talk to the researcher. Another problem that could have affected the sampling was the fact that researcher is a young white woman, which could have discouraged male participation in the study. Gender norms and values in African cultures do not predispose African men to discussing private matters with another women, not to mention a white woman as well (Sullivan et al., 2020). Sampling was a problem in this research project, however, given that the research methodology was qualitative in nature, it was felt that this aspect of the process was not such a big problem as qualitative research has proven to be able to provide researchers with information rich data (Palmerino, 2006; Rahman, 2016; Stofer, 2019).

The researcher's lack of experience also limited the research. The one – on – one interview is an extremely effective data collection tool, however, it needs an extremely experienced interviewer to preform optimally. The researcher of this project was not an extremely experienced interviewer, and as such time and opportunities could have been wasted. However, every weakness has a strength as well, and this researcher believes that their inexperience might actually have provided the participants with more freedom to guide the conversation then would have been allotted to them if a more experienced person, with a clearer grasp of protocol, led the interview. With more freedom, the participants spoke more freely and directed the researcher to aspects of their lives that the researcher had not considered before. As such the quality of the data collected was increased (DeFranzo, 2014; Opdenakker, 2006; Ryan et al., 2009; Stofer, 2019; Thompson, 2016). Therefore, the researcher's weakness both detracts and adds to the research.

The final weakness lies within the preferred research paradigm of the report. The qualitative research paradigm was selected for this research project due to the researcher's believe that it was best suited for understanding people's personal experiences and the meanings they attached to it (Moser & Korstjens, 2018; Rahman, 2016). However, qualitative research is very susceptible to the biases of the researcher because it relies on the interpretation of the researcher to make conclusions from the data collected (Rahman, 2016). And as all academics know, people's interpretations are subjective, as they are all informed by the personal views and experiences of the person performing the interpretations.

There should always be a cognisance of the influence of one's personal views and an effort must be made to curb that influence as much as possible (Butina, 2015; Edwards & Holland, 2013; Rahman, 2016). While maintaining a balance with your own experiences as to allow the researcher to be understanding and empathetic towards participants during data collection. Achieving the balance can be very difficult, just like inexperience, it can be both a severe negative and a positive force that allows for the discovery of valuable information.

In conclusion, there are three main limitations to this research report, (1) that it has a very small sample size, (2) was conducted by an inexperienced researcher, and (3) that qualitative research is subjective in nature. The subjective nature of qualitative research leaves it susceptible to co-option from the researcher's personal views and biases. As long as long as there is an awareness of one's own biases, it can consciously be controlled, however, qualitative research's weakness is also its strength. As such, a person's subjectivity must not be curbed too much. The same can be said for the problem of inexperience. Inexperience can be problematic, as well as beneficial for a person not extremely invested in accepted standard operating procedure. There is some room for difference. And then finally, the small size and gender homogeneity of the sample is problematic. Though not detrimental, as the subgroup that is being addressed with the sample does constitute the majority of South Africa's PLHV population. Therefore, the degree of transferability is not such a major issue.

3. 5 Data Analysis:

In this section, the discussion will be focused on how the collected data was analysed with the thematic analysis approach. After a second discussion about the themes that were identified during the process, a discussion will be conducted about how the research project achieved the credibility, trustworthiness and transferability standards for qualitative research. Finally, a fourth discussion about the ethical considerations that were applicable in this research will be conducted. A short summary will form the conclusion to this section.

3.5.1 Thematic Analysis:

To analyse the data, all recorded interviews were transcribed using a semi-verbatim process and was done manually, due to the frequent changes from English to Tswana or Afrikaans. Using the Thematic Analysis, as per Braun & Clarke (2018), all transcribed interviews were reviewed and initially coded into themes with the use of a colour code system. After the initial coding, the themes were reviewed and three main themes were identified. The initial eleven themes were divided into these three main themes based on similarity and fit.

The first themes that were recognized were divided into three main themes, namely (1) Experiences of stigma, (2) Stigma mitigation strategies, and (3) Family Acceptance. After the initial coding the transcriptions were reviewed again, to assist in finalising the key themes that were identified in the transcribed interviews. The sub-themes that were identified during the second review were:

Experiences of Stigma:

- The Green Card System
- Clinic Staff attitudes
- Lack of Confidentiality
- Gossiping
- Physical Abuse

Stigma Mitigation Strategies:

- Self-Isolation tactics
- Impression Management tactics

Family Acceptance:

- Rejection
- Material and Non-material support

- Internalized stigma
- Counselling

In this study the researcher wanted to do three things, namely (1) demonstrate the persistence of HIV – related stigma within the community of the P.I.S., (2) to describe how PLHVs utilize mitigation strategies like Impression management and self-isolation tactics to moderate their experiences of enacted stigma within their community, and (3), to enable the researcher to make recommendations that could possibly improve existing anti-stigma efforts within the P.I.S community and South Africa at large. To improve the quality of PLHVs lives.

What these themes mean and how they impact the three objectives of this study, will be discussed in depth in the chapter that follows. The discussion that follows will focus on demonstrating how this research project achieved the three golden standards of quality, qualitative research, namely Credibility, Trustworthiness and Transferability. After the discussion, the focus will turn to the ethical considerations that were applicable to this research project.

3.5.2 Credibility, Trustworthiness and Transferability:

In this section the focus will be on the concepts of Credibility, Trustworthiness and Transferability, the validity, reliability and generalizability of qualitative research. The discussion will start with a very short layout of the historical difficulties that qualitative research has had with achieving these standards. Afterwards, the discussion will begin with the standard of Credibility, before moving onto Trustworthiness, and then Transferability. A short summary will serve as a conclusion to this section before the focus moves onto the next section on, ethics.

The subjective nature of qualitative research has long made the achievability of these principles (i.e. validity, reliability, and generalizability) a point of heated debate (Bowen, 2005; Butina, 2015; Jager et al., 2017; Korstjens & Moser, 2018; Nowell et al., 2017; Shenton, 2004; Tracy, 2010). However, these standards proved to be bias, as the qualitative method used data collection strategies that could not subscribe to these rigorous measures. The qualitative methodology usually used data collection methods that requires smaller samples and more subjective skills for interpretation of the data (Rahman, 2016). As such the qualitative approach has often been refuted as unscientific, as it has lacked generalizability and objectivity. These problems with the quantitative quality checks led qualitative researchers to creating their own quality checks, namely credibility, trustworthiness and transferability. How each of these measures ensures quality will be discussed in the paragraphs that follow. During the discussion the researcher will also demonstrate how their work meets the criteria for these quality checks.

A point of clarification, the four criteria that must be met so that qualitative research can be viewed with trust within the academic field are Credibility, Transferability, Dependability and Confirmability (Korstjens & Moser, 2018). Dependability and Confirmability are the two standards required for achieving Trustworthiness in qualitative research. Therefore, there are three checks as previously stated. That being said, let's start by discussing how the validity of qualitative research (i.e. Credibility) was obtained in this research project. Before moving on to discussing the attainment of the other two standards.

Validity in quantitative research refers to the degree to which research instruments measure what it is intended to (Korstjens & Moser, 2018; Shenton, 2004). In qualitative research validity is referred to as Credibility (Bowen, 2005; Korstjens & Moser, 2018; Shenton, 2004; Tracy, 2010). This research project was aimed at understanding South Africans' experiences and responses to HIV-related stigma. To that end, the project used people living with HIV, who were most likely to have experienced the stigma related to HIV, and only asked them questions during the interviews that enabled the researcher to gain an understanding of their experiences as people living with HIV. The questions asked in the semi-structured interview were open ended, which allowed participants to elaborate and provide insightful examples of their experiences. The combination of the open ended questions and the information rich examples that participants provided, allowed for prolonged engagement during the data collection process. For a layout of the interview questions please refer to **Appendix B** for the interview schedule.

Aside from this broad check for credibility, there are four other mechanisms for ensuring credibility, namely prolonged engagement, member checking, triangulation, observational information (Korstjens & Moser, 2018). Despite the positive of clearing the first hurdle, there was a negative in the fact that member checking could not be conducted due to time constraints and the informal nature of the participants settlement (i.e. the Princess Informal Settlement). As such, they do not have permanent addresses, post boxes or phone numbers. Consequently, they can become untraceable when they suddenly move out of the area for work, or family reasons. As was the case with the initial Key Informant (KI) that agreed to cooperate with the study. However, the fact that the interviews were conducted in the homes of the participants allowed the researcher to gather observational information regarding the living conditions of the participants which was an additional source of information, although unofficial. Experiencing the cramped and unsanitary conditions that are present within an informal settlement, does really bring home the gravity of the struggles that the participants face in their daily lives. And therefore, a sort of triangulation could be achieved as the researcher was able to observe the experiences that the participants were sharing with them.

Additionally, in conjunction with these observations, there was also the confirmation of validity that was provided by the Key Informant (KI) that accompanied the researcher during the interviews. In addition to receiving affirmation from a third party, there was also the triangulation mechanism that exists within the thematic analysis process. Subsequently it can be concluded that the research process did incorporate three of the four mechanisms, as recommended by Korstjens and Moser (2018), that was needed to ensure the credibility of the findings. Thus, the research process has credibility, as it can be said that it measured what it was supposed to.

The next standard to discuss is, dependability. For reasons of reliability, in quantitative terms, the research instruments used in a project must be able to consistently measure what it is supposed to (Korstjens & Moser, 2018). If the research instruments does that, than it can be said to have dependability, which takes you half way to trustworthiness (Korstjens & Moser, 2018). To get to trustworthiness the rest of the way, one needs to achieve confirmability. Confirmability relies on the question of ‘can your findings be corroborated or repeated by someone else?’(Bowen, 2005; Korstjens & Moser, 2018; Shenton, 2004, 2004; Tracy, 2010). As per the previous section on credibility, the research instruments used in this project does measure what it is supposed to measure, and as such all that is left is to demonstrate the fact that the process does so, in the same way, repeatedly.

To that end, in this research project all four participants were asked questions from the same interview schedule with the same semi-structured process. The data from each interview was then transcribed in semi-verbatim and analysed according to Clarke and Braun’s (2018) prescriptions. The repetition demonstrates a standardization of the data collection and analysis process, to the degree that qualitative research allows it. Additionally, the standardization and bountiful process descriptions enables a third party to repeat the process if they so wish. The standardization of the data collection and analysis process demonstrates dependability and the dependability demonstrates that the process can be repeated. Which gives the work confirmability. Thus, both of the criteria needed for the standard of trustworthiness have been met (Nowell et al., 2017).

Additionally, in previous research the combination of interviews and thematic analysis has proven to be able to deliver when approaching the topic of HIV, as it provides the necessary confidentiality for encouraging private disclosures and enables researchers to glean the implied meanings of emotions and experiences expressed by their participants during interviews (Butina, 2015; Opdenakker, 2006).

Moving on from the standard of trustworthiness, the discussion will now be focused on the standard of transferability, the generalizability of qualitative research. This project does have a sample size limitation, as the sample only exists out of four female participants. However, the fact that this research project's methodological approach is qualitative, sees to it that the question is not whether this research is generalizable but whether it is transferable. As such, when it comes to the question of transferability, the question is, can the findings and processes of this research project be transferred to another setting (Korstjens & Moser, 2018).

In all the other research projects (Azia et al., 2016; Dlamini et al., 2009; Kagee et al., 2011; Z. Li et al., 2018; Mathibe et al., 2015) that has been reviewed in this research there has been a female dominated sample, the majority of participants were unemployed and ART receiving patients. These traits makes the sample transferable because women do constitute the largest and most stigmatized proportion of people living with HIV in South Africa (Human Sciences Research Council (HSRC), 2018; Klaas et al., 2018; Mbonu et al., 2009; Peacock, 2013; Wathuta, 2016; WHO, 2013). Additionally, 25% of Gauteng's population live in informal settlements around the province and the majority of PLHVs also reside within these informal settlements (Cornellius, 2016; HDA, 2013; Makatile, 2018; Moeng, 2010; Ndimande, 2018; South African Government, 2015).

The sample, regardless of size, is demographically transferable as it does conform to the representation that is generally found in similar research in South Africa (Azia et al., 2016; de Oliveira et al., 2017; Human Sciences Research Council (HSRC), 2015). However, there is no male voice within the sample, which is a short coming but also a representation, as samples in previously conducted research have been female dominated, as women have proven to be more willing to participate in HIV-related research than men (Azia et al., 2016; Bandeira, 2015; Bond et al., 2019; Klaas et al., 2018). Therefore, the fact that the sample is gender homogenous is an anomaly, and it does bias the findings of the research, but it is not that out of the ordinary to drastically impact on the transferability of the research.

Jager et al. (2017) argued that if a researcher is going to conduct research with convenience sampling, as is the case in the majority of qualitative research, than it is best to conduct the research with a homogenous cohort, as it can improve the transferability of the findings by removing excessive variations within the sample. By reducing the variation within the sample, one is enabled to increase the transferability of the results and to decrease the bias that can distort the findings (Jager et al., 2017, pp. 6–7), which improves the transferability of these research findings. On the other hand, they do say that the homogenous convenience sampling method does narrow the transferability of the findings, in relation to the wider population since one is only focusing on a specific subset of the population (Jager et al., 2017, p. 2), however, this problem is mostly negated in the South African context as the subgroup that is represented in this research, does constitute the majority of the wider PLHV population in South Africa. Therefore, the homogenous nature of the sample here does actually improve the transferability of the findings to the wider population in South Africa.

Another prerequisite for achieving transferability, according to Korstjens and Moser (2018), is that one must provide adequate detail of the research process and this has been provided in the preceding data collection and analysis sections of this report. Therefore, if one looks at the criteria presented here, this study can be transferred to any other setting in South Africa, regardless of the actual sample size. Although, these findings would not be transferable to communities outside of South Africa as the social, economic and cultural contexts are different and therefore the findings could possibly be different as well (Rahman, 2016).

Concluding the section, this research project does possess the necessary conditions for achieving the required standards of credibility, trustworthiness, and transferability that are necessary to give credibility to the findings of this report. Next the focus of discussion will turn to the ethical considerations of this research report.

3. 6 Ethical Considerations:

When conducting research with a living human participant, there are three universal ethical principles that researchers must always consider. These principles are (1) Informed Consent, (2) Do No Harm, and (3) Dignity and Respect (van Dijk, 2020; Vanclay et al., 2013). In this section the discussion will focus on the three universal ethical principles, and how they were met during the research process.

Informed consent is defined as when a person voluntarily confirms their willingness to participate in a particular research project, after they have been fully informed about the nature and requirements of the study (Xu et al., 2020). Due to the voluntary nature of participation, a participant can decide to withdraw whenever they so wish, without prejudice. To Do No Harm is defined as a researcher's obligation to do no harm to their participants in any social, physical or psychological way (Vanclay et al., 2013). Dignity and Respect is defined as a researcher's duty to always treat their participants with respect and dignity as human beings (Msoroka & Amundsen, 2018; Vanclay et al., 2013).

All the universal ethical considerations were observed and ethical clearance was obtain from the ethics committee of the University of Witwatersrand. Informed consent was obtained. Before the commencement of the interviews, consent was verbally obtained, and after the interviews consent was manually obtained, when the participants signed the researcher's interview notes. No physical, social or psychological harm was done to the participants as the interviews was conducted in the most covert manner possible. To proceed as covertly as possible, the researcher travelled with the KI, who was a social worker, which made it seem like the researcher was meeting with the participant in a social work capacity, and not a research one. This ruise provided the participants with some social security.

Emotional security was also provided with the presence of the KI that could provide the participants with emotional support during the interviews. Having HIV is a very sensitive matter and having a friend close by can be very reassuring for a person. As such it was beneficial for the participants to have the KI close by during the interviews. Finally, the dignity and respect of the participants were considered at all times. However, only confidentiality could be provided for the participants due to the one – on – one nature of the interviews that were conducted. Although anonymity could not be ensured, confidentiality could as all information was stored on a password protected laptop.

