INVESTIGATING HOW STIGMA AIDS THE SPREAD OF HIV INFECTIONS AMONG YOUNG WOMEN IN JOHANNESBURG AND POSSIBLE INTERVENTIONS TO AMELIORATE THE PROBLEM

by

MWENDA SITWALA IMENDA

submitted in accordance with the requirements for
the degree of

MASTER OF ARTS

in the subject

SOCIOLOGY

at the

UNIVERSITY OF SOUTH AFRICA

SUPERVISOR: MR. LEON ROETS

February 2022

DECLARATION

Name: Mwenda Sitwala Imenda

Student number: 67139361

Degree: Masters of Arts in Sociology

Exact wording of the title of the dissertation as appearing on the electronic copy submitted for examination:

INVESTIGATING HOW STIGMA AIDS THE SPREAD OF HIV INFECTIONS AMONG YOUNG WOMEN IN JOHANNESBURG AND POSSIBLE INTERVENTIONS TO AMELIORATE THE PROBLEM

I declare that the above dissertation is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.

I further declare that I submitted the dissertation to originality checking software and that it falls within the accepted requirements for originality.

I further declare that I have not previously submitted this work, or part of it, for examination at Unisa for another qualification or at any other higher education institution.

Imenda

SIGNATURE

10 February 2022

DATE

ACKNOWLEDGEMENT

First and foremost, I would like to begin by expressing praise and gratitude to the Almighty Jesus Christ for his blessings, Isaiah 41:10 has been a message that I have carried with me throughout this journey.

I'd like to express my gratitude to my supervisor Mr Leon Roets, who was instrumental throughout this entire process. As well as UNISA for affording me the opportunity to complete my study.

In addition, I'd like to express my utmost appreciation to my parents, Prof Sitwala Imenda and Dr Grace Imenda for their sound advice and sympathetic ear. You are always willing to help me. You gave me the tools I needed to determine the best path for my studies and finish it successfully. *Na itumela hahulu ku mina kwa ku ni tiisa*!

I would like to thank all my research participants without whom this would not be possible. My friends and family, without your unwavering support I would not have been able to finish this dissertation. You have all provided intriguing talks as well as enjoyable distractions from my study. Thank you!

Lastly, to Munalula Imenda and Mwangala Imenda I dedicate this dissertation to you, may you continue to rest in peace.

ABSTRACT

This was a qualitative case study exploring and describing the role that stigma plays in the spread of HIV among young women between the ages of 18 and 24. The study locale was Johannesburg, South Africa. The social ecology model and radical feminism were adopted as the conceptual framework for the study. Data were collected through interviews with thirteen young women. This study intended to explore and describe HIV-related stigma, as experienced by young women living with HIV. The major findings of the study were that (a) all the participants were familiar with the notion of stigma and held the view that it made many young women vulnerable to infection; (b) stigma kept many people living with HIV (PLHIV) from accessing prevention and destigmatisation intervention programmes, as well as healthcare facilities and services; (c) there were currently very few HIV reduction and destigmatisation intervention programmes in their communities; (d) intervention programmes could be strengthened by involving PLHIV in the planning and execution of such programmes, as well as utilising HIV positive experts and (e) extant stigma prevention and destigmatisation programmes could be strengthened at family, clinics, hospitals and community levels. It is concluded that the study has made an important contribution towards closing the literature gap in the paucity of studies on the personal lived experiences of PLHIV.

Key Terms: Destigmatisation, HIV, AIDS, discrimination, stigma, risk, vulnerable groups, women.

OPSOMMING 2

In hierdie kwalitatiewe gevallestudie is die rol van stigma in die verspreiding van MIV onder jong vroue tussen die ouderdom van 18 en 24 ondersoek en beskryf. Die studie is in Johannesburg, Suid-Afrika onderneem. Die maatskaplike-ekologiemodel en radikale feminisme het die konseptuele raamwerk daarvan gevorm. Data is ingesamel deur onderhoude met dertien jong vroue te voer. Die oogmerk van die studie was om die stigma van MIV wat kleef aan jong vroue wat met MIV leef, te verken. Die volgende bevindings is gemaak: (a) al die deelnemers was vertroud met die idee van stigma. Hulle was van mening dat dit tallose jong vroue vir infeksie kwesbaar maak; (b) die stigma ontneem talle mense wat leef met MIV (MLMIV) van toegang tot nie alleen voorkomings- en destigmatiseringsprogramme nie, maar ook van gesondheidsorg en -dienste; (c) tans word weinig MIV-verminderings- en destigmatiseringsprogramme in hulle gemeenskappe aangebied; (d) intervensieprogramme kan verbeter word deur MLMIV by die beplanning en uitvoering daarvan te betrek; en (e) bestaande stigmavoorkomings- en destigmatiseringsprogramme behoort in families, klinieke, hospitale en gemeenskappe verskerp te word. Die slotsom is dat hierdie studie die leemte aan literatuur oor die persoonlike, deurleefde ervarings van MLMIV aanvul.

Sleutelbegrippe: Destigmatisering, MIV, VIGS, diskriminasie, stigma, risiko, kwesbare groepe, vroue.

KGUTSUFATSO YA 2

Ona e ne e le mokgwa wa ho etsa patlsisio moo ho ithutwang ka ketsahalo e boima ka ho hlwaya dintho tse fapaneng tse amanang le yona, o fuputsang le ho hlalosa karolo e bapalwang ke sekgobo phatlallong ya HIV basading ba dilemong tsa botjha tse pakeng tsa tse 18 le 24. Phuputso e ne e etsetswa Johannesburg, Aforika Borwa. Ho nkilwe dikamano tsa batho le dintho tse fapaneng tse amang maphelo a bona le mohopolo o bontshang kgatello ya basadi e le moralo wa tshebetso. Datha e bokelletswe ka ho inthaviuwa basadi ba leshome le metso e meraro ba dilemong tsa botjha. Sepheo sa phuputso ena e ne e le ho ithuta le ho hlalosa sekgobo se amanang le HIV, jwalo ka ha se etsahalla basadi ba dilemong tsa botjha ba phelang ka HIV. Lesedi le fumanweng ka phuputso e ne e le hore (a)bankakarolo kaofela ba ne ba tseba hore sekgobo ke eng, mme ba ne ba dumela hore se entse hore batho ba bangata ba be kotsing ya ho tshwaetswa; (b) sekgobo se thibela batho ba bangata ba phelang ka HIV (PLHIV) hore ba se kene mekgweng ya kalafo e thibelang tshwaetso le ho tlosa sekgobo feela, empa le ho ya dibakeng tsa tlhokomelo ya bophelo le ho fumantshwa ditshebeletso; (c) ha jwale ho fanwa ka mekgwa e menyane haholo ya kalafo ya ho thusa ho fokotsa HIV le ho tlosa sekgobo baahing ba bona (d) mekgwa ya kalafo e sebedisetswang ho ntlafatsa boemo e ka matlafatswa ka ho kenya PLHIV tlhophisong le tshebedisong ya mekgwa eo, le ho matlafatswa ka ho sebedisa ditsebi tse nang le HIV; le (e)mekgwa e ntseng e le teng ya ho thibela le ho tlosa sekgobo e ka matlafatswa lelapeng, tleleniking, sepetlele le setjhabeng. Ho phethetswe ka hore phuputso e bile le seabo sa bohlokwa dingolweng tse fokolang tsa diketshalo tsa nnete tsa batho ba phelang ka PLHIV.

Mareo a bohlokwa: Ho tlosa sekgobo, HIV, AIDS, kgethollo, sekgobo, kotsi, dihlopha tse kotsing e kgolo ya fokollwa ke bophelo, basadi.

TABLE OF CONTENTS

List of Figures

List of Tables

List of Abbreviations

ACT	Acceptance and Commitment Therapy
AGYW	Adolescent Girls and Young Women
AIDS	Acquired Immune Deficiency Syndrome
ART	Anti-Retroviral Therapy
ARV	Anti-Retroviral
CDC	Centers for Disease Control and Prevention
CFT	Compassion-Focus Therapy
CHSCP	Comprehensive Health Seeking and Coping Paradigm
CHWs	Community Healthcare Workers
COVID-19	Coronavirus Disease of 2019
DREAMS	Determined, Resilient, Empowered, AIDS-free, Mentored and Safe
EOL	End-Of-Life
FBOs	Faith-Based Organisations
GBV	Gender-Based Violence
GNI	Gross National Income
HCT	HIV Counselling and Testing
HIC	High-Income Countries
HIV	Human Immunodeficiency Virus
HSRC	Human Sciences Research Council
LMIC	Low-and Middle-Income Countries
MTCT	Mother-to-Child-Transmission
NCDs	Non-communicable Diseases
NSP	National Strategic Plan

NGO	Non-governmental Organisation
PEPFAR	United States President’s Emergency Plan for AIDS Relief
PLHIV	People living with HIV
PMTCT	Prevention of mother-to-child transmission
PrEP	Pre-exposure Prophylaxis
SANAC	South African National Aids Council Trust
SEM	Social Ecological Model
SBCC	Social and Behaviour Change Communication
STDs	Sexually Transmitted Diseases
STIs	Sexually Transmitted Infections
SRH	Sexual and Reproductive Health
SRHR	Sexual and Reproductive Health Rights
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNICEF	United Nations International Children's Emergency Fund
UNISA	University of South Africa
WHO	World Health Organisation
YWLHIV	Young Women Living with HIV

CHAPTER 1
ORIENTATION TO THE STUDY

1.1. INTRODUCTION

Recent research has shown that the acquired immunodeficiency syndrome (AIDS) pandemic remains a major world health issue, with 37.7 million people estimated to be living with HIV (PLHIV) worldwide in 2020 (UNAIDS, 2021). Overall, the burden of infectious diseases, including the Human Immunodeficiency Virus (HIV) is reported to be higher in low-income than in high-income countries (World Health Organisation [WHO], 2020). In particular, Armstrong-Mensah, Hernandez, Huka, Suarez, Akosile, Joseph and Ramsey-White (2019:69) report that over 70% of HIV infections occur in sub-Saharan Africa and over 60% of all new HIV infections arise in women and teenage girls, of which most occur in South Africa.

Regarding HIV prevalence, young women and girls are at a higher risk of contracting the virus compared to their male counterparts, both due to biological and socioeconomic reasons (Mandiwa, Namondwe & Munthali, 2021:1). Indeed, HIV prevalence among young adults who are aged 25 years or younger was reported by Bicego, Nkambule, Peterson, Reed, Donnell, Ginindza, Duong, Patel, Bock, Philip, Mao & Justman (2013:1) to be five times greater than men's (26% vs 5%), which is a frequent pattern in sub-Saharan Africa. This trend is supported by UNAIDS AIDSinfo (2020) which states that in 2020, of the 7 500 000 adults living with HIV in South Africa, 4 800 000 (64 per cent) were women. This is attributed to gender inequalities with respect to factors such as poverty, stigma, health services, increase in sexual violence and an increase in young girls' socioeconomic vulnerability (Wamoyi, Stobeanau, Bobrova, Ambrasky & Watts, 2016:4). Wamoyi et al. (2016:1) attribute this differential vulnerability to the practice of transactional sex, which is mainly for monetary gain or social status. From their study, Wamoyi et al. (2016:4) reported a significant, positive, association between transactional sex and HIV in ten out of 14 studies involving women, compared to only two out of ten studies involving men. Accordingly, they surmised that transactional sex could at least partly account for the heightened vulnerability of women to HIV infections and the feminisation of the epidemic, compared to their male counterparts. Indeed, this view is supported by Pettifor, MacPhail, Bertozzi and Rees (2007:425) who opine that because of the lack of viable alternatives to earning a decent livelihood, persons from economically deprived backgrounds may be more likely to engage in sex work or other forms of transactional sex—thereby increasing their vulnerability to HIV infections. However, as is reported below and in more detail in Chapter 2, this is not the only risk factor associated with the spread of HIV (Zuma, Shisana, Rehle, Simbayi, Jooste, Zungu, Labadarios, Onoya, Evans, Moyo & Abdullah 2016:3; Miller, Nkala, Closson, Chia, Cui, Palmer, Hogg, Kaida, Gray, Dietrich, 2017; Dorward, Khubone, Gate, Ngobese, Sookrajh, Mkhize, Jeewa, Bottomley, Lewis, Baisley, Butler, Gxagxisa & Garret, 2020: 160; Scheibe, Van der Merwe, Cloete & Grasso, 2018: 69; Kabiri, Akuffo, Nortey, Eusebi & Danso-Appiah, 2021: 2).

Responding to the AIDS pandemic, many countries designed and implemented several strategies to curb the scourge (Inungu & Karl, 2006:1; Fund, 2020:5; Ehrenkranz, Grimsrud, Holmes, Preko & Rabkin, 2021:147; Van Wyngaard & Whiteside, 2021:117; Cushnie, Reintjes, Lehtinen-Jacks & Figueroa, 2021:2). Condom use is probably the most tried strategy used around the world to fight back against the pandemic—at least, just to slow down its spread (Du, Zhang, Luo, Rong, Meng, Yu & Tan, 2021:1; Ntshiqa, Musekiwa, Mlotshwa, Mangold, Reddy & Williams, 2018:2; Segala, Micheli, Seguiti, Pierantozzi, Lukwiya, Odong, Aloi, Ochola, Cauda, De Gaetano-Donati & Cingolani, 2021:2). Another strategy has been male circumcision, buoyed by the finding that circumcision lowers the risk of men catching HIV from HIV-positive women by more than half (Karim, 2011:30). Within the context of South Africa, particularly, a further preventative strategy involved experimenting with an antiretroviral (ARV) vaginal gel called Tenofovir. This heralded a shift from measures that focused on men to quell the spread of HIV to empowering women to take control of their bodies by exercising the power and prerogative to use the vaginal gel. Thus, targeting women was an empowering approach. Subsequently, Karim (2011:30) reported that the chance of heterosexual women contracting HIV while using this vaginal gel had reduced threefold. However, the spreading of HIV remains a major challenge in many African countries, although it has recently been masked by the advent of the novel Corona Virus Disease 2019 (COVID-19) (Dorward et al., 2020:163; Statistics SA, 2021:16). Nonetheless, worldwide, a preponderance of research has been placed on the socioeconomic impact that HIV and AIDS have had on people, which has been well-documented universally and reflected in the various annual reports released by global institutions as well as the mobilisation of financial resources (Gayle & Hill, 2001:1; Scheibe et al., 2018:69; Kabiri et al., 2021:2). That said, the fight to end the epidemic remains strong.

This study sets out to explore and describe the role that stigma plays in the spread of HIV among young women living with HIV, between the ages of 18 and 24, living with HIV in Johannesburg, South Africa. Accordingly, this chapter provides the attendant background information, purpose and objectives of the study; the research questions, theoretical foundation of the study and a brief description of the methodology employed in the study.

1.2. BACKGROUND TO THE STUDY

In 2021, South Africa had an estimated HIV prevalence rate of 13.7% among South Africans of all ages, translating to 8.2 million PLHIV (Statistics SA, 2021:15). This represented an increased estimate from 3.8 million in 2002 to 8.2 million by 2021, indicating an almost doubling of the prevalence rate during that nineteen-year period, which is really alarming for the country. Adults between the ages of fifteen and forty-nine accounted for an estimated 19.50% of PLHIV. In general, South Africa is characterised by various forms of social inequalities including gender inequality, which are magnified in less affluent areas; Gauteng Province, where this study will be located, also shows similar patterns. This is evident in the healthcare sector where access to primary healthcare in less affluent areas remains unjust since resources are not present where they are most needed (Grut, Mji, Braathen & Ingstad, 2012:2; Treves-Kagan, Steward, Ntswane, Haller, Gilvydis, Gulati, Barnhart & Lippman, 2015:7).

The AIDS pandemic has been widely researched and found to be highly prevalent in low- and middle-income countries (LMICs) such as Eswatini and Lesotho (World Bank, 2019). The World Bank (2019) refers to LMICs as countries with a gross national income (GNI) per capita of $1,025 or less per annum, which is calculated using the World Bank atlas method. Accordingly, South Africa is categorised as being an upper middle-income country, falling within a GNI per capita of between $3,996 and $12,375.

Notwithstanding this, South Africa is reported to have one of the highest HIV prevalence rates in the world (Kaiser Family Foundation, 2021). By comparison, however, it appears that this ranking says something about the relationship between the GNI per capita and HIV prevalence given that South Africa's overall HIV prevalence rate is estimated to be 13,5% (Statistics SA, 2021:v), the prevalence rates for Eswatini and Lesotho, both classified as LMICs, are 27% and 23%, respectively (Kharsany & Karim, 2016:34). Indeed, the HIV epidemic has disproportionately afflicted the world's poorest regions and HIV infection is concentrated among the most marginalised people within affected countries (Inungu & Karl, 2006:2; Scheibe et al., 2018:69; Kabiri et al., 2021:2). According to Inungu and Karl (2006:2), poverty, starvation, disease, political and economic instability, and structural inequality are all contributing to the worldwide epidemic. With specific reference to South Africa, Scheibe et al. (2018:69) decry 'limited interventions for socioeconomic empowerment' for people who have been affected adversely by HIV and AIDS.

Literature on the recorded high HIV prevalence among AGYW presents a number of reasons for this phenomenon. Idele, Gillespie, Porth, Suzuki, Mahy, Kasedde and Luo (2014:144) explain that this high prevalence rate is due to adolescent girls being more likely than adolescent boys in low- and middle-income nations to have their first sexual experience before the age of 15 years old. The second related reason they advance is early marriages among the AGYW, associated with early childbirth. On their part, Koech, Teasdale, Wang, Fayorsey, Alwar, Mukui, Hawken and Abrams (2014:2729) advance four reasons for this high prevalence: (a) increased survival of perinatally-infected HIV-positive (HIV+) children through the expansion of HIV testing and treatment services; (b) increase in new infections among 15–24-year-olds, primarily from sexual transmission; (c) poor retention in HIV care, leading to suboptimal health outcomes; (d) poor adherence to antiretroviral treatment (ART), leading to suboptimal health outcomes – including reduced viral suppression.

Harrison, Colvin, Kuo, Swartz and Lurie (2015:207) explain the disproportionately high HIV prevalence rate among AGYW in reference to some high risk social, behavioural and structural factors associated with this group of individuals. These include (a) gendered social norms that advantage male power in sexual relationships, (b) age disparities in relationships between younger women and older male partners, (c) the history of labour migration and the legacy of family disruptions associated with it, especially with reference to the Southern African region, and (d) the entrenched social and economic inequalities.

It is reported that many AGYW have welcomed the use of oral pre-exposure prophylaxis (PrEP) as an HIV prevention method and something to reduce HIV-related anxiety while increasing their autonomy over their sexual health, independent of sexual partners' knowledge or approval (Rousseau, Katz, O'Rourke, Bekker, Delany-Moretlwe, Bukusi, et al., 2021:2). Clinically, it is reported that, when used consistently, daily dosing of oral PrEP reduces the risk of acquiring HIV by more than 95%. However, the actual use of PrEP is reported to be dogged by a number of barriers, including (a) confusing PrEP use with antiretrovirals for treatment (ART) is common – thereby creating a large deterrent to PrEP use, seen against the pervasive HIV-related stigma; (b) poor perception of HIV vulnerability; (c) low awareness about PrEP; (d) lack of social support for PrEP use; (e) accessibility and practicalities of use, and (f) intimate partner violence (IPV), in committed relationships where a sense of trust has been established, and situations where AGYW were hiding pill taking from their significant others (Rousseau et al., 2021: 2).

On their part, MacPhail and Campbell (2001:1613) highlight the low rate of condom use in this age group as a major reason contributing towards the reported high HIV prevalence rate. According to MacPhail and Campbell (2001:1613) lack of risk perception, peer pressure, the availability of condoms, adult views about condoms and sex, gendered power dynamics, and the economic environment of adolescent sexuality are the six barriers to condom use. It was reported that many young people were critical of the norms that governed their sexual behaviour, despite clear evidence that peer and gender pressures put people's health at risk (MacPhail & Campbell, 2001:1613). Finally, Simbayi, Kalichman, Jooste, Cherry, Mfecane and Cain (2005:53) cite the following contributing factors to the high HIV prevalence among AGYW: (a) misconceptions about AIDS, including misconceptions about AIDS, (b) beliefs that condoms got in the way of sex, and (c) rates of unprotected vaginal intercourse. All these factors put together meant that the AGYW engaged in high rates of sexual practices that place them at risk for HIV infection.

The point in sketching this general picture about HIV prevalence is that HIV-related stigma, which is the main focus of this study, is a major source of concern since it is both a cause and result of secrecy and denial, which are both accelerators for HIV transmission (Inungu & Karl, 2006:2). In particular, the stigma tends to delay HIV testing, which is an important first step towards treatment and other preventative measures. For pregnant women, this results in infected mothers, in turn, infecting their babies during delivery or breastfeeding (Inungu & Karl, 2006:2). Thus, HIV prevention initiatives such as early detection through serostatus testing will fail unless the attendant stigma is taken seriously and effectively addressed (Inungu & Karl, 2006:4). Stigma is found at various levels: families, community, institution and the population at large (Finigan-Carr, Johnson, Pullmann, Stewart & Fromknecht, 2019:49). This is fully explained under Section 2.9.1 in Chapter 2.

Odimegwu, Akinyemi and Alabi (2017:7) present a long list of factors associated with HIV and AIDS-related stigma which will be elaborated on further in Chapter 2. Deacon and Boulle (2007:185) also affirm the point that HIV and AIDS is a highly stigmatised health condition such that PLHIV often suffer discrimination, more than patients with other health issues. Similarly, Gruszczyńska and Rzeszutek (2019:2) point out that HIV and AIDS is a chronic condition that leads to many psychological challenges for PLHIV, which are associated with incessant HIV-related stigma and the attendant social isolation. Unfortunately, PLHIV suffer from discrimination and stigma from many sources, including health professionals who are meant to assist them. This can easily adversely affect or compromise the quality of treatment and health care that they receive. In addition, such negative experiences might damage their self-esteem, leading to a reluctance to continue with efforts to access further treatment. The seriousness of HIV-related stigmatisation and discrimination prompted Ugarte, Högberg, Valladares and Essén (2013:38) in Nicaragua to design an instrument consisting of HIV stigma and discrimination scales to measure community-based stigma and discrimination. From their findings, they recommended that community-based intervention strategies should be designed and implemented to monitor stigma and discrimination as well as to increase the acceptance of PLHIV and reduce inequities (Ugarte et al., 2013:164). From their study, Lee, Kim, Na, Kwon, Yoon and Lee (2019:674) reported that the frequency of Korean medical professionals attaching stigma and practising discrimination increased significantly when invasive treatment included both outpatient and inpatient services and that their HIV and AIDS-related stigma and prejudice were linked to assumptions, fear of infection and a lack of understanding (Lee et al., 2019:675).

South Africa ranks high in HIV prevalence at 13.7%. It is believed that this relatively high prevalence rate is attributable to the various forms of social and structural inequalities that characterise South African society, including poverty, gender inequalities, sexual, gender-based violence, socioeconomic hardships, unfavourable cultural and traditional practices, uneven healthcare provisioning and political instability. All these forms of inequalities and inequities exacerbate the vulnerability of particularly young women to contracting HIV as they engage in social vices like transactional sex for both economic and social reasons. Against all these challenges, stigmatisation and discrimination against PLHIV run rampant in the communities and among some healthcare workers— making it very difficult to find effective ways to mitigate against the spread of HIV.

1.3. THE RESEARCH PROBLEM

Worldwide, young people in the age bracket of 15 to 24 years make up an estimated 45% of all new HIV infections, while in South Africa they account for almost 50% (Miller et al., 2017:2). Ostensibly, this is attributable to personal and adverse societal factors such as poverty, violence, poor housing and food insecurity (Miller et al., 2017:1). In addition, it is reported that the rate of new HIV infections in the country is ascribed to a combination of biological susceptibilities, socio-behavioural dispositions and contextual factors (Zuma et al., 2016:3). Similarly, Miller et al. (2017:1) also contend that the disproportionate rates of HIV faced by women are increased by biological predispositions, gender-biased economic inequity, uneven authority within relationships and sexual assault are all factors that play a role in HIV transmission. HIV susceptibility among the youth has a gendered dimension, with women having three times more HIV prevalence than men (Miller et al., 2017:1). This forms the main thrust of this study. Furthermore, considering that the researcher sought to explore HIV-related stigma among young women, it was determined that a focus on young women living with HIV, as a distinct sub-group, would be an appropriate and relevant focus area, as these would speak from personal experience, rather than speculating about it.

Overall, this researcher was moved and inspired by the views of Armstrong-Mensah et al. (2019:29) that HIV-related stigma causes PLHIV to live in continual fear of discrimination, isolation and violence from community members and to hide their HIV status from family members, spouses or partners, thwarting any possibilities of health-seeking behaviour that could improve their quality of life or prevent future transmissions.

1.3.1. Aim

This study sought to explore how HIV-related stigmatisation and discrimination influenced the spreading of HIV among young women living in Johannesburg, with specific reference to young women living with HIV (YWLHIV). It was envisaged that from the lived experiences of YWLHIV, the researcher would gain an understanding of underlying reasons why stigma appears to intensify the spread of HIV and contribute to the body of knowledge in this field by providing additional insights which may, in turn, enhance the efficacy of existing preventive and destigmatisation HIV prevention interventions and programmes.

1.3.2. Research Objectives

The research objectives of this study were to explore:

1. The perceptions of YWLHIV about HIV-related stigma and how it relates to their vulnerability to HIV infections.
2. How HIV-related stigma impedes YWLHIV HIV from accessing HIV and destigmatisation intervention programmes.
3. How stigma hinders YWLHIV from accessing healthcare and treatment.
4. The nature and types of existing prevention and destigmatisation intervention programmes related to HIV prevention among YWLHIV.
5. Possible gaps in the existing stigma prevention and destigmatisation intervention programmes.
6. How the existing intervention programmes could be streamlined to enable the programmes to achieve their intended outcomes.

1.3.3. Research Questions

The above research objectives were stated in the form of research questions as follows:

1. What are the perceptions of YWLHIV about HIV-related stigma and its effect on young women’s vulnerability to HIV?
2. How does stigma impede YWLHIV HIV from accessing HIV-prevention and destigmatisation intervention programmes?
3. How does stigma hinder YWLHIV from accessing health care and treatment?
4. What are the types and nature of existing stigma prevention and destigmatisation intervention programmes in the target communities?
5. What possible gaps do young women living with HIV see in the existing stigma prevention and destigmatisation intervention programmes?
6. How could gaps in the current destigmatisation intervention programmes be addressed to optimise the attainment of the intended outcomes?

1.4. DEFINITIONS OF CONCEPTS

The following concepts are central to this study:

1.4.1. Stigma

According to Goffman (1963:1) stigma refers to an extreme disapprobation towards someone on account of social characteristics that distinguish him or her from other members of the community. Herek (2002) in Florom-Smith and De Santis (2012:154) defines stigma as 'a lasting, negatively valued circumstance, status, or characteristic that discredits and disadvantages individuals'.

1.4.2. HIV- or AIDS-related Stigma

More specifically, Herek, Mitnick, Burris et al. (1998:36) see HIV or AIDS-related stigma to include prejudice and discrimination shown towards individuals who are believed to have or do have HIV or AIDS. Such stigma may also be extended to persons, groups and communities associated with such people. The definition adopted in this study is that HIV-related stigma 'is the collection of adverse attitudes, beliefs and actions of others against people living with or affected by HIV, which may result in deleterious internalised beliefs or actions taken by persons living with or affected by

HIV infection that may result in negative health outcomes' (Florom-Smith & De Santis, 2012:159).

1.4.3. HIV-related Discrimination

HIV-related discrimination is the 'unfair and unjust treatment (act or omission) of an individual based on his or her real or perceived HIV status' (UNAIDS, 2014 in Odimegwu, 2020:2).

1.4.4. Destigmatisation

This term is used to refer to the act of removing associations of shame or disgrace from something (Merriam-Webster: 2020).

1.4.5. Risk

This term is used to refer to the likelihood that one may acquire HIV infection (UNAIDS, 2008:65).

1.4.6. Vulnerability

In this study, the term *vulnerability* refers to different factors such as gender, age, disability, health status and other contextual life stressors that may adversely affect people’s capacity and ability to cope and survive in the context of a disaster (Ferreira, Buttell & Ferreira, 2015:31). In the context of this study, the disaster is HIV.

1.4.7. Vulnerable Groups

This term is used to refer to people who are predisposed or are susceptible to contracting HIV for various reasons. The literature identifies such at-risk groups to include adolescent girls, young women and women, generally (WHO, 2019). In the context of this study, the focus on young women has been motivated by research findings reporting that each year, adolescents continue to die from AIDS-related causes. This has remained so, notwithstanding that for other age groups 'AIDS-related deaths have been dropping' (Lake & Sidibé, n.d.: 1; Piot, Karim, Hecht, Legido-Quigley, Buse, Stover, Resch, Ryckman, Møgedal, Dybul, M., Goosby, Watts, Kilonzo, McManus, & Sidibé 2015:171).

1.5. CONCEPTUAL FRAMEWORK

In the first instance, this study is premised on the main tenets of the social ecological model (SEM) which is a theory-based framework used to understand various levels of personal, social and environmental factors that determine behaviour. SEM depicts spheres of influence over human behaviour based on four core principles: individual, interpersonal, community, organisational and policy-enabling environment (UNICEF, 2009). In this respect, SEM can be used to guide studies involving different layers of the population who may be at risk of contracting HIV. SEM recognises the direct link between an individual and his/her environment. It offers a model for addressing the complexities of socioeconomic, cultural, political, environmental and biological elements of behaviour. This is explained further and in more detail in Section 2.9.1 of Chapter 2.

The second theoretical lens used in looking at the main aspects of this study is feminism – both radical and African feminism. Radical feminism is a western philosophy that promotes equality among men and women (Harrison & Boyd, 2018:296). It projects the view that patriarchy influences women's dependency on men which, in turn, leads to gender inequality. Women are not a homogeneous group of people but differ in their individual and collective struggles. The study examines how women are positioned in South African society, which is largely traditionally patriarchal. Patriarchy influences women's dependency on men which, in turn, leads to gender inequality. This results in women not having control over their sexuality and being at a higher risk of contracting HIV.

On the other hand, African feminism is more conciliatory and defines men as allies and partners in the fight for social equality against the greater vices of colonialism and neo-colonialism (Garuba, 2021:105). African feminism was born upon the realisation that western feminist ideologies were failing to capture the conditions of the African woman in her day-to-day life social circumstances. So, in coming up with the various strands of African feminism, African female writers have established a feminine discourse which seeks to accurately represent African women’s qualities, attributes and potentials (Nnaemeka, 2005:359; Nwapa, 2010:364). These theoretical perspectives are discussed in detail in Chapter 2.

1.6. BRIEF DESCRIPTION OF THE RESEARCH PROCESS

In this study, the researcher sought to gain an in-depth understanding of how YWLHIV in Johannesburg are affected by HIV-related stigma and discrimination that advances the spread of HIV among young women. The researcher found this research paradigm to be well-suited and relevant for addressing the aim and research questions of this study, which were exploratory in nature. The specific research design followed was a case study of 13 young women living with HIV who constituted the research sample, through which the researcher sought to break down the barriers that predisposed young women to HIV and AIDS and exacerbated their vulnerability to the social stigma attached to it.

Compiling involved the transcription of the collected data from the interview format to text, disassembling involved coding the data into categories of description, reassembling involved pulling the data together according to emergent themes, while interpretation allowed the researcher to align the themes with the research questions before inferences and conclusions were drawn.

1.7. ETHICAL CONSIDERATIONS

This study was approved by the College of Human Sciences Research Ethics Committee of the University of South Africa (UNISA) (NHREC Registration #: Rec-240816-052; CREC Reference #: 67139361_CREC_CHS_2021, the Research Committee of the Johannesburg Health District (NHRD REF. NO.: GP_202110_025) and from the Edenvale Regional Hospital.