3. 7 Conclusion:

In the chapter on Methodology a thick description of the research methodology utilized in this research report, was provided for the readers. The qualitative research methodology was best suited for this research project, as it was able to provide the needed information rich data that illuminated the lived experiences of the four HIV – positive women that participated in this study. One – on – one semi - structured interviews were the data collection method of choice and it was supported by a thematic analysis that was conducted on the semi - verbatim transcribed interviews. The semi – structured nature of the interviews enabled the researcher to obtain information rich examples from the participants that aided the researcher's understanding of the participants' lived experiences. The aim of the research was to gain an understanding of PLHVs lived experiences with HIV – related stigma that was achieved with the methodology as it is laid out in the chapter.

In the chapter that follows the findings of this research process, will be discussed with relation to the three main research objectives, namely (1) demonstrating the persistence of stigma, (2) describing how PLHVs respond to experienced stigma, and (3) making recommendations that will assist in improving the effectiveness of HIV intervention in the community, so that PLHVs quality of live can be improved as well.

Chapter 4: Discussion

4. 1 Introduction:

The three objectives of the research project were (1) to demonstrate the persistence of HIV related stigma within in society, (2) to describe how PLHVs responded to experienced stigma, and (3) to suggest alternative interventions that can improve the quality of PLHVs lives. These objectives spearheaded the commencement of this research project. Thus, the discussion will start with the evidence that demonstrates the persistence of stigma within the P.I.S. before moving on to a description of the four PLHVs experiences of and responses to enacted stigma. Mainly participants experienced enacted stigma in the form of gossiping, discrimination and social judgement from fellow community members and they most often responded to these stigmatizing experiences with impression management and self – isolation tactics. These tactics were utilized in various attempts to avoid being discriminated against again. The participants' attempts were not always successful, as will be discussed in the paragraphs to follow. And then finally, a discussion about the strengths and weaknesses of the existing HIV education efforts within the community, will be conducted to demonstrate that gains have been made in relation to internalized stigma within participants and their relationships with their families. That being said, not enough has been done to address the stigma that is prevalent within the community at large.

4. 2 The persistence of stigma

As the building block of this research project, it was essential to demonstrate that stigma was still a prevalent element of daily life for PLHVs in the P.I.S. During the research it was established that stigma was still very much prevalent within the community, as participants reported experiences of being gossiped about and feelings of alienation from their community because of their HIV positive status. According to previous research (Dores Cruz et al., 2019; Feinberg et al., 2012; Martinescu, 2017; Melwani, 2012; Nelissen & Mulder, 2013; Wu et al., 2018; Xie et al., 2018), gossiping and the feelings of alienation that accompanies these experiences of humiliation, are the main forms enacted stigma takes in society today. The main gateways to the enacted stigma were the community and the clinic, where participants frequently experienced dehumanizing treatment, as well as a lack of confidentiality, due to the negative attitudes of their fellow residents and the clinic staff.

The first section of this part of the report, will focus on the green card system that is used within the clinic to identify HIV – positive patients. The discussion will be focused on the problems presented by the green card system before moving on to a discussion of the participants' experiences of enacted stigma within the community at large.

4.2.1 Institutional Stigma:

The issues surrounding the green card system was not initially one of the main areas of concern for the researcher, however, it became one, after it was highlighted by the participants as an issue during the interviews. The majority of the participants expressed an extreme dislike of the green card system. The dislike stemmed from the fact that the green card, having been associated with HIV, was placed on the outside of the participants' files, when the nurse came to call the participants from the waiting area, everyone present could see the card and identify them as HIV-positive.

The green card system was an issue for the majority of the participants, as it served as a form of indirect disclosure of their HIV statuses to others. The indirect disclosure of the participants' HIV statuses to bystanders at the clinic, had led most of the participants to experience gossiping from their fellow community members outside of the clinic. Participants 202 and 303 stated the problem very clearly in their responses to probing during the interviews that focused on the issue of the indirect disclosure that was being facilitated by the green card system. The participants' responses were very clear, as demonstrated by the quotes below:

> *"They know what is wrong, am I right?"*
>
> **Participant 202:** *"Yeah"*
>
> **Participant 303:** *"you see, so obvious when I get to the clinic, they take my card like this..."*

These disclosures led the participants to instances where they experienced forms of enacted stigma, i.e. gossiping. These instances of enacted stigma are an unfortunate occurrence as the green card system is an administrative tool that helps classify patients according to treatments for filing purposes. It is not a system that was created to intentionally bias PLHVs. That being said, biasing PLHVs was exactly what was happening in the P.I.S., and therefore, 75% of the participants expressed a dislike of the system. The only one that expressed no experience of alienation from the green card system, was participant 404. Participant 404 liked the green card because it helped her remember her appointments. However, Participant 404 was a demographic outliner as she had a job. Research (Anakwa et al., 2020) has shown that PLHVs that have access to more resources, are less likely to experience concerns surrounding disclosure. That being said she was not very open with her status towards others, which indicates a fear of stigma and a personal preference regarding the usage of the green card system.

Due to the changing nature of stigma, and the discrimination it leads to, a purely administrative tool has become a tool used for discrimination by an institution that has been well known for their discriminating attitudes towards PLHVs (Chambers et al., 2015; Manganye et al., 2013; Nyblade et al., 2020). The researcher is not claiming that the whole health care industry is discriminating against PLHVs in South Africa, however, the researcher is saying that there are people in the industry that are using institutional tools, like the green card system, to discriminate against PLHVs. The green card does not have to be on the outside of the file, and the nurses can use discretion (Galetz, 2018, p. 29) in how they call out PLHVs from mixed – treatment waiting rooms.

There is room for personal choice and unfortunately some nurses are making the wrong choices, which are leaving PLHVs open to experiencing humiliating instances of enacted stigma (i.e. gossiping). Being gossiped about has serious negative consequences for a person's social, physical and mental health (Dores Cruz et al., 2019; Hatzenbuehler et al., 2013; Link & Phelan, 2001, 2014; Xie et al., 2018). Gossiping about someone is aimed at ruining their reputation within the community, so that other people will not want to interact with them afterwards (Dores Cruz et al., 2019; Feinberg et al., 2012). Additionally, being gossiped about hurts a person's feelings which makes them less trusting of the community at large (Melwani, 2012; Nelissen & Mulder, 2013). Leading to feelings of loneliness and alienation, which can be stressful for a person (Wu et al., 2018).

Furthermore, when people do not want to interact with someone, it negatively influences their ability to get a job, make friends or access healthcare services (Link et al., 2004; Link & Phelan, 2001, 2014). All of these aspects leads to a person being physically, socially and emotionally downtrodden (Link & Phelan, 2014), and it can even lead to people committing suicide. As such, gossiping is a serious threat to PLHVs quality of life within the community (Andersson et al., 2020; Geibel et al., 2020; Kimera et al., 2020; Parcesepe et al., 2020). Subsequently, they have to work extra hard to avoid being gossiped about. In this light it makes sense as to why the green card system is such a major problem for the majority of the participants in this study. These quotes taken from the participants' interviews clearly demonstrate the problem at hand.

> ***Participant 101 said:*** *"You read my file outside, everyone will know... everybody she knows, told her, she is HIV positive, I don't like ..."*
>
> ***Participant 202 said: "****you see, so obvious when I get to the clinic, they take my card like this..."*
>
> ***Participant 303 said:*** *"obviously they do gossip but I will never know what they say"*

The majority of the participants had a serious dislike of the system, therefore it can be conclude that numerically there is a dislike of the system and a collective wish for it to be dispended with. Next, the discussion will move onto experiences of enacted stigma within the community at large.

4.2.2 Experiences of Enacted Stigma:

As mentioned in the previous section, the stigmatizing attitudes of the clinic workers also played a major role in alienating the participants. The alienation was so uncomfortable for the participants that 50% of the participants expressed a desire for a private area, just for HIV-positive patients.

> ***In relation to the specific booth for HIV patients only, Participant 303 said:*** *"For me, like I understand... they can know about the disease it is fine...* ***<u>don't have to be specific about me</u>****" [emphasis added]*
>
> ***In relation to the separate centre for PLHVs only, Participant 202 said:*** *"She asks, why is there no place that if you are positive, where you can get counselling and exercise"*

Hatzenbuehler et al. (2013, p. 815) shows that people with a hidden stigma, gained a noticeable increase in mood and confidence when they were in the presence of people who shared their specific stigma. Even though, that was also very unlikely to happen, as people with hidden stigmas actively avoided people and institutions that could indirectly disclose their stigma to others. As such, the desire from Participants 202 and 303 seems to be natural, as the logic leads one to believe that there will be less stigma among people of one's own 'kind'. Due to PLHVs documented usage of impression management and self-isolation tactics, it is very unlikely to happen. The participants in this study did report instances where they interacted with their fellow PLHVs, however, they also reported instances where their fellow PLHVs did not wish to talk to them about their illness. According to the participants, their fellow PLHVs were very difficult to approach.

This report corresponds with earlier work (Campbell et al., 2007; Weiser et al., 2006), where researchers found that PLHVs did not want to talk to them about their status. The people withdrew from conversation and often expressed their desire for the "conversation to be discontinued" (Mbonu et al., 2009, p. 5). Experiences of enacted stigma has led PLHVs to withdraw… or want to withdraw, however, they cannot because they have to maintain their impression management tactics to pass through society undetected on a daily basis. Experiences of gossiping isolates individuals from their community, the result is a feeling of loneliness. The process of isolation will be discussed in more detail in what follows.

Participant 202, communicated an experience to the researcher, where she was made to go outside the clinic to receive their medication, in full view of the rest of the community. This dehumanizing act led to Participant 202 feeling 'shy' and embarrassed as her status was indirectly disclosed to other people without her consent. Which again left her open to experiencing enacted stigma in the form of gossiping. She also felt that her status had been indirectly disclosed by the nurses giving her medication to her outside in plain view of the community. These two acts of insensitivity, clearly stigmatized the participant in front of the community. As stated, during the literature review (Andersson et al., 2020; Bagchi & Holzemer, 2020; Batchelder et al., 2020; Camacho et al., 2020; Nyblade et al., 2020; Sullivan et al., 2020; Yuvaraj et al., 2020), being stigmatized with HIV is an act that can have serious social, physical and psychological consequences for a person, as such it was utterly negligent of the nurses to expose the participant in such a way.

The negative attitudes of health care providers and its influence on the perpetuation of HIV-related stigma, has been well documented in previous work (Feyissa et al., 2012; Galetz, 2018; Larti et al., 2018; Peretti-Watel et al., 2007; Singh et al., 2017). It has also been well documented by previous work (Andersson et al., 2020; Camacho et al., 2020; Sullivan et al., 2020) that the negative attitudes of health care workers do lead PLHVs to forgo medical treatment, which can ultimately lead to their death and the deaths of others, as they unfortunately spread the virus to others. The spread of HIV becomes a very possible problem because PLHV, due to experiences of enacted stigma, do not have access to the necessary precautionary measures to prevent the spread of HIV. The fear of humiliation and exclusion has been documented (Hatzenbuehler et al., 2013; Link & Phelan, 2014; Mbonu et al., 2009; Sullivan et al., 2020) as a serious negative force in the lives of PLHVs as it forces them to utilize avoidance tactics that endangers themselves and others. Additionally, Dores Cruz et al (2019) have also noted that gossip, and the humiliation that it leads to, can evoke aggressive responses from the victims which further victimizes them as they become targets of the police and community, as violent offenders.

As was the case with Participant 202, she confronted a gossip in her community and the situation dissolved into a physical altercation, the matter was referred to the authorities and the court sided with her. The assumption can be made, due to South Africa's strong anti – discrimination laws however, Participant 202 still harboured resentment towards to the community member. Anger and resentment contributes to PLHVs sense of loneliness and isolation as they cannot trust their fellow community members (Dores Cruz et al., 2019). Again, as stated during the literature review (Mbonu et al., 2009) isolation is a big problem for a person in a community that relies on each other for its survival. If a person cannot trust their neighbour, that becomes a very dangerous and stressful living environment (Dores Cruz et al., 2019; Hatzenbuehler et al., 2013; Bruce G. Link & Phelan, 2014; Mbonu et al., 2009). Which is another factor that contributes to the poor health of PLHVs.

Mistrust of one's neighbour was also evident during Participant 303's interview, as the entire interview had to be conducted quietly due to the participant's concern that their neighbour would overhear the conversation. When asked why it was a problem that their neighbours might overhear, Participant 303 stated that the neighbour would gossip about her if she overheard the nature of the conversation. Participant 303's home was surrounded by several other residences and as such it was difficult to know which one of the neighbours she was suspecting. Although, the possibility is very high, that she was suspecting all of them. The P.I.S. is a very densely packed community, with residences often only separated by a thin metal sheet that constitutes a wall or fence. Conversations can easily be overheard by neighbours, or passers-by that are utilizing the dusty ground walk ways between the residences, that act as streets.

Interestingly though, none of the participants reported experiencing physical abuse, however, the social death of being gossiped about, which all of the participants reported having experienced, can be more psychologically traumatic than being physically abused (Mbonu et al., 2009). According to the literature (Cloete et al., 2008; Dores Cruz et al., 2019; Feyissa et al., 2012; Kelly, 2002; Koodibetse, 2015; Mbonu et al., 2009; Peretti-Watel et al., 2007), the humiliation of being gossiped about is the most common form of enacted stigma. The literature corresponds with the findings of this research report, as all of the respondents reported having been gossiped about. This finding demonstrates that the mechanisms of stigma have not disappeared, it has only transitioned into more covert forms (Gilbert & Walker, 2010; Hatzenbuehler et al., 2013; Link et al., 2004; Link & Phelan, 2001, 2014; Misir, 2015).

Gossiping is a very anonymous act, as no one can really see who said what and when they said it, while physical abuse can be traced back to an individual group or person. Additionally, physical abuse is a crime, while gossiping is not. If anything, most people believe that gossiping is a victimless crime as they are not directly, or physically hurting the person that they are gossiping about. However, Dores Cruz et al (2019) and Link and Phelan's (2014) work demonstrates that gossip is much more powerful and efficient than physical abuse. People can be jailed for physical abuse, as stated in South African laws (i.e. the Bill of Rights of 1996, the Labour Relations Act of 1995, and the Employment Equity Act of 1998) that protect people against it (Afrika, 2016; Health4Men, 2015; Modise & Mahomed, 2011).

There are no laws that protect people against gossiping, which means people do not get arrested for it. Which makes it the most ideal weapon for hurting one's opponent, as there is no blow back for the perpetrator (Link & Phelan, 2014). And usually no one knows who the perpetrator even is, but everyone contributes to their successful cause as they keep retelling the hurtful rumour to others. The successful purpose of the perpetrator is to keep their victim down and out as the people, who have heard the rumour, starts to avoid and abuse the victim for them (Link & Phelan, 2014). As such the perpetrator never actually has to lift a finger to oppress their victim, the entire community does it for them (Dores Cruz et al., 2019). Therefore, gossiping is the most dangerous form of enacted stigma. Physical abuse is often times one on one, but with gossiping it is a single victim up against a community of thousands, as the gossip sours the mood and keeps the victim from being able to access employment opportunities, medical assistance, and social and psychological services (Link & Phelan, 2014). The soured mood creates a situation where no one wants to interact with the person, and therefore they cannot access the available services or resources. Fulfilling the goal of the gossip.

Given all of the evidence, as presented above, it is very clear why the participants have such a major issue with gossiping. It is dangerous to the physical, social and psychological health of the participants and their children, within the community (Link & Phelan, 2014). Gossip needs to be avoided at all costs. It is not just words, it is livelihoods. However, it must be noted that being physically abused is emotionally very traumatic. Leading to the possibility that the participants might not have felt like sharing their experiences with outsiders, like the researcher. Therefore, it cannot be concluded that the participants have never experienced instances of physical abuse within the community.