1.8. CHAPTER SUMMARY AND CONCLUSION

This chapter presented a detailed orientation to the study, encompassing the background, problem statement, aim, research questions and the theoretical basis of the study. Thus, it can be said that this chapter has succeeded in achieving the two principal purposes of an opening chapter overall, namely (a) to assist the researcher to contextualise, refine and clarify her research focus, as reflected in the various sub-headings outlined above and (b) to orientate and assist the reader to have a bird’s-eye view of the study as a whole. The next chapter summarises the current literature and situates the research in its larger context.

1.9. STRUCTURE OF THE DISSERTATION

The dissertation comprises five chapters as well as a list of references and appendices. **Chapter 1** starts with the general orientation to the study encompassing an introduction, background, problem statement, objectives and research questions, theoretical framework and research methodology, and ending with a chapter summary. **Chapter 2** discusses the literature review with the research questions forming the basis for the literature presentation. Subsequently, the chapter presents a detailed description and elucidation of the theoretical framework. **Chapter 3** presents the study's research paradigm, research design, target population, sampling and research sample, the data collection process, data analysis procedures and ethical considerations. **Chapter 4** presents the results of the study, interpretation and discussion, while **Chapter 5** presents a summary of the study, conclusion and recommendations.

CHAPTER 2
LITERATURE REVIEW

2.1. INTRODUCTION

South Africa has made significant progress in combating the HIV and AIDS epidemic, largely due to the large scale, countrywide ART programme. In 2021, the estimated HIV prevalence rate among South Africans of all ages was 13.7%, translating to 8.2 million PLHIV. This represents an increase from the estimated 3.8 million in 2002 (UNAIDS, 2020). From 2002 to 2020, AIDS-related deaths decreased in the country from 181 497 to 85 154, mainly due to the uptake of ART (Statistics SA, 2021:7).

Despite the efficaciousness of ART, the percentage of adolescent girls and young women (AGYW) who stand to completely benefit from ART remains low. Over the years, sub-Saharan Africa has seen a steady decline in AIDS-related deaths with the 13–24-year age bracket being the only exception and an estimated total of 720 000 being infected with HIV since 2017.

The UNAIDS 95-95-95 target aims to help maximise the benefits of ART, such that by 2030, 95% of all PLHIV know their status of whom 95% will be receiving ART and 95% of the people receiving ART will present viral suppression (UNAIDS, 2020). South Africa has steadily progressed towards the UNAIDS 90-90-90 targets, such that in 2018, 90% of PLHIV knew their status, 68% were on ART and 87% of those on ART showed viral suppression (Avert.org, 2020). In the Gauteng province, of the 89% reported to be HIV positive, 61% have been initiated on ART and 88% of ART patients have displayed viral suppression. However, interruptions in the HIV and AIDS treatment programmes make achieving these UNAIDS goals difficult.

In the meantime, HIV-related stigma threatens to derail prevention and treatment efforts and is a major impediment to meeting the UNAIDS 95-95-95 targets. Accordingly, a thorough understanding of the nature of stigma is required in order to address the scourge in South African communities (Haffejee, Maughan-Brown, Buthelezi & Kharsany, 2018:1).

To avoid the derailment of the UNAIDS 95-95-95 targets, the United Nations (UN) 'General Assembly Political Declaration on Ending AIDS' (2016) set out targets to eradicate HIV related stigmatisation by 2020. Nonetheless, in South Africa, HIV- and AIDS-related stigmatisation is still a problem and is deeply embedded in social systems, necessitating internal solutions (Koodibetse, 2015:703).

Research on HIV-related stigmatisation has largely been based on the definition of stigma as a characteristic that discredits a person possessing a particular attribute or characteristic (Goffman, 1963:1). Since then, stigma has been further conceptualised as a psychological stressor that could either be manifested as anticipated negative treatment or internalised negative attitudes of society (Harper, Lemos & Hosek, 2014:543).

South Africa’s National Strategic Plan for HIV, TB and STIs (NSP) 2017-2022 places a strong focus on overcoming stigmatisation and prejudice and highlights HIV-related stigmatisation as a major impediment to patients’ commitment to care and treatment (South African National AIDS Council [SANAC], 2017:5). Of particular interest to this study is the NSP’s focus on reducing the rate of HIV infection among AGYW. Due to the exceptionally high risk of infection in this population, promoting HIV prevention among AGYW is a major emphasis of the NSP. Not only can early HIV infection alter the lives of many AGYW permanently, but South Africa’s national HIV reduction targets are also unachievable unless AGYW are prioritised (SANAC, 2017:3).

In the conceptualisation of the NSP, one way to achieve effective HIV prevention is to deal comprehensively and effectively with HIV-related stigmatisation and discrimination. During the implementation of the NSP 2017–2022, SANAC conducted a survey to better understand stigmatisation and discrimination. The survey found that of the 10 000 participants, 35.5% of PLHIV experienced externalised stigma and 43% of the participants experienced internalised stigma. However, other studies have reported a decline in stigmatisation at a personal level but an increase in community stigma (Forsyth, Vandormael, Kershaw & Grobbelaar 2008:78). By the same token, Mall, Middelkoop, Mark, Wood and Bekker (2013:196) reported an increase in HIV awareness, associated with a decrease in HIV-related stigmatisation. These improvements occurred as a result of understanding PLHIV and many of them having been screened for HIV.

In Southern Africa, where programmes to fight discrimination and stigma exist, testing and care for HIV and AIDS have been shown to improve attitudes towards PLHIV (UNAIDS, 2017a). In 2019, Avert, a local NGO conducted a study on HIV prevention and found that HIV stigma discouraged many young women from taking part in HIV prevention activities that could help them stay HIV-free. The young women in the study reported being terrified by the prospect of being wrongly diagnosed as HIV positive. They also expressed fear of the isolation and discrimination that typically accompany an HIV positive diagnosis. This fear made them adopt high-risk behaviours that predispose them to catching the virus. Therefore, to reduce stigma, there needs to be an understanding of how it manifests and how it is experienced at the various levels of the HIV care value chain and attendant policies.

This chapter presents a review of the literature related to HIV and AIDS with specific reference to stigma. In this regard, the chapter reviews literature about types of HIV and AIDS-related stigmatisation, within the context of the country's policy response to HIV and AIDS-related stigmatisation. Further, the researcher also provides insight into the two theoretical perspectives of SEM and radical feminism as well as other studies conducted on HIV-related stigma and the spread of HIV among young women. Importantly, the literature review is presented in line with the research questions in order to remain focused and relevant.

2.2. HIV AND AIDS IN SOUTH AFRICA 2021

In 2019, it was estimated that there were 38 million PLHIV worldwide, with South Africa estimated to have 7.64 million people—4.84 million of whom were 15-year-old females or older, while 2.49 million were males in the same age bracket and 310 000 were children below the age of 15 years (Pillay & Johnson, 2021:2). This marked an increase of 1.7 million people from 5.9 million in 2010 (Pillay & Johnson, 2021:2). With respect to new HIV infections, Pillay and Johnson (2021:2) reported that in 2018–2019 there were 201 000 new HIV infections involving 121 000 women, 67 000 men and 11 600 cases of mother-to-child-transmission (MTCT). It was further reported that over a quarter of South African women in the reproductive age bracket of 15 to 49-years of age were HIV positive, with an estimate of 23.92 per cent HIV prevalence among women in the country (NSP, 2021:10).

Research has shown the effects of the AIDS pandemic on communities globally. In South Africa, AGYW have been disproportionately infected by HIV (Human Sciences Research Council [HSRC], 2018). The HSRC further reports that AGYW are still disproportionally affected by HIV and AIDS. In 2017, 79% of all new HIV infections reported worldwide involved females in the 10 to 19-year age bracket from Eastern and Southern Africa (UNAIDS, 2019:6). Women in the sub-Saharan African countries were the hardest hit, in that for every three HIV infections amongst young men of 15–25-years of age, there were seven new infections amongst young women of the same age bracket, daily.

Furthermore, it was reported that KwaZulu-Natal was the epicentre of South Africa's HIV epidemic with over two million PLHIV. This was estimated to be more than all the PLHIV from five of the nine provinces in the country combined, namely Free State, North-West, Western Cape, Northern Cape and Limpopo. However, in terms of population density, KwaZulu-Natal comes second to Gauteng province. Thus, with about 15,81 million inhabitants (26,3% of the total population of South Africa), Gauteng continues to be the most populous province in the country. Four of the six districts in Gauteng Province have a high HIV burden, namely Sedibeng, Ekurhuleni, City of Johannesburg and City of Tshwane (NSP, 2021:10).

2.3. YOUNG WOMEN'S PERCEPTIONS OF STIGMA AND HOW IT RELATES TO THEIR VULNERABILITY TO HIV

This section focuses on the literature pertaining to the substantive matter of the first research question, starting with further elucidation of the term *stigma*. Stein (2003:5) explains that the Greeks coined the term stigma in reference to tattoo marks branded on an individual's skin as a result of some incriminating deed. The physical mark served as a public warning that the person was blemished and morally corrupt. Thus, originally, stigma had nothing to do with illness but with how people behaved.

Stigma is a commonly observed and experienced phenomenon worldwide in both poor and rich countries. The term is typically applied to people exhibiting specific characteristics, like physical deformities or it may arise from negative attitudes toward the behaviour of a group like prostitutes or homosexuals (Brown, Macintyre & Trujillo, 2003:50). In reality, there are numerous types of stigma that are frequently stacked on top of other forms of stigma in relation to behaviours like injectable drug usage and sex outside of marriage (Brown et al., 2003:50). Unfortunately, these layers of stigma have contributed to the spread and deepening of HIV-related stigma among those who have been infected and affected by the disease. There is also the notion of HIV-related stigmatisation by association with HIV-positive persons (secondary stigma), including those who may have died from HIV-related illnesses. Typically, this affects family members, friends, co-workers and healthcare workers who treat HIV-positive people (Brown et al., 2003:50). The groups of people affected by secondary stigma also suffer discriminatory attitudes, stereotyping and prejudice (Stangl, Earnshaw, Logie, Van Brakel, Simbayi, Barré & Dovidio, 2019:7).

In literature, much of the characterisations of the prevalence of HIV-related stigma, refer to social class (for instance men who have sex with men, transgender people, sex workers, injection drug users) rather than Black or African people, *pe se* (Ikeda, Nyblade, Srithanaviboonchai & Agins (2019:2). There is also a definition problem of Black versus African. In some countries, the term Black refers to anyone other than Caucasian, while in other countries Asians, Coloured people and those of Indian descent are not classified as Black (Brown, BeLue & Airhihenbuwa, 2010:441). Another common classification is one related to regional classifications, such as Sub-Saharan African countries, as having high risk of HIV infections among AGYW (Kimera, Vindevogel, Reynaert, Justice, Rubaihayo, De Maeyer, Engelen, Justice, Rubaihayo, De Maeyer, Musanje & Bilsen, 2020:1).

In their study based in South Africa, Brown, BeLue and Airhihenbuwa (2010:441) reported that HIV stigma in South Africa is influenced by factors such as race, culture, and religious and spiritual beliefs. Campbell, Nair, Maimane and Nicholson (2007:403) report the following drivers of stigma: the accessibility and applicability of AIDS-related knowledge, the absence of social settings for discussing HIV and AIDS; AIDS, sexual morality, and the supervision of women and young people in relation to HIV; inadequate services for managing HIV and AIDS; and how poverty affected how people reacted to HIV and AIDS. In similar vein, Bologna, Stamidis, Paige, Solomon, Bisrat, Kisanga, Usman and Arale (2021:41) list fourteen causes or drivers of stigma about COVID-19: fear; anger; loss of work/ income; economic repercussions;

frustration / confusion; distruct in the government; myths, rumours and conspiracy theories; misinformation about COVID-19 and transmission; frequent changes in information; uncertainty; lack of access to adequate healthcare; low risk perception; lack of community input / feedback and social biases / group norms.

In their study involving South African youths, Simbayi, Kalichman, Jooste, Cherry, Mfecane and Cain (2005:53) report that, despite generally high knowledge levels about HIV transmission and risk sensitization, (a) there was evidence that misconceptions about AIDS persisted, particularly myths related to HIV transmission, and (b) the youths demonstrated high rates of sexual practices that placed them at risk for HIV infection. Similarly, Kakuma, Kleintjes, Lund, Drew, Green and Flisher (2010:122) also aver that “programmes to educate adolescents to practice safe sexual practices to prevent HIV/AIDS infection have not significantly changed adolescent risk behaviour.” In concurrence, Wong (2013:60) also found that “the root causes of HIV stigma and discriminatory attitudes were not associated with knowledge deficiency.” Instead, she reported ethnicity, age, socioeconomic group, and urban–rural settings to be major contributors to HIV-transmission (Wong, 2013:60).

To Kimera et al. (2020:1) some of the causes of HIV-related stigma among the youth include (a) the general lack of youth-friendly programmes to enable them to navigate through HIV-related challenges, (b) being in the initial stages of cognitive, physical, and social development, the youth get exposed to HIV-related stigma which they may interpret, express or react to in different ways from adults, (c) HIV-related stigma has been reported to evoke maladaptive responses in youth, such as sex and substance abuse, (d) they youth typically have less control over their living situations due to their high dependence on adults/caregivers, (e) the youth are often less aware of their rights compared to adults, (f) the youth tend to suffer unjustified social blame for the infection whose genesis they often had no control over, especially in cases of perinatal infection and sexual violence, and (g) the youth’s age-group-specific construction of stigma, while its socio-cultural contextualization could also exacerbate their vulnerability to HIV infections.

Hall, Joseph, Devlin, Kerman, Schmitt, Ridgway and McNulty (2021:6) report that, like in the case of HIV, the attitudes of COVID-19 patients are characterised by fear, denial, and stigma in the early stages, which gradually develops into acceptance in the later stages. Furthermore, HIV positive people feel particularly vulnerable "due to the constant, and sometimes unclear, emphasis of the notion of 'underlying medical conditions' in regard to COVID-19" (Hall, et al., 2021:6). For the PLHIV, this exacerbates anxiety and other mental health disorders and contributes to added stress and isolation. In a significant way, PLHIV find themselves re-living their journey of HIV stigma – now going through similar experiences, anxieties and emotions as COVID-19 patients. In particular, they are adversely affected by internalised stigma which, typically, "contributes to decreased healthcare engagement" (Hall, et al., 2021:6). The situation may easily be exacerbated when an individual is faced with "multiple stigmatizing health conditions, such as HIV and COVID-19, in addition to often facing intersectional stigma related to racial, sexual, and gender minority identities" (Hall, et al., 2021: 6).

To Islam, Pakrashi, Vlassopoulos and Wang (2021:7), it is the lack of knowledge that is a major underlying root cause of stigma towards COVID-19 patients – just like for HIV. Thus, they aver that, conversely, improved knowledge about the prevention and transmission of COVID-19 and reduced stress about the disease are important channels for the reduction in stigmatisation. Similarly, Wakeel and Njoku (2021:4) aver that stigma is associated to a lack of understanding of how COVID-19 spreads, concerns of illness and death, a desire to place blame, and gossip that spreads rumours and myths, according to the study. As the case with HIV, stigma related to COVID-19 can also lead to stereotyping, discrimination, labelling, and other negative behaviours toward those who have tested positive for the disease.

Quite evidently, the above synopsis gives a picture and magnitude of the array of the major causes or drivers of HIV infections among the AGYW. The causes are many and, therefore, a multiplicity of approaches and measures are needed to successfully deal with the challenges faced by the youth, in general, and AGYW, in particular.

Typically, AGYW choose not to tell anyone about their serostatus as a result of the fear of stigmatisation, thereby blocking any possibility of attempts to get help to address the situation (Armstrong-Mensah et al., 2019:69). Overall, AGYW are adversely impacted socially, economically and mentally. This suggests that all the efforts to reduce HIV infections in the country cannot be addressed meaningfully without addressing the issue of HIV-related stigma among AGYW, especially considering that they constitute the subpopulation with the greatest risk of HIV infections. Consequently, one would like to see a concerted effort from all the main stakeholders working together on HIV prevention efforts to stem the HIV tide in the country. As Armstrong-Mensah et al. (2019:69) opine, organisations must collaborate to create an environment in which AGYW feel free and confident to disclose their HIV status and participate in HIV prevention activities. Indeed, the implementation of comprehensive community-based HIV stigma-reduction and wellness-enhancement intervention programmes in South Africa’s North-West Province, involving PLHIV, led to increased knowledge and understanding of stigma and attendant coping strategies. This was in addition to improved relationships, making the programme participants (PLHIV) feeling much better and more disposed towards disclosing their serostatus (French, Greeff, Watson & Doak, 2015:81). This approach is in line with the 'tactical argument' advanced by Birbeck, Bond, Earnshaw and El-Nasoor (2019:1) for a broader, more comprehensive and transdisciplinary approach to the challenges of HIV-based stigmatisation and discrimination—thereby giving PLHIV a voice and concomitantly promoting their dignity. Likewise, Relf, Holzemer, Holt, Nyblade and Caiola (2021:405) call for longitudinal and contextualised HIV stigma intervention programmes.

Unfortunately, once a person is associated with a certain disapproved behaviour or negative social characteristic, he or she becomes distinct from other people in society and is then subjected to different forms of humiliation (Yuh, Ellwanger, Potts & Ssenyonga, 2014:582). Accordingly, stigma serves to keep people in a specific group and away from the rest of other members of the community by enforcing social norms to avoid disease and through exclusion, keep the affected persons exploited and dominated (Hartoga, Hubbard, Krouwer, Thornicroft, Kohrt & Jordans, 2020:1). As such, stigma (a) has a deeply negative effect on the well-being of the affected individuals and groups, both physically and psychosocially; (b) can be more harmful to the affected individual than the hardship of the condition itself and (c) can hamper the normal outcomes of childhood health and growth (Hartoga et al., 2020:1).

Stigmatisation is an active process that takes place when there is a belief that there has been a violation of an aspect of the shared values, beliefs and/or attitudes that characterise a particular society. Accordingly, members of that particular society label individuals or groups for being different or deviant from the shared norms, standards or characteristics of that society. Thus, stigmatisation typically leads to prejudice and negative actions from various quarters in society including friends, co-workers, governments and government officials, employers, health care providers, friends and communities (Brown et al., 2003:50). In this respect, the perpetrators of stigma and discrimination are those persons who harbour adverse attitudes, show discriminatory behaviour and/or enact stigmatising actions, while those who are HIV-positive or associated with HIV like sex workers, are considered targets for stigmatisation (Brown et al., 2003:50).

The literature points to evidence that women suffer higher degrees of stigma and discrimination than men (Odimegwu, Alabi, De Wet & Akinyemi, 2018:1). Reporting on the situation in Nigeria, Odimegwu et al. (2018:2) aver that women were more stigmatised and discriminated against than men; stigma and prejudice are acknowledged as major barriers to universal support, care, treatment and prevention. Furthermore, stigma makes it difficult for people to seek HIV and AIDS counselling and testing to determine their serostatus and adherence to treatment. Additionally, stigma-related issues have resulted in broken relationships and HIV status not being disclosed, while the psychosocial impact of stigma and discrimination against PLHIV is vast. These include low self-esteem, loneliness (due to the avoidance by family members, friends and colleagues) as well as compromised treatment, support and healthcare.

Self-isolation, failure to disclose one's HIV status, silence, violence, self-blame, denial and rejection are manifestations of HIV and AIDS stigma (Yuh et al., 2014:582). On the negative effects of stigma, Hartoga et al. (2020:1) also point out that stigma seriously compromises HIV positive persons in several ways; socially and economically, by encouraging the adoption of harmful coping strategies, its association with poor quality of life, by preventing access to various types of services in society; by discouraging disclosure, adherence to treatment and support-seeking behaviour and by negatively affecting participation and decision-making (Hartoga et al., 2020:1). Further reported manifestations of stigmatising and discrimination towards PLHIV include being forced to stay away from their homes and having to change their daily routines, fearing that their families could stigmatise them, thereby leading to rejection. When this happens, the affected individuals could lose their shelter, children, social place of belonging and their ability to survive (The Well Project, 2020). All these are possible reasons for the vulnerability of young South African women to HIV of which some are perhaps more so than others.

Similarly, Avert.org (2019) identifies further adverse manifestations of HIV-related stigma and discrimination on PLHIV as quality of life, mental and physical health and the use of health services. Furthermore, Avert.org (2019:3) advances the following four manifestations of stigma: (a) poor access to and uptake of health services (testing, treatment and care), (b) harassment and abuse, (c) discrimination and (d) violence. Again, since YWLHIV are a subset of PLHIV, this applies to them as well. It is also reported that isolation is the direct effect of the social rejection that PLHIV experience at the hands of their communities (The Well Project, 2020). In turn, HIV-related stigma and discrimination are associated with depression, low self-esteem and even thoughts or acts of suicide (The Well Project, 2020). In the process, PLHIV tend to become increasingly marginalised by both society and the healthcare services necessary for survival (Avert. Org, 2019:3). In the same vein, the International Center for Research on Women (ICRW) (2005) outlines the following possible consequences of HIV-related stigma: (a) loss of income and livelihood, (b) reduced marriage and childbearing prospects, (c) poor healthcare, (d) diminished care in the home, (e) diminished sense of hope associated with a loss of self-worth and (f) reputational loss or damage. Since the predisposition to HIV infection is a function of people’s behaviour, certainly, factors such as the loss of income and diminished care in the home can lead to changes in the behaviour patterns of those affected, especially young women. This is where the vulnerability appears. Therefore, stigma and discrimination must be addressed to mitigate the spread of HIV and AIDS.

Furthermore, HIV-related stigma has been associated with severe adverse effects on the healthcare outcomes of PLHIV, mainly due to poor adherence to medical care (Rao, Feldman, Fredericksen, Crane, Simoni, Kitahata & Crane, 2012:711; Holzemer & Uys, 2004:163). In this regard, it is believed that addressing the various ways in which stigma limits the success of primary and secondary HIV prevention programmes could go a long way towards defeating the pandemic (Holzemer & Uys, 2004:164).

Some of the manifestations of stigma emanate from sociocultural, economic and political factors—all of which translate into different forms of inequalities (Odimegwu, 2020:2). This view is supported by Tlhako (2016:iv) who researched the influences of socioeconomic, cultural and environmental factors and identified poverty, peer pressure and multiple sexual partners as factors for young women's vulnerability to HIV in Sunnyside, Pretoria. Similarly, UNAIDS (2019:5) contends that multiple forms of discrimination exacerbate the vulnerabilities of vulnerable populations of AGYW such as stigma, discrimination, gender-based cultural norms and gender-based violence (GBV). In the same vein, Muula (2008:423) contends that the main factors contributing to young South African women's vulnerability to HIV are poverty, violence against women, cultural barriers that encourage intergenerational sex, non-use of condoms and a preference for 'dry sex', political factors and challenges that may have stymied an aggressive HIV response, recreational drug use, and biological factors such as a high prevalence of STIs. In this regard, Odimegwu (2020:2) asserts that HIV stigma occurs at individual, family, community and institutional levels as a result of these multidimensional influences and that many of these elements vary among cultures, necessitating context-specific methods to address the phenomenon.

2.4. STIGMA AS AN IMPEDIMENT TO YOUNG WOMEN ACCESSING HIV PREVENTION AND DESTIGMATISATION INTERVENTION PROGRAMMES

This section presents literature on stigma as an impediment to young women accessing HIV prevention and destigmatisation intervention programmes in South Africa, to shed light on the second research question of this study.

Earlier, it was reported that HIV and AIDS disproportionately affected AGYW. This could suggest that services for AGYW are failing to reach their intended target, accordingly, this vulnerable group continues to fall behind the farthest regarding HIV prevention (UNAIDS, 2019:178-179). Correspondingly, Petros, Airhihenbuwa, Simbayi, Ramlagan and Brown (2006:60) state that HIV-related stigma is one of the reasons for the disparities in HIV prevalence between genders as well as for accessing healthcare services. As such, they believe that responding to stigma as a social driver of vulnerability is key to controlling the epidemic.

Stigma reduction interventions seek to stem both the prevalence and burden of stigma, especially for those in the high-risk categories like AGYW (Hartoga et al., 2020:2). In literature, it is difficult to find studies that focus solely on young women's access to HIV-related destigmatisation intervention programmes, separate from access to other general healthcare services. One reason for this is that destigmatisation intervention programmes are ordinarily offered alongside educational and healthcare services (Rousseau et al., 2021:12). As such, a focus on access to healthcare services (which is the focus of the next section) also covers the main substance of this section.

Ma et al. (2018:1) report that the stigma associated with HIV and AIDS remains widespread worldwide among the public 'due to misinformation, erroneous information about HIV and AIDS, fear of unintentional transmission and unwarranted moral judgments of HIV-positive people's behaviour'. Thus, factors such as stigma, public stereotypes and discrimination against PLHIV (including AGYW) drive them away from visiting healthcare facilities and other venues where HIV prevention programmes are available (Tlhako, 2016:iv; Armstrong-Mensah et al., 2019:18; UNAIDS, 2019:6).

Typically, the social identity and full humanity of a person who is stigmatised are called into question, leading to devastating consequences for those stigmatised persons. In the process, other social challenges like social isolation and rejection, health inequalities, family discord, human rights violations and poor health outcomes may ensue (Ma et al., 2018:1). In this regard, stigma and discrimination remain barriers to the uptake of treatment and counselling as well as reduction and prevention programmes related to HIV and AIDS (Odimegwu et al., 2018:2).

Some studies have revealed that social constructions of HIV-stigma are deeply rooted in cultural perceptions and beliefs concerning the infected persons' lifestyles and focusing on the possible circumstances that could have led to HIV infections in the first place (Adeokun, Okonkwo & Ladipo, 2006:2 as reported by Odimegwu et al., 2017:6). Unfortunately, some of these cultural beliefs can impede or prevent PLHIV from accessing HIV prevention and destigmatisation intervention programmes. Cultural beliefs are not easily altered since they form very strong and sensitive bonds by which groups of people characterise themselves. As UNAIDS (2019:6) points out, the stigma associated with cultural practices arising from gender discrimination fuel the HIV epidemic, as reflected in specific roles that are performed by girls and young women in the home.

Thus, effective destigmatisation interventions are overall very important for biomedical prevention initiatives to succeed (Stangl et al., 2019:1) considering that stigma has a negative impact on primary and secondary preventive behaviours like HIV testing and other services, condom use, contraception and adherence to treatment (Harper et al., 2014:543). However, as explained above, AGYW's perceptions of stigma could impede their desire and ability to access HIV-related stigma prevention and destigmatisation programmes—hence, their potential vulnerability to HIV infections.

Like other members of society, AGYW experience stigma in different ways which may, in turn, affect their decisions regarding accessing HIV-related stigma prevention and destigmatisation programmes. Thus, it is important to address individual-level manifestations of stigma such as the anticipation of experiencing stigma when one tests positive or the belief and understanding that the stigmatisation of PLHIV is very high in one's community. These fears and perceptions tend to stop people from going to be tested for HIV or disclosing their HIV serostatus to intimate partners or family members (Stangl et al., 2019:1). These fears and perceptions, coupled with many other reasons, make many people wrongly believe that (a) having HIV is as good as a death penalty; (b) is as a result of bad behaviour such as using drugs, doing sex work, having sex outside marriage or being a homosexual; (c) spread through sex only (which is not an easy topic to talk about in many cultures) and (d) is deserved punishment for wrongdoing (Avert.org, 2019). In concurrence, Sengupta, Banks, Jonas, Miles and Smith (2011:2) affirm that HIV and AIDS stigma is multifaceted and amplified by previously stigmatised behaviours as well as in vulnerable groups like prisoners and migratory communities.

In summary, this section presented the fears and perceptions that prevent people from participating in HIV-related programmes to prevent or forestall stigma and discrimination. In this regard, many people (including AGYW) wrongly believe that (a) having HIV is as good as a death penalty; (b) is a result of bad behaviour such as using drugs, doing sex work, having sex outside marriage or being a homosexual; (c) is spread through sex only (which is not an easy topic to talk about in many cultures) and (d) is deserved punishment for wrongdoing. These perceptions, therefore, act as barriers to the effectiveness of treatment and counselling related to HIV and AIDS as well as to participation in HIV reduction and prevention programmes. Evidently, the beliefs of many people (including AGYW) are associated with incorrect information concerning the spread of HIV which lead to some irrational actions that heighten the risk of HIV infections.

2.5. STIGMA AS A HINDRANCE TO YOUNG WOMEN'S ACCESS TO HEALTHCARE AND TREATMENT

The third research question of this study focuses on stigma as a hindrance to young women accessing health care and treatment. This is the focus of the literature review in this section.

The success of HIV care and treatment programmes are seriously threatened by the spectres of stigma and discrimination by, *inter alia*, limiting 'HIV testing, disclosure of serostatus, retention, and adherence to treatment' (Odimegwu et al., 2020:2). This is acknowledged by UNAIDS (2016:15), namely that stigma acts as a barrier to accessing healthcare services, particularly those related to HIV and AIDS.

It has already been stated that healthcare facilities could, by themselves, be hostile environments acting to discourage PLHIV from accessing care and treatment. In this regard, UNAIDS (2019:10) reports that AGYW face stigma and discrimination from healthcare facilities, which manifests in being judged by the staff (nurses) for being sexually active when seeking sexual and reproductive health (SRH) services. On this point, Avert.org (2019) avers that stigmatisation perpetrated by healthcare professionals and communities preserves the HIV epidemic because PLHIV, especially women, are vulnerable and should be supported in making the correct and well-informed decisions about their health. In line with this, research has shown that in high burden HIV prevalence areas, the persistence of stigma is an important, albeit difficult, focus of study (Bonnington, Wamoyi, Ddaaki, Bukenya, Ondenge, Skovdal, Rengu, Moshabela & Wringe, 2017:2; Kharsany & Karim, 2016:37). Consequently, these researchers call for not only government but also international public health communities to be creative in the design and implementation of anti-AIDS stigma campaigns and interventions. Healthcare facilities could essentially be at the forefront of, *inter alia*, the establishment of support systems for vulnerable AGYW, thereby ultimately leading to improved healthcare for PLHIV.

According to Sengupta et al. (2011:2), a preponderance of research points to HIV- and AIDS-related stigma as a barrier associated with (a) disclosure of one’s HIV serostatus and poor health outcomes, adversely affecting HIV preventive behaviours; (b) HIV care-seeking behaviours, (c) quality of care for PLHIV and (d) treatment of PLHIV. For this reason, adverse health outcomes resulting from stigma have necessitated a refocusing of HIV prevention and treatment programmes by foregrounding stigma reduction and prevention. It is also reported that stigma discourages potentially exposed individuals from accessing testing, which limits the success of both treatment and prevention interventions. For those who have already been tested, stigma prevents them from disclosing their HIV status and taking ARV drugs (World Health Organisation, 2011; UNAIDS, 2014).

Overall, stigma is a perceived negative attribute that causes one to think of others as of diminished worth (Mahajan, Sayles, Patel, Remien, Ortiz, Szekeres & Coates, 2008:3). Therefore, addressing stigmatisation continues to be an important research topic towards finding ways to mitigate the adverse effects stigma continues to have on PLHIV and their families (Mahajan et al, 2008:5; Treves-Kagan, El Ayad, Pettifor, MacPhail, Twine, Maman, Peacock, Kahn & Lippman, 2017:2585).

Since the beginning of the HIV outbreak, healthcare facilities have been at the forefront of the fight against HIV and AIDS. Nonetheless, HIV infections have presented significant challenges to healthcare systems around the world (Kitahata, Tegger, Wagner & Holmes, 2002:954). There is even a view that healthcare workers may have occasionally violated patients’ rights by disclosing their personal HIV serostatuses to family members and other third parties without authorisation (Avert.org, 2019). Thus, when PLHIV visit healthcare facilities, they often express a fear of possible violations of their privacy. Compounding the matter further, in South Africa, the way public hospitals and clinics are configured and administered is not always conducive to protecting patients' privacy. After a patient has received an HIV positive diagnosis, nurses are frequently heard shouting the information across the room to a colleague for recording, completely disregarding the possible damage of their actions to the dignity of their patients. This often causes severe embarrassment and serves as the origin of stigma, social embarrassment and all the other adverse ramifications that result from being HIV positive (Armstrong-Mensah et al, 2019:71).

In particular, UNAIDS (2019:15) reports that PLHIV suffer stigmatisation and discrimination at the hands of healthcare workers, including poor-quality care, denial of care, breach of confidentiality or being compelled to partake in specific services. It is, therefore, a great pity that this has not only been a distressingly common occurrence for HIV-positive people but also put important demographics at increased risk of HIV infection, according to that report (UNAIDS, 2019:15). Consequently, AGYW living with HIV are often afraid of either anticipated or actual mistreatment and abuse by healthcare workers who routinely even go as far as preventing them from linking and adhering to HIV care services (UNAIDS, 2019:15). In this regard, UNAIDS (2019:15) reports that a study involving nineteen countries revealed, *inter alia*, that one out of five PLHIV had been refused health care because of their HIV serostatus, one in four had experienced some form of discrimination at healthcare facilities and one in three YWLHIV had experienced discrimination related to their sexual and reproductive health.

UNAIDS (2019:4) identifies stigma as a factor that predisposes AGYW to HIV infections. Their fear of being stigmatised and discriminated against causes AGYW to shy away from visiting healthcare facilities; yet, for them to be empowered and achieve gender equality, they need to access counselling services and high-quality information on integrated sexual and reproductive health, HIV prevention, STI prevention and early and unwanted pregnancy prevention (UNAIDS, 2019:5). As a result of not accessing healthcare facilities and services timeously, women with HIV have a four-to five-fold higher risk of invasive cervical cancer, compared to HIV negative women (UNAIDS, 2019:5).

Another layer is that of stigma, whereby young women living with HIV fear visiting healthcare facilities in case they are recognised by other people. This fear often results in negative consequences regarding their interest in treatment and adherence to ART (Bond, Nomsenge, Mwamba, Ziba, Birch, Mubekapi-Musadaidzwa, Vanqa, Viljoen, Pliakas, Ayles, Hargreaves, Hoddinott, Stangl & Seeley, 2019:87; Horter, Thabede, Dlamini, Bernays, Stringer, Mazibuko, Dube, Rusch & Jobanputra, 2017:20). In this regard, public stigma could lead to adverse physical, mental and social well-being for PLHIV. This is mainly due to being subjected to discriminatory behaviours such as blaming, gossiping, rejection, unemployment, social isolation, verbal and physical abuse, mistreatment by or refusal of treatment by healthcare providers and violations of confidentiality (Ma et al., 2018:1).

In their study involving health workers in twenty-one government health facilities in Zambia and South Africa (Bond, et al., 2019: 88) reported some important aspects of healthcare facilities that have a bearing on stigma, namely (a) the policies of the particular facility, (b) adherence to medical ethics and universal precautions instructions and (c) the availability of protective supplies to avoid occupational transmission. To build a more inclusive atmosphere for PLHIV seeking treatment, interventions to minimise stigma in health facilities have to be primarily centred on improving provider perceptions and changing institutional policies. Patients' attendance at healthcare facilities to receive ARV drugs and routine medical check-ups may particularly be affected by the fear of stigma. This could further exacerbate the unnecessary atmosphere of secrecy and silence, which is founded on prejudice and the fear of being victimised (Bond et al., 2019:87; Horter et al., 2017:20). Hansoti, Hill, Whalen, Stead, Parrich, Rothman, Hsieh and Quinn (2017:4) report that healthcare workers transfer their biases onto patients. Of the sample group, 54.2% believed that people would not contract HIV if they had fewer sexual partners, 41% avoided performing certain procedures on HIV positive patients and 72% of providers were concerned about contracting HIV from HIV-positive patients.

Stigmatisation in healthcare facilities is not limited to Africa only – or, only in government hospitals and clinics. In a study involving doctors, nurses and ward staff in both governmental and nongovernmental healthcare settings in Mumbai and Bengaluru, India, high levels of stigmatisation from all these groups of healthcare workers were reported (Ekstrand, Ramakrishna, Bharat & Heylen, 2013:23). The stigmatisation was reflected in the following actions: (a) prohibiting women living with HIV from having children, (b) making it compulsory for female sex workers and surgery patients to go for HIV testing and (c) holding the view that having HIV is well deserved. In addition, all categories of participants (i.e., doctors, nurses and ward staff) conceded that they would treat PLHIV differently in professional circumstances involving both a high and low probability of fluid exposure. Further, they preferred to have as little as possible contact with patients with HIV. The respondents also displayed significant levels of misconceptions related to HIV transmission.

Ekstrand et al. (2013:22) recommend intervention programmes for healthcare providers in urban India to reduce stigma, address the fear of transmission and improve universal precaution skills. They further recommended that PLHIV must be involved at all stages of programme design, development and implementation aimed at reducing symbolic stigma and ensuring that the relevant patient interaction skills are taught. These studies indicate that HIV stigma influences not only healthcare workers' ability to provide HIV testing but also a patient's willingness to be tested. Household wellbeing evaluations and referrals to comprehensive HIV/TB/STI/Sexual and Reproductive Health and Rights (SRHR) and GBV programmes must be taught to community healthcare staff and caregivers. This necessitates the implementation of more stringent anti-discrimination measures in healthcare settings. In South Africa, many healthcare professionals and researchers contend that HIV and AIDS will not be defeated until the attendant stigma has been overcome (Uys, 2000:160).

In conclusion, the conditions and circumstances that prevent AGYW from accessing HIV-related stigma prevention and destigmatisation programmes are also the ones that prevent them from accessing healthcare services and treatment. Unfortunately, stigmatisation is also sometimes perpetrated at healthcare facilities by healthcare workers in different ways. The effect of this could impact (a) disclosure and negative health outcomes, including adversely affecting AGYW's behaviours towards HIV-related healthcare services; (b) quality of care for AGYW and (c) the treatment of AGYW by family members, health care providers and the larger community.

2.6. TYPES AND NATURE OF EXISTING STIGMA PREVENTION AND DESTIGMATISATION INTERVENTION PROGRAMMES

In this subsection, a synopsis of the extant prevention and destigmatisation intervention programmes is presented to shed light on the fourth research question.

2.6.1. Overview

In history, many diseases such as mental illness, leprosy, cancer, tuberculosis and many sexually transmitted diseases (STDs) have been stigmatised. HIV and AIDS have lately joined this list of stigmatised health conditions. (Brown et al., 2003:62). The most common manifestations of HIV- and AIDS-related stigma are adverse attitudes towards YWLHIV and AIDS (Brown et al., 2003:62). Thus, interventions to increase tolerance and acceptance of YWLHIV aim to decrease these adverse attitudes and promote favourable ones, thereby limiting their vulnerability to contracting the virus (Brown et al., 2003:65).

To Stangl et al. (2019:1), most destigmatisation interventions fall under two methodological approaches, namely those that use two or more strategies and those that use structural or biomedical components. Stangl et al. (2019:1) further explain that most interventions have tended to target one issue at a time, while measurements of their impact generally lacked reproducibility, standardisation and trustworthiness—making it difficult to both interpret and compare study results. Indeed, reliable and valid measurements have proven to be a major challenge for researchers and implementers of destigmatisation interventions (Yuh et al., 2014:583). One reason for this difficulty is that the construct of stigma is complex and therefore, cannot be measured easily with only one type of instrument (Yuh et al., 2014:583). However, Stangl et al. (2019:1) decry the paucity of studies aimed at assessing the effects of destigmatisation initiatives related to HIV. Indeed, such studies are necessary to ensure that the effectiveness or efficacy of preventive interventions can also be ascertained. According to Relf et al. (2021:398), much of the difficulty can be attributed to the lack of reliable and valid measurement instruments to be used for this purpose. As Relf et al. (2021:398) explain, because of a lack of psychometrically standardised instruments or scales, investigators used proxy measures like depression, self-esteem and anxiety to ascertain the occurrence of the presence of stigma. Accordingly, Relf et al. (2021:405) recommend that future research be longitudinal and more rigorous in design. Unavoidably, reliable and valid standardised instruments will need to be developed and adjusted to the context of the stigma experience so that the effects and influence of stigma reduction or prevention programmes can be more accurately measured.

2.6.2. Extant Prevention Programmes in South Africa

Most prevention programmes in South Africa initially involved the surveillance of HIV prevalence only and then shifted to surveillance interventions focusing on behavioural risk factors and HIV prevalence, before finally moving to the third-generation approach where additional testing for ART was included (Zuma et al., 2016:68). Thus, as Zuma et al. (2016:68) explain, the focus was on monitoring the prevalence, incidence, ART usage and comprehending the intricacies of the disease, particularly in tracking the HIV and AIDS epidemic in the country. These programmes included HIV prevention, treatment, care and support (PTCS), focusing on the prevalence of HIV among children below the age of 14 years; promoting condom use; biomedical interventions including medical male circumcision (that was started in 2010) and a large HIV antiretroviral treatment (ART) programme.

The condom use campaign was extensive. In the 2012/13 fiscal year alone, over 500 million condoms were dispersed freely at public hospitals and clinics and evidence emerged that this was one of the most effective prevention interventions regarding heterosexually transmitted HIV (Zuma et al., 2016:67). For its part, the country-wide roll-out of the ART programme has been successful in extending life and averting new infections. The overall combined effect of all these measures was a decline in HIV prevalence in the country over time as well as extending life expectancy. However, there doesn't seem to have been a significant national effort focused mainly on curtailing HIV-related stigma.

These HIV prevention programmes were further reinforced by the introduction of the Determined, Resilient, Empowered, AIDS-free, Mentored and Safe (DREAMS) initiative in five South African districts in 2014 under the aegis of the United States

President’s Emergency Plan for AIDS Relief (PEPFAR) in ten sub-Saharan African states, namely Uganda, Kenya, Tanzania, Zambia Malawi, Zimbabwe, Mozambique, South Africa, Eswatini and Lesotho (Zuma et al., 2016:68). The main aim of the initiative was to reduce the incidence of HIV among AGYW by 25% in the first year of implementation and by 40% in the second year. Furthermore, the DREAMS programme comprised evidence-based interventions meant to address both structural and behavioural factors that contributed to the increase in the AGYW risk of acquiring HIV through collecting the necessary evidence. Additionally, the initiative sought to strengthen school-based HIV and GBV prevention efforts as well as mobilise community, families, parents and caregivers, social protection initiatives and interventions that specifically target male sex partners. The strategy targets already known drivers of HIV infections, such as poverty, GBV, gender inequality and others.

The specific areas participating in the South African chapter of the DREAMS interventions are Ekurhuleni, City of Johannesburg, eThekwini, uMkhanyakude and uMgungundlovu. The present study was based in the City of Johannesburg, one of the areas in Gauteng that has participated in the DREAMS programme. The implementing partners of the DREAMS programme are communities, non-governmental organisations (NGOs), faith-based organisations (FBOs) and the relevant government bodies operating at the provincial, district, sub-district, metro, ward and village levels. The targeted strategies are GBV prevention and post-violence support and care, the promotion and provision of condom use; HIV counselling and testing (HCT) and linkages to care, pre-exposure prophylaxis and linkage to sexual reproductive health services; targeting sex workers, social asset building and comprehensive sexuality education.

Regarding interventions that specifically addressed HIV-related stigma-prevention in South Africa, Armstrong-Mensah et al. (2019:72) report that these have revolved around three main pedestals, namely (a) HIV treatment centres, (b) faith-based organisations and (c) national HIV and AIDS policies and strategies.

2.6.2.1. HIV treatment centres

The South African government, supported by outside funders, has established many HIV treatment centres/clinics to offer treatment and other forms of health care to

PLHIV as well as to educate the public about HIV and HIV-related stigma prevention and destigmatisation. However, Armstrong-Mensah et al. (2019:72) report that these efforts haven't properly addressed the issues pertaining to the stigmatisation of AGYW, as the most vulnerable group. As such, not many AGYW have benefitted from the services being publicised and promoted, mainly because of the associated shame and the fear of exposure. Stigmatisation prevents them from receiving HIV prevention medications like antiretroviral drugs, from which they would greatly benefit, both in the management of the disease and the prevention of future transmission, resulting in an improved quality of life. It is further reported that even when it comes to trials involving HIV, women leave the trials due to the fear of being mistaken as having HIV (Armstrong-Mensah et al., 2019:72).

2.6.2.2. Faith-based organisations

In the 2001 census, over 80% of South Africans indicated having a religious affiliation (Statistics SA, 2004:24) which places the religious community, more specifically FBOs such as churches, mosques and synagogues, in a uniquely advantageous position to speak about barriers to HIV prevention, including HIV-related stigma (Kruger et al., 2018; Armstrong-Mensah, et al., 2019:72). In South Africa, FBOs have had and continue to have a tremendous impact on many communities by, *inter alia*, providing support and care to PLHIV and using religion as 'a tool to fight the stigma and discrimination associated with HIV' (Armstrong-Mensah et al., 2019:72).

Therefore, FBOs can generally influence aspects of community life and in addressing their followers and the general public, FBOs can discourage behaviours that may exacerbate the risk of HIV infections and encourage those that may help stem the scourge of HIV and AIDS. Thus, FBOs can have a significant influence on communities since they already spend a lot of time interacting with the community and in the process, influence their social norms, behaviours and values. This makes them important collaborators in HIV and AIDS prevention campaigns. However, reports show that some members of faith congregations still believe that when a person has been infected with HIV, it is a 'punishment' from God for immoral behaviour (Armstrong-Mensah et al., 2019:72; Famoti, Fernandes & Chima 2013:6).

2.6.2.3. National HIV and AIDS policies and strategies

The South African government has developed numerous policies to address the HIV and AIDS epidemic and in recent years' policies have shifted towards a more collaborated approach between government and civil society (Chibango, 2013:241). The policy shift was necessitated by the desire to achieve the UNAIDS 95-95-95 goals, as reflected in the national strategic plan where it is stipulated that HIV-related stigma is one of the underlying factors that negatively impact the HIV care continuum (NSP, 2018:32). Thus, the main goal of the NSP (2017–2022) is to keep track of how close the country is to eradicating HIV as a threat to public health by 2030 as well as to supervise and monitor the execution of an HIV prevention plan for AGYW. However, despite the inclusion of an AGYW strategy, there is no specific and exclusive focus directed at redressing stigma towards AGYW. The NSP of 2017–2022 has eight goals; goal number five is of particular importance to this study since it seeks to specifically address challenges pertaining to HIV, TB and STIs from a human rights point of view, by reducing internalised and externalised stigma by 50% by 2022. Accordingly, implementing interventions to combat the negative effects of stigma has remained a vital component of the government's fight against HIV and AIDS, particularly considering its negative effects on prevention and treatment programmes (NSP, 2018).

South Africa has had only two national strategic plans that addressed HIV-related stigma. The NSP (2018:32) specifically notes the need to have a national multi-sector strategy to reduce stigma, the key to which is social and behaviour change communication (SBCC). The plan emphasises SBCC as a tool to highlight stigmatising behaviours by using behaviour-based communication strategies to positively influence awareness, behaviours and social norms among individuals and communities. This was to be achieved through media campaigns, community outreach programmes and peer counselling, especially considering that SBCC is critical in fostering healthy behaviours, increasing service demand, mobilising communities and improving service retention and adherence. However, the mid-term review found that progress towards HIV reduction had been hindered by persistent barriers which included stigma (NSP, 2018:32).

2.6.3. Unintended Negative Consequences of the Interventions

It is important to ensure that stigma-reduction interventions do not yield or lead to negative consequences. Yuh et al. (2014:583) report on social stigma having resulted from official campaigns dealing with the HIV and AIDS epidemic because the messages are linked to socially undesirable behaviour, particularly those campaigns that focused solely on HIV transmission through sexual contact. Similarly, Ma et al. (2018:32) report that in one case, where the delivery of antiretroviral medication was shifted from healthcare professionals to informal community health workers, one of the support interventions that targeted adherence to ART was shown to be a very efficient approach of delivering excellent care, especially in locations with limited human resources. Unfortunately, it turned out that peer encouragement towards adherence to ART exacerbated the stigma among PLHIV. This intervention led to feelings of shame and the fear of disclosure among the participants. In the same vein, Odimegwu et al. (2017:7) fear that some well-intentioned social interventions for PLHIV (such as packaged food parcels for nutritional supplementation) could end up stigmatising them. Accordingly, Ma et al. (2018:32) recommended that supportive community-based programmes should be sympathetic to the possible adverse outcome of identity disclosure.

With respect to delivery modes, most stigma-reduction interventions have so far been implemented using the conventional contact format, with the attendant benefits of enabling the sharing of experiences and emotions, thereby increasing peer/social support and limiting the social isolation of PLHIV (Ma et al., 2018:32). In addition, Ma et al. (2018:32) further report that inexpensive technology (i.e., radio, telephone, video) has also been used to send information to stigmatised populations and communities in remote areas. For reasons of greater privacy and confidentiality, it is believed that the use of these low-cost technologies enhanced and encouraged wider participation (Ma et al., 2018:32). In general, the duration, frequency and the interventions' follow-up time varied widely, ranging from two to twenty-two sessions, with each session lasting from one to two hours (Ma et al., 2018:25). With specific reference to South Africa, there were three main ways in which HIV and AIDS-related stigma prevention and destigmatisation efforts were presented, namely the use of HIV treatment centres, faith-based organisations and through national HIV and AIDS policies and strategies.

2.7. POSSIBLE GAPS IN THE EXISTING STIGMA PREVENTION AND DESTIGMATISATION INTERVENTION PROGRAMMES

Although researchers have noted that much progress has been made in the effort to curtail HIV-related stigma, it is still necessary to undertake a deeper analysis of the comparative successes of the various strategies applied so far (Odimegwu et al., 2018:2). Furthermore, there have also been calls for more rigorous evaluation studies of the various interventions at different levels, particularly those that seek to explore the individual-level expressions and enablers of stigma to guide the most efficient and effective ways of achieving longer lasting health outcomes (Stangl et al., 2019:11). In addition, more research is needed to explore the effectiveness of individual and combinations of strategies for improving the attitudes of communities and producing favourable environments for PLHIV. The fifth research question sought to outline the extant HIV-related stigma prevention and destigmatisation interventions, intending to identify gaps that need to be addressed to strengthen service delivery in this area.

Stangl et al. (2019:11) see the lack of enduring interventions that seek to support YWLHIV to fulfil their human rights to receive care and live in dignity as another gap needing some attention. In concurrence, Odimegwu et al. (2017:2) emphasise the importance of (a) an enabling legislative and policy environment, (b) coherent and broad-based integrated destigmatisation programmes that consider the actual experiences of PLHIV and extant research findings and (c) effective monitoring and evaluation mechanisms, as critical ingredients in destigmatisation programmes. Consequently, when addressing gaps, it is important to ensure that these factors are taken seriously in building up destigmatisation programmes and interventions.

Regarding an enabling legislative and policy environment specifically: research has revealed that in many countries, government legal environments are weak in effectively supporting human rights-based responses to HIV and AIDS, although these countries' constitution's guarantee individual rights against discrimination and stigma of any kind or form (Odimegwu et al., 2017:8). Therefore, countries are both advised and urged to enact new legislation or expand existing laws to protect the rights of

PLHIV against discrimination and stigmatisation. Accordingly, legal aid services and legal education are needed to ensure that PLHIV are supported to access justice and systems of redress against violations of their basic human rights. It ought to be noted, however, that some laws might indeed lead to an increase in stigmatisation and discrimination against PLHIV. An example of this was when Nigeria enacted legislation outlawing same-sex relationships. This was followed by an increase in the prevalence of stigma and discrimination against people in same-sex relationships, leading to people involved in same-sex relationships becoming afraid to access HIV care and treatment from public hospitals and clinics (Odimegwu et al., 2017:9).

Another limitation is that interventions to reduce stigma are usually siloed and isolated, focusing on individual stigmatised groups and using disease-specific approaches—mainly for HIV and AIDS individuals, mental illness, tuberculosis and leprosy (Hartoga et al., 2020:2). This calls for coherent and broad-based integrated destigmatisation programmes that consider the actual experiences of PLHIV and extant research findings (Odimegwu et al., 2017:2). One Nigerian study reported that stigma reduction could be achieved by using educational interventions (Odimegwu et al., 2017:2).

Some gaps have been pointed out in the extant knowledge and understanding of how to reduce stigma. First, there is a shortage of interventions for reducing HIV and AIDS stigma; thus, many more interventions need to be tried and the results widely disseminated (Brown et al., 2003:64; Odimegwu et al., 2017:2; Hartoga et al., 2020:1). Secondly, not all types of interventions have been tried out and tested in various population settings, pointing to the need for evidence from multichannel, comprehensive programmes that target whole communities (Brown et al., 2003:65). Such evidence should not only come from healthcare workers whose reactions to HIV-related stigma are influenced by community norms but instead from PLHIV themselves, whose lives are centred within the milieu of stigma and discrimination. Third, there is reportedly a limited number of studies examining the differences between boys/men and girls/women that are designed to look at possible specific intra-gender differences on variables such as messaging, impact and others (Brown et al., 2003:65). Another gap pointed out by Hartoga et al. (2020:1) is that in LMICs, adolescents and children are underrepresented in stigma reduction initiatives.

As a critical gap in HIV and AIDS-related destigmatisation efforts, Odimegwu et al. (2017:3) further decry the lack of evidence concerning the personal experiences of PLHIV and AIDS, with stigma. Odimegwu et al. (2017:2) further report a general paucity of population-based studies and interventions concerning HIV destigmatisation and the assessment of various health educational intervention programmes' efficaciousness on stigma reduction. In a similar vein, Hartoga et al. (2020:1) recommend that more stigma reduction interventions should be conducted to address a wider range of stigmas, with the interests of children in mind.

With respect to researching the efficacy of HIV-related stigma reduction interventions, Stangl et al. (2019:10) decried the complexities of appropriate research methodologies to evaluate structural stigma-reduction interventions, especially those targeted at the community level. In part, this is because of the multiplicity or broad range of intervention types and levels, making it very difficult to compare their effectiveness (Ma et al., 2018:9). In concurrence, Stangl et al. (2019:1) point out that one reason for this could be that such interventions mostly involve multiple components occurring simultaneously at multiple levels, causing huge design challenges. Furthermore, the interventions differ in their methodological designs: some use quasi-experimental designs, others use pre- and post-in-depth interviews, while others use approaches such as programme monitoring data collection methods. All these variations in research and intervention types make it very difficult to compare results.

Nonetheless, the overall picture from the literature is promising as regards the efficaciousness of most interventions targeting PLHIV and their family members. The main and most common approach fell under the category of psycho-educational interventions. However, there exists a gap since the results highlight the importance of more interventions targeting family members of PLHIV as well as to explore the efficacy of using mixed-methods intervention studies. More specifically, reducing stigma among family members is very important since this is the first level of support and care for most people diagnosed with HIV (Ma et al., 2018:8). Consequently, this gap must be addressed with some urgency. It is envisaged that research and interventions with this focus could contribute significantly to improvements regarding family members' support for their relatives living with HIV. It is expected that this will, in turn, reduce HIV- and AIDS-related self-stigma among family members. In addition, it is expected that the success of the interventions will depend on the collective effort and ability of healthcare workers and communities to translate effective biomedical prevention approaches into efficacious ones at the population level (Stangl et al., 2019:1). However, Stangl et al. (2019:11) contend that the success of doing this will depend on the ease of removing the social and structural barriers that hinder uptake and adherence.

Sengupta et al. (2011:8) reported several limitations in the extant research and programmes on HIV-related stigma and discrimination. In particular, they reported that (a) a shortage of interventions based on evidence, (b) the preponderance of studies having been disparate and uncoordinated, (c) a lack of evidence as to whether most intervention trials have been of much public health importance and (d) a paucity of good-quality studies.

Ethnicity is a big issue in Africa. In Nigeria, Odimegwu et al., (2018:1) reported ethnic heterogeneity, secondary school exit level (attributed to knowledge about HIV and AIDS) and socioeconomic status as determinants of HIV stigma. From these results, they surmised that identifying ethnic differentials and homogeneity was critical to reducing HIV and AIDS prevalence. Overall, Karim (2011:32) joins other researchers who are calling for further research on stigma, seeing that it continues to block progress in the fight against HIV infections. He points out that the vital components of most HIV prevention programmes include HIV testing, the use of PMTCT (a critical paediatric AIDS prevention method), antiretroviral medication initiatives and community awareness programmes. With the challenge of stigma remaining unresolved, these preventive interventions and programmes will not succeed.

In South Africa, one gap that has been identified is that some healthcare workers are reported to display negative attitudes towards HIV positive patients and treat them with clear prejudice (UNAIDS, 2019:15). Furthermore, apart from the negative attitudes of some healthcare workers towards PLHIV, poor infrastructural provisioning at public healthcare facilities like clinics and hospitals pose serious challenges to matters of confidentiality. As a result, patients receive their results or treatment in ways that expose their HIV status to other patients. This is also a gap that needs to be addressed. Another gap relates to pre- and post-testing counselling services. Due to workload and other reasons, some people have complained that they either received no counselling at all or that they were not satisfied with the counselling service they had received (Van Dyk & Van Dyk, 2003:5). There is also the issue of education about various aspects of HIV which probably contributes to the reported stigmatisation and discrimination against PLHIV. This happens at family, school and community levels when people do not fully understand how HIV is transmitted. On the matter of HIV, there cannot be too much education because the more people's knowledge and understanding about the virus improve, the less likely they will be to stigmatise PLHIV.

In summary, the identified gaps are that most stigma prevention and destigmatisation interventions have: a) tended to be incoherent, narrowly-focused and siloed; b) lacked effective, built-in monitoring and evaluation mechanisms; c) had their results known only by very limited audiences and not widely disseminated; d) tended to be limited to single strategies and have not been broad-based enough to cover whole communities in order to produce comprehensive evidence that could be generalised to whole populations; e) neglected to explore possible intra-gender differences between boys/men and girls/women on various aspects of HIV-related stigma; f) tended to address only one or a few types of stigmas at a time, particularly with respect to children and adolescents from LMICs; g) tended to avoid targeting family members of PLHIV; h) neglected to explore the efficacy of using multi-strategy approaches; i) avoided documenting the personal experiences of stigma and discrimination by PLHIV and AIDS and j) had not tested the efficaciousness of the interventions.

2.8. ADDRESSING GAPS IN THE CURRENT INTERVENTION PROGRAMMES TO OPTIMISE ATTAINMENT OF INTENDED OUTCOMES

In this section, the researcher presents literature on how the identified gaps from the literature presented in the preceding section could be closed or, at least, minimised in optimising the attainment of espoused goals of the stigma prevention and destigmatisation intervention programmes. This is meant to address the final research question.

2.8.1. Intervention strategies versus the identified gaps

In most countries, including South Africa, SRH support and services have been made available including—albeit not limited to—STI prevention, treatment and testing, fertility planning, unplanned pregnancy care, contraception, antepartum and postpartum care, sexual assault prevention and victim support services, and medical male circumcision (Miller, Nkala, Closson et al., 2017:2). However, in general, access to HIV and SRH services in many countries is poor, mainly because the packaging and delivery methods used are not relevant, appropriate and acceptable to young people (Shisana, Rehle, Simbayi, Zuma, Jooste, Zungu, Labadarios & Onoya, 2014:2). For instance, in South Africa, despite a greater focus on the gendered epidemic, there are still gaps in addressing the specialised needs of teenagers and young adults (Shisana, 2014:8). Furthermore, studies have reported a low uptake of HCT services, despite adolescents showing high levels of awareness and willingness to test for HIV. In part, HIV-related stigma plays a part in discouraging young women from seeking these services. Indeed, Shisana et al. (2014:6) found that when given the option to test in a safe and friendly atmosphere, many adolescents and young adults were eager to do so. However, they feared learning their status, especially if the test returned a positive result. Therefore, public health systems should do more to destigmatise HIV testing and dispel worries and misunderstandings about knowing one's HIV status (Shisana, 2014:8). From their study, Shisana et al. (2014:7) further opined that engaging adolescents and other young people in HIV research could yield positive public health benefits. This suggests that when interventions are being contemplated, it would be advisable to involve the targeted young beneficiaries of such programmes in the planning of these interventions. They should also be involved in the intervention's implementation, monitoring and evaluation.

The literature presented has highlighted gaps, notably from Sengupta et al. (2011); Karim (2011); Odimegwu et al. (2017); Ma et al. (2018) and Hartoga et al. (2020). These gaps indicate that whatever choice of HIV- and AIDS-related stigma-prevention or destigmatisation intervention is implemented, the design and implementation of such a strategy (or combination of strategies) must, as far as possible, ensure that the identified gaps are closed or at least, minimised. Specifically, to alleviate the gaps in the existing stigma prevention and destigmatisation interventions, there is a need to have programmes that (a) are coherent, broad-based and integrated; (b) have effective built-in monitoring and evaluation mechanisms; (c) allow for the wide dissemination of results; (d) are whole community-based to produce multichannel and comprehensive evidence; (e) are population-based to enable systemic changes in communities; (f) explore possible intra-gender differences between boys/men and girls/women in aspects such messaging, impact and others; (g) address a wider variety of stigmas involving children and adolescents, especially from LMICs; (h) target family members of PLHIV; (i) explore the efficacy of using multi-strategy approaches; (j) document the personal experiences of discrimination and stigma and (k) assess the effectiveness of the interventions.

In the literature surveyed, there was a paucity of destigmatisation programmes and strategies designed specifically to document stigmas commonly experienced by vulnerable populations. Such programmes and strategies would be crucial for encouraging the participation of vulnerable populations in stigma prevention and destigmatisation initiatives (Sengupta et al., 2011:8). If this is done, such programmes would satisfy five of the identified gaps discussed above, namely, having programmes that are (a) coherent, broad-based and integrated; (b) community-based; (c) population-based; (d) target family members and (e) address a wider variety of stigmas.

The issue of testing is particularly regarded as important and South African HIV-prevention strategies encourage testing. According to Karim (2011:29), testing is a preventative measure and people will fail to take the most effective preventive measures unless they know their HIV serostatus. In this respect, Karim (2011:30) reports that although a lot of testing has been carried out in sub-Saharan Africa in the years leading up to 2011, only a relatively small proportion of both men (20%) and women (28%) in South Africa had done an HIV test and received a result during the past year. He further reported that in Kenya, only 17% of those who had tested HIV positive knew that they were infected, compared to China where 44% of PLHIV knew that they were infected.

Wider participation in the design and implementation of HIV-related stigma and destigmatisation programmes has been highlighted. Karim (2011:31) extols the importance of engaging local communities to find out what is preventing them from making the best choices about prevention and treatment. Certainly, community members and patients are best placed to make this call. In concurrence, Odimegwu, et al. (2017:8) present three stakeholders who could play significant roles in promoting HIV and AIDS-related stigma reduction and destigmatisation programmes. These are (a) legislative assemblies: to promote policy dialogue and lead advocacy, (b) FBOs: to champion support for care, (c) traditional and religious leaders: to support HIV and AIDS programmes and promote stigma reduction.

Adding further voice to this, Jacobi, Atanga, Bin, Fru, Eppel, Mbome, Etonde, Bogner & Malfertheiner (2020:6) assert that clinical staff, religious and political leaders must be supported in working with community members, to come up with new ways of preventing HIV infections and fighting stigma. They propose further that HIV healthcare be provided to communities in flexible and subtle ways to accommodate those who have fears about visiting hospitals and clinics (Jacobi et al., 2020:6). There is undoubtedly no point in insisting that these community members attend public healthcare facilities that carry the potential of exposing themselves to situations that may bring them shame. Thus, in following these recommendations, two of the above gaps would be addressed, namely (a) documenting the personal experiences of PLHIV and (b) investigating various aspects of the lives of PLHIV such as possible intra- and inter-sex differences as well as the impact of the pandemic.

HIV-related stigma interventions having internal validity with stringent robustness to be able to assess their effectiveness has been revealed as being a gap that needs to be addressed. In responding to this call, three of the above gaps will be addressed, namely (a) exploring the efficacy of using multi-strategy approaches, (b) assessing the effectiveness of the interventions and (c) the credibility of findings on the efficaciousness of interventions and their wider dissemination so that they have a bearing on policy and strategies that address HIV-related stigma and discrimination.