In conclusion, the findings of this section demonstrate that stigma is still present in society. Its main mechanism of operation is gossiping. Additionally, there is also an issue of institutional stigma within the clinic setting. The green card system that is utilized by the clinic for filing purposes are being repurposed by staff, to stigmatize PLHVs by disclosing their HIV – positive status to the community, without their permission. These acts of unlawful disclosure are violations of PLHVs rights to confidentiality. These violations expose the participants to gossiping within the community and puts their livelihoods and health at stake. Therefore, the participants expressed a desire for the green card system to be dispended with. The gossiping also needs to be addressed, as it poses a serious threat to the participants' social, physical and psychological health.

The following section will focus on how the participants react to the enacted stigma that they have experienced as PLHVs with the P.I.S.

4. 3 PLHVs Reactions to experienced stigma:

The second objective of this research project was to describe how PLHVs responded to enacted stigma. In the previous section it was established that PLHVs did experience enacted stigma within their community. These experiences of enacted stigma came in two forms, namely institutional and individual discrimination. In the section that follows the discussion will focus on how the participants reacted to the enacted stigma that they experienced. According to the data collected, the participants responded to enacted stigma with self – isolation and impression management tactics. The participants utilized these two tactics to protect themselves from experiencing further instances of enacted stigma. In essence the participants adopted tactics that helped them to avoid being discriminated against within their community. PLHVs stigma mitigation strategies will be the focus of the discussion that follows from here.

4. 3. 1 Self – Isolation:

When faced with the reality of an abnormal identity (i.e. spoiled) Goffman (1963) says that people will employ coping mechanisms that can help them manage their identity so that they can remain socially acceptable to others. In Goffman's (1963) terms, these coping mechanisms are tactics that allows a person to re-align their spoiled actual identity with their accepted virtual identity. As explained during the literature review, a person's virtual identity is what people expect that person to be like, it is not who they actually are (Goffman, 1963). Self – Isolation is one of the tactics that people employ to help them manage their actual identity (Dores Cruz et al., 2019; Hatzenbuehler et al., 2013; Link & Phelan, 2001, 2014; Misir, 2015). Self – Isolation is a social process where a person with a discrediting actual identity, consciously and actively avoids interacting with people that can directly or indirectly disclose their spoiled identity (Goffman, 1963; Link & Phelan, 2013; Link & Phelan, 2001, 2014). In the most extreme form of isolation, people will even avoid being seen in close proximity to anyone, or anything that can betray their actual identity. As such, life in self – isolation is a very lonely existence. People who are in self – isolation, due to the loneliness, tend to have very poor mental health, and can be suicidal (Hatzenbuehler et al., 2013; Link & Phelan, 2014).

As was established during the previous section, being identified as a HIV – positive person within the P.I.S. community exposes a person to gossip which can have serious negative consequences for a person's reputation (Dores Cruz et al., 2019) and health (Link & Phelan, 2014). As such, there is a very high motivation for the participants to avoid having the community identify them as HIV – positive. For the purpose of avoiding suspicion, all of the participants in this study engaged in self – isolation tactics. All four of the participants only had one or two persons outside their immediate family that knew about their status. Due to their self – imposed isolation the participants did not frequently access any available assistance, (i.e. food assistance) within the community. Additionally, the participants also reported feelings of loneliness as they had no one to share their emotional and physical burdens with.

When asked if she would like to talk to someone about her experiences and feelings as a person living with HIV, Participant 101 responded in a way that indicated a strong feeling of loneliness and a desire to talk about her situation. It became very clear when she responded with *"That is true"* after a discussion about the emotional loneliness that PLHVs experience within their communities at large. The conclusion around the loneliness that PLHVs experience due to their self – isolation, was also supported by Participant 202's adamant *"uh-huh* **[in the negative]***",* when she was asked if her friend, who was supervising her children during the researcher's interview with her, knew of her status. These admissions indicate that the participants did not have a lot of intimate relations with other people, due to their desire for secrecy which has led them to isolate themselves from most of their friends and family. This finding corresponds with the literature, as stated previously.

Inquiring about the emotional support available in the community, the researcher was surprised to find out that the community did not have any active support groups for people living with

HIV. However, all of the participants indicated that they would be willing to attend a support group, if one existed. This willingness is an indication of their desire to express their struggles to others and receive emotional and physical support. As stated in the previous section, research has shown that PLHVs have a marked increase in self confidence in the presence of people with a similar stigma (Hatzenbuehler et al., 2013). As such, support groups would be very beneficial for PLHVs. However, at the moment that desire is not being met because there are no support groups within the community. That being said, Participant 202 and the KI did indicate that there had been support groups in the community in the past, but due to time constraints and safety reasons the practice could not be sustained. The P.I.S. is a community highlighted by high levels of crime, as noted during the literature review. Which was a major contributing factor to the discontinuation of the support groups within the community, according to Participant 202.

The participants' need for emotional support was further emphasized when the researcher asked the participants if they would be willing to start the new support group. All the participants expressed a willingness to do so. However, there was also an apprehension of the fact that the people in their community did not want to disclose their status to each other. This concern was very evident in the desire of Participant 303 for the researcher to talk quietly during the interview so that their neighbour would not overhear the conversation. Additionally, Participant 202 had a friend that was looking after her children during the interview, however, she indicated that this friend did not know why the researcher was there, or whether she was HIV positive or not. All of these examples indicated a desire to reach out, but also a deep fear of reaching out due to the serious negative consequences that can follow if, their status was to become known. Again, Participant 303's statement is very clear.

Participant 303 said: *"oh, my neighbour will gossip, I know how we live here".*

As is evident from the discussion above, the participants did all report living in self – isolation as they did not tell their friends or neighbours about their illness out of suspicion that they would gossip about them. The coping mechanism has made the participants experience feelings of loneliness, as they did not have anyone that they could share their emotional and physical burdens with. To this end, the participants thought that the establishment of a PLHV support group would help them feel less lonely. In the section that follows the focus will shift to a discussion of the utilization of Impression Management tactics as another way of avoiding enacted stigma.

4. 3. 2 Impression Management:

The only people that seemed to know about their status, as indicated by the participants and outside of the KI and the Researcher, were the participants' immediate family (i.e. children, parents and siblings). How they managed such a level of secrecy in a neighbourhood where people live less than a meter apart from each other, brings the discussion to the next tactic, namely Impression Management. Impression Management, as defined by Goffman (1959), is an active social process through which people try to manipulate other people's perceptions of themselves. The manipulation is done through the regulation of verbal and non – verbal information on the part of the manipulator. In essence, the manipulator only does and says things that promote a certain image of themselves, to others (Dunne et al., 2020). This image is usually a false representation of the person, meant to hide a perceived weakness or undesirable trait (Goffman, 1959).

With the use of impression management tactics, the participants have managed to avoid minimal (outside of the clinic) suspicion, by not engaging in any activities that would indirectly or directly identify them as PLHVs, sometimes to their own determent. A prime example of the detrimental health consequences of Impression Management tactics, is Participant 202's reported default on her ART medication. As noted during the literature review, if a PLHV defaults on their ART medication, they can become drug resistant which increases the chances that their HIV can transition into full blown AIDS (Azia et al., 2016; Kagee et al., 2011). AIDS is incurable and deadly, as such it is very important for PLHVs to take their medication as prescribed.

Due to Participant 202's Impression Management efforts, she was unable to eat and as such she could not take her ART medication as prescribed. Participant 202 does have access to food assistance at the Tshepang Program, where her children eat their dinner every day. However, Participant 202 was unable to go collect her food herself due to some back pain that she was experiencing, and rather than appear ill and let her son bring a plate of food home for her, she decided to stay without a meal. Thus, she was unable to take her medication, as a consequence. The sequence of events stood out as an example of impression management due to previous research showing that in poor communal communities, such as the P.I.S., being perceived to be more ill, or needy then the rest of the community can lead people in the community to think that a person is HIV – positive (Mbonu et al., 2009).

As such, Participant 202 employed an impression management tactic to hide the fact that she was ill, from her community, which protected her social health but seriously endangered her physical health. These consequences for Link and Phelan (2001), is the problem with stigma coping mechanisms, they have such a negative impact on a person's health, that the benefits a person receives from utilizing them are so little that the juice is just not worth the squeeze. According to Link and Phelan's (2014) theory, coping mechanisms actually benefit the stigmatizing individual more, than the stigmatized individual because they isolate and impoverish the victim so much that their social, physical and psychological health is detrimentally affected. This negative impact on the victim's health and standing benefits the instigator, as that was exactly what they wanted when they started stigmatizing the victim. As such, their cause has succeeded, while the victim's health has only deteriorated (Link & Phelan, 2014). As was the case for Participant 202, who had to go to bed hungry that evening.

Another consequence of Participant 202's impression management and subsequent ART default came later when she went to the clinic for her appointment. According to Participant 202, her default led the nurses to order her out of the clinic, this actions indicates judgement on the part of the nurses. It also indicates a secondary consequence of Participant 202's impression management tactic. The secondary consequence being an experience of enacted stigma as the nurses, who judged her default negatively, humiliated her outside the clinic, in front of her fellow community members. That being said, there are logistical reasons why Participant 202 could have been ordered out of the clinic. All of the participants have reported that the long queues at the clinic are a problem, as such the participant could have been asked to go outside due to over crowdedness inside the clinic. Additionally, the HIV service tent is outside the clinic, as noted during Participant 404's interview. However, during Participant 404's interview she also noted that when she went inside the clinic, the nurse very rudely ordered her outside, as such the possibility of judgement being a motivator here, is high despite the logistical factor that could have contributed to the situation.

To conclude this point, in order to not appear dependent, Participant 202 choose to forfeit her meal and thus forfeit her medicine. Forfeiting her medicine is a dangerous behaviour as discontinuation of ART, can lead to drug resistance, and ultimately death (Azia et al., 2016; Mbonu et al., 2009). It seems that this is the extent to which PLHVs will go to avoid being identified.

Another instance that indicated efforts among the participants to control fellow community members' perceptions of them, were evident in the fact that at least 50 percent of the participants expressed a desire to have their medication delivered to their homes, instead of having to collect it at the clinic. This desire correlates with Gilbert and Walker's (2010) work in which they documented a case of a young woman, who travelled across the country to collect her ART medication, as she did not want someone from her community to spot her at their local HIV clinic. Therefore, a desire not to be seen at an HIV clinic, is indicative of a desire not to be identified as HIV – positive (Wolf et al., 2014). As such, avoiding the clinic will aid the participants in their efforts to avoid identification.

A final example of the participants' attempts to avoid detection as PLHVs, was evident in Participant 202‘s indicated consciousness, that the sound of her medication shaking in her handbag, as she walked home from the clinic could disclose her status to others. This consciousness of one's neighbours was also demonstrated by Participant 303 in her request for the interview to be conducted quietly so that her neighbours could not over hear the conversation. Another indication of this consciousness, comes from Participant 202 stating that they cannot call an ambulance when they are unwell, because the medics asks them about their medication in front of everyone in attendance. The high density of the community makes the appearance of an ambulance a community event and therefore a public disclosure could occur. As such, Participant 202 stated that she could not call for an ambulance if she was unwell. This behaviour indicates that the participants' consciousness of their neighbours' presence, forces them to engage in impression management tactics that can have detrimental effects on their lives. Additionally, this example is also indicative of another case of insensitivity, on the part of the medics when dealing with possible PLHV patients.

The point that all of these examples illustrate is that Goffman (1959, 1963) was right, people have two identities, i.e. who they are and who other people expect them to be. People will actively try and ensure that other people continue to believe in their secondary identity through the practice of impression management. These examples show that the participants do engage in impression management and self-isolation tactics, to minimize their exposure as people living with HIV. On at least one occasion, as laid out above, these tactics has led the participants to experience negative interactions with their fellow community members. It can be concluded, impression management and self-isolation tactics help the participants to get by in their community, but it also severely disadvantages them in terms of their physical, psychological and social health.

In the section that follows the discussion will focus on the impact HIV has on the participants' relationships with their families. The government's standard advocating procedure recommends full disclosure of one's HIV status to one's family, friends and community for the purposes of awareness and acceptance (Gilbert & Walker, 2010; SA DoH, 2015). This advocacy is based on the idea that if a PLHV informs their family of their illness, they can be understanding and provide support to the PLHV (Maman et al., 2014). Additionally, disclosures aides' education efforts as people are exposed to the disease, which theoretically helps normalize the disease and the person within the community (SA DoH, 2015). However, research (Maman et al., 2014) has also shown that sometimes the opposite happens and PLHVs are physically abused or abandoned by their families and friends. The type of relationship that PLHVs in the P.I.S. have with their families will be the main focus of discussion in the section that follows.

4. 4 Family Acceptance:

Historically, after disclosure many PLHVs have experienced being shunned, or excommunicated by their partners, families and friends (Gilbert & Walker, 2010), which has resulted in an unwillingness to do so by many PLHVs (Maman et al., 2014). However, a positive that has emerged from this research, was that all of the participants had disclosed their HIV status to their family members without the negative experiences associated with it. In fact, all of the participants expressed that they received support from their family, especially their children, in ensuring that they took their medication and lived healthy. This finding was an unexpected result that stems from the fact that most of the participants' children had received HIV education at school. In the case of Participant 202 her children actually encouraged her to get tested in the first place.

This finding corresponds with the literature that have noted a decrease in internalized stigma and familial rejection, due to the education efforts that have been carried out in schools and clinics (AVERT, 2020b; Yigit et al., 2020). However, despite this acceptance from their families all of the participants lived in isolation within their community. As such, they were accessing or receiving very little assistance from the community and the government due to the self – isolation they had engaged in. All of the participants were receiving social grants in one form or another from the government, however, only Participant 202 and 303 had access to child assistance from a friend, and those friends did not know their status.

There was no continual anti-stigma education effort in the community, however, participants stated that the education they and their families received before and after testing, informed them about their illness and this information allowed them to overcome their shame and accept their status. Unfortunately, it does not seem to have had an impact on the attitudes of the community, as these women lived in secrecy, too afraid to access food assistance for fear of being gossiped about in the community.

These findings demonstrate that existing HIV education efforts are helping PLHVs to find acceptance within themselves and their families. Although it has done little to address the rampant stigma that is evident within the wider community. As such, it can be concluded that the existing HIV education efforts, are addressing issues surrounding internalized stigma, if it wishes to be effective in the long term, it needs to be expanded to address the stigma that exists within the wider community (Hatzenbuehler et al., 2013). Therefore, existing HIV education efforts are not expansive enough, which corresponds with the findings of existing literature (Andersson et al., 2020; Kimera et al., 2020; Link & Phelan, 2014).

4. 5 Conclusion:

Summarizing the preceding sections, it is evident from the participants' examples that stigma, in the form of gossiping, discrimination and judgement, was still active within the community and that the participants were utilizing self – isolation and impression management tactics to actively avoid being stigmatized. Additionally, the participants had also indicated that the existing HIV education efforts within the community, had helped them deal with their internalized stigma, and had helped their families to be more supportive and caring towards them, however, stigma was still very much prevalent within the community at large which negatively influenced the way the participants interacted with their fellow community members. Due to their strained relations with their neighbours, all the participants reported feeling lonely and isolated.

Given this isolated condition, the findings of this research report has led the researcher to make a few recommendations that would hopefully improve the quality of life, of the PLHVs in the P.I.S. These recommendations will be laid out in the chapter that follows, along with some concluding remarks.

Chapter 5: Conclusion and Recommendations

5.1 Introduction:

It has been concluded that (1) HIV – related stigma continues to exist within South African society, (2) people living with HIV respond to HIV - related stigma with impression management and self – isolation tactics, and (3) there are alternative interventions that will be recommended by the researcher, in the hopes of improving PLHVs quality of life. These recommendations include support groups, mass media representation and multi – level HIV information campaigns. In this final chapter, the focus of discussion will be on discussing the conclusions drawn from the previous chapter and the recommendations the researcher will be making based off of the conclusions. Finally, this research report will be concluded with a summary of the work.