Referring to South Africa specifically, Armstrong-Mensah et al. (2019:72) advise that a deliberate effort must be made to reduce stigma and discrimination for the most vulnerable populations like AGYW to be free to divulge their serostatus and make responsible decisions about their health. This should include community members freely participating in HIV prevention efforts as well as taking the necessary measures to prevent future transmission without fearing economic loss, discrimination or violence. In this respect, they recommend that HIV-related stigma should be addressed by, *inter alia*, creating a higher level of awareness about HIV-based stigma among healthcare providers, involving social workers and PLHIV in destigmatising activities, investing in educational anti-stigma interventions and humanising HIV such that people accept that PLHIV are equal as human beings to those living without it.

For their part, Treves-Kagan et al. (2015:10) recommended: 'crafting stigma reduction programming through a gendered-lens and specifically considering the social context of stigma'. Further, they felt that community-based, social- or family-based intervention approaches could be more successful for women in reducing stigma. Relf et al. (2021:12-13) call for longitudinal HIV stigma-reduction intervention programmes, using standardised measurement instruments to ascertain effectiveness. This is undeniably important because trustworthy and reproducible measurements are essential for researchers, governments and NGOs to validate the effectiveness of the interventions they introduce.

2.8.2. HIV stigma awareness

As previously indicated, there is ample evidence to suggest that HIV-related stigma and discrimination discourage people from seeking HIV prevention, care and treatment from public healthcare settings as well as preventing them from engaging in crucial preventive behaviours (Armstrong-Mensah, 2019:73). According to Armstrong-Mensah (2019:73), there are three main drivers of HIV-related stigma in health facilities, namely (a) the lack of information among healthcare providers about stigma and its detrimental consequences on patients, (b) healthcare workers' fears about contracting the disease and (c) HIV being linked to immoral and socially unacceptable behaviour. Young women, in particular, are still at a developmental stage where they are being guided to adhere to societal norms. In this respect, the tension between the desire to conform to approved societal norms and the day-to-day life challenges can be quite daunting for a young person. The major challenge, however, is that the stigma that comes with being diagnosed HIV positive fuels the notions of blame perpetrated against young women, particularly for not conforming to accepted cultural practices (UNAIDS, 2019:6). In the process, young women are made vulnerable to HIV infections because they fear accessing healthcare services, in case they are labelled as women of loose moral values and standards. Accordingly, only if these issues are addressed satisfactorily can we expect healthcare facilities to adequately accomplish what they are designed to achieve.

The challenges of HIV- and AIDS-related stigma are not only restricted to healthcare practitioners and healthcare facilities; there are also HIV-related stigma challenges in family, social, cultural and historical contexts. For this reason, there is a call for stigma prevention and reduction approaches that empower families and communities to be able to positively deal with HIV-related stigmatisation challenges within their families and communities. As Ma, et al. (2018:9) opine 'the empowerment approach focuses on enhancing participants' autonomy, self-efficacy, self-esteem, family function and social relationships, human rights and anti-discriminatory laws'. Similarly, Armstrong-Mensah et al. (2019:73) argue that rights-based campaigns must be implemented and enforced to raise community awareness about HIV stigmatisation. In the same vein, Hartoga et al. (2020:13) call for community-based awareness campaigns to fight HIV-related stigma like community walks, awareness-raising workshops, door-to-door campaigns and mobilising communities to take up actions to fight stigma. Indeed, it is inconceivable that the spectre of HIV-related stigma can be defeated without the community being directly mobilised against it.

2.8.3. Anti-HIV stigma interventions

Educational anti-stigma intervention programmes need to be designed and implemented, focusing on providing information about the stigmatisation of PLHIV. Such programmes should aim to correct the spread of misinformation and adverse cultural attitudes and beliefs about the disease as well as to rectify inaccurate stereotypes or myths. According to Armstrong-Mensah et al. (2019:73), such interventions could take the form of national television and radio shows as well as frequent educational initiatives that explore and provide information on stigmatising actions and behaviours, the adverse effects of stigma suffered by HIV-positive people and the activities that may be undertaken to reduce HIV-related stigma in order to boost preventative initiatives (Armstrong-Mensah et al., 2019:73).

2.8.4. Humanising HIV – A Case for *Ubuntu*

To forestall the typical negative effects of HIV on the quality of life of PLHIV, South Africa could work to increase people's acquiescence to HIV as just any other type of health condition. The government might even consider making it illegal for anyone to communicate negative, sensational and/or false stories about PLHIV. This could help to educate people and the media in better understanding the reality of living with HIV or AIDS as well as the consequences of being subjected to stigma, discrimination and violence, simply because of someone's HIV serostatus. Communities should also be encouraged and supported to organise their own initiatives to counter HIV-related stigma and discrimination.

These efforts can be enhanced by referring to the *ubuntu* African philosophy. Jacobi et al. (2020:6) advance *ubuntu* or African humanism as offering a framework that could help in the fight against discrimination and stigmatisation targeted at PLHIV. In their view, *ubuntu* values correlate positively with what is needed to correct conceptions of HIV and AIDS and adolescent sexual behaviour. The reason for this is that *ubuntu* is based on foundations of spirituality familiar to many Africans. This philosophy of life can easily complement the knowledge of HIV and AIDS to achieve positive community attitudes toward PLHIV.

Essentially, *ubuntu* advocates compassion and basic respect for other people, whose dignity is inalienable. As a philosophy of life, *ubuntu* has been successfully applied in various interventions to fight HIV and AIDS, such as in Uganda (Tarkang, Pencille & Komesour, 2018:97). As one of the countries most devastated by HIV and AIDS, Uganda actualised the *ubuntu* philosophy by taking the collaboration and multi-sectoral approach that was based on collective effort as demonstrated by the involvement of political and religious leaders as well as community coalitions. This concerted effort to fight the epidemic earned Uganda commendations and recommendations around the world.

2.8.5. Involvement of PLHIV

By putting PLHIV at the centre, the South African government could provide them with legal advice and psychological support to tackle stigma, in whatever form it is directed at them. The government could also be lobbied to adopt a basic human rights-based approach in their official destigmatisation campaigns aimed at raising the awareness of communities about the adverse effects of HIV-related stigma and the attendant discriminatory attitudes and actions directed at PLHIV. Throughout this, AGYW should not be forgotten; they should constitute a priority group that is provided with the necessities of life, to whatever extent this may be possible. What most people normally require are decent opportunities to access education, food, healthcare, housing as well as the backing necessary to exercise their rights as citizens, irrespective of their HIV serostatus.

2.8.6. Involvement of social workers

Social workers could also be drawn into providing leadership and advocacy in mobilising community responses to HIV and HIV-related stigmatisation and discrimination. In this respect, social workers will need to work closely with community members to ensure that the information that goes out to the public is correct and does not contain any misrepresentations that may give rise to some misunderstandings about HIV and HIV-related stigma. This could be one way to promote social justice and protect the basic human rights of PLHIV. In the discharge of their advocacy role, social workers can work to bring pressure to bear on the South African government and the relevant non-governmental organisations to ensure that they adhere to and uphold the principles of human rights and the dignity of PLHIV.

2.9. THEORETICAL FRAMEWORK

Over the years, there have been many theoretical frameworks published to assist in understanding stigma. For example, Parker and Aggleton (2003:13) proposed a theoretical theory of social injustice as a method for comprehending stigma. Campbell, Foulis, Maimane and Sibiya (2005) proposed a framework for understanding the economic, political and local community contexts in which stigma exists. Deacon, Stephney and Prosalendis (2005:40) examined social theories of stigma as a phenomenon of fear and guilt, as opposed to being an issue of prejudice or a social control mechanism. To explain the stigma mechanism unique to HIV in Africa, Relf et al. (2021:404) suggested a conceptual model of HIV stigma. This shows that different researchers and authors have attempted to understand stigma from different points of view and is to be expected, considering the multi-perspective world in which we live where striving for uniformity or consensus could be unrealistic. This study has principally relied on social ecology model (SEM) to investigate how HIV-related stigma manifests itself in society. This is augmented by perspectives from both radical and African feminism, which seek to understand societal dynamics from the position of power relations. Feminism as a political positioning is a dedication to social and material change, with the goal of producing knowledge that will reduce social and personal disparities (Green, 2012:2). It is a standpoint that focuses on relationship dynamics while acknowledging the role of institutional and social power structures (Green, 2012: 2). Accordingly, feminist research is political from a stance, gendered from a point of view, reflective from a method, and transformative from a result (Green, 2012:2). Therefore, within the aegis of knowledge-making, feminists dispute the traditional and dominant scientific research paradigm which conceives of rigour as steeped in the use of describable, testable, replicable techniques derived from scientific research that, in turn, is based on objective, consensual, cumulative and convergent knowledge (Parton, 2003:1). However, feminists argue that, whereas this dominant scientific model of scientific practice extols strict professional conduct as a test of reason involving the use of research-based knowledge to address issues with instrumental selection it fails to capture how professionals operate and how they ‘know’ in practice, because problems are not presented in ways where such rational-technical approaches easily fit (Parton, 2003:1). On the contrary, real-world problems present themselves as m unknown (Parton, 2003:2). This means that a researcher needs to possess the ability to accommodate notions of ambiguity and uncertainty – which tend to pose major challenges for the ‘rational-technical’ model of knowledge production (Parton, 2003:2).

2.9.1. Social Ecology Model

Bronfenbrenner's ecological model of human development emphasises the value of viewing HIV-related stigma and prejudice at a systemic level rather than as an individual issue. It is important to think about the SEM of health to understand how HIV stigma develops and affects AGYW health (see Figure 1). This structure can be used to describe how stigma manifests itself at the human, interpersonal, institutional, cultural and policy levels. Figure 1 below details the various levels as discussed by UNICEF (2009).

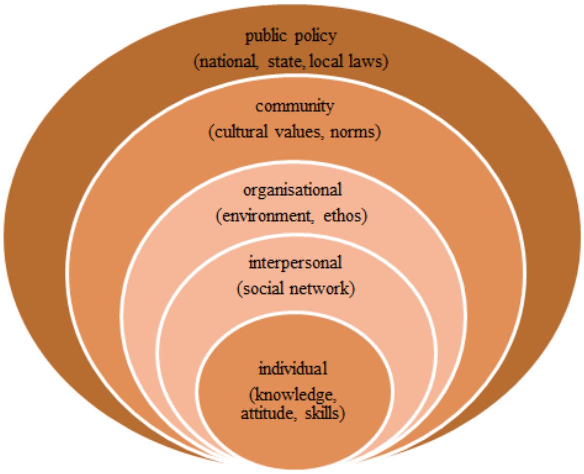


Figure 1: The Social Ecological Model

These levels are hereby briefly explained:

Individual level: HIV stigma is often a reaction to social expectations that marginalise PLHIV. This may take the form of a) internalised stigma, in which AGYW may experience humiliation, guilt and embarrassment; b) fear of disclosure, whereby AGYW may be afraid of people finding out about their status, seeing them taking antiretroviral (ARVs) drugs and/or seeking care and treatment at healthcare facilities; c) the desire to defer lifelong HIV identification such that AGYW may resist testing, care and treatment, thereby disrupting the care continuum and d) low self-esteem, where HIV stigma may result in feelings of stress and a low sense of self-worth.

Interpersonal level: HIV stigma can occur in AGYW's relationships with those in their immediate environment such as partners, friends, families and community members. This may take the form of rejection, whereby those in AGYW's immediate environment may convey stigmatising emotions and may be rejected as a result of revealing their status.

Institutional level: Stigma that can affect AGYWs' health originates in organisations and institutions at this level. Schools, youth-serving groups, colleges and universities, workplaces and healthcare settings are examples of such organisations and institutions. This may take the form of: 1) Organisational personnel being unprepared to deal with a diverse community of people. 2) Institutional practices that do not take into account policies and procedures for a diverse community of people 3) Organisations and entities with negative or erroneous HIV attitudes and beliefs.

Community level: Through social and cultural pressures, community stigma may affect AGYW through 1) Cultural norms and customs: societal norms, gender roles and social codes can all exacerbate HIV-related stigma. It can be exacerbated by the emphasis on one's sexuality, gender, race, social status and culture. 2) Inclusion of HIV prevention programs in churches, schools, community organisations and businesses are lacking.

Policy level: Governmental laws and policies can contribute to HIV-related stigma, especially at the national, provincial and district levels where HIV stigma, incidence and prevalence are linked to state discrimination and rights policies.

2.9.2. Radical Feminism

Radical feminism concentrates on a single component of culture (mainly patriarchy) which is propagated through socialisation from within society to various institutions (Leburu & Phetlho-Thekisho, 2015:410). Radical feminists’ core argument is that patriarchy contributes to gender inequality, with men benefiting mainly by subordinating women to the point where females have little influence over their sexuality (Kambarami, 2006:1). The example that is cited is that various African cultures practise the traditional custom of polygyny whereby a man may marry more than one wife in a customary marriage (Gazimbi, Magadi, Onyango-Ouma, Walker, Creswell Kaseje & Wafula, 2020:198). Polyandry, on the other hand, is labelled as being 'loose' and if a married woman has an extramarital affair, could be grounds for divorce (Leburu & Phetlho-Thekisho, 2015:410). Leburu and Phetlho-Thekisho (2015:410) go on to discuss the notion that women are supposed to be sexually passive and submissive as well as fulfil their partners' sexual needs. This scenario is troubling because it allows HIV to spread and women might be placed in roles that prevent them from negotiating safer sex interventions in certain situations of infidelity.

In patriarchal cultures, men are very influential at the levels of both family and society as well as being regarded as more intelligent and superior to women (Wathula, 2015:55). In these communities, women and girls face a range of specific challenges because of their social positions, which affect their ability to shield themselves from HIV and/or AIDS and its devastating effects. The epidemic's disproportionate effect on women, especially in sub-Saharan Africa, demonstrates this point (Klaas, Thupayagale-Tshweneagae & Makua, 2018:2). Due to this disproportionality concerning infections, concomitantly, women are more likely to endure stigma and discrimination in their communities and society at large. In other words, women’s disproportionately higher exposure to HIV and AIDS exacerbates their vulnerability to social stigma at various levels of society.

In the twenty-first century, it is necessary to discard prescriptive gender roles that construe women solely in terms of procreation. Indeed, gender equity is imperative for a modern society to attain the conditions for healthy lives and wellbeing for all. This must start with efforts to promote gender equity in leadership, considering that gender roles, relations, norms and expectations shape the manner and ways in which society progresses (Dhatt, Theobald, Buzuzi, Ros, Vong, Muraya, Molyneux, Hawkins, González-Beiras, Ronsin, Lichtenstein, Wilkins, Thompson, Davis & Jackson, 2017:1). Therefore, radical feminism could shed some light on—and provide a framework for—how matters of oppression and discrimination against women that are making them vulnerable to contracting HIV could be addressed. Thus, whereas SEM provides us with the understanding of the levels at which HIV-related stigmatisation and discrimination occur in society, radical feminism gives a deeper and more nuanced perspective to understand and address the sociocultural aspects of society that will need to be addressed to arrest the scourge of HIV infections, especially among AGYW.

2.9.3. African Feminism

Goredema (2010:41) distinguishes western feminism from African feminisms on the basis of a) culture/tradition, b) socio-economic and socio-political issues, c) the role of men, d) race, and e) sex and/or sexuality. Overall, the rallying point for African feminism appears to be the need to challenge the culturally constructed patriarchy, which is seen as responsible for unequal treatment of women, in comparison to men (Garuba, 2021:106). However, given of the term's varied conceptual ramifications and connotations, developing a unique definition of African feminism has always constituted a challenge (Garuba, 2021:105). Nonetheless, be that as it may, Goredema (2010:2) has ventured to offer a perspective of what African feminism is a feminist epistemology and a style of speech that has offered justifications for the experiences of African and African American women in opposition to the dominant feminist discourse. It is a social movement that strives to increase worldwide awareness of African women's history, present circumstances, and future expectations. It is a justice that seeks to distinguish between women who were colonized and those who were considered the colonisers.

However, Goredema (2010:41) avers that although the African feminism discourse has valid support and claims the African feminism discourse cannot speak for all people who identify as African women or men. For this reason, she believes that African feminism cannot be reduced to a single or several movements that are different to western feminism. Feminism for African women is heavily influenced by a temporal scale that is shaped by political eras, pre-colonial, colonial, and post-colonial Africa (Goredema, 2010:35).

Thus, she argues that if African feminism contends that it is fundamentally a separate theory from western feminism, the movement still has a long way to go before it can persuade middle-class African women of all races to join it (Goredema, 2010:41). To Mekgwe (2008:21) the task begins with an interrogation of the term ‘African’ as used in feminist discourse. According to Mekgwe (2008:21), this is important for creating a feminist theory that is not narrow but, critically, applicable to modern-day Africa and further argues that if African feminism theories are unlikely to advance beyond "hinting the vision of a more emancipated future" if they are defined as "reactionary" and "against" western feminism. Thus, given that issues and attitudes are changing all the time, African feminism discourse must be nurtured in a new popular, dynamic African culture because, like any other movement, African feminism cannot be formed in a vacuum but needs to acknowledge the ‘other’, which consists of women from other races, and men” (Goredema, 2010: 35).

Overall, the evolution of a collective definition of African feminism is constrained by several factors, including (a) not having ‘absolute knowledge’ because of communal involvement in knowledge construction and knowledge acquisition, (b) spiritual obligations that are influenced by the metaphysical world – suggesting a complex knowledge context, (c) communal knowledge, as social change depends on collective responsibility, and (d) gender roles/expectations as critical for processing knowledge. So, when one takes into account the continued marginalization of diverse indigenous African cultures, the issue is compounded even further, resulting in the exclusion of potentially new insights from the positive development of a unified and collective identity that would define African feminism.

Mekgwe (2008:22) recommends developing a theoretical model that would move beyond both the (post) colonial and (post) Africa construct of African feminism. Entailed in this would be to move beyond the notion of African victimhood within the colonial process, but to recognising Africa as ‘participant’ in the different phases/faces of ‘colonialism’ and not simply as recipient. In the process, consideration should be made of the point that colonial eras, and the attendant histories of the liberation struggles, are dissimilar across African countries. Similarly, Goredema (2010:35) observes that, in Africa, regional divisions add further problems when defining African feminism.

With respect to its purpose, Goredema (2010:2) explains that African feminism is inclusive of women’s rights living in the diaspora and not only those from Africa. For her part, Garuba (2021:120-121) gives a useful overview of African feminism – starting from Emecheta (1979), who could be described as an African Marxist feminist with a radical feminist approach, to those describable as African liberal feminists who deal with gender issues in a more complementary manner, with respect to the roles men and women play in their co-existence to battle the socio-cultural, economic and political challenges confronting them (e.g., Alkali, 1984; Ogundipe-Leslie, 1994; Adimora-Ezeigbo, 2012). Radical African feminists posit that all Black women have experienced living in a society that devalues them by controlling them ideologically, economically, socially and politically, resulting in a highly discriminative but effective system, perfectly designed to keep them in a submissive and subordinate place (Gatwiri & McLaren, 2016: 263). Therefore, they argue that many women have been silenced by patriarchy and that their conformance to conventional practices is based on a lack of alternative discourses (Gatwiri & McLaren, 2016: 268-269). For this reason, these authors call for a critical attack on the male institutionalisation and systemic dominance, which prevents women from comprehending how their actions contribute to and maintain their own oppression (Gatwiri & McLaren, 2016: 269). It will, therefore, be logical to conceive of radical African feminism as an ideological phenomenon which, like western feminism, tumultuously grew out of the claimed patriarchal paradigm, or culture, in specific socio-cultural settings. By this, syllogistically, it means radical African feminism is non-existent without the so-called patriarchy which it seeks to undermine and uproot (Garuba, 2021:106).

In contrast, liberal African feminists are united by the common view that women's challenges are also men's, therefore, collaborative measures and/or efforts by both genders are required to solve or address them. Overall, these feminists place primary emphasis on the relationship between culture and gender perceptions and connotations with respect to African women's daily activities and interactions with men in African societies which are considered to be dominated by patriarchal values or masculine ideologies (Garuba, 2021: 120). In this regard, culture and society are central to the discourse of African feminism, which emphasises the complementarity of economic and socio-cultural roles between women and men. Thus, the important aspect of African feminism to this study is the realisation that both women and men need to work collaboratively, and in complementary ways, for the sake of society's survival and prosperity (Alkali, 1984; Ogundipe-Leslie, 1994, 2007; Mekgwe, 2008; Adimora-Ezeigbo, 2012).

Over the years, the general conception of feminism has been confounded by fundamental ideological variations from one socio-cultural milieu to another. As a result, several conceptions have evolved, including Motherism, Nego-feminism, Africana Womanism, African Womanism, Stiwanism, Snail-Sense Feminism (Garuba, 2021: 107).

Motherism is conceptualised as an alternative to feminism and primarily focuses on motherhood experiences of African women. The ‘motherist’ theory seeks to empower African women by praising and promoting the value of motherhood as the true expression of Africanness (Garuba, 2021:109). So, unlike most white feminists who consider motherhood as a serious impediment to women’s emancipation and progress in society, motherism rejects notions of patriarchy and matriarchy as being purely western creations and inventions which have nothing to do with the realities of African society (Garuba, 2021:109). So, instead of using the terms ‘patriarchy’ or ‘matriarchy’ in her African feminist theory discourse, Catherine Acholonu (the leading proponent of motherism) has rather coined the terms: ‘patrifocality’ and ‘matrifocality’ to explain the complementarity between men and women in African society, without implying any gender domination between the two (Garuba, 2021: 109).

The term ‘nego-feminism’ (coined by Nnaemeka, 2005:359) denotes the kind of feminism which thrives on the principle of negotiation, involving compromise, and balance. According to Nnaemeka (2005: 359) in addition to knowing when, when, and how deal with patriarchal ideologies, nego-feminism also knows how to avoid them. The main point of departure for nego-feminism is that space must be created wherein all pertaining to African women be discussed and negotiated through compromise within the understanding that African men and women co-exist in a complementary manner (Garuba, 2021: 107-108).

The notion of Africana Womanism is largely rooted in the value of African culture and Afrocentrism and refers to a form of feminist ideology that has a wider applicability in respect of all women of African ancestry (Garuba, 2021: 108). African Womanism evolved from the early 1980s and sought to aggregate the African female experiences in all the spheres of patriarchal societies; their yearnings, needs and social recognition (Garuba, 2021: 108).

Like nego-feminism and Africana Womanism, African Womanism is black centred and believes in the freedom and independence of women (Garuba, 2021:108). However, unlike radical feminism, African Womanism advocates for a collaborative co-existence among all black people – men, women and children. So, African Womanism does not see men as the enemy, but as collaborators and partners in their collective struggle against the greater evils of racial discrimination and exploitation – and to get over the predicament thrust upon Africans by both colonialism and neo-colonialism.

The notion of Social Transformations including Women in Africa (STIWA) stresses the point that instead of waging war on the men, switching roles, or treating men the way women believe men have been treating them for millennia, it aims to create a harmonious community (Ogundipe-Leslie's, as quoted by Gabura, 2021:110). In this regard, Stiwanism advocates for the type of social transformation where both men and women work collaboratively to transform society in a complimentary manner. Accordingly, Stiwanism contends that African women should understand and know the sociocultural context in which their feminism is born and should not reproduce the same western thought and attitude against the customs and traditions of Africa (Garuba, 2021:110). Accordingly, a stiwanist can either be a woman or a man, as long as he or she embraces the imperative of transforming society by removing all barriers which prevent African women from achieving the goals that men can achieve.

For its part, Snail-Sense feminism theoretically relies on African women's use of negotiation and diplomacy to assert and affirm their self-actualisation in patriarchal systems (Garuba, 2021:111). It is based on the metaphor that the snail carries its house on its back without feeling the strain. The snail strolls along and goes wherever it wishes and arrives at its destination intact and safe by withdrawing into its shell when danger looms. So, Snail-Sense feminism avers that this is what African women often do to survive the harsh patriarchal African culture. So, Snail-Sense feminism is built on this reality – which highlights the female tendencies to accommodate or tolerate the male and cooperate with him to survive. It is held that there are virtues in the Snail-Sense feminism which reflect those possessed by African women – and that these could serve as the bedrock upon which African feminism could be built. So, frail as the snail and its attitudes are, it is maintained that these are virtues that must not be seen as a weakness on the part of the woman. On the contrary, they should be viewed as a means of strategically supporting and complementing man and working in tandem to advance society for the good of all (Garuba, 2021:111).

So, in summing up, the advent of the above strands of African feminism was consequent upon the consciousness of the fact that the western feminist ideology has failed to capture the conditions of the African women as obtained in their various social backgrounds. In coming up with the various strands of African feminism, African female writers have evolved a feminine discourse which seeks to accurately represent African women’s qualities, attributes and potentials (Garuba, 2021:115). This discourse is centred on female experiences in the society and portrays as active, determined, outspoken and ambitious African woman who is capable of achieving desired social developmental goals. In doing so, African female writers have taken stock of the ways patriarchal societies marginalise African women and girls as well as how African women can be empowered and emancipated in a variety of ways, including socially, economically, politically, and even intellectually (Garuba, 2021:115).

They African female writers have mastered the art of using African genres of communication– such as oral narratives like irony, repetition, dialogues, riddles and proverbs, use of images of animals, metaphysics to re-create the lives of African women and traditions (Garuba, 2021:115). By so-doing, they have purposefully and critically discussed the predicament of African women within their immediate socio-cultural environment and worked at dismantling male stereotypical depictions of women in their writings and opposed patriarchal ideals, which are seen by African women as indicators of degrading oppression and denial of their independence (Garuba, 2021:115).

Although there is no definitive perspective that may presently be regarded as the preferred or accepted strand of African feminism, the dominant ‘key words’ that have emerged from the various ideologies and theories briefly sketched above are: negotiation, diplomacy, compromise, balance, collaboration, complementarity – buttressed by the importance of respecting African culture and traditions. The dominant view of African feminists is not to regard men as enemies, against whom war must be waged, but as allies and partners in the fight against the greater evils of colonialism and neo-colonialism, in the quest for achieving equitable social transformation. So, in relation to this study, this means that the fight to defeat HIV related stigma, must be seen as the responsibility of the whole community. African feminism would ensure that through negotiation, diplomacy, compromise, collaboration, complementarity and the quest to attain a good social balance, entire communities are mobilised to accept HIV positive persons and defeat the social stigma associated with the condition. Such attitudes would also extend to treatment regimes, which would also embrace the principle of feminist ‘ethics of care’.

2.9.4 The Adopted Theoretical Framework

This study adopted the SEM, radical and African feminism as its theoretical framework. The reason for this is that it encompasses many of the concepts and principles that emerged from the literature review, namely (a) the importance of an enabling legislative and policy framework, (b) the importance of community and populations-level interventions, (c) the role of institutional involvement in programmes that deal with stigma prevention and destigmatisation—be they governmental or non-governmental—and (d) the importance of interpersonal care and support activities for PLHIV and AIDS, as well as (e) the centrality of individual-based (or intrapersonal) interventions.

For some time now, several communities of scientists have paid more attention to the utility of social ecology research, most of whom have adopted SEM to guide them (e.g., Lounsbury & Mitchell, 2009; Rothwell, Shepherd, Murphy, Burgess, Townsend & Pimm, 2010:471; Nyambe, Van Hal & Kampen, 2016:5; Huang, Yates, Thorberg & Wu, 2020:475). In their study, Lounsbury and Mitchell (2009:214) adopted SEM to help them understand the dynamic complexity and full contextual reality surrounding community health problems. For their part, Rothwell et al. (2010:471) adopted SEM in their single-case study on the implementation of the Welsh Network of Healthy School Schemes. Nyambe et al. (2016:10) used SEM in their study on vaccinations and screening. Huang et al. (2020:476) applied SEM in their study on the significance of cultural, community, interpersonal and individual determinants of end-of-life (EOL) communication and healthcare planning. This was against their thesis that social background and culture shape how people regard illness, death and health in addition to playing a significant role in EOL decision-making against distress and uncertainty (Huang et al., 2020:477). Theories and models have wide applications. Although these studies may not have dealt with young women's vulnerability to HIV, one can still learn from how other researchers within the health sector have applied the social ecological model in their studies. Therefore, the researcher is satisfied that this theoretical framework will enable her to adequately address all the research questions.

Concerning radical feminism, there is a need to critically examine whether or not, or the extent to which, South Africa (the locale of this study) is patriarchal and accordingly, constitutes an unjust society that unfairly predisposes young women to contracting HIV through various types of discrimination, exploitation and oppression. This is the radical feminist view, which is predicated upon the three key interrelated elements of oppression, patriarchy and power. In the present study, is it possible that some cultural and traditional constructs in South African society conspire to make young women vulnerable to contracting HIV or to allow HIV-related stigmatisation to be unfairly perpetrated against young women? Such questions are legitimate, considering that radical feminists contend that the social construction of female sexuality and femininity are done through the presentation and creation of a subordinate image of females (Vukoičić, 2013:35). It is for this reason that radical feminists challenge 'structural inequalities that increase vulnerability to gendered, racialized, geographic, and socioeconomic violence' (Hall, 2015:394).

With respect to African feminism, negotiation, diplomacy, compromise, collaboration, complementarity and the quest to attain an overall good social balance – buttressed by the importance of respecting African culture and traditions are the important constructs which have emerged (Garuba, 2021:106).

2.10. CONCLUSION

HIV prevention efforts have been hampered by the impact of stigma and prejudice meted out to PLHIV (including AGYW) as well as those merely suspected of being HIV-positive. This has resulted in people, especially PLHIV, being unable to adhere to care and treatment for fear of reprisals. This literature review has shown that although much has been achieved to prevent and destigmatise HIV and AIDS over the years, much remains to be done. Specific gaps in the HIV-related stigma prevention and destigmatisation programmes have been identified and ways to address these gaps were suggested. In the next chapter, the methodology and research methods are presented.

CHAPTER 3

RESEARCH DESIGN AND METHODOLOGY

3.1. INTRODUCTION

This chapter describes the research methods followed in this study, starting with the research approach or paradigm, followed by the research design. Other aspects of the research methodology as presented include the description of the target and accessible populations, sampling, instrumentation (including validation), data collection procedures and processes, techniques for data analysis and ethical considerations. The chapter ends with some reflections on the possible methodological limitations of the study.

3.2. POSITIONALITY

Holmes (2020:1) describes positionality as the way a researcher reveals his or her world view and the position, he or she adopts on a research task and its social and political context. To use the ordinary parlance, this is an issue of a researcher revealing ‘where he or she is coming from’ with respect to his or her an individual’s beliefs about the nature of (a) social reality and what is knowable about the world (ontological assumptions), (b) knowledge, (epistemological assumptions), and (c) value and valuation, and of the kinds of things that are valuable – including assumptions about human nature and agency (axiology). In short, as a social being, everyone is tainted by his or her values and beliefs. These are often shaped by one’s “political allegiance, religious faith, gender, sexuality, historical and geographical location, ethnicity, race, social class, and status, (dis) abilities and so on” (Holmes, 2020:1). Accordingly, Haynes (2012:78) advises researchers to be aware of how their ontological, social and political positioning affects the choices they “make about research topics, questions, approaches, methodologies and outcomes.

Therefore, positionality reflects the position that the researcher has chosen to adopt within a given research study. Once established, positioning influences both how a piece of research is conducted and its outcomes (Savin-Baden & Major, 2013:71; Rowe, Baldry & Earles, 2015:296). This point is echoed by Corlett and Mavin

(2018:377) in their statement that theoretical assumptions influence the researcher’s positionality on issues relating to representation and truth, to the researcher’s role and power relations with others, and to criteria for evaluating qualitative research. Accordingly, Haynes (2012:78) advises researchers to be aware of how their ontological, social and political positioning affects the work that they do. In this regard, in order to navigate and reflect on relevant areas during fieldwork, it is the researcher's job to make a conscious effort to understand how important her position is (Adeagbo, 2021:181).

There are three levels at which positionality is normally determined: (a) the subject under investigation, (b) the research participants, and (c) the research context and process (Grix, 2019). According to Holmes (2020:2) “some aspects of positionality are culturally ascribed or generally regarded as being fixed while others are more fluid, subjective and contextual – for example, political views, personal life-history, and experiences.

The researcher is currently employed as a Business Development Assistant at a local not-for-profit organisation focused on strengthening public health systems through supporting health programmes and conducting research towards realising universal health care. Being part of the Business Development Unit, the researcher is in a privileged position of seeing and understanding key health programmes targeted towards South Africa achieving the 95-95-95 targets. Early in her career the researcher formed part of a team, tasked to conduct a process evaluation on the HIV testing services component of the Global Fund’s Young Women and Girls Programme implemented in ten South African districts. This sparked the interest of the researcher in forming a deeper understanding of the barriers faced by adolescent girls, particularly young women in receiving HIV prevention, care and treatment services. The researcher’s epistemological position is that the ‘truth’ is always a moving target, which shifts depending on what is known at the time of an investigation. Accordingly, the researcher’s choice of the qualitative research paradigm was deliberate as it allowed the informants the freedom to share their experiences. Furthermore, this research paradigm allowed the researcher to delve deeper into this topic and help to discovery of new ideas and unique viewpoints. It provided the researcher with in-depth details and a human voice/personal element to the study.

3.3. RESEARCH APPROACH

A research paradigm is a consistent and systematic method of conducting research that reflects a researcher's philosophical focus and guides his/her interpretation of facts or occurrences. It 'constitutes *(sic)*researcher’s worldview, abstract beliefs and principles that shape how he/she sees the world, and how s/he interprets and acts within that world' (Khatri, 2020:1436). A research paradigm is also defined as a framework that is impacted and/or led by people's beliefs about how the world should be viewed (Cohen, Manion & Morrison, 2018:22).

In this study, the researcher sought to explore the perceptions of YWLHIV about HIV and document their lived experiences with respect to HIV-based stigma and discrimination. Accordingly, the researcher found the qualitative/interpretative research paradigm to be well-suited and relevant for addressing the aim and research questions of the study, which were exploratory in nature—focusing on understanding people’s beliefs, attitudes, experiences, behaviours and interactions. The qualitative case study design was chosen as it has been used successfully in similar studies. Teterina (2020:10) carried out a qualitative case study to examine the experiences of PLHIV, focusing on the stigmatisation of HIV positive people in Georgia. Data were collected using a semi structured interview schedule to explore the participants’ perceptions and uncover their experiences concerning stigmatisation. Similarly, Brennan-Ing and Emlet (2020:723) used a qualitative case study design to investigate how age, gay identity and HIV serostatus affected the respondents’ identity disclosure. Lastly, Scheibe et al. (2018:69) used the qualitative case study design to provide insight into how outreach workers supported their clients to cope with stigma and discrimination. Accordingly, the researcher was satisfied that the use of a qualitative case study design would be appropriate for the current study.

3.4. RESEARCH DESIGN

For any study, the research design is the blueprint for the collection and analysis of data. As stated above, this was a qualitative study (Creswell, 2014:12), interpretative in nature and aimed at exploring the perceptions of YWLHIV and their lived experiences with respect to stigmatisation and discrimination. Typically, qualitative research designs are comprehensive, naturalistic and interpretive, drawing on numerous methods of enquiry. In qualitative research, the researcher and participants interact with each other as they go about working together to resolve challenges of common interest.

The specific research design followed in this study was the qualitative case study (Baxter & Jack, 2008:550; Harrison, Birks, Franklin & Mills, 2017:3). Case studies enable researchers to explain, describe or explore events or phenomena in the everyday contexts in which they live. In the context of this study, the case under investigation were young women living with HIV in the Johannesburg metropolitan area.

Yin (2018:16) provides four guidelines for using the case study design, namely when (a) 'how' and 'why' research questions are being pursued, (b) there is no manipulation of the behaviour of the participants, (c) contextual conditions are an important aspect to explain the behaviour or decision taken by participants or (d) one cannot easily separate the aspect under investigation from the context in which it is embedded. In the current study, it was envisaged that the choices or decisions that young women living with HIV took concerning the variables under investigation, were influenced by the environmental contexts in which they found themselves. These decisions were centred around the 'why' questions. Furthermore, the research focused on 'how' they experienced HIV-related stigma, how they were being treated by family members, healthcare workers, community members and others. Because data were to be collected in the participants’ day-to-day living environments, it ensured that they would not be manipulated in any way, in contrast with positivist approaches where participants would have been subjected to some treatment or experimental conditions. Hence, in this case study, the researcher was interested in the participants’ conduct within their contextual circumstances, from which they could not be separated. Consequently, this study fulfilled all the conditions for a good case study as described by Yin (2018:22). More specifically, this was a multiple-case study (Baxter & Jack, 2008:550; Gustafsson, 2017:3; Belhadi, Zkik, Cherrafi & Sha'ri, 2019:15). As Baxter and Jack (2008:550) explain, multiple-case studies examine 'several cases to understand the similarities and differences between the cases'. Explaining the notion of a multiple-case study, Halkias and Neubert (2020:59) give the example of 'a person as a case' and explain that a single case involves one person, whereas in a multiple-case study there will be more than one individual involved. In this study, the researcher examined the experiences of thirteen young women living in different areas within the Johannesburg metropolitan area. As such, the triangulations that were held took place in the context of looking for similarities and differences in the participants’ experiences with family members, community members and members of society at large.

According to Carter, Bryant-Lukosius, DiCenso, Blythe and Neville (2014:545), triangulation involves using 'multiple methods or data sources' to develop a comprehensive understanding of a phenomenon. Similarly, Halkias and Neubert (2020:64) view triangulation as a process of strengthening the credibility of a study by integrating several data sources. Within the context of a multiple-case study involving more than one person, data triangulation is done to enhance construct validity for the simple reason that many sources of data offer different perspectives of the phenomenon (Halkias & Neubert, 2020:55). As a further detail, triangulation may assume the character of method, investigator, theory and/or data source triangulation (Denzin, 1978; Patton, 1999). In this study, the multiple data sources were thirteen participants and the type of triangulation that was carried out was data triangulation. Accordingly, in analysing the data obtained from the thirteen participants, the researcher conducted both within-case and cross-case analyses (Halkias & Neubert, 2020:56). A similar approach was taken by Langstrand and Drotz (2016:2) who used several persons in their multiple-case study.

3.5. TARGET POPULATION

The target population comprised YWLHIV who resided in the Johannesburg metropolitan area. More specifically, the study focused on young women in the 18- to 24-year age bracket, inclusive. In the literature, this represents the most vulnerable group of young women. As Birdthistle, Tanton, Tomita, de Graaf, Schaffnit, Tanser and Slaymaker (2019:2) report: in high-burden nations, surveys and mathematical modelling of HIV prevalence data consistently demonstrate that prevalence rises rapidly in the 15- to 24-year age bracket, inclusive. South Africa is one of the HIV high-burden countries (Birdthistle et al., 2019:3).

A further justification for using this age group is that the participants were deemed to be capable of supplying the required information about their experiences and challenges associated with HIV-related stigma—especially considering the emotional, social, self-esteem, trust and psychological impact of living with HIV (Dias, De Oliveira, Turato, Turato & De Figueiredo, 2013:2). Thus, in defining the target population, the study excluded those younger and older than the defined age group as well as those who live outside Johannesburg.

3.6. SAMPLING

The study consisted of a research sample of 13 participants, identified through the snowball (or chain-referral) sampling technique. This is a nonprobability sampling technique that is used where potential participants are difficult to locate and the researcher uses participants' networks to access specific populations and 'recruit' further participants for a particular study (Etikan, Alkassim & Abubakar, 2015:2). Thus, using snowball sampling, the researcher started with one participant who fitted the research criteria. Four criteria were used to identify participants, namely (a) being a resident of Johannesburg, (b) falling within the age bracket of 18 to 24 years, (c) being a young woman living with HIV and (d) being willing to share personal experiences concerning stigmatisation related to HIV. The first participant was identified through the assistance of a healthcare practitioner working at one of the healthcare facilities in Johannesburg. This required the study to be registered on the National Health Research Database (NHRD) and approved by the Regional Hospitals' ethics committee. She had agreed to ask one of the young women living with HIV at the facility and find out if she would accept participating in this study. This was important for confidentiality purposes. The first participant agreed to participate in the study on the condition that the interview was conducted in a non-invasive manner, such as telephonically, to protect her identity. In these circumstances, the researcher found this to be acceptable especially since she was not a healthcare practitioner and the topic being investigated in this case study was indeed a sensitive one.

After securing the first participant, the snowballing sampling technique was followed to identify other participants, as each participant was asked to refer an additional participant to take part in the study. This sampling technique was suitable for the study as it allowed for the identification of research participants who possessed the relevant experiences and information suitable for addressing the research questions of the study while adhering to the tenets of confidentiality and anonymity. In each case, the researcher requested the participant first to speak to the person to whom they were referring me and to give me her contact details only once she had agreed to take part in the study. A pseudonym was agreed upon, to be used when contacting the potential participants formally to request their participation in the study. By following this process, it was envisaged that the respondents would enable the researcher to collect the required data, which was indeed achieved. The confidence to use snowball sampling came from authors who have also used the same sampling technique for target populations that prefer to remain anonymous. As Dragan and Isaic-Maniu (2013:160) explain, snowball sampling is appropriate when dealing with 'hidden populations' such as drug users and illegal immigrants. As a result of stigmatisation and discrimination, PLHIV could also be regarded as being in the category of hidden populations. Similarly, Ongowo, Ngetich and Murenga (2021:2) also state that snowball sampling is useful in situations where the population is hard to identify but the respondents are somewhat interconnected. Adama (2019:38) used snowball sampling to find street children to participate in his study on strategies and interventions that could improve the social development of street children.

3.7. DATA COLLECTION

Data collection refers to the process of how data are collected, organised and summarised (McMillan & Schumacher, 2001:78). Before undertaking fieldwork, several authorities must grant permission. Accordingly, the researcher approached and obtained permission from the relevant provincial, district and facility authorities for access to potential participants. This entailed securing ethical clearance from the Research Committee of the Johannesburg Health District where this research was registered on the National Health Research Database and assigned the Reference Number: NHRD Number: GP_202110_025 (Please refer to Annexure 4). Further, the study was given permission by the Edenvale Regional Hospital (Annexure 5) which subsequently helped to initiate the snowballing identification of participants by introducing the researcher to the first participant. Data collection was not hospital-based, so once the first participant had been identified, interviews were scheduled according to the availability of the subsequent participants.

The data collection process was based on the following three steps advanced by Baškarada (2014:8), namely orientation, information gathering and closing.

Orientation

The researcher introduced herself to the participant and confirmed contact details, used the opportunity to explain the purpose of the study and requested consent from the participant to participate in the study and for the interview to be recorded. Once consent had been secured, the researcher explained how the interview process would be conducted, how the collected information would be handled and kept—emphasising matters of confidentiality and anonymity. The participant was then given an opportunity to ask any questions for clarification and/or any other issues about the study which the participant may have wished to raise. When all the issues had been clarified, the researcher and participant arranged the date and time for the interview.

Information Gathering

On the day of the interview, the researcher (as interviewer) again introduced herself and the purpose of the study and reminded the participant about the voluntary nature of her participation and her right to withdraw from participation at any point during the interview if she felt uncomfortable and did not wish to continue. The interviews were conducted through *Zoom* (audio), guided by the interview schedule and lasted between 30 and 40 minutes. Permission to voice-record the interviews was obtained independently from each participant and each recording will be kept only for the duration of this study, after which all recordings will be destroyed. Notes were taken during the interviews.

Closing

At the end of the interview, the researcher thanked the participant and together with the interviewee, reflected on the interview process and gave her the opportunity to raise any questions about what had just transpired. Thereafter, the researcher thanked the interviewee again and sought her permission to contact her again after the transcriptions had been completed for her to receive the record and confirm its accuracy. Lastly, the interviewee was invited to provide feedback on the interview process and the researcher thanked her for her time and the valuable information that she had provided in the interview.

Some social and behavioural researchers have voiced several possible drawbacks to virtual interviews, particularly in terms of how they can affect data dependability and validity as well as that the nature of the internet communication medium may have negative consequences, such as the development of ambiguities and misunderstandings (Hewson, 2017; 60). Despite these limitations, studies across a variety of disciplines have now shown that virtual interview processes can produce valid, trustworthy data that is comparable to that obtained in an offline research setting (Hewson, Vogel & Laurent, 2016:60; O’Connor & Madge, 2017:140)

3.7.1 Procedural Issues

In line with UNISA’s Guidelines on Conducting Research in COVID-19 (2020) and lockdown restrictions in force at the time of data collection, prohibiting non-essential travel, all interviews were conducted virtually. Conducting the interviews virtually removed the constraints of travelling to individuals who were geographically dispersed, thereby decreasing the costs related to the research. Similarly, it has been suggested that virtual interviews allowed for individuals to 'open up' easier than they would have done in face-to-face conversations (Joinson & Payne, 2007:59; Hewson, 2017:59; O’Connor & Madge, 2017:135).

3.7.2 Data Collection Instrument

For this study, a semi structured interview schedule comprising both closed and open-ended questions was used. The interview focused on the respondents’ perceptions of stigma and how it related to their vulnerability to HIV; how stigma impeded them from accessing HIV and destigmatisation intervention programmes; how stigma hindered them from accessing care and treatment; the nature and types of existing prevention and destigmatisation intervention programmes related to HIV and AIDS available to them; possible gaps in the existing intervention programmes and how the existing intervention programmes could be streamlined to enable the programmes to achieve their intended outcomes (see Annexure 1). A semi structured interview schedule format allowed the researcher to follow up on issues and conduct discussions with the respondents based on their initial responses to the primary questions. The interview schedule (Annexure 1) had two sections: A and B. Section A consisted of structured items that focused on biographical data, namely, the age of the participants, their place of residence and duration at the place of residence; the people residing in the household and their relationship to the participants; their highest education level attained and employment status. Section B consisted of open-ended questions that focused on the experiences of the participants with respect to each of the research questions.

3.7.3 Triangulation of data

The purpose of multiple case research is 'to replicate the same results across multiple cases by exploring the differences and similarities between and within cases'. In this study, the multiple data sources were thirteen participants interviewed about their experiences with HIV-related stigma and discrimination (Langstrand & Drotz, 2016:4; Carter et al., 2014:545). To validate the findings, the researcher employed the technique of data triangulation which, within the context of multiple-case research, involved both within-case and cross-case analyses (Halkias & Neubert, 2020:59). According to Halkias and Neubert (2020:55), data triangulation is done to enhance construct validity, considering that multiple sources of data offer different perspectives of a given phenomenon. Indeed, the circumstances of the thirteen participants in this study were all different, although they were all called upon to share their experiences on the same matter, i.e., stigma related to HIV.

3.8. DATA ANALYSIS

The unit of analysis for this study was the individual participant since the study aimed to understand the underlying reasons why stigma appeared to exacerbate the spread of HIV (Creswell, 2014:12). In reporting the findings of a case study, Baxter and Jack (2008:555) declare that there is no single, correct way to present the results of a case study. Nonetheless, they explain that the researcher must present the report in such a complete way that the reader feels as if they, themselves, actively participated in the research and can determine whether or not the study's findings are relevant to their own circumstances. This entails describing the context in which the data had been obtained in a way that the data can only be best understood within the context wherein they were embedded. In analysing and presenting the results and findings, the researcher followed the research questions as the organising fields for the data. This is what Baxter and Jack (2008:555) refer to when stating that taking care of the propositions guarantees that the report stays on track and addresses the research topic. Earlier, Yin (2018:16) suggested six ways to present case studies, namely linear, comparative, chronological, theory building, suspense and unsequenced. This researcher preferred to present the results by following the six research questions as the organising fields for the data.

In keeping with qualitative research modes of data analysis, the researcher looked for recurring themes based on research questions in ways that led to documenting the aggregated experiences of the participants. This was done through the following steps: (a) Once all data/information had been collected, the information about the interview schedule was organised and aligned with the research questions; (b) organising ideas, concepts and findings by identifying key ideas/words that were prominent in the responses; (c) creating an overarching theme emerging from the data from recurring subthemes or categories of description, to allow for deeper meaning to emerge from the data; (d) ensuring trustworthiness in the data analysis and findings, as the themes materialised from the data as well as searching the data for outliers and providing explanations for their occurrence and (e) finding plausible explanations for the findings including reviewing what had been found from the data through summarising the findings and themes. Thus, data were analysed following an interpretative, reiterative approach, whereby recurring themes were used to form primary categories of description (Creswell, 2014:195; Creswell & Poth, 2017:15–16). Through a reiterative process, the data were further integrated and consolidated into increasingly focused categories, leading to a sharper refinement of the findings.

In analysing the data from the structured part of the instrument, the researcher focused on common characteristics and attributes of the interviewees and their responses while the main purpose of the open-ended part of the instrument was to allow the respondents an opportunity to elaborate on their initial responses, thereby yielding the required detailed information.

3.9. TRUSTWORTHINESS, CREDIBILITY, TRANSFERABILITY, CONFIRMABILITY AND DEPENDABILITY

In qualitative research, the traditional notions of validity and reliability, as used in the positivist research paradigm, do not apply. Instead, new terms to characterise the notions of validity and reliability have emerged (Polit & Beck, 2012:489; Leung, 2015:324). These include trustworthiness, credibility, transferability, confirmability and dependability. The trustworthiness or rigour of a study refers to the extent to which the data, interpretation and methods used can be trusted to assure the quality of the study (Polit & Beck, 2012:489; Leung, 2015:324). Credibility refers to how reliable or credible the findings of qualitative research are from the available perspectives, as obtained from the research participants (Trochim & Donnelly, 2007:22). Therefore, to ensure credibility, the researcher closely examined the participants' experiences regarding their vulnerability to HIV as well as how HIV-related stigma may have influenced their decisions on attending HIV- and stigma-prevention events and accessing healthcare services. Nyirenda, Kumar, Theobald, Sarker, Simwinga, Kumwenda et al. (2020:2) opine that the credibility of qualitative research findings is judged by the extent of the concordance of findings from different participants. In this study, thirteen participants were asked about their experiences on a number of similar questions. The concordance of the findings came about as the researcher looked for common experiences from the individual findings. Furthermore, to maintain credibility, the researcher also provided the participants with the transcripts and data analysis to ensure the accuracy of the case descriptions and findings.

This is based on the contention that effects could be generalised or extended to other groups or settings (Polit & Beck, 2012:489). To maximise the potential for the transferability of the findings, the researcher fully explained the objectives, intentions and data collection process to the participants and allowed them time to ask any questions for further understanding or clarification. However, the extent to which the results of this study may apply to similar contexts and settings will be a matter of discretion on the part of the reader, given that transferability in qualitative studies, generally and this study, in particular, was not the primary purpose.

In qualitative research, confirmability refers to the extent to which results can be confirmed or validated by other researchers (Nyirenda et al., 2020:2). First, it is vital that the data accurately represent the information provided by the participants and that the investigator or researcher does not create his or her own interpretations of the data, unlike the meanings that were intended by those who supplied the data (Polit & Beck, 2012:490). This ensures that the findings correctly reflect the experiences, perceptions and ideas of the participants and not those of the researcher. To ensure confirmability in the current study, the researcher maintained a concise and consistent summary of each participant's responses to questions, which were later given to the specific participant for concurrence. In addition, the researcher endeavoured to describe and explain the step-by-step data collection process and procedures that had been followed. It is envisaged that this will allow other researchers to effectively assess the credibility and integrity of the entire research process, as recommended by Noble and Smith (2015:34). Regarding the dependability of the study, the findings, interpretations and recommendations were checked to ensure that they were all related to the data collected from the participants. Dependability refers to the stability of data over time and under different conditions (Nyirenda et al., 2020:3).

3.10. ETHICAL CONSIDERATIONS

3.10.1. Ethical Clearances and Permission to Conduct Research

The first ethical clearance obtained to undertake this study was from UNISA's Research and Ethics Committee (CREC Reference #: 67139361_CREC_CHS_2021, appended here as Annexure 3). Subsequently, permission for access to potential participants was secured from the relevant provincial, district and facility authorities. Accordingly, ethical clearance was obtained from the Research Committee of Johannesburg Health District where this research is registered on the National Health Research Database and assigned Reference Number: NHRD Number: GP_202110_025 (Please refer to Annexure 4). Further, the study was given permission by the Edenvale Regional Hospital (Annexure 5) which subsequently helped to initiate the snowballing identification of participants by introducing the researcher to the first participant. Data collection was not hospital-based and once the first participant had been identified, the interviews were scheduled according to the availability of the subsequent participants. While conducting the study, ethical requirements were adhered to, especially in identifying potential participants, ensuring that they remained anonymous and that the information they had supplied was kept confidential. This study specifically took cognisance of the two main principles highlighted in the UNISA Policy on Research Ethics: beneficence and respect for human dignity.

3.10.2. Beneficence

Beneficence is a concept in research ethics that states that researchers should always uphold the best welfare of research participants (UNISA Policy on Research and Ethics, 2016:1). Typically, a determination of the level of risk is made concerning the data collection procedure and process. Unfortunately, the UNISA guidelines on determining the level of risk are not very explicit. In seeking further clarity, the researcher was guided by a document from Stellenbosch University on determining the level of risk.

Accordingly, in reference to the abovementioned document, the current study fell in the medium risk category, mainly on the basis that the target participants were construed to be ‘vulnerable’ as ‘people living with HIV or other chronic disease'. In general, risks to participants are mitigated by using procedures that are consistent with sound research design and do not expose them to risk unnecessarily and consequently, that was the adopted strategy for this research. However, the following specific steps were taken to mitigate adverse risks to participants. Firstly, snowball sampling ensured that only a person well known to the potential participant would have known who had participated in the study. Secondly, there was no physical contact with participants, therefore none of the participants are physically recognisable to the researcher. Fourthly, the interviews were held privately while the participants were sitting in the comfort of their own private spaces in their homes and the researcher in her own private space at her home (as explained in Sections 3.5 and 3.6). Fifthly, pseudonyms, not the real names of the participants, were used during interviews.

Finally, the researcher informed the participants of their right to withdraw from the study if they felt uncomfortable in any way.

The researcher sees all these conditions as aligned to the feminist ‘ethics of care’ – which needed to be borne in mind in a study of this nature, focusing on a vulnerable target population of AGYW. Feminist ethics of care have evolved from feminist theories which argue that traditional ethical philosophy have empowered male recipients of ethical rights and duties through the exclusion of the majority of people in society, especially women, children, the socially, economically, politically, mentally and physically disadvantaged (Taylor, 2005: 219; Dempsey, Dowling, Larkin & Murphy, 2016). As an aspect of thought and action, the feminist ‘ethic of care’ is based on the notion that women exemplify care, as an important moral characteristic that improves interpersonal relationships and resolves issues without turning to the enforcing authority of rules and ideals. The concept is rooted “in the moral frameworks of responsibility and relationships rather than rights and rules and that any care orientation is inseparable from contextual circumstances, rather than being a formal and abstract system of thought. As such, the feminist ethic of care is grounded in the daily activity of life rather that a set of universal principles (Green, 2012:3). It suggests a conceptual shift away from the stance that care is objective, individualistic, and universal but rather that care and caring are influenced by connections, partiality, and conceptions of autonomy (Green, 2012: 3).

The participants were informed that the study had been approved by the relevant authorities at UNISA and in the Gauteng province. They were further informed that there would be no monetary compensation for their participation in the study but that their participation was important as it may benefit society later through the recommendations that would be made based on the information they had supplied; that the findings of the study will be shared with the relevant authorities in government and health care establishments. It was hoped that the authorities would be interested in acting to help improve the quality of assistance afforded to young women living with and without HIV in the province and elsewhere. In addition, the participants were assured that their participation would cause them no harm or damage. This was also in line with the feminist ‘ethics of care’ which advocate that when interviewing young and vulnerable women, such as those constituting this study’s research sample, the researcher must take steps to do no harm to them – or re-victimise them. Thus, although there was no system put in place to deal with any possible negative outcomes of the interview, the use of technology (Copes, Tchoula, Brookman & Ragland, 2018:475) gave them a level of comfort and anonymity which placed them in ‘safe space’ to talk about their experiences with minimal potential to experience a sense of revictimization. Indeed, as Voltelen, Konradsen and Østergaard (2018:515) state, a researcher is obligated to ensure a safe environment during the interview and to find a delicate balance between the requirements of the participants, fostering equitable and neutral but committed attention before, during, and after the joint interviews, utilising nonconfrontational tactics. Moreover, they were also informed of their right to withdraw from participation, should they have felt uncomfortable with continuing. It is against the background of the combination of all these measures that the researcher was satisfied that adequate steps had been taken to mitigate potential and actual risks to the participants.

3.10.3. Human dignity and Informed Consent

Researchers have a moral and ethical duty and responsibility to protect the dignity of all human research participants. The concept of informed consent refers to permission granted by the potential respondent to the researcher to participate in a study (Wiles, Crow, Charles & Heath, 2012:3). This means that all forms of research should be viewed as optional and the refusal to participate must be respected. This was achieved by ensuring the participants’ autonomy and anonymity as well as by obtaining their informed consent (refer to Annexure 2). The informed consent form was shared with the participants by email and *WhatsApp*. The essence of this is the importance of upholding the principle of respect for all individuals.

In addition, the study was guided by Section 3 of UNISA’s Policy on Research Ethics (2016:14) related to research ethics and upheld strict ethical standards in adherence to the principles of informed consent, confidentiality and anonymity as discussed below.

3.10.4. Voluntary Participation

It is necessary to inform potential participants in research that their participation is voluntary and to ensure that no coercion compels them to participate. Accordingly, in this study, the participants were duly informed about the voluntary nature of their participation, including their right to withdraw at any point. This position was explained to all participants, they freely acceded to the request to participate in the study and signed the informed consent forms.

3.11. CONCLUSION

This chapter presented the main research methods used in this study. Although the attendant field study was undertaken under challenging circumstances during the COVID-19 pandemic with adjusted Level 3 lockdown, the investigation was duly accomplished. In the next chapter, the results and findings of the study are presented and discussed.

CHAPTER 4
RESULTS AND DISCUSSION

4.1. INTRODUCTION

This chapter deals with the data analysis, interpretation and results. The purpose of this study was to explore the perceptions of YWLHIV and document their lived experiences with respect to HIV-related stigma and discrimination. Accordingly, in presenting the chapter, the biographical data related to the respondents are first presented, followed by the data presentation and interpretation in line with the six research questions that framed the study as the organising fields. After each subsection, the research questions were used as themes for analysis and presentation of results.

4.2. BIOGRAPHICAL DATA

This study focussed on YWLHIV. The research sample consisted of thirteen participants of whom four were aged 24, eight were aged 23 and one was 22 years old. As this study was located in the Johannesburg metro, all the respondents came from various locations within the area. Of particular interest to the study regarding the specific areas within the city, were the socioeconomic categories of the places where the respondents resided, for how long and with whom they had lived there. The variable of socioeconomic status was included in the interview schedule in response to the claim that this is one of the factors that explain why girls and women remain at the centre of the AIDS pandemic (UNAIDS, 2019:16). Seven of the 13 participants lived in historically ‘black townships’, Soweto and Vosloorus. Considering that poverty and educational level have been linked to the spread of HIV (De Walque, 2007:686; Audet, Burlison, Moon, Sidat, Vergara & Vermund, 2010:2; Mwamwenda, 2014:28), it is reassuring that the research sample of this study held what one may consider being good levels of education: nine of the 13 participants were in gainful employment, three were university students and only one was unemployed. As Mwamwenda (2014:28) surmises, 'education remains the social vaccine in the absence of a cure for HIV/AIDS'. This information was cross-referenced with the participants’ employment statuses as reflected in Table 1.

Table 1: Participants' residential, educational and employment profiles

Part No.	**Age (Years)**	**Location**	**Duration**	**Household Composition**	**Education Level**	**Employed**
1	24	Vosloorus	8 years	Parents and own child	Matric	Yes
2	24	Bloubosrand	2 years	Younger sister	Diploma	Yes
3	23	Midrand	5 years	Two brothers	BA Hons	Yes
4	23	JHB Central	23 years	Mother	Matric	Yes
5	23	Midrand	23 years	Parents	Grade 10	No
6	24	Randburg	4 years	Friend	BA	Yes
7	23	Vosloorus	23 years	Parents and two siblings	B Tech	Yes
8	24	Randburg	8 months	Two friends	Matric	Yes
9	23	Midrand	3 months	Fiancé	Diploma	Yes
10	22	Berea	5 years	Mother and sister	Matric	Yes
11	23	Soweto	23 years	Four brothers and two sisters	Matric	No (Univ student)
12	23	Soweto	23 years	Mother, two sisters, three brothers and grandparents	Grade 10	No (Univ student)
13	23	Soweto	20 years	Mother, two brothers, sister and own son	Matric	No (Univ student)

4.3. ADDRESSING RESEARCH QUESTIONS

As stated above, the information presented in this section seeks to provide answers to the six research questions around which this study was framed.

4.3.1. The Perceptions of YWLHIV about HIV-Related Stigma and How It Relates to their Vulnerability to HIV

The first research question pertained to the perceptions of YWLHIV about HIV-related stigma and how this relates to the vulnerability of young women to HIV infections. Their responses are reflected below under several subthemes, as indicated:

4.3.1.1. Understanding the meaning of *stigma*

In response to this question, all respondents, but two, professed to have previously heard the term ‘stigma’ and that they knew the meaning of the term. This is what they had to say:

> '*I would basically say it is discrimination or a lack of understanding something*.' (Participant 1; P1); '*It’s a word which means that you are not like other people; you are different from them, which makes them to criticise you*.' (P12); '*Stigma means different things to different people… it's the shame or disgrace attached to something regarded as socially unacceptable*.' (P13)*; 'I can say it’s more associated with a circumstance a person has or some form of a disgrace in society that one can have …* ' (P3); '*My understanding would be a mark of disgrace associated with a particular circumstance*.' (P9)

From the verbatim statements presented above and those that were not included because of limited space, one can conclude that the participants’ perceptions are consistent with the operational definition adopted in this study (see Chapter 1). Their perceptions reflected key concepts commonly associated with stigmas like discrimination (due to race, religion, cultural practices, sexuality, physical appearance, etc.), lack of understanding, disgrace in society, negativity and others. As UNAIDS (2019:16) states, HIV-related stigma includes factors such as age, ethnicity, gender inequities, disability, sexual orientation, profession and socioeconomic status.