5. 2 Discussion:

This research project has demonstrated that stigma continues to exist within the Princess Informal Settlement, and despite research to the contrary, the researcher was presented with no evidence that suggested that the enacted stigma had a physical nature. The two main forms of stigma that was active within the community was, the social forms of gossiping and institutional discrimination. Although these forms of stigma are less physical, they can be just as devastating to PLHVs physical, social and psychological health. Therefore, as argued by Goffman (1959), Link and Phelan (2001, 2014), and Hatzenbuehler at al. (2013), PLHVs actively engage in impression management and self – isolation tactics to avoid identification with a stigmatized identity. Consequently these tactics leave the PLHVs with a strong sense of loneliness which was expressed through a desire to participate in PLHV support groups.

In accordance with Link and Phelan (2001, 2014), it can be said that the emotional burden that stigma mitigation strategies imposes on their users, are so severe that they, indirectly and directly, weaken the person's social and psychological health. This in turn weakens the person's physical health even more. As such, stigma, directly and indirectly, exacts a physical and psychological toll on its victims, as demonstrated in the preceding chapter, which far outweighs the burden of physical abuse. Physical abuse is very traumatic, but physical bruises heal eventually, emotional ones rarely do. These participants also do not have the necessary access to services (i.e. psychologists, support groups, etc.) that would enable them to heal the emotional trauma that they have experienced.

Given the documented history of shunning, that was presented in the literature, I was rather surprised to note the positive effect that HIV education had on the PLHVs and their families. The participants showed little negative effects of internalized stigma due to the post-test counselling that they received which seemed to have debunked most of the common myths that underpin these believes. Additionally, their families were also more supportive and accepting of their condition. Although, due to the presence of stigma mitigating strategies, within the community it seems that the existing efforts were mostly ineffective as it did not address the attitudes of the community members, or the negative interactions that PLHVs were experiencing with the clinic staff.

The tendency to only focus on one aspect of stigma, has been sighted by Link and Phelan (2001, 2014) as the reason why stigma interventions have failed. Stigma is a social process that operates on both the micro and macro - level of society, as demonstrated in **Chapter 2 (Literature Review)** and **Chapter 4** (**Discussion)**, and therefore if one wishes to effectively combat the problem of stigma, one's intervention needs to be multi levelled as well. Existing efforts within the P.I.S. community is only focused on the micro – level, consequently it is not surprising that it has been ineffective at addressing the stigma that is present within the community at large (i.e. the macro – level).

Considering all of these findings, the focus will now shift to the recommendations that the researcher has made based off of the findings in this research report.

5. 3 Recommendations:

Based off of the findings of this research report the following recommendations have been made by the researcher.

5.3.1 Support Groups:

To address the very prevalent issue of the loneliness that PLHVs reported experiencing, due to the implementation of their stigma mitigation strategies, it is imperative that PLHV support groups be created within the community. Where there are none, support groups must be established. Where there have been, support groups need to be re-established. Where there are support groups they need to be supported and expanded to incorporate as many PLHVs as they can to maximize the positive emotional and social benefits that they can supply to PLHVs (e.g., group solidarity, collective bargaining). Social programs, like the Tshepang program in the Princess Informal Settlement, are possible locations for the hosting of these groups, support group gatherings must be flexible in time and location to accommodate the social and economic responsibilities of the PLHVs that will possibly be attending. Support groups in the morning and in the afternoon would be ideal to cater for personal preferences.

Support groups can provide PLHVs with much needed emotional, physical and psychological assistance, as it enables its members to bond and support each other (Bateganya et al., 2015; Tumwikirize et al., 2015; Tumwikirize & Zwane, 2016). Additionally, support groups also facilitates cohesion which could help PLHVs to assert their demands as a group. This group solidarity might also provide the PLHVs with safety in numbers and solidarity which could possible increase PLHVs collective self-confidence. Finally, support groups could also guide future research and government enquiry to the issues that have the highest priority for PLHVs. PLHV participation would increase the efficacy of interventions aimed at improving PLHVs quality of life. Thus, it is imperative that PLHV support groups are re-established within the P.I.S.

5.3.2 Institutional Responses:

Institutional discrimination was one of the two main forms of enacted stigma that the PLHVs reported experiencing within their community. As such there are a number of recommendations that will be made to improve the interactions that PLHVs have with members of their community, the police force, health care industry and social workers.

Firstly, Community policing needs to be implemented to ensure the safety of PLHVs that want to attend the support groups. Especially in poor areas where the police presence is the lowest. As stated previously, due to the horrendous conditions in the Princess Informal Settlement police have stopped working in the area, which is also the case in many other poor areas where the majority of PLHVs live (Makatile, 2018). As such, community policing needs to be re-established in these areas, to create a safe and trusting environment for PLHVs to thrive in. Community policing will also benefit the community at large. Sewage removal and infrastructure in and around the communities also needs to be improved to ensure that PLHVs live in a healthy environment and can travel safely to and from the clinic or support groups. Government institutions need to reinvest in these poor communities to improve service delivery and general safety. Research (Anakwa et al., 2020) has shown that PLHVs with access to food, treatment, safety, and services enjoy a better quality of life than those PLHVs that are deprived of these human rights. Therefore, service delivery is very important as it plays a key role in empowering PLHVs by providing them with a better standard of living.

Secondly, the insensitive attitudes of the clinic staff needs to be addressed. Strict public relation protocols need to be implemented that regulates interactions between patients and staff, with more direct and easy official channels for complaints to be made available (Nyblade et al., 2019). A lot of negative behaviour against PLHVs are not reported due to fear of further stigmatization and these channels need to be more easily accessible and anonymous to ensure no retaliation, on the part of health care workers. Thirdly, a multi-level information campaign needs to be launched on an individual, community and government level, with a focus on spreading information about the social inequalities that are perpetuated by stigma in society. Additionally, more localized and independent avenues of redress needs to be implemented to discourage stigmatization and those social institutions that perpetuate it. There needs to be a presence within the community that can act immediately to address any acts of enacted stigma, of any kind.

These recommendations serve to do two things, (1) to change the attitudes of stigmatizing people, and (2) to change the power relations that support the ability of people to enact their stigmatizing attitudes. These recommendations conform to the multi-faceted approach that Link and Phelan (2001, 2014) suggested was necessary for an intervention on stigma to be successful. According to Link and Phelan (2001, 2014), an intervention must either empower the victim or disempower the perpetrator. With these recommendations, the hope is to do both.

5.3.3 Empathetic Training for Police, Healthcare and Social Workers:

For a more positive relationship to develop between PLHVs and the first responders, there must be a change in how the first responders approach and interact with the PLHVs. Therefore, it is recommended that all first responders receive continual Empathetic Role Play training. Role play training and social exposure to PLHVs will be useful for inducing a mind change in the work force, with the idea of 'what if it was you, and how would you want people to treat you' as the guiding principles of the program. Role playing enables people to step into each other's shoes and by doing so, they gain an understanding of each other's struggles as individuals (Galetz, 2018; Larti et al., 2018; Singh et al., 2017).

Empathetic role playing training is highly effective but will have to be reinforced every six months, as the above research (Galetz, 2018; Singh et al., 2017) has shown, people's empathy starts to fade over time as they become desensitized to their environment. Empathetic role play training will have to be continuously reinforced with refresher training occurring periodically, as indicated above. Improved training programs will lead to a more positive relationship with the PLHV community as the front liners, will be more receptive to the needs of the PLHVs that they are interacting with.

A more positive relationship between PLHVs and front liners will encourage increased disclosure of crimes to the police, increased uptake of ART treatment, testing at clinics, and increased disclosure of sensitive issues that are impacting on PLHVs lives, to social workers. Also, increased openness within the community would help police, health care workers and social workers to improve their service delivery to PLHVs and the community as a whole. Making these professionals more effective in delivering the services that the PLHVs so desperately need, to ensure that they can live a good quality of life. Additionally, it will also enable PLHVs to have the courage to access these services without fear of stigmatization from the staff.

5.3.4 PLHV Pride Walk:

To boost group cohesion and confidence, something akin to a PLHV pride walk needs to be started with an attitude similar to 'we're queer and we're here'. A PLHV pride walk would be very beneficial for PLHVs as it would encourage a sense of self confidence. This pride walk builds on the potential positive aspects of impression management, where one resists stigma by doing the opposite of what is expected of you (Link & Phelan, 2014; Misir, 2015). Instead of hiding your supposed shame, you proudly flaunt it for everyone to see. Creating a group attitude that being HIV positive is not something to be ashamed of and that a person does not have to hide from society if they are HIV - positive. The approach creates pride from a tradition of rebelling against the establishment, in which case the PLHVs become revolutionaries, as opposed to victims or criminals. Which in itself can be empowering to people that do not want to be treated as victims or criminals.

PLHVs need a mind-set change that will empower them to resist the stigma that is oppressing them. This PLHV pride walk can be the first step in achieving that change. However, due to the logistics and costs associated with such a large event, it will only be able to be held annually but, if the point is exposure and solidarity that will be enough. For the pride walk to be successful and safe, the cooperation of the police and community needs to be induced first (Beresford, 2017).

5.3.5 HIV education:

Pre- and Post-test counselling for PLHVs and Sex education in schools, has proven to be successful, however, these efforts need to be expanded to the community at large and work places, with monthly seminars. Reinforcement of the anti - stigma principles need to be consistent and public, or else people can just close their doors and ignore it all, like they are currently doing.

There are 13 HIV days annually that address HIV - related stigma around the world (U.S. Department of Health & Human Services, 2020). However, it is not enough, awareness and advocacy needs to be persistent and obvious. Including more HIV-related content on TV will also assist in fermenting the minds of the people. Currently, Ishidigo is one example of these efforts but there needs to be more such cases and they need to be more diverse (Kerr et al., 2015; Koodibetse, 2015; Peek et al., 2015; Wildermuth, 2006). For these interventions one can borrow from the experiences of LGBTi+ advocacy programs that have subtly over the years strived to introduce more positive imagery of the community into the collective consciousness through mass media and television (Gomillion & Giuliano, 2011; Wildermuth, 2006). The LGBTi+ community struggled for decades, they are still struggling, for acceptance and equality (Broster, 2019). It should be expected that the fight against HIV-related stigma will follow the trajectory of the LGBT model and that the fight will need to be continuous and everywhere.

Link and Phelan (2001, 2014) calls for a multi – tier response to stigma that addresses the individual and institutional elements that perpetuates stigma within society. The list of recommendations attempts to address the issue of HIV – related stigma on an individual and institutional level in the P.I.S. and by doing so, the hope is to improve the quality of PLHVs lives within the settlement.

5. 4 Conclusion:

HIV - related stigma has been shown to cause PLHVs to engage in avoidance behaviour that negatively influences their physical, social and psychological health. These avoidance behaviours are called, stigma mitigation strategies and they involve the deployment of impression management and self – isolation tactics that hide the fact that PLHVs are HIV - positive from their family, friends and neighbours. These avoidance behaviours are physically and psychologically dangerous as stigma mitigation tactics forces PLHVs, firstly, to avoid seeking out medical assistance which negatively impacts their physical health as the HIV virus goes untreated. Secondly, it impacts their psychological health, as stigma mitigation tactics socially isolates PLHVs from their neighbours, which has made many PLHVs suffer from depression and suicidal thoughts, as they are unable to reach out and ask for social or emotional support.

Being stigmatized with the HIV virus, can ruin a person's reputation and life chances, as such, a lot of HIV – positive people do not want to be associated with the disease by being tested or committing to continuous ART treatment. A lot of people that have tested HIV – positive have been shunned by their families, fired from their jobs or physically abused. Therefore, a lot of people are afraid of testing positive. They would rather live life in ignorance than be identified as HIV – positive. This desire is a major problem, while they remain ignorant they unknowingly spread the HIV virus to other people which contributes to the perpetuation of the HIV pandemic in South Africa. That is why it is so fundamentally necessary for HIV interventions to address the issue of HIV – related stigma. It is one of the main reasons the HIV virus continues to be spread in the world today. By addressing the issue of HIV – related stigma, society will be addressing the issue of the HIV pandemic as well.

This research report has contributed to the HIV cause by researching the question of "How do South Africans experience and respond to HIV stigma?" During the research the objectives of the project was to 1) demonstrate the persistence of HIV – related stigma, 2) to describe how PLHVs responded to experienced stigma, and 3) to suggest alternative interventions that can improve the quality of PLHVs lives. With the use of one – on – one semi – structured interviews, four HIV – positive women from the Princess Informal Settlement was interviewed about their experiences as people living with HIV within their community. The four participants provided the researcher with information rich examples of incidents of enacted stigma and how they responded to their experiences. All of the participants deployed impression management and self - isolation tactics to avoid suspicion from their neighbours. The employment of these tactics led the participants to feel very lonely and isolated within their communities.

The examples provided by the participants, enabled the researcher to do three things, 1) demonstrate that there were instances of enacted stigma within the community, 2) to describe how the participants responded to their experiences of enacted stigma, and 3), to recommend alternative interventions that can improve the quality of life of PLHVs inside the Princess Informal Settlement community. Therefore, the researcher has successfully carried out the project and is able to make a few recommendations that could improve the quality of PLHVs lives. To address the factors that were contributing to the low quality of life of PLHVs within the P.I.S. community the following recommendations were made to inform a multi-levelled approach, as suggested by Link and Phelan (2001, 2014).

The recommendations are as follows:

- Multi – tiered approach to HIV information campaigns throughout the country at individual, community and government levels
- PLHV Support Groups
- PLHV pride walk
- Reinvestment of municipal service delivery within the community
- Continual Empathetic Role Play Training for all PLHV front liners (i.e. police officers, health care workers, and social workers)
- HIV education workshops within the P.I.S. community
- PLHV Mass Media representation

It is hoped that these alternative interventions will assist PLHVs to improve their own lives, by empowering them through group solidarity and support. Finally, it is hoped that the work will contribute to improving existing HIV - related intervention programs and that people will be reminded, that the problem of the HIV pandemic cannot be addressed without first addressing the problem of HIV – related stigma as well.

Reference List

Afrika, L. “Laws in South Africa That Protects HIV Positive Citizens.” GoLegal, 2016. https://www.golegal.co.za/laws-south-africa-protect-hiv-positive-citizens/.

Aggleton, P., R., Parker, G., and Joint United Nations Programme on HIV/AIDS. *A Conceptual Framework and Basis for Action: HIV/AIDS Stigma and Discrimination*. Geneva: UNAIDS, 2004.

“Aids Activist ‘Attacked Twice.’” *News24*, 2001. https://www.news24.com/news24/aids-activist-attacked-twice-20010719.

AIDS.gov. “A Timeline of HIV and AIDS.” HIV.gov, n.d. https://www.hiv.gov/hiv-basics/overview/history/hiv-and-aids-timeline.

Anakwa, N., O., Teye-Kwadjo, E., and Kretchy, I., A. “Effect of HIV-Related Stigma and HIV-Related Stress on HIV Disclosure Concerns: A Study of HIV-Positive Persons on Antiretroviral Therapy at Two Urban Hospitals in Ghana.” *Applied Research in Quality of Life*, 2020. https://doi.org/10.1007/s11482-020-09813-6.

Andersson, G., Z., Reinius, M., Eriksson, L., E., Svedhem, V., Esfahani, F., M., Deuba, K., Rao, D., Lyatuu, G., W., Giovenco, D., and Ekström, A., M. “Stigma Reduction Interventions in People Living with HIV to Improve Health-Related Quality of Life.” *The Lancet HIV* 7, no. 2 (2020): e129–40. https://doi.org/10.1016/S2352-3018(19)30343-1.

Antonie, S. “Protests Bring Fire and Looting to Princess.” *The Citizen*, 2017. https://citizen.co.za/news/south-africa/1452747/roodepoort-protest-action-spills-onto-albertina-sisulu-rd-truck-set-alight/.