4.3.1.2. Perceptions and experiences of young women living with HIV about stigma

With respect to the participants' perceptions and experiences of the reality of HIV-related stigma in their communities, the participants reported as follows:

> *Yes, there is so much stigma because in my community, where I grew up, when someone says they are infected people don't want to be associated with them; people kept away, they view them as this person who is diseased just by touching you or looking at you, yeah!* (P1)

Likewise, all the remaining participants also felt that HIV-related stigma was an ever-present negative force in their communities. The experiences of some of them were recorded as follows:

> *Yes, there is stigma because like with my health status that I have been referring to, so, Ja! Man, it's affecting your emotional well-being and mental health. Uhm, when you're living with this disease and people just don't understand … uhm, and they just do things to make you feel like you know it's the end of whatever is going on.* (P3)

> *Yes, definitely, definitely, we are experiencing stigma first-hand … uhm … there's lots of stigma around HIV and AIDS. There's a lot of stigma, definitely. I mean I still live in the locations, so some things are still like that; so, if you have it, it's like, 'Oh, stay away from her' or, 'Oh, my gosh, she's about to die' or, 'She doesn't behave, that's why she has it'. So, there's, definitely, things like that are still happening, even till this day.* (P7)

> *Ja, definitely. Uhm … Like, I'll speak from experience … I remember growing up, there was this stigma of saying that only certain type[s] of people can contract HIV; that HIV was for poor people and if you're rich you can't have it.* (P8)

"I can speak from my own experiences that there is stigma associated with being HIV positive." *(P10).* A couple of responses went further to state how you may find yourself being treated by community members, once they know your serostatus:

> *Yes, there is a stigma associated with HIV and AIDS where people mostly criticise people who are HIV positive and do not think they are people who are like them … they treat people with HIV like these are people who need to die and not live with other people... who are negative.* (P11)

> *Yes, if people find out about your HIV status, they will start neglecting you and gossip around your name. In doing so, it will be hard for you to find a stable relationship*. (P12)

What all this says is that one must be particularly aware of the sentiments of the people in one's environment before taking certain decisions, including accessing HIV and AIDS-related healthcare services; taking part in HIV and AIDS-related programmes or talking publicly about one's HIV status. This community-level stigma which makes it very difficult for PLHIV to access treatment or information about HIV, has been reported by many authors (Ekstrand et al., 2013:23; Horter et al., 2017:20; Bond et al., 2019:87). This is one of the reasons why HIV- and AIDS-related stigma and discrimination affect adherence to ART and the mental health status of PLHIV (Odimegwu et al., 2017:7). Thus, it is clear that the HIV- and AIDS-related stigma could hinder HIV positive individuals from participating in programmes that could reduce or prevent HIV- and AIDS-related stigma. It is a vicious cycle. From the findings of this study, it was evident that there were no specific arrangements at public clinics and hospitals to accord the HIV positive AGYW the required confidentiality and privacy when accessing treatment. Accordingly, they remained vulnerable to stigmatisation all the time they visited these health facilities to secure medication. This stood in stark opposition to the expectations of the feminist tenets of ethics of care (Parton, 2003:1; Green, 2012:2; Keller & Kittay, 2017:540).

In short, all the participants reported experiencing HIV-related stigma in one form or another and attributed this to their communities' lack of education about it:

> *I think, it's because people are just not well informed about … uhm, the causes of the disease; people not being well informed on how it can spread; people not*

> *being well informed that it’s not a disability, you can still live your life even if you are infected.* (P4)

The same sentiments were echoed by Participant 6 who stated: “*I think there is a stigma around HIV and AIDS because people are not educated well enough about it, people stigmatise us and are not treated the same way as someone who doesn’t have HIV.”* In a similar vein, Participant 2 also blamed the absence of education for the HIV-related stigma:

> *Yes, there’s definitely stigma associated with HIV and AIDS. As a community we still don’t understand what HIV is, how we contract it and just everything around it. So, when you test HIV positive, you would have to hide it because if you come out you are going to be discriminated or treated in a different way.* (P2)

This response also speaks to a possible reason for people's nondisclosure of their HIV-serostatus.

Recounting how they were affected by these experiences, the participants all decried the negative gossip that was associated with being known by community members to be HIV positive. They felt that they were continually being judged, which they thought was very unfair and unjustified. The difficulty with this situation is that as a result of the HIV-related stigma (internalised, perceived or anticipated), the negative experiences that young women living with HIV go through determine their subsequent behaviour and decisions about whether or not to access healthcare services. This observation supports the finding that one of the most common coping strategies for PLHIV is to maintain a low public profile by avoiding public functions as well as to avoid seeking healthcare services from public facilities (Odimegwu et al., 2017:7). Treves-Kagan et al. (2015:1) also reported that community members delayed going for HIV testing, accessing health care and adhering to medication. Accordingly, it is reasonable to recommend that HIV health care should be provided in 'clever' ways that accommodate the fears, circumstances and preferences of the targeted persons and groups, rather than to insist on more formal ways that may not work for the majority of the people (Jacobi et al., 2020:6). Such an approach will avoid creating a vicious cycle whereby young women (and other PLHIV) shy away from healthcare facilities where they should access care and treatment because of bad experiences caused by HIV-related stigma. In turn, this aggravates their vulnerability to HIV and AIDS. For this reason, the researcher sought to find out how becoming HIV positive affected the participants' dispositions towards accessing healthcare and treatment. For instance, Participant 10 reported that stigma affected her badly in that she ended up being:

> ... *diagnosed with depression because I couldn't understand why people … were so mean and I would think that there was … uhm, there was something wrong with me and that I deserved the treatment that I got.* (P10)

This is quite sad, as is the plight of a young woman (P11) who dropped out of school after experiencing stigma and being called names by schoolmates; *"no-one wanted to live with me, they all talked about my status throughout the whole school."*

These results agree with those reported by Odimegwu et al. (2017:7) who state that patients who have experienced stigmatising events also had posttraumatic stress disorder (PTSD) and that PLHIV experience considerable levels of rejection and discrimination. This was particularly the case in the early stages of community infections when many people believed that caring for someone infected with HIV was a waste of resources because they would soon be dying, anyway. The participants further reported that as a result of community members getting to know their HIV status, they were negatively affected in various ways. Participant 2 reported:

> *a really, really rough ride because you feel isolated, you feel worthless, you feel like you don't belong; that sense of belonging just goes away. You feel like you are just on your own with your family, isolation is just the word, yeah!* (P2)

Participant 13 also endured loneliness*: "I felt so lonely, I had no friends and no one to talk to because they isolated themselves from me, because of the situation I was facing by that time."*

Participant 3 lost her urge and desire to continue studying:

> *... because I would think that people, who were in the same neighbourhood as me, did attend the same universities or the same colleges. I wished to attend too but kept thinking that they would share my business with other people that I wouldn't have even known, yeah, yeah.* (P3)

Likewise, Participant 8 resented being judged, especially by people that she knew, while Participant 11 reported that the stigma had adversely affected her self-esteem and prevented her 'to live life at the fullest'. Overall, she decried the many '*stereotypes and lies with this disease'* and attributed this to the lack of education about HIV and AIDS. In her view, HIV-related stigma was being 'created' on social media by '*people who are just joking about the disease'.* What disturbed Participant 11 the most was that *'most people are dying because they are afraid to take certain measures to protect themselves or which will help them to live with this disease'.*

In concurrence, Odimegwu et al. (2017:7) also reported that PLHIV initially experience self-isolation, fear of death, family withdrawal, rejection and abandonment but that this subsequently turns into a better or healthier physical appearance for the affected people, as family and community members begin to accept them, thereby leading to improvements in status disclosures. Hopefully, the above participants will also find support from family members and friends, in time.

4.3.1.3. Stigma associated with testing for HIV

One of the major HIV reduction campaigns in South Africa was the country-wide rollout of the ART programme which depended on ascertaining individuals' serostatuses and CD4 counts (Centers for Disease Control and Prevention, 2011; Peltzer, Parker, Mabaso, Makonko, Zuma & Ramlagan, 2012:1). In this study, the participants were asked about their experiences at the time they had tested positive for HIV. This is what the participants said:

> *The experience was scary, due to the … what do they call the counselling that they do … before you take the test. Yes, I think the questions are rather too much it just scares you before you take the test, you feel like pulling out. Because they ask you everything you have never thought of. I was scared because so many people see you going into that room and they think that you have it. There're no questions asked about it, they are like okay, it's like you know when you are in a clinic and then these people are your pregnant people, these are the babies, these are your HIV people without even naming you. Because as soon as you go into Room 9 you are going in for HIV testing, you know and for you to be taking the test they are like what did you do that makes you take the test? So, it means you have done something wrong in a way that would make you take the test.* (P1)

Participant 3 added her voice to the lack of privacy and confidentiality and circumspection in the manner that healthcare workers go about dealing with HIV testing:

> *Sho! The experience is not great because there is a way you feel discriminated when the nurses say publicly, 'If you are coming to test for HIV and AIDS this is the line'. You kno, and … uhm, you kind of tuck your tail between your legs and join that line and everybody is looking at you wondering you've got AIDS or not, wondering why you are testing, wondering what happened and also that just affects you because the number of eyes looking at you, the number of ... the stares that you get it becomes uncomfortable and you just feel like why can't the ground just open up and swallow me.* (P3)

For Participant 2, it all happened in an unplanned way:

> *Uhm when I tested for HIV, okay, so, I can say it was … erm, first of all I went into the hospital testing for something else well I was sick and then … uhm … then they tested me for HIV and told me this is the result. I got counselling and I actually became pretty close … well, I actually got all the information I needed from this healthcare professional whom I'm still in contact with currently*. (P2)

Participant 4 shared the good, caring and supportive experience when she got tested for HIV:

> *Uhm, yes, although I was very scared to do it before, uhm, when I found out I was with this man I was with and only after we broke up someone told me that he was positive and he had never bothered to tell me and I also didn't ask because I thought we were on the same page. Once I told a friend of mine … uhm, she encouraged me to, to go to the local clinic and she was with me and held my hand and … and I got tested and found out I was positive then. … Uhm, the lady who did the testing for me was, I could say that she was welcoming and she calmed me down and before the test she would explain what she would be doing and if I tested positive or I tested negative how to deal with it and they could help and assist or I could find counselling just to help deal with whatever the answer would be … uhm, she was really … she was really helpful in that aspect; they were really good.* (P4)

Participant 5 stated differences in when she tested at a local clinic, versus testing at private GPs:

> *Ah! The experience the first time I tested in the clinic is not the same as when I tested at the doctors. I tested at the clinic and there is not enough time for counselling compared to when you go to the doctors. Even when they give results it was not the same. At the clinic, they just test and give you your results but at the doctors when you are positive they talk to you and explain how you should take care of yourself. I think if the public clinics were doing the same thing, it was going to be better. I think people who go there, they don't get enough … what can I say, uhm, enough support.* (P5)

Participant 6 also expressed having had a good experience when she tested at a private hospital, where the hospital environment was '*really nice*'. She contrasted this with her previous experience of testing at a public healthcare facility where she was '*treated like trash*'. Participant 7 was tested at a university campus where everything went well: pre- and post-testing had been handled very well, as were matters of privacy and confidentiality. The remaining participants also reflected this trend, that testing at public healthcare facilities was messy, while private healthcare facilities conducted HIV-testing in a professionally acceptable manner. Where the testing had been handled very well, participants' anxieties and fear were well contained within the pre- and post-testing counselling sessions. As Participant 7 testified, she was assured that '*if you are positive, it doesn't mean it's the end of the world*'. This calmed her down and she was ready for any outcome of the HIV test.

4.3.1.4. Attitudes of family members after testing positive for HIV

Participants were asked about their experiences within their families after testing positive for HIV:

> *Uhm well I … er, when I was diagnosed it took a while for me to actually come out to my family and friends because I was still trying to process the whole thing internally. So, the only people who knew where the health practitioners. So, uhm, when I then eventually came out it was my family first, and they were very supportive.* (P2)

Participant 7 found the family to be supportive but was unsure about the community:

> *I know my family is supportive, although it is difficult. But I don't know about other people but my family is there for me. I don't know about the community, there are people who are now educated about it and those that feel like you are gonna make everybody die just because you have HIV.* (P7)

Participant 10 experienced support from part of her family coupled with extreme stigma from others:

> *Uhm, Ja! Yes and No. It took a while for me to accept my status but, once I did, I told my sister and mom and my close friends and I was lucky … uhm, that they treated me the same. They made me feel like I was not alone, you know, but like I told you my aunt was like a demon, sorry to say, but she was very mean and she changed on me and definitely treated me differently.* (P10)

The overall dominant response from the majority of the participants was that their families had been supportive and did not show any hostility or stigmatisation towards them.

4.3.1.5. Attitudes of community members towards young women living with HIV

The participants were asked about how they were treated by their communities after they tested positive for HIV. They recounted their experiences as follows:

> *The stigma I got was from outside my family, in the community, and them seeing me going to collect medication and being told to go stand there and people seeing me and I know of a lady from the community who came to get an injection for her child and they saw me standing there in the queue and that's when the talks started; it started coming, and ja*. (P2)

The issue of stigma at a community level came out very strongly in the testimony of Participant 11:

> *I dropped out of school because of my HIV status; learners were laughing at me and criticising me, no one wanted to stay with me at the same desk or in the classroom. They all said I was going to infect them with the virus that I had. Then I had to drop out of school because I felt like a disgrace. I also felt very shy to even go out with someone because no one wanted to be my friend. So, I took my path to just drop out of school before being deeply hurt… They also talked about my status throughout the whole school, whereas I only told one person who was my friend, who I got tested with and she came out negative and I was positive. Then she spread the rumours about me and my status and I ended up dropping out of school because of that stigma.* (P11)

As was the case with Participant 2, Participant 3 also reflected on the ever-present stigma associated with HIV, particularly regarding how people viewed her, as an HIV positive person:

> *Yes, you're definitely treated differently, because when you test positive people literally put an X on you. It's like you are kind of dead or like you are dying today or tomorrow. Uhm, there's lots of stigma around you: people don't wanna be close to you; people don't wanna tell you things because they don't know how you are going to react. People start acting differently towards you, people don't wanna share food with you, people don't want to go to different places with you because they feel like other people can see you have HIV so, ja, it's a lot.* (P3)

For Participant 4, the initial negativity towards her died down and gave way to a level of acceptance:

> *I think at first, they did treat me differently and I also felt awkward. I didn't know how to relate to people after testing positiv, but now it's getting better with the people that do know and the people that used to talk about me they've come to terms with it, if I can say, they don't talk as much.* (P4)

However, the dominant view was that the communities in which the participants lived were not supportive enough and instead, treated people who were HIV positive differently and in a negative way. As Participant 8 put it, '… *the same thing as what we have been talking about, the stigma: society is just messed up, people think that if you have a certain disease you are different*'. Participant 9 summed it up in her statement: '*there's no information about HIV in my community, they don't know how to treat one who has the infection, they don't really view us as normal people*'.

4.3.1.6. Public advocacy

In reflecting further, the participants were asked if they felt free to speak about their HIV status publicly:

> *Not at all, because of the stigma. People are judgemental, people are not educated enough. They don't have an understanding or they'll think you're dying tomorrow and start distancing themselves from you and start labelling you ... So, I'd rather deal with the disease and keep quiet than having to deal with people on top of that.* (P1)

Participant 1 likened disclosing her HIV status to having another disease to deal with. So, she surmised that apart from just dealing with HIV and AIDS, disclosing her HIV status would just add further problems for her. Participant 3 held the same view:

> *No, I really do not want to go public with it because of everything that comes with that: isolation, discrimination, not being able to walk around freely in the community, gossip around me, yho! No.* (P3)

In a similar vein, Participant 7 was also not ready to speak publicly about her HIV status:

> *It will take time for me to open up, even those people opening up, they weren't like that. They had to go through different kinds of stages, you know, because the first stage is acceptance and that is not easy. You have to accept that, 'Okay, now I am going to live with this for the rest of my life'. Before you can include other people in the circle, you need to do this by yourself first. But eventually I will spread the awareness.* (P7)

Among the thirteen participants, only Participants 2 and 8 had defeated the spectre of fear and shame to express willingness to go public with their HIV status: '*Uhm, I think so, because I am at a stage where …uhm, I'm getting there, so I definitely would be willing to talk around new people.* (P2*)*

> *Yes, it is important to talk about it publicly, you know, especially just to educate and let people know what I am going through; to have a group that I know that, okay, this is what is happening and if I know I have the support I will be very comfortable to talk about it.* (P8)

In summing up the above remarks it can be said that whereas some of the participants were free to divulge their HIV status in public, the majority would rather approach the matter cautiously. The dominant feature in their unwillingness to divulge their HIV status publicly was fear of stigmatisation. They felt that this would be an extra burden to contend with, as Participant 1 put it, '*It will just become another disease, I will have HIV and I will have now to deal with people on the side which I think it is too much*'.

4.3.2. How Stigma Impedes Young Women from Accessing HIV and Destigmatisation Programmes

Having established that the participants were *au fait* with the meaning of stigma, they were asked to express themselves on how they thought stigma impeded young women from accessing HIV and destigmatisation intervention programmes. This related to the second research question, which sought to explore how HIV-related stigma impedes YWLHIV from accessing HIV and destigmatisation intervention programmes. The respondents had the following to say:

> *No, mina I cannot go because the people in my community will think I'm HIV and will probably tell my family or whatever. People will not want to support the next person, instead they gonna label you, so I think it definitely plays a role.* (P1)

The same sentiments were echoed by Participants 2 and 3:

> *It's like this, the people always think those who attend HIV prevention programmes are people who are living with the disease or virus–it shouldn't be like that but that is the problem. It's actually a great idea that you can go and get training and get help and you get support from other people living with the disease. The problem is the stigma associated with those activities. So, you have to think twice before you can go.* (P2)
>
> *Sometimes when I try to get pamphlets for myself and my brother, I get scared because I don't know what people are thinking. So, I think it's just that association and the stigma around HIV and AIDS. People don't want to be seen whether taking information, collecting pills, reading anything along those lines, HIV and AIDS related matters. So, yes, definitely, stigma is a big problem.* (P3)

The response from Participant 7 put a different dimension to the challenge of accessing HIV-prevention programmes by implicating healthcare workers as part of the problem:

> *I'm speaking of something that I know, not just making an example. You know that this lady … she talks too much and she likes gossiping. It's so weird to me because you are a professional, you have to be like different and actually be the help to the community, like, I mean, you're the only person who made it in the community; who is a nurse; the person who we can go to and speak to as young women–but you're the one gossiping about people. So, you don't want that people see you in the queue of ARVs or in the queue of people fetching a pamphlet or you know, you always avoid, hence, I said earlier those others prefer going to clinics that are not around Vosloorus and now that's costly because you are running away from people who will say things about you.* (P7)

The negative role played by healthcare workers in discouraging people from visiting healthcare facilities will be revisited in the next section, suffice it to say, that it is one of the major issues highlighted in the literature as needing urgent attention. Proceeding with this research question, participants were asked if they knew of some people in their communities who avoided going to hospitals or clinics to receive healthcare services or information about HIV or AIDS, for fear of being known or suspected to be HIV positive or to be suffering from AIDS, they all agreed that they knew of such people. They gave the following explanations:

> Y*es, there are people I'll make an example of. Me and my friend, one of my friends wants to test but they are scared to go because of the stigma, but finally, we all decide to go.* (P1)

Participant 2 also concurred:

> *Hmm, well yeah! I think there are a lot of people living in this community who are … who wouldn't or don't go to the hospitals because of that. So, I mean it's a lot that is going on in the world as well; you know people are scared of being victimised because of their HIV status.* (P2)

Participant 3 referred to the attitude of some healthcare workers as a factor that might discourage some people from accessing healthcare services:

> *Yeah, … if the nurse comes and gives people some information, let's say they are going to test for an STD or something, they would give you pamphlets for a lot of other things including HIV. Some people will hide those pamphlets or they quickly throw them away because they don't want to be associated with HIV.* (P3)

The issue of broken trust between community members and some healthcare workers was also echoed by Participants 7 and 9:

> *Yes, I do know some people in the community who are scared. I mean as I've said, I live in a township and township people talk. They always gossip about people behind their backs. It is better, because now we have nurses who don't stay in Vosloorus. They come from other areas, but there are still those who stay in the township. Imagine going to the clinic and bumping into your neighbour who is a nurse, you know … sorry!* (P7)
>
> *Yes, actually, I do know of people who can't even go to clinics just to get … uhm, contraceptives like condoms or anything it's free but just to go there it's too much for them. I think it's because of the treatment that they get at these facilities … I believe that our medical practitioners or people who work at facilities, doctors, nurses should be more educated, should be … they should know how to address people, but it doesn't seem to be the case … it doesn't seem to be the case.* (P9)

All these sentiments point to a perception of communities being generally hostile towards PLHIV and AIDS. This hostility manifests itself as stigmatising such people. Undoubtedly, these perceptions of a community stigmatising PLHIV will affect and influence the HIV-positive community with respect to the decisions they make concerning their health status and whether or not to access support and care. Overall, the dominant response was that most community members avoided being associated with HIV prevention programmes or even being seen reading materials on HIV or AIDS, for fear of courtesy stigma. This was highlighted by Participant 5 when she stated:

> *Yes, I don't think people go there and ask because they know that if they go and ask about HIV and AIDS other people will be thinking they are positive so people they don't go there for more information.* (P5)

4.3.3. How Stigma Impedes Young Women from Accessing Care and Treatment

The results under this subsection address the third research question and are presented under two subthemes: how stigma impedes accessing care and treatment and how the respondents/participants were affected by stigma in their communities.

It is clear from the responses in Section 4.3.2 that there is a lot of stigma associated with HIV and AIDS in the respondents' communities. Taking this point further and relating it to the respondents' ability to access HIV treatment, some of them recounted the following experiences:

> *… when I was diagnosed, I obviously had to attend … I had to go to the clinic … uhm … to get my medication and with that came people who are in the community that I was staying in, knowing of my status because of, obviously, the monthly visits and … uhm … when you go to a clinic you are told to queue ... you know, at a certain place in order to get your medication. So, people seem to know what that means when you are told to go there so, people find out and then you become a target, so to say … uhm … of comments, looks and you know, emotional attacks and stuff like that. Well, not really physical, but you know the stares and stuff and people did find out.* (P2)

This testimony clearly explains a lot about stigma in the community where the participant lives. Unfortunately, this experience appears to be typical when one looks at the responses of other participants. Thus, Participant 3 also recounted having experienced stigma when accessing healthcare services:

> *I have experienced stigma. I'm gonna share something very personal. I also live with one of my brothers who is HIV positive. We have experienced stigma as a family because of the assumptions that are associated with someone living with HIV and AIDS and … uhm… We get discriminated against at times at events, at family functions, … uhm… in the community … uhm … in the complex where we stay, you know, because once people kind of know your*

> *status then I don't know whether it's lack of education but they think that, ah, it can easily be spread like an airborne disease. So, ja, that has been very difficult for us as a family.* (P3)

For her part, Participant 10 was particularly disturbed by being '*discriminated against for a number of things like my sexual preferences …*'. Therefore, it became important to ascertain how the HIV-related stigma experienced by the participants influenced their disposition towards accessing health care and treatment, if at all. From the above sentiments, it did appear that there might be a relationship between the two.

4.3.3.1. Healthcare workers as an impediment to accessing care and treatment

Sadly, very strong sentiments were suggesting that through their negative attitudes and poor handling of patients, healthcare professionals impeded PLHIV, of whom YWLHIV are a distinct and significant sub-population, access to health care services and treatment. More specifically, it appeared that HIV-positive young women possibly avoided accessing healthcare services because of the stigmatisation and discrimination meted out to them by healthcare professionals (Turan, Miller, Bukusi, Sande & Cohen, 2008:938; Treves-Kagan et al., 2015:1; Arrey, Bilsen, Lacor & Deschepper, 2017:578). In particular, Treves-Kagan et al. (2015:1) found anticipated stigma to be a significant barrier to accessing care, as community members wanted to avoid being known as being HIV-positive. So, many avoided visiting healthcare facilities altogether, opting to use alternative remedies, including traditional medicines or paying to see private healthcare practitioners. Accordingly, Treves-Kagan et al. (2015:11) concluded that community members 'will remain hesitant to seek care as long as they fear that doing so will lead to prejudice and discrimination'. As a case in point, the participants in this study had mixed feelings about whether or not healthcare workers could be trusted to keep HIV test results secret or confidential. Participant 1 felt that healthcare workers could not be trusted, especially if they lived near one's home. Similar sentiments were expressed by other participants like Participant 3, who opined that '*we are very closely-knit communities, so, once a lady next door who is a nurse at the local hospital knows my status, she is likely to tell somebody in the community*'.

This kind of mistrust keeps people away from visiting healthcare facilities, thereby increasing their vulnerability. For instance, they become reluctant to go to healthcare facilities to ask for information, condoms, pre-exposure prophylaxis (Pre-EP) or even just to attend HIV-related programmes. The alternative is to visit far-away healthcare facilities where they are likely to remain anonymous, with a low risk of meeting someone they know. As Participant 6 put it, '*I'd rather go to a place where I am not known*'*.* Similar sentiments were expressed by Participant 12, albeit with a sense of inevitability that in the final analysis, it is futile to try to hide one's HIV positive status:

> *I do not trust healthcare workers to keep my HIV test results a secret because once you tell one person that you have HIV they tend to tell other people about your status, then in the end everyone knows of your status. However, the difficulty is that it's not a thing you can easily hide because at home you live with your pills and when you have to take them and someone has visited you, maybe your neighbour, then the neighbour will go tell someone and someone will tell someone... then it becomes the society story, so it cannot be hidden, anyway. So, yes, even if I trust someone at the hospital but at the end it will be visible to all, then the one who wants to discriminate against me can still do so.* (P12)

However, for logistical and affordability reasons, not everyone can do this, so the only practical option left, quite unfortunately, is simply to stay away from healthcare facilities.

Nevertheless, Participants 2, 8, 11 and 13 reported that they trusted healthcare workers, particularly with respect to keeping their HIV test results secret or confidential. However, they decried the conditions at public clinics and hospitals when it came to testing and collection of medicines, as Participant 2 put it:

> *It's just that when it comes to the actual collection of medication that I feel all that effort of keeping things confidential has now gone to the dogs because I find myself standing in a queue that is known by everyone to be for HIV medication.* (P2)

Participants 4, 5, 7, 9 and 10 had mixed feelings about secrecy and confidentiality:

> *Uhm, I would like to say yes but unfortunately, it's not happening everywhere. Maybe some other places they do keep it confidential and I'm happy about that, but some places they don't because they know your family, your mother or your grandmother they think that it's okay to share your status with people, or with your family, without your consent, and then share it with their friends and things like that.* (P4)

> *I'm a bit sceptical about that … but I think it's better because some of these nurses are not from our community, most of them are from other places. But I remember when I was still in high school, okay this was not related to HIV but … my friend, a classmate of mine fell pregnant, like, at school we were doing Grade 10. She was scared and all, she couldn't tell her parents and now she asked me to accompany her to the clinic. When we got there, she was scolded instead of helping her. They said to her, 'You know what, you need to tell your parents! …. Why are you not focusing on your books as a teenager, you are busy opening your legs!' … she didn't wanna go back there ever again. So, ja, there are nurses that you can trust and those that you know that person will tell everybody about my business.* (P7)

Similarly, Participant 9 believed that some communities did not care about keeping patients' information confidential. In his words, '*they don't have work ethics, they just talk about people's statuses, they just gossip all the time, yes*'. In concurrence, Participant 10 reported that in her community, gossiping was a big thing: '*I grew up in the locations and there was a nurse who would tell people that,* "*you see that one, don't think they are healthy they have HIV*" *… they like gossiping and talking about other people'.* However, in all fairness, she conceded that some nurses did their work professionally and took their job seriously and wouldn't risk it by telling other people.

Still on the topic of secrecy and confidentiality, the participants were asked to reflect on their experiences of being tested for HIV and state how HIV-related stigma would affect people's decision to go for HIV testing as well as to access care, treatment and programmes aimed at stopping or reducing HIV-related stigma. They were asked to do this, in particular, considering that HIV testing has been a key factor in the success of South Africa's ART programme. In South Africa, HIV testing is typically provided at healthcare facilities—both public and private. Evidently, the success recorded in the decrease of HIV infection rate in the country has been attributed to the campaign to have as many people as possible turn up for voluntary HIV testing (Zuma et al., 2016).

The participants had a lot to say about this. Participant 1 was of the view that just be stepping forward to visit an HIV testing facility, one was already exposing oneself to the possibility of stigmatisation: '*Certainly, as I told you before, as soon as you see people going there, already you will be labelled as someone who has HIV*'*.* Indeed, as Participant 5, pointed out, '*People are scared of being seen as HIV positive; they don't want to do anything that will get people saying they are positive*'*.* Participant 11 also supported this view: '*In my experience, I would say that stigma does affect a lot of people, you know. People really shy away from testing for HIV*'*.*

In concurrence, Participant 4 had the following to say:

> *Uhm, people are not so keen to go get tested because, obviously, of the stigma and how they will be looked at in their respective communities … uhm, that quick testing centre, sometimes people go there, but still, if they see you walking in or out, again it's a thing.* (P4)

Without suggesting a cause-and-effect relationship, some participants held the view that HIV-related stigma, notwithstanding a combination of lack of knowledge, misinformation and some social beliefs, fuelled people's apprehension towards testing:

> *Uhm, okay, so in my view, people don't want to be associated with HIV. There is a lot of misinformation about the disease, you know. Sometimes even those who are positive don't want to be associated with HIV. Uhm, but ja, people are not comfortable going to get tested or attending programmes because they are not educated, they believe the stories they hear, uhm, in the streets and don't wanna learn for themselves.* (P10)

Similarly, Participant 7 added her voice to this view by saying:

> *Obviously, you wouldn't want to go and test because there is a belief that if you keep on testing for HIV, even if you don't have it, one day you will go and find that you are HIV positive because you are busy testing and testing, you know.* (P7)

Thus, the issue of misinformation and social beliefs picked up from people's communities, including social media, was taken by Participants 8 and 9 to be major factors in discouraging people from getting tested for HIV:

> *I think that is a big insecurity to most people. So, it will affect them, some will think they know but because of the stories they hear they will decide not to test … They hear a lot of stories of how people will die because they are positive with HIV and AIDS.* (P8)

> *People think it is the end of the world when they are HIV positive; they think 'I'm going to die'. … Therefore, people don't want to be associated with any programmes about HIV or AIDS, including testing.* (P9)

Stigma plainly featured highly in the minds of these participants; whether this is real or just imagined is of little consequence. The fact of the matter was that much of their reactions to accessing healthcare services and HIV preventive or destigmatisation programmes were influenced by these perceptions. Thus, the views and experiences reflected in the above responses are very important to the essence of this study. Regardless, it was quite clear that HIV-related stigma had a detrimental or damaging effect on the participants' disposition towards accessing health care and treatment. The dominant factors were communities' negative attitudes towards PLHIV and stigmatisation, ostensibly due to misinformation and unsubstantiated social beliefs. The unprofessional conduct of some healthcare workers and their unguarded prejudices against PLHIV were just the final indiginity. The major challenge is that there are multiple sources of young women's vulnerability to HIV infections with the attendant stigma and discrimination. These include but are not limited to poverty and violence against women (Muula, 2008:423); cultural practices, such as specific roles that have to be performed by girls and young women in the home, arising from gender discrimination (UNAIDS, 2019:6); sociocultural beliefs like the notion that HIV is a punishment from God or that it is deserved (Armstrong-Mensah et al., 2019:72); social inequalities (Harrison & Boyd 2018:296); economic hardship (Miller et al., 2017:1) and the relationship between the level of education and the incidence of HIV (Mwamwenda, 2014:28).

4.3.4. The Nature and Types of Existing Prevention and Destigmatisation Intervention Programmes

There was very little knowledge among the participants about existing prevention and destigmatisation programmes that took place within their communities or surrounding areas.

Seven participants were not aware of any programmes that targeted stigma reduction in their respective communities, while the rest indicated that they were aware of such programmes. For instance, Participant 3 responded as follows:

> *Uhm, there have been some aspects of it being addressed in our community … uhm, at our local church we do have, ah, sometimes kind of these … kind of discussions, especially when it is towards, ah, 1 December, so we do have these kinds of discussions.* (P3)

Participant 3 further explained that she found these events to be:

> ... *very helpful because it's people who we trust, people in the church. There was once, if I remember correctly, there was once an event in Tembisa and Midrand, where there was community kind of development on HIV and AIDS. I am not sure if it was being hosted by a political party or was it a different church or was it the community, but it was very informative, it was big. It was just an inspiration to be there.* (P3)

It sounded like this was a one-off event that may have been successful, but that was all that Participant 3 could remember. Similarly, Participant 4 gave the following account:

> *Uhm, I know a couple of years ago there were some, like, those small gatherings where people come through and educate people on what HIV is and to get tested and how it spreads and then they would give free condoms*

> *and obviously they would also say they have a testing centre. But that was a couple of years ago, but I haven’t seen some in a while.* (P4)

According to Participant 9, there were '*some counselling sessions at clinics; there are meetings at schools, but people don’t attend such stuff, it’s just a no-go topic*'. Likewise, Participant 11 reported that HIV stigma was being addressed through community awareness programmes held at schools and clinics and aimed to educate the community on HIV, how it is transmitted and how one’s actions could negatively impact those living with HIV. Participant 13 reiterated the same experiences and stated that community groups in her community addressed matters related to HIV and AIDS.