AVERT. “History of HIV and AIDS Overview.” AVERT.org, 2020. avert.org/professionals/history-hiv-aids/overview#footnote95_y08xm08.

AVERT. “HIV and AIDS in South Africa.” AVERT.org, 2020. https://www.avert.org/professionals/hiv-around-world/sub-saharan-africa/south-africa.

AVERT. “HIV Stigma and Discrimination.” AVERT.org, 2015. https://www.avert.org/professionals/hiv-social-issues/stigma-discrimination.

AVERT. “I’m Worried about Hiv and Aids.” AVERT.org, 2020. https://www.avert.org/about-hiv-aids/worried-about-hiv.

Azia, I., N., Mukumbang, F., C., and Van Wyk, B. “Barriers to Adherence to Antiretroviral Treatment in a Regional Hospital in Vredenburg, Western Cape, South Africa.” *Southern African Journal of HIV Medicine* 17, no. 1 (2016). https://doi.org/10.4102/sajhivmed.v17i1.476.

Bagchi, A., D., and Holzemer, W., L. “HIV-Related Stigma among Health Care Workers in New Jersey.” *Stigma and Health*, 2020. https://doi.org/10.1037/sah0000234.

Bandeira, M. “The People Living With HIV Stigma Index: South Africa 2014.” SA AIDS 2015 Conference: Human Sciences Research Council (HSRC), 2015. https://health-e.org.za/search/The+people+living+with+HIV+stigma+index+2014.

Batchelder, A., W., Foley, J., D., Wirtz, M., R., Mayer, K., and O’Cleirigh, C. “Substance Use Stigma, Avoidance Coping, and Missed HIV Appointments Among MSM Who Use Substances.” *AIDS and Behavior*, 2020. https://doi.org/10.1007/s10461-020-02982-3.

Bateganya, M., H., Ugo Amanyeiwe, Uchechi Roxo, and Maxia Dong. “Impact of Support Groups for People Living With HIV on Clinical Outcomes: A Systematic Review of the Literature.” *JAIDS Journal of Acquired Immune Deficiency Syndromes* 68 (2015): S368–74. https://doi.org/10.1097/QAI.0000000000000519.

Beresford, M. “Uganda Pride Cancelled amid Threats Police Arrest and Physical Harm.” *Pink News*, 2017. https://www.pinknews.co.uk/2017/08/17/uganda-pride-cancelled-amid-threats-police-arrest-and-physical-harm/.

Bhardwaj, S, Barron, P., Pillay, Y., Treger-Slavin, L., Robinson, P., Goga, A., and Sherman, G. “Elimination of Mother-to-Child Transmission of HIV in South Africa: Rapid Scale-up Using Quality Improvement.” *South African Medical Journal* 104, no. 3 (2014): 239. https://doi.org/10.7196/SAMJ.7605.

Blacklock, C., Gonçalves Bradley D., C., Mickan, S., Willcox, M., Roberts, N., Bergström, A., and Mant, D. “Impact of Contextual Factors on the Effect of Interventions to Improve Health Worker Performance in Sub-Saharan Africa: Review of Randomised Clinical Trials.” Edited by E. Faragher B. *PLOS ONE* 11, no. 1 (2016): e0145206. https://doi.org/10.1371/journal.pone.0145206.

Bloem, A. “Watch: Roodepoort Police Remove Illegal Connections at Princess Informal Settlement.” Roodepoort Record, 2020. https://roodepoortrecord.co.za/2020/07/17/watch-roodepoort-police-remove-illegal-connections-at-princess-informal-settlement/.

Bolderston, A. “Conducting a Research Interview.” *Journal of Medical Imaging and Radiation Sciences* 43, no. 1 (2012): 66–76. https://doi.org/10.1016/j.jmir.2011.12.002.

Bond, V., Nomsenge, S., Mwamba, M., Ziba, D., Birch, A., Mubekapi-Musadaidzwa, C., Vanqa, N. et al. “‘Being Seen’ at the Clinic: Zambian and South African Health Worker Reflections on the Relationship between Health Facility Spatial Organisation and Items and HIV Stigma in 21 Health Facilities, the HPTN 071 (PopART) Study.” *Health & Place* 55 (2019): 87–99. https://doi.org/10.1016/j.healthplace.2018.11.006.

Bowen, A., G. "Preparing a Qualitative Research-Based Dissertation: Lessons Learned." *The Qualitative Report* 10, no. 2 (2005): 208–22.

Burton, R., Giddy, J., and Stinson, K. "Prevention of Mother-to-Child Transmission in South Africa: An Ever-Changing Landscape." *Obstetric Medicine* 8, no. 1 (2015): 5–12. https://doi.org/10.1177/1753495X15570994.

Butina, M. "A Narrative Approach to Qualitative Inquiry." *American Society for Clinical Laboratory Science* 28, no. 3 (2015): 190–96. https://doi.org/10.29074/ascls.28.3.190.

Camacho, G., Kalichman, S., and Katner, H. "Anticipated HIV-Related Stigma and HIV Treatment Adherence: The Indirect Effect of Medication Concerns." *AIDS and Behaviour* 24, no. 1 (2020): 185–91. https://doi.org/10.1007/s10461-019-02644-z.

Campbell, C., Nair, Y., Maimane, S., and Nicholson, J. "`Dying Twice': A Multi-Level Model of the Roots of AIDS Stigma in Two South African Communities." *Journal of Health Psychology* 12, no. 3 (2007): 403–16. https://doi.org/10.1177/1359105307076229.

Chabalala, J. "Man Beaten to Death in Roodepoort Informal Settlement." *News24*, 2017. https://www.news24.com/SouthAfrica/News/man-beaten-to-death-in-roodepoort-informal-settlement-20170309.

Chabalala, J. "'We Are Going to Fight until They Give Us Keys' - Protest for RDP Houses." *News24*, 2017. https://www.news24.com/news24/southafrica/news/we-are-going-to-fight-until-they-give-us-keys-protest-for-rdp-houses-20170309.

Chambers, L., A., Rueda, S., Baker, N., D., Wilson, M., G., Deutsch, R., Raeifar, E., Rourke, S., B., and the Stigma Review Team. "Stigma, HIV and Health: A Qualitative Synthesis." *BMC Public Health* 15, no. 1 (2015): 848. https://doi.org/10.1186/s12889-015-2197-0.

"Choice Condoms Go to the Max." *Western Cape Government Website*, 2019. https://www.westerncape.gov.za/general-publication/choice-condoms-go-max.

Clarke, V., and Braun, V. "Using Thematic Analysis in Counselling and Psychotherapy Research: A Critical Reflection." *Counselling and Psychotherapy Research* 18, no. 2 (2018): 107–10. https://doi.org/10.1002/capr.12165.

Claybrick. "Roodepoort's Princess Plots Informal Settlement." Claybrick.org, n.d. https://claybrick.co.za/news/roodepoort%E2%80%99s-princess-plots-informal-settlement.

Cloete, A., Simbayi, L., C., Kalichman, S., C., Strebel, A., and Henda, N. "Stigma and Discrimination Experiences of HIV-Positive Men Who Have Sex with Men in Cape Town, South Africa." *AIDS Care* 20, no. 9 (2008): 1105–10. https://doi.org/10.1080/09540120701842720.

Cornellius, G., S. “Revisiting the Approach to Informal Settlement Development in South Africa, with a Special Focus on the Impact of HIV/AIDS.” Dissertation for Master Degree, North-West University, 2016. https://pdfs.semanticscholar.org/6be8/0e70e4a1aa1a3e2de886b616e897918b0e8a.pdf.

Correspondent. “Alleged Rapist Burnt to Death in Mob Justice Attack.” *News24*, 2017. https://www.news24.com/news24/SouthAfrica/News/alleged-rapist-burnt-to-death-in-mob-justice-attack-20170212.

Dahab, M., Kielmann, K., Charalambous, S., Karstaedt, A., S., Hamilton, R., Lettie La Grange, L., Fielding, K., L., Churchyard, G., J., and Grant, A., D. “Contrasting Reasons for Discontinuation of Antiretroviral Therapy in Workplace and Public-Sector HIV Programs in South Africa.” *AIDS Patient Care and STDs* 25, no. 1 (2011): 53–59. https://doi.org/10.1089/apc.2010.0140.

Deacon, H., Stephney, I., and Prosalendis, S. *Understanding HIV/AIDS Stigma: A Theoretical and Methodological Analysis*. HSRC Research Monograph. Cape Town, South Africa : Chicago, IL: HSRC Press ; Distributed worldwide, except Africa, by Worldwide Publishers Group, 2005.

DeFranzo, S., E. “Advantages and Disadvantages of Face-to-Face Data Collection.” Snap Surveys Blog, 2014. https://www.snapsurveys.com/blog/advantages-disadvantages-facetoface-data-collection/.

Demme, J. *Philadelphia*. Drama. Tristar Pictures, 1993.

Denis, P. “New Patterns of Disclosure: How HIV-Positive Support Group Members from KwaZulu-Natal Speak of Their Status in Oral Narratives.” *Medical History* 58, no. 2 (2014): 278–97. https://doi.org/10.1017/mdh.2014.23.

Van Dijk, D. “First Do No Harm.” *Netherlands Journal of Critical Care* 28, no. 1 (2020): 1–5.

Dlamini, P., S., Wantland, D., Makoae, L., N., Chirwa, M., Kohi, T., W., Greeff, M., Naidoo, J., Mullan, J., Uys, L., R., and Holzemer, W., L. “HIV Stigma and Missed Medications in HIV-Positive People in Five African Countries.” *AIDS Patient Care and STDs* 23, no. 5 (2009): 377–87. https://doi.org/10.1089/apc.2008.0164.

Dores Cruz, T. D., Beersma, B., Dijkstra, M., T., M., and Bechtoldt, M., N. “The Bright and Dark Side of Gossip for Cooperation in Groups.” *Frontiers in Psychology* 10 (2019): 1374. https://doi.org/10.3389/fpsyg.2019.01374.

Du Toit, L. “Shifting Meanings of Postconflict Sexual Violence in South Africa.” *Signs: Journal of Women in Culture and Society* 40, no. 1 (2014): 101–23. https://doi.org/10.1086/676895.

Duby, Z., Fong-Jaen, F., Nkosi, B., Brown, B., and Scheibe, A. “‘We Must Treat Them like All the Other People’: Evaluating the Integrated Key Populations Sensitivity Training Programme for

Healthcare Workers in South Africa." *Southern African Journal of HIV Medicine* 20, no. 1 (2019). https://doi.org/10.4102/sajhivmed.v20i1.909.

Duffy, L. "Suffering, Shame, and Silence: The Stigma of HIV/AIDS." *Journal of the Association of Nurses in AIDS Care* 16, no. 1 (2005): 13–20. https://doi.org/10.1016/j.jana.2004.11.002.

Dunne, N., J., Brennan, N., M., and Kirwan, C., E. "Impression Management and Big Four Auditors: Scrutiny at a Public Inquiry." *Accounting, Organizations and Society*, 2020, 101170. https://doi.org/10.1016/j.aos.2020.101170.

Edwards, R., and Holland, J. *What Is Qualitative Interviewing?* What Is? Research Methods Series. London : New Delhi: Bloomsbury, 2013.

Ekstrand, M., L., Ramakrishna, J., Bharat, S., and Heylen, E. "Prevalence and Drivers of HIV Stigma among Health Providers in Urban India: Implications for Interventions." *Journal of the International AIDS Society* 16 (2013): 18717. https://doi.org/10.7448/IAS.16.3.18717.

Engelbrecht, L. "Cultural Friendliness as a Foundation for the Support Function in the Supervision of Social Work Students in South Africa." *International Social Work* 49, no. 2 (2006): 256–66. https://doi.org/10.1177/0020872806061240.

Etikan, I. "Comparison of Convenience Sampling and Purposive Sampling." *American Journal of Theoretical and Applied Statistics* 5, no. 1 (2016): 1. https://doi.org/10.11648/j.ajtas.20160501.11.

Fanon, F. *Black Skin, White Masks.* United States: Grove Press, 1952.

Feinberg, M., Willer, R., Stellar, J., and Keltner, D. "The Virtues of Gossip: Reputational Information Sharing as Prosocial Behaviour." *Journal of Personality and Social Psychology* 102, no. 5 (2012): 1015–30. https://doi.org/10.1037/a0026650.

Ferreira, S., and Ferreira, R., J. "Teaching Social Work Values by Means of Socratic Questioning." *Social Work/Maatskaplike Werk* 51, no. 4 (2015). https://doi.org/10.15270/51-4-463.

Feyissa, G., T., Abebe, L., Girma, E., and Woldie, M. "Stigma and Discrimination against People Living with HIV by Healthcare Providers, Southwest Ethiopia." *BMC Public Health* 12, no. 1 (2012): 522. https://doi.org/10.1186/1471-2458-12-522.

Friedland, B., A., Gottert, A., Hows, J., Baral, S., D., Sprague, L., Nyblade, L., McClair, T., L., et al. "The People Living with HIV Stigma Index 2.0: Generating Critical Evidence for Change Worldwide." *AIDS* 34, no. 1 (2020): S5–18. https://doi.org/10.1097/QAD.0000000000002602.

Galetz, E., A. "Simulated Role-Play to Improve Attitudes and Empathy towards Older Adults in Accelerated Nursing Students." Doctor of Philosophy, the University of Texas at Tyler, 2018. http://hdl.handle.net/10950/1181.

Geffen, B., N. "Mbeki Confirms He Is an AIDS Denailist." *Groundup News*, 2016. https://www.groundup.org.za/article/mbeki-confirms-he-aids-denialist.

Geibel, S., Gottert, A., Friedland, B., A., Jeremiah, K., McClair, T., L., Mallouris, C., Kentutsi, S., Hows, J., Sprague, L., and Pulerwitz, J. "Internalized Stigma among People Living with HIV: Assessing the Internalized AIDS-Related Stigma Scale in Four Countries." *AIDS* 34, no. 1 (2020): S33–41. https://doi.org/10.1097/QAD.0000000000002649.

Gerbert, B., Sumser, J., and Maguire, B., T. "The Impact of Who You Know and Where You Live on Opinions about Aids and Health Care." *Social Science & Medicine* 32, no. 6 (1991): 677–81. https://doi.org/10.1016/0277-9536(91)90146-4.

Gilbert, L. "'The Mercurial Piece of the Puzzle': Understanding Stigma and HIV/AIDS in South Africa." *SAHARA-J: Journal of Social Aspects of HIV/AIDS* 13, no. 1 (2016): 8–16. https://doi.org/10.1080/17290376.2015.1130644.

Gilbert, L., and Walker, L. "'My Biggest Fear Was That People Would Reject Me Once They Knew My Status…': Stigma as Experienced by Patients in an HIV/AIDS Clinic in Johannesburg, South Africa." *Health & Social Care in the Community* 18, no. 2 (2010): 139–46. https://doi.org/10.1111/j.1365-2524.2009.00881.x.

Gisselquist, D. "Denialism Undermines AIDS Prevention in Sub-Saharan Africa." *International Journal of STD & AIDS* 19, no. 10 (2008): 649–55. https://doi.org/10.1258/ijsa.2008.008180.

Goffman, E. *Stigma: Notes on the Management of Spoiled Identity*. A Touchstone Book. New York: Simon & Schuster, 1963.

Goffman, E. *The Presentation of Self in Everyday Life*. London: Penguin, 1959.

Gomillion, S., C., and Giuliano, T., A. "The Influence of Media Role Models on Gay, Lesbian, and Bisexual Identity." *Journal of Homosexuality* 58, no. 3 (2011): 330–54. https://doi.org/10.1080/00918369.2011.546729.

Gottert, A., McClair, T., L., Pulerwitz, J., and Friedland, B., A. "What Shapes Resilience among People Living with HIV? A Multi-Country Analysis of Data from the PLHIV Stigma Index 2.0." *AIDS* 34, no. 1 (2020): S19–31. https://doi.org/10.1097/QAD.0000000000002587.