From this very limited information, it is difficult to describe and discuss the nature and types of existing prevention and destigmatisation intervention programmes in the communities from which the participants were drawn. Indeed, one gets the sense that there was a paucity of HIV and AIDS prevention and destigmatisation programmes in the communities in which the participants resided.

4.3.5. Gaps or Shortcomings in Current Intervention Programmes

The answer to this research question largely depended on the participants' responses to the question immediately above. Since the participants had very little knowledge of any extant stigma prevention and destigmatisation intervention programmes, the suggestions on how to improve such programmes were, therefore, also limited. In this respect, Participant 3 said the following:

> *I think the shortcomings of the programmes include that the invitations ... not everybody got the invitations due to various reasons. So, it was a friend inviting a friend and sometimes the information that gets to us is at a later stage and the event would have already passed. So, that’s one of the shortcomings. Another shortcoming is that you go to these event, and I feel like they don’t have the people who are knowledgeable or experienced to speak on this topic. The people that they have, have little knowledge, hence, when we ask difficult questions then it becomes awkward, there are long pauses because nobody really knows the answer because they don’t have the lived experience or the experience of living with someone who has HIV or AIDS, or being affected with HIV and AIDS themselves. It’s just stuff that they read in, you know, in books or the internet or*

> *even learn at school. Uhm, so, I think it's very important to have sessions with people with the lived experience of HIV or AIDS.* (P3).

So, the issues here are about notification or invitations to the events as well as the practical knowledge of the presenters. She preferred to attend sessions with people who had the lived experience of HIV and/or AIDS. For Participant 4, the issues of privacy and confidentiality were important:

> *Uhm, the shortcoming I don't know because it has to do with the willingness of the community to come through and attend and test. So, I don't know. Maybe they can try to put the testing facilit, not in the same area where there are pamphlets and people talking but put it somewhere where it is closed off and not a lot of people can see you. Maybe that would help, I'm not too sure.* (P4).

Participant 7 wished that there should be more open discussions about various issues related to HIV and AIDS:

> *Oh okay, I feel like people don't talk about this, but with these kinds of things, we only learn about them at school and any other places but when you come back to the community nobody wants to talk about HIV, unless they are having those horrible things to say about HIV and people who have HIV and people who have lost weight are HIV positive, you know, but other than that, no.* (P7)

Like Participant 7, Participant 9 called for more open discussion:

> *Ah! There needs to be a more open topic. People can take to social media to address us because we are all on social media lately and then make it a campaign that it's okay to attend these sessions; it's okay to want to know more; it doesn't mean that there is anything wrong with people needing to make it an open topic.* (P9)

4.3.6. Ways to Strengthen Current Stigma Prevention and Destigmatisation Programmes

In response to how the current stigma prevention and destigmatisation programmes could be strengthened, the participants contended that this could be done at three levels, namely family, healthcare facilities (clinics and hospitals) and community. The participants' views in respect of these three levels of intervention were as follows:

4.3.6.1. Family

At the family level, the participants' felt that this was essentially the first important level of support for persons who had tested positive for HIV. In this respect, all participants strongly expressed the importance of family members providing support to those who tested HIV positive within the family circle. They also reiterated the importance for family members to become educated on HIV and AIDS as well as to encourage and motivate them to live healthy, positive lives coupled with providing a sense of security.

4.3.6.2. Healthcare Facilities: Clinics and Hospitals

The participants felt very strongly that healthcare facilities are in a very strong/good position in ensuring that current stigma prevention and destigmatisation programmes were strengthened. Accordingly, they advised on many actions that clinics and hospitals might consider, to make people feel safer and not fear going there to get treatment or information on HIV.

The participants felt that healthcare facilities and healthcare workers needed more education, particularly health education, ostensibly because nurses were seen not to be easily approachable and therefore, needed more training on how to deal with those who request more information on HIV and AIDS. It was suggested that the use and distribution of pamphlets and other materials would be a good strategy to assist people not to fear going to hospitals or other health care facilities. Other suggestions included having outreach programmes as well as an emphasis on privacy and confidentiality for patients because information was being shared in spaces where recipients were not comfortable to receive it and ask questions without the fear of stigma.

The issue of confidentiality was crucial to the work of healthcare workers, for the promotion of their services to be strengthened. In addition, they (nurses) needed to encourage communities to come forward for testing, while privacy and confidentiality were guaranteed. It was also recommended that the involvement of social workers was needed as well as the need for healthcare workers to be friendly, professional and approachable.

4.3.6.3. Communities

In addressing stigma in communities and South Africa as a whole, the issue of education was also emphatically raised by all participants. Other issues related to creating spaces and opportunities to speak about HIV and AIDS openly, including the use of community radio stations and various types of media, particularly social media. Li, Rotheram-Borus, Lu, Wu, Lin and Guan (2009:424) reported that mass media sources like television programmes, newspapers and magazines were more frequently associated with being outlets for HIV information dissemination than interpersonal sources like service providers and friends. In addition, they reported that the use of multiple sources of HIV information dissemination, including mass media, could be effective in addressing stigmatising attitudes toward PLHIV and AIDS (Li et al., 2009:424). Similarly, from their study based in two districts in South Africa, Shamu, Khupakonke, Farirai, Slabbert, Chidarikire, Guloba and Nkhwashu (2020:1256) reported that using various media channels to publicise HIV prevention messages could yield good results for HIV prevention. This was supported by Jesmin, Chaudhuri and Abdullah (2013:303), in reference to their combined index from the use of television, radio and newspapers.

In this study, the use of community halls to educate and inform people about HIV and AIDS was seen by P3 to have the potential to make a difference in educating communities. She also highlighted the use of media and churches in information sharing and addressing issues of stigma. Participant 7 called for more community-based talk shows and the opening of public community spaces, including schools, for purposes of educating people about HIV and AIDS. These sentiments were also echoed by Participant 8 who further proposed the use of motivational speakers targeting age-specific audiences as well as generally creating forums that would provide the opportunity for people to '*tell their own stories*'. Participant 9 also emphasised the importance of education and open conversations about HIV and AIDS, while Participant 10 echoed the importance of teaching the various stages that one goes through when diagnosed with HIV as well as having campaigns that go beyond HIV education, including social media, in broadcasting educational messages. Participant 13 highlighted the importance of having health promoters in teaching the community about communicable and non-communicable diseases.

4.4. DISCUSSION OF RESULTS AND FINDINGS

HIV and AIDS-related stigma make young women vulnerable to HIV and AIDS by discouraging and/or preventing them from openly and freely (a) going for HIV-testing, (b) disclosing their HIV serostatus, (c) attending HIV prevention and destigmatisation programmes and (d) seeking and/or accessing HIV-related health care and treatment (Sengupta et al., 2011:2). This observation is similarly echoed by Odimegwu et al. (2017:7) who state that one of the most common ‘coping mechanisms’ is the nondisclosure of serostatus, which seriously threatens secondary prevention of HIV infections. Per the SEM, stigma initially affects the first three levels of individual, interpersonal and community (see Figure 2.1). Subsequently, stigma becomes notable at the organisational and national (policy levels). The discussion of the major findings of this study is conducted according to the six research questions that framed this study.

4.4.1. Young Women’s Perceptions of Stigma and their Vulnerability to HIV

Much of the results presented in this study concurs with the literature presented in Chapter 2. Overall, the results of this study showed that participants had experienced various types of HIV- and AIDS-related stigma, namely, experienced, perceived, internalised, symbolic and courtesy stigma. These findings agree with those reported by Chidrawi, Greeff, Temane & Doak (2016:196) who found that PLHIV (including young women living with HIV) experienced stigma on all the five subscales of stigma used in their study namely verbal abuse, negative self-perception, healthcare neglect, social isolation and fear of contagion. These subscales signified comprehensive community-based HIV stigma as well as general, symbolic and instrumental stigma. Furthermore, in agreement with the findings of this study, Pannetier et al. (2016:173) also reported from their study that the community used the words 'gossip', 'being looked down upon', 'disgust' and 'dislike' about PLHIV—just as had been reported in this study.

In their study, Takada, Takada, Weiser, Kumbakumba, Muzoora, Martin, Hunt, Haberer, Kawuma, Bangsberg and Tsai (2014:3) reported that PLHIV experienced avoidance, shunning and verbal insults from their friends and/or family. A further problem with this is that although HIV-related stigma presents a strain on current relationships, it may also limit the ability of PLHIV to seek new relationships (Takada et al., 2014: 3). This leads to isolation and other negative effects such as a sense of worthlessness, loss of income, depression, loss of reputation and dropping out of school, to name but a few. Indeed, as Odimegwu, et al. (2017:7) points out, the prevalence of depression and anxiety among HIV positive young women, associated with a negative self-image, should be a matter of great concern. Takada et al. (2014:9) reported evidence that showed that PLHIV and experienced discrimination tended to lose social support, while those who had less access to instrumental social support experienced more subsequent discrimination. Overall, the results reported in this study support these earlier findings.

4.4.2. How Stigma Impedes Young Women from Accessing HIV and Destigmatisation Programmes

The study found that despite the focus age group of this study being part of the younger generation that one would presume to have information about HIV and AIDS readily available, the participants expressed a deep fear of being discriminated against not only by their peers but also their respective communities. Some participants in this study essentially attributed the spectre of stigma to their respective community members' lack of knowledge and understanding about HIV. This finding ties into the literature discussed in Chapter 2, which pointed to a scarcity of intervention programmes that aim to educate individuals, families, communities and even healthcare professionals about different aspects of HIV-related stigma (e.g., Mathiti, 2003; Petros et al., 2006; HSRC, 2018; Ma et al., 2018; UNAIDS, 2019:6). In some cases, community members' resentment of PLHIV is reported to run palpably deep. For instance, Pannetier, Lelièvre and Le Coeur (2016) report that from their study, 14% of respondents were opposed to PLHIV attending community events or preparing meals for community members during community events.

It was found that by being HIV positive some of the participants were labelled as being sexually promiscuous, being on the verge of death, being punished for their immorality or having contracted the virus based on their sexuality. These insights resulted in delayed uptake of treatment and it is because of such hostile stigmatisation that many PLHIV avoid accessing HIV-reduction and destigmatisation programmes.

4.4.3. How Stigma Impedes Young Women from Accessing Care and Treatment

Healthcare facilities and healthcare workers have been labelled as being deterrents to accessing care and treatment. The study found that private and public institutions did not provide the same level of security and confidentiality in accessing care and treatment. In this study, it was reported that based on the current operational structures within the public sector and the lack of privacy, stigma leads to community members', including PLHIV's, unwillingness to access healthcare and treatment. Without a sense of protection from local, public healthcare facilities, participants indicated a high level of apprehension in accessing care and treatment, believing that they would be discriminated against by healthcare workers and community members. Indeed, in this study, some participants reported switching over from seeking help at public healthcare facilities to private ones where they found better reception and higher quality of health care service and treatment. Participant 5, as reported above, found a distinct difference between testing at a public clinic versus being tested at a private healthcare facility. She stated that unlike private clinics, going to the doctor or a public clinic resulted in inadequate time for counselling. So, considering that young women are still in the process of establishing their careers and some are not even employed, they become vulnerable to HIV infections when, because of stigma, they decide to stay away from public healthcare facilities. Many of them will not be able to afford seeking healthcare and treatment from private healthcare establishments—not many people can afford to make the switch from public healthcare facilities to private ones. In other instances, some participants left their areas of residence to seek health care elsewhere to increase the chances of being attended to by healthcare professionals who did not know them: '*I'd rather go to a place where I am not known*'*.* (P6).

Furthermore, HIV and AIDS-related stigmatisation perpetrated at the organisational level by healthcare workers often leads to poor healthcare processes, procedures and outcomes. As a result of suffering bad experiences at public healthcare facilities, many are discouraged and prevented from returning for further healthcare and treatment (Kharsany & Karim, 2016: 37; Bonnington et al., 2017: 2; Avert.org, 2019). Tragically, Participant 3 was discouraged from studying further for fear of finding some of the people who knew about her HIV serostatus at university. She feared that these people would spread information about her serostatus, while Participant 11 stopped attending high school altogether. Therefore, HIV-related stigma is an undeniably powerful negative force in the lives of young women. Young women's vulnerability is certainly exacerbated by decisions not to visit healthcare facilities to receive ARV drugs and routine medical check-ups, as a result of a fear of stigmatisation from healthcare workers. Associated aspects of this would be the perpetuation of the unnecessary atmosphere of secrecy and silence which is founded on prejudice and the fear of being victimised (Bond et al., 2019: 87; Horter et al. 2017: 20). When perpetuated by healthcare professionals, stigmatisation is reported to involve actions such as prohibiting YWLHIV from having children, mandatory testing for young women who are sex workers or those requiring surgery and blaming them if they are HIV positive for 'getting what they deserved' (Ekstrand et al., 2013:23).

Based on the evidence reported in this study, although healthcare facilities are vital in the reduction of the stigma associated with HIV and AIDS, unfortunately, they also seem to be serious perpetrators of attaching stigma. Accordingly, they (inadvertently or otherwise) remain a barrier to PLHIV's access to healthcare services. The sentiments expressed in this study pointed to the general perception of a community being hostile towards YWLHIV and AIDS, manifested in the stigmatisation of such people. From the results reported in this study, this perceived community stigmatising of YWLHIV undoubtedly affected and influenced the HIV-positive community regarding decisions to access healthcare services.

The various ways in which stigma acts as a barrier to accessing healthcare facilities were reported in Chapter 2 by various authors (Sengupta et al., 2011:2; UNAIDS, 2016:3; Avert.org, 2019; Odimegwu et al., 2020:3). The main difficulty lies in the reported stigma perpetuated by both the communities and personnel at healthcare facilities. It is for this reason that Avert.org (2019) avers that the level of stigma in communities and at healthcare facilities works to preserve the AIDS pandemic, together with the attendant stigma.

One important aspect of this stigma lies in PLHIV being reluctant to openly disclose their serostatus, which is a prelude to accessing help. As Takada et al. (2014:3) point out, although the disclosure of one's status is essential for receiving health care and social support, this is thwarted by the fear of discrimination. Additionally, the attendant higher levels of internalised stigma among PLHIV further make them likely to avoid disclosing their statuses and interacting with others. Unfortunately, the stigma also extends to family members and friends due to 'courtesy' stigma (Takada et al., 2014:9). As a result, some family members and friends distance themselves from the affected persons, end up abandoning the HIV-positive persons and may even discriminate against them. In this regard, the loss of social support from family members and friends becomes a terrible blow to PLHIV. As Takada et al. (2014:9) observe, the emotional support of family and friends helps PLHIV to develop a more positive sense of self, leading to less internalisation of stigma. Certainly, in the absence of such support, PLHIV remain helpless. In this study, there were reports of some hostile treatment of the participants by the community, including some family members. The study of the young lady who had to leave school because of stigma was heart-breaking.

A further unfortunate element of stigma is that as both a sociological and anthropological experience, the effects of stigma encompass the social networks of PLHIV. In turn, these social networks shape the experiences of the stigmatised individuals such that even family members of PLHIV develop a reluctance to disclose their serostatuses to others because of the fear of discrimination and diminished social standing (Takada et al., 2014:3). One reason for this is that they, themselves, may be subjected to associated stigmatisation and discrimination. Similarly, Odimegwu et al. (2017:7) report that personalised or internalised stigma is associated with a diminished social standing among PLHIV, which limits their self-esteem, confidence and adversely affects their mental health.

The responses given by participants in this study were emphatic as regards nondisclosure, resulting from the fear of community stigma, in addition to the poor and unprofessional treatment meted out to them by some healthcare workers.

4.4.4. The Nature and Types of Existing Prevention and Destigmatisation Intervention Programmes

Literature on HIV and AIDS stigma and discrimination reduction interventions shows four major strategies, namely, information-based approaches, skills building, counselling/support and contact with affected groups (Sengupta et al., 2011:8). Therefore, much of what needs to be done is to find ways of improving service delivery for these major strategies. However, despite extensive literature on the various types of existing HIV- and AIDS-related stigma prevention and destigmatisation intervention programmes, this did not appear to have filtered down to communities in the research area.

The dominant HIV prevention programmes in South Africa have mainly been focused on the surveillance of HIV prevalence and interventions measuring socio-behavioural and contextual risk factors as well as the introduction of the ART programme. It has been in the latter aspect of the intervention programmes that HIV-related stigma has mostly been touched upon, mainly through the distribution of educational materials (Zuma et al., 2016:36). The underlying strategy appears to have been that stigma would be adequately handled through media campaigns and the distribution of educational materials. Even the DREAMS programme mainly targeted the curtailment of national priorities like the prevalence and incidence of HIV, GBV prevention, post-violence care and support, promotion and provision of condom use, HCT, linkages to care and sexual reproductive health services, pre-exposure prophylaxis and comprehensive sexuality education—not stigma. The City of Johannesburg was one of the participants in the DREAMS programme but none of the participants in this study referred to it. There was, however, some reference to FBOs being involved in destigmatisation activities although it was not clear whether or not these activities took place under the aegis of the DREAMS programme or some other initiatives.

In this study, less than half of the participants reported that various intervention programmes took place in their communities. The popular events included church organised events, health jamborees and community group events. However, these were solely based on HIV and AIDS awareness and not specifically on HIV- and AIDS-related stigma. According to the participants, these interventions were not current interventions but activities that had taken place in previous years. This is in line with the views expressed by Armstrong-Mensah et al. (2019:74) in the literature review.

The paucity of destigmatisation activities in the research locale is unfortunate because the literature presented earlier in this study was replete with examples of programmes that could be put in place to fight HIV- and AIDS-related stigma. These included psycho-educational interventions, support group interventions for adherence to ART, psychotherapy interventions, narrative interventions and community participation interventions (Ma et al., 2018: 9). Other ways in which destigmatisation intervention programmes could be delivered were advanced by Allport (1954:30); Brewer and Miller (1984:281); Brown et al. (2003:50); Chibango (2013:241) and Hartoga et al. (2020:1).

It is not clear why so few destigmatisation activities had taken place in the research locale. It could have been due to the COVID-19 pandemic, HIV 'fatigue', sponsorship challenges, a combination of these factors or other unknown reasons.

4.4.5. Gaps or Shortcomings in Current Intervention Programmes

Stangl et al. (2013:1) report that although a lot of successes have been recorded in the stigma-reduction field, there is still a lot of work to be done to remove the many impediments that hinder the effective implementation of large-scale stigma-reduction strategies. Furthermore, the literature has revealed that most stigma prevention and destigmatisation interventions are incoherent, narrowly-focused and siloed; lacked effective, built-in monitoring and evaluation mechanisms; not widely known; limited to single strategies and not broad-based enough to cover whole communities; too limited in scope and avoided documenting the personal experiences of PLHIV.

This study found inconsistencies with intervention programmes targeted at HIV awareness with over half of the participants not knowing of any interventions taking place in their communities. However, a few gaps or shortcomings of interventions were noted in the programmes that were reported to have taken place. There was a general lack of awareness of campaigns, resulting in low attendance rates as well as missed opportunities for the community. It was further reported that some guest speakers had limited knowledge and non-lived experiences. Furthermore, it was felt that having health-specific topics added to the community's unwillingness to attend such programmes.

Nonetheless, despite the limited responses towards intervention programmes, the discussed shortcomings and gaps tie in with those outlined in Chapter 2, which included the conventional face-to-face group format as the most popular, for its advantage of enabling the sharing of emotions and experiences, increasing peer/social support and reducing social isolation among PLHIV (Ma et al., 2018:32). However, even if the COVID-19 pandemic might have taken away some impetus from the destigmatisation programmes by government, NGOs and other bodies, other platforms could have been utilised. Such platforms could have included the use of low-cost information technologies such as radios, print media, jingles/drama, telephones and videos to inform stigmatised populations, including those living in remote areas (Sengupta et al., 2011:3; Ma et al., 2018:33). Thus, the challenges that resulted in the lull in destigmatisation intervention programmes signify problems and gaps that have hampered the development of effective stigma-reduction measures that could have been deployed on a bigger scale.

4.4.6. Strengthen Current Stigma Prevention and Destigmatisation Programmes

A common theme in the study was centred around the use of education, indicating that education was key to strengthening stigma prevention programmes (Brown et al., 2003:50; Ma et al., 2018:32; Hartoga et al., 2020:2). The public and healthcare providers need to be educated not only on HIV and AIDS and stigma but also on the various stages that people go through once they test positive for HIV and how the former's reactions, actions and words may have a negative impact on their lives. The reason for this is that most participants believed that education is crucial to addressing stigma because of the limited knowledge and numerous misconceptions concerning HIV and AIDS within their communities.

Another recurring theme was the importance of using social media, considering the much wider reach of social media platforms. Participants contended that using applications such as *Twitter* and *WhatsApp* would provide a sense of protection for the public in allowing them to interact with HIV stigma prevention programmes. It was also suggested that in order to strengthen current programmes, healthcare providers needed sensitivity training on how to deal with HIV- and AIDS-related matters. Other suggestions included an increased inclusion of community healthcare workers (CHWs) or health promoters to educate communities on communicable diseases and non-communicable diseases (NCDs), churches being proactive in HIV and AIDS education, community-based programmes specifically aimed at the various types of stigmas related to HIV and AIDS and creating safe spaces for HIV positive individuals and family members.

These suggestions tie in with what the literature review discussed, however, they do not provide key solutions to the challenges faced by current interventions. From the literature presented in Chapter 2, authors expressed the view that current stigma prevention and destigmatisation intervention programmes could be strengthened by (a) conducting a comparative analysis of the various extant stigma-reduction strategies (Odimegwu et al., 2018:2), (b) addressing some critical challenges and gaps that have remained and continued to impede the effective implementation of appropriate strategies for stigma-reduction on a large scale (Stangl et al., 2013), (c) placing HIV-related stigma and discrimination at the centre of the HIV response, (d) strengthening the legislative and policy environment; (b) having an integrated, coherent, research-based and broad-based stigma prevention and destigmatisation programme and (c) effective monitoring and evaluation mechanisms (Chibango, 2013:242; Odimegwu et al., 2017:2) and (d) ensuring a culture of and respect for the protection of individuals' basic human rights (Odimegwu et al., 2017:1). Certainly, all these perspectives are relevant to South Africa as investigated in this study. Although the study revealed the shortage of stigma prevention and destigmatisation intervention programmes, it is advisable that when programmes are conceptualised and implemented, these suggestions are seriously considered. It will be within the letter and spirit of the findings of this study to do so.

4.5. CONCLUSION

In conclusion, this chapter provided ample biographical background on the 13 young women who participated in this study. The data analysis revealed that despite there being some programmes that address HIV in South Africa, HIV-related stigma remains a major challenge for the country. Participants in this study reported experiencing mistreatment and being negatively judged, not only by healthcare workers but also by their communities of residence. Overall, the researcher wishes to point out that despite conducting this study under difficult COVID-19 lockdown conditions, the investigation was completed successfully. Accordingly, the researcher extends her sincere thanks, appreciation and gratitude to all the participants in this study.

In the next chapter, the researcher presents a summary of the findings, proffers a conclusion, reflects on the limitations of the study and advances some recommendations for the consideration of healthcare practitioners, policymakers, government, NGOs, relevant stakeholders and researchers.

CHAPTER 5

SUMMARY, CONCLUSION, RECOMMENDATIONS AND LIMITATIONS OF THE STUDY

5.1. INTRODUCTION

This chapter presents a comprehensive summary of the study: its main objectives, conceptual framework, research methodology, important findings, limitations as well offer some recommendations. In doing so, the chapter brings the study to a close by contrasting the research objectives with the findings. The study's main research focus was whether stigma aids in the spread of HIV among young women in Johannesburg.

5.2. SUMMARY OF THE STUDY

Stigma refers to an extreme disapprobation towards someone on account of social characteristics that distinguish him or her from other members of the community (Goffman, 1963:1). It has been identified from extant literature which highlights it as an important factor that could have an effect on the spread of HIV among young women. This study set out to explore how stigma contributes to the spread of HIV among young women in the age bracket of 18 to 24 years. In this study, the researcher aimed to gain an understanding of underlying reasons why stigma appears to exacerbate the spread of HIV, to contribute to the field and provide additional insights which may, in turn, enhance the efficacy of existing preventive and destigmatisation intervention programmes.

This study adopted the social ecology model (SEM) of human development for its theoretical framework (Baral, Logie, Grosso, Wirtz & Beyer, 2013). SEM is a theoretical perspective used to understand various levels of personal and environmental factors that determine behaviour (UNICEF, 2009). It emphasises the value and importance of viewing HIV-related stigma and prejudice at a systemic level rather than just as a purely individual issue. Furthermore, SEM was found to encompass many of the concepts and principles that emerged from the literature review. Accordingly, it provided a conceptual structure to describe how the phenomenon of stigma manifests itself at the human (individual), interpersonal, institutional, cultural and policy levels (UNICEF, 2009). At a personal level, HIV-related stigma is often a reaction to social expectations that marginalise PLHIV in terms of (a) internalised stigma, making YWLHIV experience humiliation, guilt and embarrassment; (b) experiencing the fear of disclosure, making young women afraid of people finding out about their status if they saw them taking their ARVs and/or seeking care and treatment at healthcare facilities; (c) making them defer lifelong HIV identification by resisting testing, seeking care and treatment—thus disrupting the care continuum and finally; (d) experiencing low self-esteem, which typically manifests as feelings of stress and a low sense of self-worth.

At an interpersonal level, HIV-related stigma affects young women's relationships with those in their immediate environment, such as partners, friends, families and community members. This may take the form of rejection whereby those in young women's immediate environment may convey stigmatising emotions and them possibly being rejected as a result of revealing their status. At the institutional level, stigma may manifest where (a) organisational personnel are not equipped to deal with diversity; (b) organisational practices, processes and procedures do not cater for diversity and (c) organisations and entities hold negative or erroneous HIV attitudes and beliefs. At the community level, social and cultural pressures, emanating from society’s social and cultural norms as well as customs, can exacerbate HIV-related stigma profoundly—particularly with the usual emphasis on one's sexuality, gender, race, social status and culture. This is amplified by the paucity of HIV prevention programmes in public spaces like churches, schools, community organisations and businesses. At the policy level, the country’s laws and policies can contribute to HIV-related stigma.

Methodologically, the study was located within an interpretative/qualitative research paradigm to enable the researcher to collect data from participants in their natural settings by using interviews (Creswell & Poth, 2017:15). Accordingly, the researcher deemed this research paradigm to be well-suited and relevant for addressing the aim and research questions of her study which were exploratory in nature, focusing on understanding people’s beliefs, attitudes, experiences, behaviours and interactions.

The specific research design followed in this study was a case study through which the researcher sought to identify the barriers that predisposed young women to HIV and AIDS and exacerbated their vulnerability to the social stigma attendant thereto. The target population comprised young women in the age bracket of 18 to 24 years, living in the Johannesburg metropolitan area. The research sample consisted of thirteen participants of whom four were aged 24, eight were aged 23 and one was 22 years old. The rationale for using this age group was that the participants were deemed to be intellectually, emotionally and physically capable of supplying the required information about their experiences and challenges associated with HIV-related stigma; especially considering the emotional, social, self-esteem, trust and psychological impact of living with HIV (Dias et al., 2013:2).

Data were collected through interviews and conducted telephonically as preferred by candidates due to COVID-19 regulations and restrictions. Each interview was voice-recorded, then later transcribed verbatim and subsequently destroyed to preserve the confidentiality of the participants. Permission to record the interviews was obtained independently from each participant. The unit of data analysis was the individual participant, as the study aimed to document each participant’s experiences of HIV-related stigma. Construct validity was employed and determined using the conceptual framework and literature in the design of the interviews. The researcher’s supervisor was requested to cross-validate the instrument in line with the research questions to achieve both construct and content validity.

With respect to the study’s major findings, the first research question pertained to the participants’ perceptions about stigma and how this related to their vulnerability to HIV. The main result was that all the participants were familiar with the notion of stigma and felt that it was a very negative force that weighed heavily on PLHIV, including YWLHIV. As such, the participants held the view that HIV-related stigma contributed to young women’s vulnerability to HIV by, *inter alia*, discouraging and preventing them from being tested for HIV, divulging their HIV serostatus, attending HIV prevention and destigmatisation programmes and seeking and/or accessing HIV-related healthcare and treatment. All participants reported having experienced stigma in one form or another. In their experiences, the main spaces where stigma was felt were the communities in which they lived and healthcare facilities, particularly public clinics and hospitals. In a few cases, stigmatisation by family members was also experienced but stigmatising experiences within the family are generally fewer than what is experienced outside the family (Odimegwu et al. (2017:7).

With regard to accessing HIV prevention and destigmatisation intervention programmes (second research question) as well as healthcare facilities and services (third research question), the participants reported that HIV-related stigma kept many PLHIV from such programmes and services, including young women living with HIV. Overall, the participants reported many negative sentiments being expressed by community members towards them as PLHIV. Inevitably, this influenced their decisions concerning whether or not to access HIV-reduction and destigmatisation intervention programmes, as well as healthcare facilities and services.

On the nature and types of existing HIV prevention and destigmatisation intervention programmes (fourth research question), a little over half of the participants indicated that they were not aware of any such programmes taking place in their respective communities. Those who were aware of such programmes explained that the events had taken place in previous years, not currently (or even recently). Furthermore, most of such activities had been one-off events, which had included some counselling sessions at clinics and meetings at local schools. Overall, the study found that there was a paucity of HIV and AIDS prevention and destigmatisation initiatives in the communities where the participants resided.

Given that the participants had very little knowledge of any extant stigma prevention and destigmatisation intervention programmes taking place in their communities, the suggestions on how to improve such programmes (fifth research question) were, accordingly, limited. Specifically, the participants decried the short notification times about or invitations to the events as well as the apparent limited practical knowledge of the presenters. They stated that these were major limitations as regards the organisers of these activities. In the view of the participants, the issue of the presenters' lack of lived experiences (i.e., not living with HIV and/or AIDS) was a major limitation. They preferred to deal with 'experts' who were themselves living with HIV, not those who just came to theorise about it.

Concerning how the current stigma prevention and destigmatisation programmes could be strengthened (sixth research question), the participants contended that this could be done at three levels, namely family, healthcare facility (clinics and hospitals) and community. At the family level, the emphasis was on education. The participants felt that if family members better understood how the virus was transmitted, instrumental stigma would be much less and therefore, family members would care for and interact with PLHIV in a much more positive manner. At the community level, the participants stressed the issue of education and open conversations about HIV and AIDS: spaces and opportunities should be created to speak openly about HIV and AIDS on talk shows, in community halls, churches, schools, on radio stations and various types of media including social media. For healthcare practitioners, the issues of privacy and confidentiality were emphasised as being crucial to their work, for their services to be strengthened. It was pointed out that it would be very difficult, if not impossible, to encourage communities to come forward for testing while privacy and confidentiality were not guaranteed. Accordingly, healthcare workers were urged to become more friendly, professional and approachable. The participants also recommended that social workers should be made available at healthcare facilities to assist those in need of their services.

5.3. CONCLUSION

The literature pointed to the scarcity of studies that have investigated the personal lived experiences of YWLHIV as a major gap that researchers can address. The study aimed to contribute filling this gap, albeit only from the point of view of stigma. Although further studies are still needed to document the personal lived experiences of PLHIV in general and young women living with HIV, in particular, the researcher believes that this study has made an important contribution in this regard. Concerning the overall study, the researcher remains satisfied that all the research questions have been addressed adequately, notwithstanding the study being conducted under very strict COVID-19 regulations. Equally significantly, the researcher reflected on the conceptual framework adopted in this study and expressed her gratitude and appreciation that it enabled her to address all the research questions and explain the attendant findings. Certainly, the conceptual framework helped the researcher to understand the various levels of personal and environmental factors that determined the behaviours of YWLHIV, their families and community members, NGOs working in the HIV and AIDS field, other support organisations, healthcare workers and government officials at the policy level. The theoretical power of the model lay in Its depiction of *spheres of influence* over human behaviour, based on the four core principles that describe these multiple influences. This was undoubtedly an appropriate and adequate conceptual framework for this study. Therefore, the researcher remains satisfied and happy that the study achieved its objectives and was accordingly, a great success.