Govender, V., Fried, J., Birch, S., Chimbindi, N., and Cleary, S. "Disability Grant: A Precarious Lifeline for HIV/AIDS Patients in South Africa." *BMC Health Services Research* 15, no. 1 (2015): 227. https://doi.org/10.1186/s12913-015-0870-8.

Greeff, M., Phetlhu, R., Makoae, L., N., Dlamini, P., S., Holzemer, W., L., Naidoo, J., R., Kohi, T., W., Uys, L., R., and Chirwa, M., L. "Disclosure of HIV Status: Experiences and Perceptions of Persons Living With HIV/AIDS and Nurses Involved in Their Care in Africa." *Qualitative Health Research* 18, no. 3 (2008): 311–24. https://doi.org/10.1177/1049732307311118.

Hamann, C., Thembani, M., and Götz, G. "Backyard and Informal Dwellings (2001-2016)." GCRO Map of the Month. Gauteng City - Region Observatory, 2018. https://www.gcro.ac.za/outputs/map-of-the-month/detail/backyard-and-informal-dwellings-2001-2016/.

Hartwig, K., A., Kissioki, S., and Hartwig, C., D. "Church Leaders Confront HIV/AIDS and Stigma: A Case Study from Tanzania." *Journal of Community & Applied Social Psychology* 16, no. 6 (2006): 492–97. https://doi.org/10.1002/casp.897.

Hatzenbuehler, M., L., Phelan, J., C., and Link, B., G. "Stigma as a Fundamental Cause of Population Health Inequalities." *American Journal of Public Health* 103, no. 5 (2013): 813–21. https://doi.org/10.2105/AJPH.2012.301069.

HDA. "Gauteng: Informal Settlements Status." HDA Research Report. Johannesburg: The Housing Development Agency, 2013. http://thehda.co.za/pdf/uploads/multimedia/HDA_Informal_settlements_status_Gauteng.pdf.

HDA. "Gauteng: Informal Settlements Status (2013)." Johannesburg: The Housing Development Agency, 2013. http://thehda.co.za/pdf/uploads/multimedia/HDA_Gauteng_Report_lr.pdf.

Health4Men. "The Rights of People with HIV and AIDS." Health4Men, 2015. https://www.health4men.co.za/rights_disclosure/07/23/the-rights-of-people-with-hiv-and-aids/.

Hodgson, I., Nakiyemba, A., Seeley, J., Bitira, D., and Gitau-Mburu, D. "Only Connect – the Role of PLHIV Group Networks in Increasing the Effectiveness of Ugandan HIV Services." *AIDS Care* 24, no. 11 (November 2012): 1368–74. https://doi.org/10.1080/09540121.2012.656568.

Human Sciences Research Council (HSRC). "The Fifth South African National HIV Prevalence, Incidence, Behaviour and Communication Survey, 2017: HIV Impact Assessment Summary Report." Cape Town: Human Sciences Research Council, 2018.

Human Sciences Research Council (HSRC). "The People Living With HIV Stigma Index: South Africa 2014." South African National AIDS Council (SANAC), 2015. http://www.hsrc.ac.za/uploads/pageNews/259/Abridged%20Stigma%20Index%20Report-1.pdf.

Hymes, K., B., Greene, J., B., Marcus, A., William, D., C., Cheung, T., Prose, N., S., Ballard, H., and Laubenstein, L., J. "Kaposi's sarcoma in homosexual men—a report of eight cases." *The Lancet* 318, no. 8247 (1981): 598–600. https://doi.org/10.1016/S0140-6736(81)92740-9.

Jager, J., Putnick, D., L., and Bornstein, M., H. "II. More than Just Convenient: The Scientific Merits of Homogeneous Convenience Samples: Developmental Methodology." *Monographs of the*

Society for Research in Child Development 82, no. 2 (2017): 13–30. https://doi.org/10.1111/mono.12296.

Johnson, L., F., Dorrington, R., E., and Moolla, H. "Progress towards the 2020 Targets for HIV Diagnosis and Antiretroviral Treatment in South Africa." *Southern African Journal of HIV Medicine* 18, no. 1 (2017). https://doi.org/10.4102/sajhivmed.v18i1.694.

Jones, M., L. "Perceptions of Rural Community-Based Nurses and Perceived Stigma Related to HIV/AIDS: A Mixed-Methods Study." Hampton University: ProQuest Dissertations Publishing, 2020. https://search.proquest.com/openview/ecc75a380bb951a35218479326b4cbe3/1?pq-origsite=gscholar&cbl=18750&diss=y.

Kagee, A., Remien, R., H., Berkman, A., Hoffman, S., Campos, L., and Swartz, L. "Structural Barriers to ART Adherence in Southern Africa: Challenges and Potential Ways Forward." *Global Public Health* 6, no. 1 (2011): 83–97. https://doi.org/10.1080/17441691003796387.

Kelly, G., and Groundup. "Everything You Need to Know about Social Grants." Groundup, 2017. https://www.groundup.org.za/article/everything-you-need-know-about-social-grants_820/#:~:text=The%20value%20of%20the%20Child%20Support%20Grant%20is,must%20provide%20proof%20of%20your%20primary%20caregiver%20status.

Kelly, M., M. "Fighting AIDS-Related Stigma in Africa." *Population Reference Bureau*, 2002.

Kerr, J., C., Valois, R., F., DiClemente, R., J., Carey, M., P., Stanton, B., Romer, D., Fletcher, F., et al. "The Effects of a Mass Media HIV-Risk Reduction Strategy on HIV-Related Stigma and Knowledge among African American Adolescents." *AIDS Patient Care and STDs* 29, no. 3 (2015): 150–56. https://doi.org/10.1089/apc.2014.0207.

Kimera, E., Vindevogel, S., Reynaert, D., Justice, K., M., Rubaihayo, J., De Maeyer, J., Engelen, A., Musanje, K., and Bilsen, J. "Experiences and Effects of HIV-Related Stigma among Youth Living with HIV/AIDS in Western Uganda: A Photovoice Study." Edited by Tamara Taggart. *PLOS ONE* 15, no. 4 (2020): e0232359. https://doi.org/10.1371/journal.pone.0232359.

Klaas, N., E., Thupayagale-Tshweneagae, G., and Makua, T., P. "The Role of Gender in the Spread of HIV and AIDS among Farmworkers in South Africa." *African Journal of Primary Health Care & Family Medicine* 10, no. 1 (2018). https://doi.org/10.4102/phcfm.v10i1.1668.

Kleingeld, C. "An Evaluation of the 'Colleague Sensitivity' Personnel Capacity Building Programme of the South African Police Service." Masters, University of Pretoria, 2004.

Knapik, M. "The Qualitative Research Interview: Participants' Responsive Participation in Knowledge Making." *International Journal of Qualitative Methods* 5, no. 3 (2006): 77–93. https://doi.org/10.1177/160940690600500308.

Koodibetse, K., G. “HIV/AIDS Stigma and Discrimination in South Africa – Still a Problem.” *South African Medical Journal* 105, no. 9 (2015): 703. https://doi.org/10.7196/SAMJnew.7811.

Korstjens, I., and Moser, A. “Series: Practical Guidance to Qualitative Research. Part 4: Trustworthiness and Publishing.” *European Journal of General Practice* 24, no. 1 (2018): 120–24. https://doi.org/10.1080/13814788.2017.1375092.

Laher, S., Fynn, A., and Sherianne Kramer, S. eds. *Transforming Research Methods in the Social Sciences: Case Studies from South Africa*. Wits University Press, 2019. https://doi.org/10.18772/22019032750.

Larti, N., Ashouri, E., and Aarabi, A. “The Effects of an Empathy Role-Playing Program for Operating Room Nursing Students in Iran.” *Journal of Educational Evaluation for Health Professions* 15 (2018): 29. https://doi.org/10.3352/jeehp.2018.15.29.

Leerkes, E., M., Bailes, L., G., and Augustine, M., E. “The Intergenerational Transmission of Emotion Socialization.” *Developmental Psychology* 56, no. 3 (2020): 390–402. https://doi.org/10.1037/dev0000753.

Li, L., Lin, C., Feng, N., Nguyen, D., B., Cao, W., Le, A., T., and Nguyen, A., T. “Stigma Related to HIV and Drug Use: Layers, Types, and Relations to Mental Health.” *AIDS and Behavior* 24, no. 8 (2020): 2347–54. https://doi.org/10.1007/s10461-020-02794-5.

Li, Z., Morano, J., P., Khoshnood, K., Hsieh, E., and Sheng, Y. “HIV-Related Stigma among People Living with HIV/AIDS in Rural Central China.” *BMC Health Services Research* 18, no. 1 (2018): 453. https://doi.org/10.1186/s12913-018-3245-0.

Link, B., G., and Phelan J., C. “Labelling and Stigma.” In *Handbook of the Sociology of Mental Health*, edited by C. S. Aneshensel, J. C. Phelan, and A. Bierman, 525–41. Handbooks of Sociology and Social Research. Springer, Dordrecht, 2013.

Link, B. G., Yang, L., H., Phelan, J., C., and P. Y. Collins, P., Y. “Measuring Mental Illness Stigma.” *Schizophrenia Bulletin* 30, no. 3 (2004): 511–41. https://doi.org/10.1093/oxfordjournals.schbul.a007098.

Link, B., G., and Phelan, J., C. “Conceptualizing Stigma.” *Annual Review of Sociology* 27, no. 1 (2001): 363–85. https://doi.org/10.1146/annurev.soc.27.1.363.

Link, B., G., and Phelan, J., C. “Stigma Power.” *Social Science & Medicine* 103 (2014): 24–32. https://doi.org/10.1016/j.socscimed.2013.07.035.

MacQuarrie, K., Eckhaus, T., and Nyblade, L. “HIV-Related Stigma and Discrimination: A Summary of Recent Literature.” the International Centre for Research on Women, 2009. https://data.unaids.org/pub/report/2009/20091130_stigmasummary_en.pdf.

Mahamboro, D., B., Fauk, N., K., Ward, P., R., Merry, M., S., Siri, T., A., and Mwanri, L. “HIV Stigma and Moral Judgement: Qualitative Exploration of the Experiences of HIV Stigma and Discrimination among Married Men Living with HIV in Yogyakarta.” *International Journal of Environmental Research and Public Health* 17, no. 2 (2020): 636. https://doi.org/10.3390/ijerph17020636.

Makatile, D. “Nothing Royal about Princess Squatter Settlement.” *IOL*, 2018. https://www.iol.co.za/sundayindependent/nothing-royal-about-princess-squatter-settlement-20798098.

Maman, S., van Rooyen, H., and Groves, A., K. “HIV Status Disclosure to Families for Social Support in South Africa (NIMH Project Accept/HPTN 043).” *AIDS Care* 26, no. 2 (2014): 226–32. https://doi.org/10.1080/09540121.2013.819400.

Manganye, B., S., Maluleke, T., X., and Lebese, R., T. “Professional Nurses’ Views Regarding Stigma and Discrimination in the Care of HIV and AIDS Patients in Rural Hospitals of the Limpopo Province, South Africa.” *African Journal of AIDS Research* 12, no. 1 (2013): 33–40. https://doi.org/10.2989/16085906.2013.815411.

Mantell, J., E., Correale, J., Adams-Skinner, J., and Stein, Z., A. “Conflicts between Conservative Christian Institutions and Secular Groups in Sub-Saharan Africa: Ideological Discourses on Sexualities, Reproduction and HIV/AIDS.” *Global Public Health* 6, no. sup2 (2011): S192–209. https://doi.org/10.1080/17441692.2011.604039.

Marks, M. “Stresses in the South African Police Service.” Centre for the Study of Violence and Reconciliation, 1995. https://csvr.org.za/index.php/publications/1774-stresses-in-the-south-african-police-service.

Martinescu, E. “Why We Gossip: A Functional Perspective on the Self-Relevance of Gossip for Senders, Receivers and Targets.” University of Groningen, 2017.

Masuku, S. “HIV/Aids Fight: Daughter Recalls Murdered Mom.” *The Citizen*, 2015. https://citizen.co.za/news/400816/hivaids-fight-daughter-recalls-murdered-mom/.

Mathibe, M., D., Hendricks, S., J., H., and Bergh, A. “Clinician Perceptions and Patient Experiences of Antiretroviral Treatment Integration in Primary Health Care Clinics, Tshwane, South Africa.” *Curationis* 38, no. 1 (2015): 11 pages. https://doi.org/10.4102/curationis.v38i1.1489.

Mbonu, N., C., van den Borne, B., and De Vries, N., K. “Stigma of People with HIV/AIDS in Sub-Saharan Africa: A Literature Review.” *Journal of Tropical Medicine* 2009 (2009): 1–14. https://doi.org/10.1155/2009/145891.

McNeil, D., G. “Neighbors Kill an H.I.V.-Positive AIDS Activist in South Africa.” *New York Times*, 1998. https://www.nytimes.com/1998/12/28/world/neighbors-kill-an-hiv-positive-aids-activist-in-south-africa.html.

McNeil, J. “A History of Official Government HIV/AIDS Policy in South Africa.” South African History Online, 2011. https://www.sahistory.org.za/article/history-official-government-hivaids-policy-south-africa.

Melwani, S. “A Little Bird Told Me So...: The Emotional, Attributional, Relational And Team-Level Outcomes Of Engaging In Gossip.” *Publicly Accessible Penn Dissertations* 548 (2012). https://repository.upenn.edu/edissertations/548.

Merriem - Webster Dictionary. “Definition of Self-Isolation.” Merriem - Webster Dictionary, 2020. https://www.merriam-webster.com/dictionary/self-isolation.

Mgolozeli, S., E., and Duma, S., E. “‘They All Laughed and Asked Me If I Enjoyed Having Sex with Those Guys’: Exploring Men’s Lived Experiences When Reporting Rape to Police in South Africa.” Edited by C. A. Latkin. *PLOS ONE* 15, no. 8 (2020): e0235044. https://doi.org/10.1371/journal.pone.0235044.

Mill, J., Harrowing, J., Rae, T., Richter, S., Minnie, K., Mbalinda, S., and Hepburn-Brown, C. “Stigma in AIDS Nursing Care in Sub-Saharan Africa and the Caribbean.” *Qualitative Health Research* 23, no. 8 (2013): 1066–78. https://doi.org/10.1177/1049732313494019.

Misir, P. “Structuration Theory: A Conceptual Framework for HIV/AIDS Stigma.” *Journal of the International Association of Providers of AIDS Care (JIAPAC)* 14, no. 4 (2015): 328–34. https://doi.org/10.1177/2325957412463072.

Modise, L., and Mahomed, N. “SA Law Protects Those with HIV.” *Sowetan Live*, 2011. https://www.sowetanlive.co.za/business/2011-02-08-sa-law-protects-those-with-hiv/.

Moeng, K. “Squatter Sites Rise.” *Sowetan Live*, 2010. https://www.sowetanlive.co.za/news/2010-08-02-squatter-sites-rise/.

Mokwele, R., and Strydom, H. “The challenges and perceptions of community caregivers with regard to antiretroviral treatment adherence of patients: a phenomenological study.” *Social Work/Maatskaplike Werk* 53, no. 1 (2017). https://doi.org/10.15270/53-1-544.

Moser, A., and Korstjens, I. “Series: Practical Guidance to Qualitative Research. Part 3: Sampling, Data Collection and Analysis.” *European Journal of General Practice* 24, no. 1 (2018): 9–18. https://doi.org/10.1080/13814788.2017.1375091.

Msoroka, M., S., and Amundsen, D. “One Size Fits *Not Quite* All: Universal Research Ethics with Diversity.” *Research Ethics* 14, no. 3 (2018): 1–17. https://doi.org/10.1177/1747016117739939.

Muula, A., S., and Mfutso-Bengo, J., M. "When Is Public Disclosure of HIV Seropositivity Acceptable?" *Nursing Ethics* 12, no. 3 (2005): 288–95.

Muula, A., S. "HIV Infection and AIDS among Young Women in South Africa." *Croatian Medical Journal* 49, no. 3 (2008): 423–35. https://doi.org/10.3325/cmj.2008.3.423.

Naidoo, J., R., Uys, L., R., Greeff, M., Holzemer, W., L, Makoae, L, Dlamini, P., Phetlhu, R., D., Chirwa, M., and Kohi, T. "Urban and Rural Differences in HIV/AIDS Stigma in Five African Countries." *African Journal of AIDS Research* 6, no. 1 (2007): 17–23. https://doi.org/10.2989/16085900709490395.

Naidu, T., and Sliep, Y. "Contextual Reflexivity: Towards Contextually Relevant Research with South African HIV/AIDS Home-Based Care Volunteers." *International Journal of Qualitative Methods* 10, no. 4 (2011): 431–43. https://doi.org/10.1177/160940691101000409.

NASTAD. "MSM Sensitization Training for Health Care Workers in South Africa." NASTAD, 2020. https://www.nastad.org/resource/msm-sensitization-training-health-care-workers-south-africa.

Ndimande, L. "Informal Settlements to Be Electrified." *Roodepoort Record*, 2019. https://roodepoortrecord.co.za/2019/06/13/print-a-number-of-informal-settlements-to-be-electrified-web-informal-settlements-to-be-electrified/.

Ndimande, L. "The Community at Princess Informal Settlement Witnessed yet Another Fire." *Roodepoort Record*, 2018. https://roodepoortrecord.co.za/2018/08/13/print-another-raging-fire-leaves-families-without-a-roof-over-their-headsweb-the-community-at-princess-informal-settlement-witnessed-yet-another-fire/.

Nelissen, R., M., A., and Mulder, L., B. "What Makes a Sanction 'Stick'? The Effects of Financial and Social Sanctions on Norm Compliance." *Social Influence* 8, no. 1 (2013): 70–80. https://doi.org/10.1080/15534510.2012.729493.

Newham, G., Masuku, T., and Dlamini, J. "Diversity and Transformation in the South African Police Service: A Study of Police Perspectives on Race, Gender and the Community in the Johannesburg Policing Area." *Centre for the Study of Violence and Reconciliation* 52 (2006).

Nilsen, P., and Bernhardsson, S. "Context Matters in Implementation Science: A Scoping Review of Determinant Frameworks That Describe Contextual Determinants for Implementation Outcomes." *BMC Health Services Research* 19, no. 189 (2019). https://doi.org/10.1186/s12913-019-4015-3.

Nkonki, T. "Residents Start Rebuilding Shacks." *Eyewitness News (EWN)*, 2012. https://ewn.co.za/2012/07/09/Princess-residents-start-to-rebuild.

Nkosi, N. “R23bn Spent on HIV/AIDS Each Year.” IOL, 2016. https://www.iol.co.za/business-report/economy/r23bn-spent-on-hivaids-each-year-2042364.

Nowell, L., S., Norris, J., M., White, D., E., and Moules, N., J. “Thematic Analysis: Striving to Meet the Trustworthiness Criteria.” *International Journal of Qualitative Methods* 16, no. 1 (2017): 160940691773384. https://doi.org/10.1177/1609406917733847.

Nyblade, L., Mbuya-Brown, R., J., Ezekiel, M., J., Addo, N., A., Sabasaba, A., N., Atuahene, K., Kiwia, P., et al. “A Total Facility Approach to Reducing HIV Stigma in Health Facilities: Implementation Process and Lessons Learned.” *AIDS* 34, no. 1 (2020): S93–102. https://doi.org/10.1097/QAD.0000000000002585.

Nyblade, L., Stockton, M., A., Giger, K., Bond, V., Ekstrand, M., L, McLean, R., Mitchell, E., M., H, et al. “Stigma in Health Facilities: Why It Matters and How We Can Change It.” *BMC Medicine* 17, no. 1 (2019): 25. https://doi.org/10.1186/s12916-019-1256-2.

Nyoka, N. “Man Dies after Alleged Mob Justice Attack.” *News24*, 2017. https://www.news24.com/SouthAfrica/News/man-dies-after-alleged-mob-justice-attack-20170305.

Oke, O., O., Akinboro, A., O., Olanrewaju, F., O., Oke, A., O., and Omololu, A., S. “Assessment of HIV-Related Stigma and Determinants among People Living with HIV/AIDS in Abeokuta, Nigeria: A Cross-Sectional Study.” *SAGE Open Medicine* 7 (2019): 205031211986910. https://doi.org/10.1177/2050312119869109.

De Oliveira, T., Kharsany, A., B., M., Gräf, T., Cawood, C., Khanyile, D., Grobler, A., Puren, A., et al. “Transmission Networks and Risk of HIV Infection in KwaZulu-Natal, South Africa: A Community-Wide Phylogenetic Study.” *The Lancet HIV* 4, no. 1 (2017): e41–50. https://doi.org/10.1016/S2352-3018(16)30186-2.

Opdenakker, R. “Advantages and Disadvantages of Four Interview Techniques in Qualitative Research.” *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research* Vol 7: No 4 (2006): Qualitative Research in Ibero America. https://doi.org/10.17169/FQS-7.4.175.

Palmerino, M., B. “One - on - Ones Put the Quality in Qualitative.” In *Qualitatively Speaking*. Centre for Strategy Research, 2006. https://csr-bos.com/wp-content/uploads/2006/12/Qualitatively-Speaking-2006-11.pdf.

Parcesepe, A., M., Nash, D., Tymejczyk, O., Reidy, W., Kulkarni, S., G., and Elul, B. “Gender, HIV-Related Stigma, and Health-Related Quality of Life among Adults Enrolling in HIV Care in Tanzania.” *AIDS and Behaviour* 24, no. 1 (2020): 142–50. https://doi.org/10.1007/s10461-019-02480-1.

Parker, R., and Aggleton, P. “HIV and AIDS-Related Stigma and Discrimination: A Conceptual Framework and Implications for Action.” *Social Science & Medicine* 57, no. 1 (2003): 13–24. https://doi.org/10.1016/S0277-9536(02)00304-0.

Peacock, D. “South Africa’s Sonke Gender Justice Network: Educating Men for Gender Equality.” *Agenda* 27, no. 1 (2013): 128–40. https://doi.org/10.1080/10130950.2013.808793.

Peek, H., S., Richards, M., Muir, O., Chan, S., R., Caton, M., and MacMillan, C. “Blogging and Social Media for Mental Health Education and Advocacy: A Review for Psychiatrists.” *Current Psychiatry Reports* 17, no. 11 (2015): 88. https://doi.org/10.1007/s11920-015-0629-2.

Peretti-Watel, P., Spire, B., Obadia, Y., Moatti, J., and the VESPA Group. “Discrimination against HIV-Infected People and the Spread of HIV: Some Evidence from France.” Edited by M. Baylis. *PLoS ONE* 2, no. 5 (2007): e411. https://doi.org/10.1371/journal.pone.0000411.

Pindral, B. “Land Grab next to Local Mall – Could This Be the next Princess Informal Settlement?” *Krugersdorp News*, 2018. https://krugersdorpnews.co.za/351965/land-grab-next-to-local-mall-could-this-be-the-next-princess-informal-settlement/.

Power, J., Westle, A., Dowsett, G., W., Lucke, J., Tucker, J., D., Sugarman, J., Lewin, S., R., et al. “Perceptions of HIV Cure Research among People Living with HIV in Australia.” Edited by Peter A. Newman. *PLOS ONE* 13, no. 8 (August 24, 2018): e0202647. https://doi.org/10.1371/journal.pone.0202647.Preston, J. “Obama Lifts a Ban on Entry into U.S. by H.I.V.-Positive People.” *The New York Times*, 2009. https://www.nytimes.com/2009/10/31/us/politics/31travel.html?_r=0.

“Princess Plot Housing Project to Start in Feb.” *The Citizen*, 2014. https://citizen.co.za/news/south-africa/116940/princess-plot-housing-project-start-feb/.

Pulerwitz, J., Michaelis, A., Weiss, E., Brown, L., and Mahendra, V. “Reducing HIV-Related Stigma: Lessons Learned from Horizons Research and Programs.” *Public Health Reports* 125, no. 2 (2010): 272–81. https://doi.org/10.1177/003335491012500218.

Rahman, M., S. “The Advantages and Disadvantages of Using Qualitative and Quantitative Approaches and Methods in Language ‘Testing and Assessment’ Research: A Literature Review.” *Journal of Education and Learning* 6, no. 1 (2016): 102. https://doi.org/10.5539/jel.v6n1p102.

Rankin, W., W., Brennan, S., Schell, E., Laviwa, J., and Rankin, S., H. “The Stigma of Being HIV-Positive in Africa.” *PLoS Medicine* 2, no. 8 (2005): e247. https://doi.org/10.1371/journal.pmed.0020247.

Retief, R., and Green, S. “Some Challenges of Policing Domestic Violence.” *Social Work/Maatskaplike Werk* 51, no. 1 (2015). https://doi.org/10.15270/51-1-432.

Ryan, F., Coughlan, M., and Cronin, P. "Interviewing in Qualitative Research: The One-to-One Interview." *International Journal of Therapy and Rehabilitation* 16, no. 6 (2009): 309–14. https://doi.org/10.12968/ijtr.2009.16.6.42433.

SA DoH. "National HIV Counselling and Testing Policy Guidelines." Republic of South Africa's Department of Health, 2015. https://www.nicd.ac.za/assets/files/HCT-Guidelines-2015.pdf.

Said, E., W. *Orientalism.* United States: Pantheon Books, 1978.

Dos Santos, M., M., L., Kruger, P., Mellors, S., E., Wolvaardt. G., and van der Ryst, E. "An Exploratory Survey Measuring Stigma and Discrimination Experienced by People Living with HIV/AIDS in South Africa: The People Living with HIV Stigma Index." *BMC Public Health* 14, no. 1 (2014): 80. https://doi.org/10.1186/1471-2458-14-80.

Scambler, G. "Health-Related Stigma." *Sociology of Health & Illness* 31, no. 3 (2009): 441–55. https://doi.org/10.1111/j.1467-9566.2009.01161.x.

Section27. "Chapter 2: HIV/AIDS, Power and Discrimination." Section27.org.za, 2010. https://section27.org.za/wp-content/uploads/2010/04/02Manual.pdf.

Serwadda, D., Sewankambo, N., K., Carswell, J., W., Bayley, A., C., Tedder, R., S., Weiss, R., A., Mugerwa, R., D., et al. "slim disease: a new disease in Uganda and its association with HTLV-III infection." *The Lancet* 326, no. 8460 (1985): 849–52. https://doi.org/10.1016/S0140-6736(85)90122-9.

Shah, S., Elgalib, A., Al-Wahaibi, A., Al-Fori, M., Raju, R., Al-Skaiti, M., Al-Mashani, H., N., et al. "Knowledge, Attitudes and Practices Related to HIV Stigma and Discrimination Among Healthcare Workers in Oman." *Sultan Qaboos University Medical Journal [SQUMJ]* 20, no. 1 (2020): 29. https://doi.org/10.18295/squmj.2020.20.01.005.

Shenton, A., K. "Strategies for Ensuring Trustworthiness in Qualitative Research Projects." *Education for Information* 22, no. 2 (2004): 63–75. https://doi.org/10.3233/EFI-2004-22201.

Sherman, G., G., Mazanderani, A., H., Barron, P., Bhardwaj, S., Niit, R., Okobi, M., Puren, A., Jackson, D., J., and Goga, A., E. "Toward Elimination of Mother–to–Child Transmission of HIV in South Africa: How Best to Monitor Early Infant Infections within the Prevention of Mother–to–Child Transmission Program." *Journal of Global Health* 7, no. 1 (2017): 010701. https://doi.org/10.7189/jogh.07.010701.

Shisana, O., and Simbayi, C., L. "Nelson Mandela/HSRC Study of HIV/AIDS: South African National HIV Prevalence, Behavioural Risks and Mass Media: Household Survey 2002." Human Sciences Research Council (HSRC), 2002. http://www.hsrc.ac.za/en/research-outputs/view/66.

Shokane, A., L., and Masoga, M., A. “African Indigenous Knowledge and Social Work Practice: Towards an Afro-Sensed Perspective.” *Southern African Journal of Social Work and Social Development* 30, no. 1 (2018). https://doi.org/10.25159/2415-5829/2320.

Simbayi, L., Zuma, K., Cloete, A., Jooste, S., Zimela, S., Blose, S., Wabiri, N., et al. “The People: Living with HIV Stigma Index: South Africa 2014: Summary Report.,” 2015. http://hdl.handle.net/20.500.11910/1917.

Simbayi, L., C., Kalichman, S., Strebel, A., Cloete, A., Henda, N., and Mqeketo, A. “Internalized Stigma, Discrimination, and Depression among Men and Women Living with HIV/AIDS in Cape Town, South Africa.” *Social Science & Medicine* 64, no. 9 (2007): 1823–31. https://doi.org/10.1016/j.socscimed.2007.01.006.

Singh, K., Bhattacharyya, M., Veerwal, V., and Singh, A. “Using Role-Plays as an Empathy Education Tool for Ophthalmology Postgraduate.” *International Journal of Applied and Basic Medical Research* 7, no. 5 (2017): 62. https://doi.org/10.4103/ijabmr.IJABMR_145_17.

Snodgrass, L. “Survivors of Sexual Violence in South Africa Are Finally Finding Their Voices.” The Conversation, 2018. https://theconversation.com/survivors-of-sexual-violence-in-south-africa-are-finally-finding-their-voices-106458.

South African Government. “Child Support Grant.” www.gov.za, 2014. https://www.gov.za/services/child-care-social-benefits/child-support-grant.

South African Government. “Gauteng Human Settlements on Princess Plot Housing Project.” *Press Release*. 2015. https://www.gov.za/speeches/gauteng-human-settlemens-says-princess-plot-housing-project-officially-track-8-jul-2015.

Stadler, J. “Rumor, Gossip and Blame: Implications for HIV/AIDS Prevention in The South African Lowveld.” *AIDS Education and Prevention* 15, no. 4 (2003): 357–68. https://doi.org/10.1521/aeap.15.5.357.23823.

Stangl, A., L., Earnshaw, V., A., Logie, C., H., van Brakel, W., Simbayi, L., C., Barré, I., and Dovidio, J., F. “The Health Stigma and Discrimination Framework: A Global, Crosscutting Framework to Inform Research, Intervention Development, and Policy on Health-Related Stigmas.” *BMC Medicine* 17, no. 1 (2019): 31. https://doi.org/10.1186/s12916-019-1271-3.

Stangl, A., L., and Grossman, C., I., eds. “Global Action to Reduce HIV Stigma and Discrimination.” *Journal of the International AIDS Society* 16 (2013): 18934. https://doi.org/10.7448/IAS.16.3.18934.

Stofer, K., A. “Preparing for One-on-One Qualitative Interviews: Designing and Conducting the Interview.” Agricultural Education and Communication, 2019. https://edis.ifas.ufl.edu/wc338.

Sullivan, M., C., Rosen, A., O., Allen, A., Benbella, D., Camacho, G., Cortopassi, A., C., Driver, R., Ssenyonjo, J., Eaton, L., A., and Kalichman, S., C. "Falling Short of the First 90: HIV Stigma and HIV Testing Research in the 90–90–90 Era." *AIDS and Behavior* 24, no. 2 (2020): 357–62. https://doi.org/10.1007/s10461-019-02771-7.

Tau, S. "Princess Informal Settlement Protesters Await Govt's Response." *The Citizen*, 2014. https://citizen.co.za/news/south-africa/113919/stprincesssl/.

Thompson, K. "Interviews in Social Research: Advantages and Disadvantages." ReviseSociology, 2016. https://revisesociology.com/2016/01/23/interviews-in-social-research-advantages-and-disadvantages/.

Tong, R., and Botts, T., F. *Feminist Thought: A More Comprehensive Introduction*. 4th ed. Routledge, 2018. https://doi.org/10.4324/9780429493836.

Tracy, S., J. "Qualitative Quality: Eight 'Big-Tent' Criteria for Excellent Qualitative Research." *Qualitative Inquiry* 16, no. 10 (2010): 837–51. https://doi.org/10.1177/1077800410383121.

Tumwikirize, S., Torpey, K., Adedokun, O., and Badru, T. "The Value of Support Group Participation in Influencing Adherence to Antiretroviral Treatment among People Living with Human Immunodeficiency Virus (HIV)." *World Journal of AIDS* 05, no. 03 (2015): 189–98. https://doi.org/10.4236/wja.2015.53022.

Tumwikirize, S., and Zwane, S., M. "Participation in PLHIV Support Groups: Does It Enhance Behavioural Outcomes?" *HIV: Current Research* 01, no. 01 (2016). https://doi.org/10.4172/2572-0805.1000104.

U.S. Department of Health & Human Services. "'Awareness Days.'" HIV.org, 2020. https://www.hiv.gov/events/awareness-days.

Ulasi, C., I., Preko, P., O., Baidoo, J., A., Bayard, B., Ehiri, J., E., Jolly, C., M., and Jolly, P., E. "HIV/AIDS-Related Stigma in Kumasi, Ghana." *Health & Place* 15, no. 1 (2009): 255–62. https://doi.org/10.1016/j.healthplace.2008.05.006.

UN News. "HIV -Related Stigma, Discrimination Prevent People from Accessing Health Services." *UN News*, 2017.

UNAIDS. "Ambitious Treatment Targets: Writing the Final Chapter of the AIDS Epidemic'." Geneva, 2014. https://www.unaids.org/sites/default/files/media_asset/JC2670_UNAIDS_Treatment_Targets_en.pdf.

UNAIDS. "'Ending AIDS: Progress towards 90-90-90'." Presented at the Global AIDS Update, Geneva, 2017. https://www.unaids.org/sites/default/files/media_asset/Global_AIDS_update_2017_en.pdf.

UNAIDS. "Global HIV & AIDS Statistics — 2020 Fact Sheet." UNAIDS, 2020. https://www.unaids.org/en/resources/fact-sheet.

UNAIDS. "HIV and Social Protection." Joint United Nations Program on HIV/AIDS, 2014. https://www.unaids.org/sites/default/files/media_asset/2014unaidsguidancenote_HIVandsocialprotection_en.pdf.

UNAIDS. "Reduction of HIV-Related Stigma and Discrimination." Geneva: Joint United Nations Program on HIV/AIDS, 2014. https://www.unaids.org/sites/default/files/media_asset/2014unaidsguidancenote_stigma_en.pdf.

UNAIDS. "UNAIDS AIDSinfo," 2017. http://www.unaids.org/en/resources/documents/2017/20170720/_global_aids_update_2017.

UNAIDS. "UNAIDS Announces That the Goal of 15 Million People on Life-Saving HIV Treatment by 2015 Has Been Met Nine Months Ahead of Schedule." *UNAIDS.Org*, 2015. https://www.unaids.org/en/resources/presscentre/pressreleaseandstatementarchive/2015/july/20150714_PR_MDG6report.

UNAIDS. "World AIDS Day." UNAIDS.org, 2020. https://www.unaids.org/en/World_AIDS_Day.

University of Pretoria. "Sensitizing the South African Police Service (SAPS) to the Challenges Faced by Persons with CCN." Research Matters, 2020. https://www.up.ac.za/research-matters/article/2801960/sensitizing-the-south-african-police-service-saps-to-the-challenges-faced-by-persons-with-ccn.

Van Zyl, R. "Man Shot during Roodepoort Armed Robbery." *The Citizen*, 2018. https://citizen.co.za/news/south-africa/1975373/man-shot-during-roodepoort-armed-robbery/.

Van Zyl, R. "Princess RDP Housing Grinds to a Halt." *Roodepoort Record*, 2013. https://roodepoortrecord.co.za/2013/09/12/princess-rdp-housing-grinds-to-a-halt/.

Van Zyl, R. "Roodepoort Protest Action Spills onto Albertina Sisulu Rd, Truck Set Alight." *The Citizen*, 2017. https://citizen.co.za/news/south-africa/1452747/roodepoort-protest-action-spills-onto-albertina-sisulu-rd-truck-set-alight/.

Vanclay, F., Baines, J., T., and Taylor, C., N. "Principles for Ethical Research Involving Humans: Ethical Professional Practice in Impact Assessment Part I." *Impact Assessment and Project Appraisal* 31, no. 4 (2013): 243–53. https://doi.org/10.1080/14615517.2013.850307.

Visser, M., J., Makin, J., D., Vandormael, A., Sikkema, K., J., and Forsyth, B., W., C. "HIV/AIDS Stigma in a South African Community." *AIDS Care* 21, no. 2 (2009): 197–206. https://doi.org/10.1080/09540120801932157.

Visser, M.. J. and Sipsma, H., L. "The Experience of HIV-Related Stigma in South Africa." In *Stigma, Discrimination, and Living with HIV/AIDS: A Cross-Cultural Perspective*, by P. Liamputtong, 205–27. Springer Publishing Company, 2013. https://www.researchgate.net/publication/286485732_The_Experience_of_HIV-Related_Stigma_in_South_Africa.

Volks, C. "AIDS and South Africa: The Social Expression of a Pandemic." In *The Role of Tertiary Institutions in the HIV/AIDS Epidemic*, edited by K. Kauffman and D. Lindauer. Palgrave Macmillan UK, 2003.

Wathuta, J. "Gender Inequality Dynamics in the Prevention of a Heterosexual HIV Epidemic in Sub-Saharan Africa." *African Journal of AIDS Research* 15, no. 1 (2016): 55–66. https://doi.org/10.2989/16085906.2016.1150310.

Weiser, S., D., Heisler, M., Leiter, K., Percy-de Korte, F., Tlou, S., DeMonner, S., Phaladze, N., Bangsberg, D., R., and Iacopino, V. "Routine HIV Testing in Botswana: A Population-Based Study on Attitudes, Practices, and Human Rights Concerns." Edited by Joep Lange. *PLoS Medicine* 3, no. 7 (2006): e261. https://doi.org/10.1371/journal.pmed.0030261.

WHO. "Gender Inequalities and HIV." World Health Organization (WHO), 2013. http://www.who.int/ gender/hiv_aids/en/.

Wildermuth, N. "'Isidingo - The Need': A Mainstream Approach to HIV/AIDS Communication." *Glocal Times*, no. 5 (2006). https://forskning.ruc.dk/en/publications/isidingo-the-need-a-mainstream-approach-to-hivaids-communication.

Wolf, H., T., Halpern-Felsher, B., L., Bukusi, E., A., Agot, K., E, Cohen, C., R, and Auerswald, C., L. "'It Is All about the Fear of Being Discriminated [against]…the Person Suffering from HIV Will Not Be Accepted': A Qualitative Study Exploring the Reasons for Loss to Follow-up among HIV-Positive Youth in Kisumu, Kenya." *BMC Public Health* 14, no. 1 (2014): 1154. https://doi.org/10.1186/1471-2458-14-1154.

Wouters, E., Sommerland, N., Masquillier, C., Rau, A., Engelbrecht, M., Janse Van Rensburg, A., Kigozi, G., Ponnet, K., and Van Damme, W. "Unpacking the Dynamics of Double Stigma: How the HIV-TB Co-Epidemic Alters TB Stigma and Its Management among Healthcare Workers." *BMC Infectious Diseases* 20, no. 1 (2020): 106. https://doi.org/10.1186/s12879-020-4816-3.

Wu, L., Birtch, T., A., Chiang, F., F., T., and Zhang, H. "Perceptions of Negative Workplace Gossip: A Self-Consistency Theory Framework." *Journal of Management* 44, no. 5 (2018): 1873–98. https://doi.org/10.1177/0149206316632057.

Xie, J., Huang, Q., Wang, H., and Shen, M. “Coping with Negative Workplace Gossip: The Roles of Self-Monitoring and Impression Management.” *Academy of Management Proceedings* 2018, no. 1 (2018): 10649. https://doi.org/10.5465/AMBPP.2018.10649abstract.

Xu, A., Baysari, M., T., Stocker, S., L., Leow, L., J., Day, R., O., and Carland, J., E. “Researchers’ Views on, and Experiences with, the Requirement to Obtain Informed Consent in Research Involving Human Participants: A Qualitative Study.” *BMC Medical Ethics* 21, no. 1 (2020): 93. https://doi.org/10.1186/s12910-020-00538-7.

Yang, H., Xie, X., Nie, A., Yin, Y., Wang, H., and Chen, H. “HIV-Related Stigma Among People Living With HIV in Liangshan Yi Autonomous Prefecture, China:” *Journal of the Association of Nurses in AIDS Care* 31, no. 2 (2020): 199–207. https://doi.org/10.1097/JNC.0000000000000119.

Yigit, I., Modi, R., A., Weiser, S., D., Johnson, M., O., Mugavero, M., J., Turan, J., M., and Turan, B. “Effects of an Intervention on Internalized HIV-Related Stigma for Individuals Newly Entering HIV Care.” *AIDS* 34, no. 1 (2020): S73–82. https://doi.org/10.1097/QAD.0000000000002566.

Yuvaraj, A., Mahendra, V., S., Chakrapani, V., Yunihastuti, E., Santella, A., J., Ranauta, A., and Doughty, J. “HIV and Stigma in the Healthcare Setting.” *Oral Diseases* 26, no. S1 (2020): 103–11. https://doi.org/10.1111/odi.13585.

Zuch, M., and Lurie, M. “‘A Virus and Nothing Else’: The Effect of ART on HIV-Related Stigma in Rural South Africa.” *AIDS and Behavior* 16, no. 3 (2012): 564–70. https://doi.org/10.1007/s10461-011-0089-6.

Appendixes

Appendix A: Ethics Clearance Certificate

SOSS Human Research Ethics Committee

Clearance Certificate

Protocol Number: **DVS20190501**

Project Title: **Does the South African government's anti-HIV program address the issue of HIV-related Stigma and Discrimination?**

Investigator's Name: **Ferreira, Cherie (752176)**

Department: **Sociology**

Date Reviewed: **June 20 19**

Decision of Committee: **Approved / Unconditionally**

Expiry Date: **May 2021**

Date:

Head of School ______________________________

Professor Mucha Musemwa

CC supervisor: **Rajohane Matshedisho**

Declaration of Investigator

To be completed in duplicate and one copy to be returned to Ms. Sarah Mfupa in the School of Social Sciences, Room 152, 1st Floor, Robert Sobukwe Block.

I fully understand the conditions under which I am authorised to carry out the abovementioned research and I guarantee to ensure compliance with these conditions. If any departure from the research procedure as approved, I undertake to resubmit the protocol to the committee.

______________________________ **26/06/2019**

Student Signature **Date**

Appendix B: Interview Schedule

Participant Interview Schedule

Person's Number:____________________________

1. How old are you?
2. What gender do you identify as?
3. What is your current occupation?
4. Where do you currently live?
    a. Do you live with your family?
    b. Later, why do you live with your family, or not?
    c. Where do you collect your medicine?
        i. If at the orphanage, why do you collect your medicine there instead of at the clinic?
        ii. Is there other better place where you would like to collect your medicine?
5. Apart from your social worker, have you told anyone you are HIV positive?
    a. Why did you feel that you could share your status with your social worker?
    b. Why have you not shared your status with your family?
    c. Why have you not disclosed your status to your family?
6. Why do you think people become HIV positive?
    a. Do you think people are to blame for their illness?
    b. Do you think that a person should feel ashamed about being HIV positive?
        i. Are you ashamed of being HIV positive?
    c. If so, do you think they should be removed from your community?
    d. Do you think poverty, or being poor, is a cause of becoming HIV positive?
7. What problems do you face as a person who is HIV positive (e.g. difficulty finding time to go to the clinic regularly due to long working hours, etc.)?

  - a. Have you experienced:
    - i. Being mocked or humiliated?
    - ii. Being gossiped about?
    - iii. Abandoned by your friends and family (i.e. job loss)?
    - iv. Judged and insulted by others?
    - v. From who (general references are acceptable, there is no need to incriminate anyone)?
  - b. Do you get your medication regularly?
      - i. Where do you collect your medicine?
      - ii. Why?
      - iii. Have you ever missed taking your medicine?
      - iv. Why?

8. Do you have friends that are HIV positive like you?
  - a. Do you help them/ do they help you in any way as a person with HIV?
    - i. Like for example:
      1. Remind you to take your medication
      2. Groups chats or counsel (e.g. emotional support)
      3. Looking after children while you work (e.g. physical support)
      4. Financial support
      5. Food assistance
      6. Transportation assistance (i.e. social support).

9. Do you have friends that are not HIV positive like you?
    - a. Do you help them/ do they help you in any way as a person with HIV?
      - i. Like for example:
        - Remind you to take your medication

2. Groups chats or counsel (e.g. emotional support)
3. Looking after children while you work (e.g. physical support)
4. Financial support
5. Food assistance
6. Transportation assistance (i.e. social support).

Appendix C: Participant Information Sheet

UNIVERSITY OF THE
WITWATERSRAND,
JOHANNESBURG

Participant Information Sheet

University of Witwatersrand, Johannesburg

Tel: 011 717 4424

Email: Sedzani.Malada@wits.ac.za (Postgraduate)

Private Bag 3, Wits 2050

Good day Sir/Madam

My name is Cherie Ferreira and I am a Masters student in General Sociology at the University of the Witwatersrand in Johannesburg. As part of my studies, I have to undertake a research project, and I am looking to understand how people understand and respond to HIV-related stigma.

As part of this project, I would like to invite you to take part in One – on - One discussion. This activity will involve participating in a conversation exercise, namely a one – on- one interview and it will take around 1 - 2 hours. It is just one exercise that will organize our discussion around your experiences as a HIV-positive person. With your permission, I would also like to record our conversations using my phone.

You will not receive any direct benefits from participating in this research, and there are no disadvantages or penalties for not participating. You may withdraw at any time or not answer any question if you do not want to. Our conversation will be completely confidential as I will not be asking for any distinct identifying information (except for some general demographic information), and the information you give to me will be held securely and not disclosed to anyone else. I will be using a Number label (false name) to represent your participation in my final research report. If you experience any distress or discomfort at any point in this process, we will stop the focus group or resume another time. If you need some support or counselling services following the interview, these are available free of charge at LifeLine.

Lifeline Johannesburg Physical Address:

Office Tel.: 011 728 1331 2 The Avenue

Crisis line: 011 728 1347 Cnr Henrietta Street

Whatsapp and Counseling line: 065 989 9238 Norwood

Website: lifeline@lifelinejhb.org.za Johannesburg

Lifeline telephone counselling is toll free and open 24/7.

If you have any questions during or afterwards about this research, feel free to contact me or my Supervisor on the details listed below. This study will be written up as a research report which will be available online through the university library website. If you have any concerns or complaints regarding the ethical procedures of this study, you are welcome to contact my supervisor on Rajohane.Matshedisho@wits.ac.za.

Yours sincerely,

Cherie Ferreira

Cherie Ferreira, cherieferreira123@outlook.com, 082 382 9221

Raji Matshediso, Rajohane.Matshedisho@wits.ac.za, Tel no.:

Participant Consent Form

How do South Africans experience and respond to HIV-related stigma?

Cherie Ferreira

I, ……………………………………….., agree to participate in this research project. The research has been explained to me and I understand what my participation will involve. Please circle the relevant options below.

I agree that my participation will remain confidential, if this is not possible I agree to a pseudonym (fake name) being used for me in the publication of the report.

YES NO

I agree that the interview may be audio recorded YES NO

…………………………………… (signature)

…………………………………… (name of participant)

…………………………………… (date)