5.4. RECOMMENDATIONS

In view of the findings reported in this study, the researcher wishes to recommend as follows:

a) On the finding to the first research question that stigma impeded the participants' ability to access HIV prevention and destigmatisation intervention programmes: governments, healthcare workers, NGOs, communities and families must play their part to ensure that YWLHIV are treated fairly and assisted in every way possible for them to access the help they may need.

b) On the negative sentiments and discrimination meted out to young women living with HIV by community members, the researcher wishes to call upon community leaders and civil society leaders, in general, to conduct awareness programmes to educate community members about HIV and AIDS. Indeed, there is evidence from the literature that education programmes change participants' behaviour to be more caring and tolerant towards YWLHIV.

c) Concerning the paucity of HIV and AIDS prevention and destigmatisation programmes: this says a lot about those who are charged with the responsibility of promoting good health in the country, especially the Department of Health. The divisions dealing with outreach, as well as public health, need to improve on their service delivery and conduct ongoing HIV reduction and destigmatisation programmes to help communities better deal with various aspects of HIV and AIDS.

d) Regarding ways to strengthen stigma prevention and destigmatisation programmes: educational programmes must be reinforced, creative ways must be found and different media platforms must be used to capture the minds of everyone. It is not only HIV-positive individuals who should be targeted concerning information on HIV and AIDS, there should be programmes for families, communities and organisations on how they can all play a part in HIV-reduction and destigmatisation intervention programmes.

e) Given the poor and unprofessional ways in which healthcare workers in public clinics and hospitals reportedly treat PLHIV, it appears justified to recommend in-service training interventions for healthcare workers in these facilities so that they are better equipped to assist young women living with HIV much better than they currently do.

f) More research is needed on the experiences of YWLHIV and how they deal with HIV-related stigma and other related matters, as they endeavour to access healthcare services.

5.5. LIMITATIONS OF THE STUDY

It is difficult, if not impossible to carry out a study that satisfies all the elements of an ideal study. Thus, a researcher needs to do all he or she can humanly do to enhance both the internal and external validity of his or her study. In this study, the following issues may have detracted from achieving ‘the ideal study’:

a) The sampling technique used was one of the study's limitations in the sense that snowballing carries the prospect of excluding potential participants who would otherwise have been included had other approaches, such as simple random sampling, been used. The exclusion happens because the sampling technique relies on the initial participants’ social networks, therefore, those who lie outside those social circles are automatically excluded. However, given that the main object of qualitative research is to collect personal views and experiences of participants and not to generalise findings to other populations, the researcher remains satisfied that the information collected met the needs of the study.

b) Dealing with a sensitive topic such as HIV and AIDS added a further limitation to the study due to the usual constraints associated with accessing information on sensitive topics. Additionally, gaining access to the specified sample size provided further challenges as not many NGOs, healthcare facilities and other organisations in this space were willing for their clients to be part of the study.

c) It is possible that some of the questions posed to the participants made them feel uneasy, although the researcher never felt that any of the participants were holding back at any point during the interview.

d) Language barriers could also have been another limitation since all the interviews were conducted in English. Although conversation with all participants went smoothly, one cannot completely rule out the possibility that the use of English, a second language for both the interviewer and the interviewees, might have introduced some language nuancing.

e) It is also important to report that several young ladies declined to participate in the study. To the extent that they did not disclose their reasons for not wanting to be interviewed, it is difficult to know how their participation would have influenced the results of the study.

REFERENCES

Adama, M. 2019. Strategies to improve effectiveness of rehabilitation interventions for street children's social development in Kakamega central sub-county, Kenya. *Public Policy and Administration, 9*(6), 38–48. https://doi.org/10.7176/ppar/9-6-05.

Adeagbo, M.J. 2021. An 'outsider within': considering positionality and reflexivity in research on HIV-positive adolescent mothers in South Africa. Qualitative Research, 21(2), 181-194.

Adeokun, L. Okonkwo, P. and Ladipo, O. 2006. 'The stigmatization of people living with HIV and AIDS' *in AIDS in Nigeria: A Nation on the Threshold, O. Adeyi.* (ed.). Harvard University Press, Boston, Mass, USA.

Adimora-Ezeigbo, Akachi T. 2012. "Snail-Sense Feminism: Building on an Indigenous Model." Faculty of Arts Monograph Series, No. 17, 1-56.

Aggleton, P. 2000. *Comparative Analysis: Research Studies from India and Uganda.* Switzerland, Geneva: UNAIDS Best Practice Collection.

Alkali, Z. 1984. The stillborn. Harlow: Longman.

Allport, G.W. 1954. The nature of prejudice. Addison-Wesley.

Armstrong-Mensah, E. Hernandez, P. Huka, M. Suarez, A. Akosile, A. Joseph, A. and Ramsey-White, K. 2019. HIV Stigma among Women and Adolescent Girls in South Africa: Removing Barriers to Facilitate Prevention*. Madridge J AIDS. School of Public Health,* Georgia State University, Atlanta, Georgia, USA.

Arrey, AE., Bilsen, J., Lacor, P. and Deschepper, R. 2017. Perceptions of stigma and discrimination in health care settings towards sub-Saharan African migrant women living with HIV/AIDS in Belgium: a qualitative study. *Journal of biosocial science*, *49*(5), 578-596.

Audet, C. M., Burlison, J., Moon, T. D., Sidat, M., Vergara, A. E. and Vermund, S. H. 2010. Sociocultural and epidemiological aspects of HIV/AIDS in Mozambique. *BMC international health and human rights*, *10*(1), 1-10.

Avert. 2020. *HIV and AIDS in South Africa*. Available at: https://www.avert.org/professionals/hiv-around-world/sub-saharan-africa/south-africa#footnote6_1s06atz (Accessed on 02/04/2021).

Avert. 2019. *HIV and AIDS in South Africa*. Available at: https://www.avert.org/professionals/hiv-around-world/sub-saharan-africa/south-africa#footnote46_zuen30m (Accessed on 18/11/2019).

Avert. 2019. South Africa: *Women still carry burden of stigma*. Available at: http://data.unaids.org/pub/report/2002/brglobal_aids_report_en_pdf_red_en.pdf (Accessed on 15/11/2019).

Avert (2019). *HIV Stigma and Discrimination*. Available at: https://www.avert.org/professionals/hiv-social-issues/stigma-discrimination Accessed on 18 April 2020).

Baral, S. Logie, CH. Grosso, A. Wirtz, AL. and Beyer, C. 2013. Modified social ecological model: a tool to guide the assessment of the risks and risk contexts of HIV epidemics*. MBC Public Health,* 13:482.

Baškarada, S. 2014. Qualitative case study guidelines. *Qualitative case studies guidelines. The Qualitative Report*, 19(40), 1-25.

Baxter, P. and Jack, S. 2008. Qualitative Case Study Methodology: Study Design and Implementation for Novice Researchers. *The Qualitative* Report, 13(4), 544-559.

Belhadi, A., Zkik, K., Cherrafi, A. and Sha'ri, M. Y. 2019. Understanding big data analytics for manufacturing processes: insights from literature review and multiple case studies. *Computers & Industrial Engineering*, *137*, 106099.

Bicego, GT., Nkambule, R., Peterson, I., Reed, J., Donnell, D., Ginindza, H., Duong, Y., Patel, H., Bock, N., Philip, N., Mao, C. and Justman J. 2013. Recent patterns in population-based HIV prevalence in Swaziland. *PLoS One*. doi: 10.1371/journal.pone.0077101. PMID: 24143205; PMCID: PMC3797108.

Birdthistle, I., Tanton, C., Tomita, A., de Graaf, K., Schaffnit, S.B. and Tanser, F., Slaymaker, E. 2019. Recent levels and trends in HIV incidence rates among adolescent girls and young women in ten high-prevalence African countries: a systematic review and meta-analysis. *Lancet Glob Health,* 7: e1521–40.

Birbeck, G.L., Bond, V., Earnshaw, V. and El-Nasoor, M.L. 2019. Advancing health equity through crosscutting approaches to health-related stigma. *BMC Medicine*, *17*(1), 1-5.

Bologna, L., Stamidis, K. V., Paige, S., Solomon, R., Bisrat, F., Kisanga, A., Usman, S. and Arale, A. 2021. Why communities should be the focus to reduce stigma attached to COVID-19. The American Journal of Tropical Medicine and Hygiene, 104(1), 39.

Bond, V. Nomsenge, S. Mwamba, M. Ziba, D. Birch, A. Mubekapi-Musadaidzwa, C. Vanqa, N. Viljoen, L. Pliakas, T. Ayles, H. Hargreaves, J. Hoddinott, G. Stangl, A. and Seeley, J. 2019. 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, 87-99.

Brennan-Ing, M., & Emlet, C. 2020. The Impact of Intersectional Identities on Older People With HIV. *Innovation in Aging*, *4* (Supplement_1), 723-723.

Brewer, M., and Miller, N. 1984. Beyond the contact hypothesis: theoretical perspectives on desegregation. In N. Miller M.B. Brewer (Ed.), Groups in contact: The psychology of desegregation (p, Academic Press, Orlando FL: 281-302

Bronfenbrenner, U. 1979. *The ecology of human developments: Experiment by nature and design.* Cambridge, MA: Harvard University Press.

Brown, DC. BeLue, R. and Airhihenbuwa, C.O. 2012. HIV and AIDS-related stigma in the context of family support and race in South Africa. *Ethn Health*, 15(5), 441–458.

Campbell, C., Nair, Y., Maimane, S., & Nicholson, J. 2007. Dying Twice' A Multi-level Model of the Roots of AIDS Stigma in Two South African Communities. Journal of health psychology, 12(3), 403-416.

Campbell, C., Foulis, C.A., Maimane, S. and Sibiya, Z. 2005. “I have an evil child at my house”: Stigma and HIV/AIDS management in a South African community. *American Journal of Public Health*, 95(5), 808-815.

Carter, N., Bryant-Lukosius, D., DiCenso, A., Blythe, J. and Neville, A.J. 2014. The Use of Triangulation in Qualitative Research. *Oncology Nursing Forum*, 41(5), 545-547.

Centers for Disease Control and Prevention. 2011. CDC's HIV/AIDS Care and Treatment Programs in South Africa. Available at: https://www.cdc.gov/globalhealth/countries/southafrica/what/hiv_aids_treatment.htm (Accessed on 04/01/2022).

Chibango, C. 2013. South Africa’s HIV and AIDS Policy and Legislation: An Analysis. *Greener Journal of Medical Sciences*, 3 (6), 240-250, DOI: 10.15580/GJMS.2013.6.052413638.

Chidrawi, H.C., Greeff, M., Temane, Q.M. and Doak, C.M. 2016. HIV stigma experiences and stigmatisation before and after an intervention. *Health SA Ges on dheid*, 21, 196-205. http://creativecommons.org/licenses/by-nc-nd/4.0/.

Cohen, L., Manion, L. and Morrison, K. 2018. *Research method in education.* 8th edition. London/New York: Routleigh Farmer.

Copes, H., Tchoula, W., Brookman, F., and Ragland, J. 2018. Photo-Elicitation Interviews with Vulnerable Populations: Practical and Ethical Considerations, Deviant Behavior, 39:4, 475-494, DOI: 10.1080/01639625.2017.1407109

Corlett, S. and Marvin, S. 2018. Reflexivity and Researcher Positionality. In Cassell C., Cunliffe, A.L., and Grandy, G. (eds.): The Sage Handbook of Qualitative Business and Management Research Methods: History and Traditions, Los Angels, London, New Delhi and Singapore: Sage Publications Ltd.

Creswell, J.W. and Poth, C.N. 2018. *Qualitative Inquiry and Research Design: Choosing Among Five Approaches (4th ed.).* SAGE Publications Thousand Oaks • London 11 New Delhi.

Creswell, J.W. 2014. *Research design: Qualitative, Quantitative and Mixed Methods Approaches. Fourth edition*. Sage Publications, London.

Creswell, J.W. 2013. Research design: Qualitative, quantitative, and mixed methods approaches: *Sage* publications.

Cushnie, A., Reintjes, R., Lehtinen-Jacks, S. and Figueroa, J. P. 2021. HIV program outcomes for Jamaica before and after "Treat All": A population-based study using the national treatment services database. *PloS one*, *16*(8), 1-12.

Deacon, H., and Boulle, A. 2007. Commentary: Factors affecting HIV/AIDS-related stigma and discrimination by medical professionals. *Int J Epidemiol,* 36(1):185-6. doi: 10.1093/ije/dyl255.

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

Dempsey, L., Dowling, M., Larkin, P., & Murphy, K. 2016. Sensitive interviewing in qualitative research. Research in nursing & health, 39(6), 480-490.

Denzin, N. K. and Lincoln, Y. S. 2011; 2018. *The Handbook of Qualitative Research*. London: Sage Publications, Inc.

Denzin, N.K. 1978. *Sociological methods: A sourcebook.* New York, NY: McGraw-Hill.

De Walque, D. 2007. How does the impact of an HIV/AIDS information campaign vary with educational attainment? Evidence from rural Uganda. *Journal of Development Economics*, *84*(2), 686-714.

Dhatt, R., Theobald, S., Buzuzi, S., Ros, B., Vong, S., Muraya, K., Molyneux, S., Hawkins, K., González-Beiras, C., Ronsin, K., Lichtenstein, D., Wilkins, K., Thompson, K., Davis, K. and Jackson, C. 2017. The role of women's leadership and gender equity in leadership and health system strengthening. *Global Health, Epidemiology and Genomics*, *2*, 1-9.

Dias, A.A.L., de Oliveira, D.M.F., Turato, E.R., Turato, E.R. and de Figueiredo, R.M. 2013. Life experiences of patients who have completed tuberculosis treatment: a qualitative investigation in South-East Brazil. *BMC Public Health*, 13, 595: 1-9. doi:10.1186/1471-2458-13-595.

Dorward, J., Khubone, T., Gate, K., Ngobese, H., Sookrajh, Y., Mkhize, S., Jeewa, A., Bottomley, C., Lewis, L., Baisley, K., Butler, C., Gxagxisa, N. and Garret, N. 2020. The impact of the COVID-19 lockdown on HIV care in 65 South African primary care clinics: an interrupted time series analysis*. Lancet HIV* 2021; 8, e158–65.

Dragan, I. M. and Isaic-Maniu, A. 2013. Snowball sampling completion. *Journal of Studies in Social Sciences*, *5*(2), 160-177.

Du, X., Zhang, L., Luo, H., Rong, W., Meng, X., Yu, H. and Tan, X. 2021. Factors associated with risk sexual behaviours of HIV/STDs infection among university students in Henan, China: a cross-sectional study. *Reproductive Health*, *18*(1), 1-11.

Earnshaw, V., Bogart, L., Laurenceau, JP., Chan, B., Maughan-Brown, B., Dietrich, J., Courtney, I., Tshabalala, G., Orrell, C., Gray, G., Bangsberg, D. and Katz, I. 2018. Internalized HIV stigma, ART initiation and HIV-1 RNA suppression in South Africa: exploring avoidant coping as a longitudinal mediator. *Journal of the International AIDS Society*, 21(10), e25198. DOI: 10.1002/jia2.25198/full.

Earnshaw, V., Smith, L., Chaudoir, S., Amico, K. and Copenhaver, M. 2013. HIV stigma mechanisms and well-being among PLWH: a test of the HIV stigma framework. *AIDS Behaviour*, 17(5),1785-95.

Earnshaw, V. A., Bogart, L. M., Dovidio, J. F. and Williams, D. R. 2013. Stigma and racial/ethnic HIV disparities: Moving toward resilience. *American Psychologist*, 68, 225-236.

Ehrenkranz, P., Grimsrud, A., Holmes, C. B., Preko, P. and Rabkin, M. 2021. Expanding the vision for differentiated service delivery: a call for more inclusive and truly patient-centered care for people living with HIV. *Journal of Acquired Immune Deficiency Syndromes (1999)*, *86*(2), 147-152.

Ekstrand, ML., Ramakrishna, J., Bharat S. and Heylen, E. 2013. Prevalence and drivers of HIV stigma among health providers in urban India: implications for interventions. *Journal of the International AIDS Society*, 16(Suppl 2):18717.

Emecheta, Buchi. 1979. The Joys of Motherhood. New Hampshire: Heinemann.

Etikan, I., Alkassim, R. and Abubakar, S. 2015. Comparison of Snowball Sampling and Sequential Sampling Technique. *Biom Biostat Int J*, 3(1): 55. DOI: 10.15406/bbij.2015.03.00055.

Famoti, T. Fernandes, L. and Chima, S. 2013. 'Stigmatization of people living with HIV and AIDS by healthcare workers at a tertiary hospital in KwaZulu-Natal, South Africa: a cross-sectional descriptive study.' 3rd Ethics, Human Rights and Medical Law Conference, Africa Health Congress

Ferreira, R.J., Buttell, F. and Ferreira, S.B. 2015. Ethical Considerations for Conducting Disaster Research with Vulnerable Populations**.** *Journal of Social Work Values and Ethics*, 12(1): 29-40.

Finigan-Carr, N.M., Johnson, M.H., Pullmann, M.D., Stewart, C. J., and Fromknecht, A.E. 2019. A traumagenic social ecological framework for understanding and intervening with sex trafficked children and youth. *Child and adolescent social work journal*, 36(1), 49-63.

Florom-Smith, A.L**.** and De Santis, J.P. 2012. Exploring the Concept of HIV-Related Stigma *Nurs Forum*, 47(3): 153–165.

Forsyth, B., Vandormael, A., Kershaw, T. and Grobbelaar, J. 2008. The political context of AIDS-related stigma and knowledge in a South African township community. *SAHARA-J: Journal of Social Aspects of HIV and AIDS*, 5(2), 74–82. doi:10.1080/17290376.2008.9724904.

French, H., Greeff, M., Watson, M. J. and Doak, C. M. 2015. A comprehensive HIV stigma-reduction and wellness-enhancement community intervention: A case study. *Journal of the Association of Nurses in AIDS Care*, *26*(1), 81-96.

Fund, G. 2020. 'Prospective Country Evaluation. Guatemala: 2019–2020 Annual Country Report', Commissioned by the Technical Evaluation Reference Group (TERG) of the Global Fund.

Garuba, I. O. 2021. African feminism in the Nigerian context: A house of affirmations and denials. Critical Literary Studies, 3(1), 105-123.

Gatwiri, G. J., and McLaren, H. J. 2016. Discovering my own African feminism: Embarking on a journey to explore Kenyan women's oppression. Journal of International Women's Studies, 17(4), 263-273.

Gayle, H. and Hill, G. 2001. Global Impact of Human Immunodeficiency Virus and AIDS. *Clinical Microbiology Reviews*, 14(2), 327-35. doi:10.1128/CMR.14.2.327-335.2001.

Gazimbi, M. Magadi, M. Onyango-Ouma, W. Walker, E. Cresswell, R. Kaseje, M. and Wafula, C. 2020. Is polygyny a risk factor in the transmission of HIV in sub- Sahara Africa? A systematic review. *African Journal of Reproductive Health December*, 24(4):198.

Goffman, E. 1963. *Stigma*. London: Penguin. Available at: https://www.freelists.org/archives/sig-dsu/11-2012/pdfKhTzvDIi8n.pdf. (Accessed on 20/08/2020).

Goredema, R. 2010. African feminism: the African woman's struggle for identity. *African Yearbook of Rhetoric*, *1*(1), 33-41.

Green, B. 2012. Applying feminist ethics of care to nursing practice. *Journal of Nursing & Care*, *1*(03), 1-4.

Grix, J. 2019. *The Foundations of Research,* Macmillan International.

Gruszczyńska, E. and Rzeszutek, M. 2019. Trajectories of health-related quality of life and perceived social support among people living with HIV undergoing antiretroviral treatment: does gender matter? *Frontiers in psychology*, *10*, 1664.

Grut, L., Mji, G., Braathen, S.H. and Ingstad, B. 2012. Accessing community health services: Challenges faced by poor people with disabilities in a rural community. *South African Journal of Disability*, 1(1), Art. #19, 7 pages.

Gustafsson, J. 2017. 'Single case studies vs. multiple case studies: A comparative study.' Academy of Business, Engineering and Science, Halmstad University, Halmstad, Sweden, pp. 1-15.

Haffejee, F. Maughan-Brown, B. Buthelezi, T. and Kharsany, A. 2018. Perceived HIV-related stigma among university students in South Africa: implications for HIV testing. *African Journal of AIDS Research*, *17*(2), 109-118. DOI: 10.2989/16085906.2018.1439512.

Hall, A., Joseph, O., Devlin, S., Kerman, J., Schmitt, J., Ridgway, J. P., and McNulty, M. C. 2021. That same stigma... that same hatred and negativity: a qualitative study to understand stigma and medical mistrust experienced by people living with HIV diagnosed with COVID-19. *BMC infectious diseases*, *21*(1), 1-8.

Halkias, D. and Neubert, M. 2020. Extension of Theory in Leadership and Management Studies Using the Multiple-Case Study Design. *International Leadership Journal*,12(2), 48-73.

Hansoti, B., Hill, S.E., Whalen, M., Stead, D., Parrich, A., Rothman, R., Hsieh, Y.H. and Quinn, T.C. 2017. Patient and provider attitudes to emergency department-based HIV counselling and testing in South Africa. *Southern African Journal of HIV Medicine*, 18(1), 1-7).

Harper, G. Lemos, D. and Hosek, S. and the Adolescent Medicine Trials Network for HIV and AIDS Interventions. 2014. Stigma Reduction in Adolescents and Young Adults Newly Diagnosed with HIV: Findings from the Project ACCEPT Intervention. *AIDS Patient Care and STDs*, 28:10.

Harrison, K. and Boyd, T. 2019. *Understanding political ideas and movements*: *Feminism*. Manchester University Press.10.7765/9781526137951.00019

Harrison, H., Birks, M., Franklin, R. and Mills, J. 2017. Case study research: Foundations and methodological orientations. *Forum: Qualitative Social Research,* 18(1), 1-17.

Harrison A, Colvin CJ, Kuo C, Swartz A, Lurie M. 2015. Sustained High HIV Incidence in Young Women in Southern Africa: Social, Behavioral, and Structural Factors and Emerging Intervention Approaches. *Curr HIV/AIDS Rep*., 12(2): 207-15. doi: 10.1007/s11904-015-0261-0. PMID: 25855338; PMCID: PMC4430426.

Haynes, K. 2012. Reflexivity in qualitative research. In G. Symon and C. Cassell (eds.), Qualitative Organizational Research: Core Methods and Current Challenges. London: Sage., 72-89.

Herek, G. Mitnick, L. Burris, S. Chesney, M. Devine, P. Fullilove, M. Fullilove, R. Gunther, H. Levi, J. Michaels, S. Novick, A. John Pryor, J. and Snyder, M. 1998. 'AIDS and Stigma: A Conceptual Framework and Research Agenda Final Report.' A Research Workshop Sponsored by the National Institute of Mental Health.

Hewson, C. 2017. *The Sage Handbook of Online Research Methods* (2nd Ed.): *Research design and tools for internet research*. 2nd edition, Sage Editors: Fielding N.G. (ed.), Lee R.M., Blank G (ed.)

Hewson, C., Vogel, C. and Laurent, D. 2016. *Internet Research Methods* (2nd ed.). London: Sage.

Holmes, A.G.D. 2020. Researcher Positionality – A Consideration of Its Influence and Place in Qualitative Research – A New Researcher Guide. *Shanlax International*

Journal of Education, 8(4), 1-10.

Horter, S., Thabede, Z., Dlamini, V., Bernays, S., Stringer, B., Mazibuko, S., Dube, L., Rusch, B. and Jobanputra, K. 2017. Life is so easy on ART, once you accept it: acceptance, denial and linkage to HIV care in Shiselweni, Swaziland. *Soc. Sci. Med*, 176, 52–59.

Huang, Y. L., Yates, P., Thorberg, F. A. and Wu, C. J. J. 2020. Application of social ecological model to Taiwanese end-of-life communication and healthcare planning. *Collegian*, *27*(5), 477-486.

Idele, P., Gillespie, A., Porth, T., Suzuki, C., Mahy, M., Kasedde, S., and Chewe Luo, C. 2014. Epidemiology of HIV and AIDS Among Adolescents: Current Status, Inequities, and Data Gaps. *J Acquir Immune Defic Syndr*, 66(2): S144–S153.

Ikeda, D. J., Nyblade, L., Srithanaviboonchai, K., and Agins, B. D. 2019. A quality improvement approach to the reduction of HIV-related stigma and discrimination in healthcare settings. *BMJ Global Health*, *4*(3), e001587.

Inungu, J. and Karl, S. 2006. Understanding the scourge of HIV/AIDS in sub-Saharan Africa. *Journal of the International AIDS Society*, DOI:10.1186/1758-2652-8-4-30.

Islam, A., Pakrashi, D., Vlassopoulos, M., Wang, L.C. 2021. Stigma and misconceptions in the time of the COVID-19 pandemic: A field experiment in India. *Social Science & Medicine*, 278, 1-9.

Jacobi, C. A., Atanga, P. N., Bin, L. K., Fru, A. J. C., Eppel, G., Mbome, V. N., Etonde, H.E.M., Bogner, J.R. and Malfertheiner, P. 2020. "My Friend with HIV Remains a Friend": HIV/AIDS Stigma Reduction through Education in Secondary Schools – A Pilot Project in Buea, Cameroon. *Journal of the International Association of Providers of AIDS Care (JIAPAC)*, *19*, 2325958219900713.

Jesmin, S. S., Chaudhuri, S. and Abdullah, S. 2013. Educating women for HIV prevention: Does exposure to mass media make them more knowledgeable? *Health care for women international*, *34*(3-4), 303-331.

Joinson, A. and Paine, C.B. 2007. Self-disclosure, privacy and the internet. The Oxford handbook of internet psychology 2374252.

Johnson, R.B., Onwuegbuzie, A.J. and Turner, L. 2007. Toward a Definition of Mixed Methods Research. *Journal of Mixed Methods Research*, 1(2), 112-133

Johnson, R.B. and Onwuegbuzie, A.J. 2004. Mixed Methods Research: A Research Paradigm Whose Time Has Come. *Educational Researcher*, 33(7), 14–26. doi:10.3102/0013189x033007014.

Kabiri, M., Akuffo, K.O., Nortey, P., Eusebi, P. and Danso-Appiah, A. 2021. 'Uptake of HIV Testing and Counselling among the Youth in Kintampo South District, Ghana.' University of Ghana School of Public Health, 1-20. https://orcid.org/0000-0003-1747-0060.

Kaiser Family Foundation. 2021. The Global HIV/AIDS Epidemic. Available at: https://www.kff.org/global-health-policy/fact-sheet/the-global-hivaids-epidemic/#footnote-513952-10. (Accessed on 1 April 2021).

Kakuma, R., Kleintjes, S., Lund, C., Drew, N., Green, A., & Flisher, A. J. 2010. Mental health stigma: what is being done to raise awareness and reduce stigma in South Africa?. *African Journal of Psychiatry*, *13*(2).

Kambarami, M. 2006. 'Femininity, sexuality and culture: patriarchy and female subordination in Zimbabwe.' Master’s thesis, University of Fort Hare, Alice.

Karim, S.S.A. 2011. Stigma impedes AIDS prevention. *Nature*, 474, 29-31.

Keller, J., and Kittay, E. F. 2017. Feminist ethics of care. In *The Routledge Companion to Feminist Philosophy*, Routledge, 540 - 555.

Kharsany, A.B.M. and Karim, Q.A. 2016. HIV Infection and AIDS in Sub-Saharan Africa: Current Status, Challenges and Opportunities. *The Open AIDS Journal*, 2016, 10, 34-48.

Khatri, K. 2020. Research Paradigm: A Philosophy of Educational Research. *International Journal of English Literature and Social Sciences*, 5(5), 1435-1440.

Kimera, E., Vindevogel, S., Reynaert, D., Justice, K. M., Rubaihayo, J., De Maeyer, J., Engelen, A-M., Musanje, K., and Bilsen, J. 2020. Experiences and effects of HIV-related stigma among youth living with HIV/AIDS in Western Uganda: A photovoice study. *PLoS One*, *15*(4), e0232359.

Kitahata, M. Tegger, M. Wagner, E. and Holmes, K. 2002. Comprehensive health care for people infected with HIV in developing countries. *BMJ,* 325(7370), 954-957.

Klaas, N., Thupayagale-Tshweneagae, G. and Makua, T. 2018. The role of gender in the spread of HIV and AIDS among farmworkers in South Africa. *Afr J Prim Health Care Fam Med*, 10(1): 1668.

Koech, E., Teasdale, C.A., Wang, C., Fayorsey, R., Alwar, T., Mukui, I.N., Hawken, M., and Abram, E.J. 2014. Characteristics and outcomes of HIV-infected youth and young adolescents enrolled in HIV care in Kenya. *AIDS*, 28(18): 2729–2738. doi:10.1097/QAD.0000000000000473.

Koodibetse, K.G. 2015. HIV and AIDS stigma and discrimination in South Africa - still a problem. *South African Medical Journal*,105(8):703. DOI:10.7196/SAMJnew.7811.

Langstrand and Drotz 2016. Total Quality Management & business Excellence. *Total quality management and business excellence* (Online), 1-19. http://dx.doi.org/DOI:10.1080/14783363.2015.1004307.

Leburu, G. and Phetlho-Thekisho, N. 2015. Reviewing gender-based violence against women and HIV and AIDS as intersecting issues. *Social Work*, *51*(3), 399-420. http://socialwork.journals.ac.za/pub doi:http://dx.doi.org/51-1-455

Leung, K. 2015. Validity, reliability, and generalizability in qualitative research. *J Family Med Prim Care*, Jul-Sep; 4(3): 324–327. Doi: 10.4103/2249-4863.161306.

Li, L., Rotheram-Borus, M.J., Lu, Y., Wu, Z., Lin, C., Guan. J. 2009. Mass media and HIV/AIDS in China. *J Health Commun*, 14(5):424-38. doi: 10.1080/10810730903032994. PMID: 19657923; PMCID: PMC2743950.

Lincoln, Y. S., Lynham, S. A. and Guba, E. G. 2018. Paradigmatic Controversies, Contradictions, and Emerging Confluences Revisited. In N. K. Denzin and Y. S. Lincoln (Eds.), *The Sage handbook of Qualitative Research, Thousand* Oaks, CA: Sage Publications, *(5): 108-150.*

Lounsbury, D. W. and Mitchell, S. G. 2009. Introduction to special issue on social ecological approaches to community health research and action. *American journal of community psychology*, *44*(3), 213-220.

Ma, P. Chan, Z. and Loke, A. 2018. Self-Stigma Reduction Interventions for People Living with HIV/AIDS and Their Families: A Systematic Review. *AIDS and Behavior*, *23*(3), 707-741. https://doi.org/10.1007/s10461-018-2304-1.

MacPhail, C., and Campbell, C. 2001. 'I think condoms are good but, aai, I hate those things': condom use among adolescents and young people in a Southern African township. *Social science & medicine*, *52*(11), 1613-1627.

Mahajan, A.P., Sayles, J.N., Patel, V.A., Remien, R.H., Ortiz, D., Szekeres, G. and Coates, T.J. 2008. Stigma in the HIV and AIDS epidemic: A review of the literature and recommendations for the way forward. *AIDS*, 22 (Suppl 2): S67–S79. doi:10.1097/01.aids.0000327438.13291.62.

Makoae, L.N., Seboni, N.M., Molosiwa, K., Moleko, M., Human, S., Sukati, N.A. and Holzemer, W.L. 2005. The Symptom Experience of People Living with HIV and AIDS in Southern Africa. *Journal of the Association of Nurses in AIDS Care,* 16(3):22–32.

Mall, S., Middelkoop, K., Mark, D., Wood, R. and Bekker, L. 2013. Changing patterns in HIV and AIDS stigma and uptake of voluntary counselling and testing services: The results of two consecutive community surveys conducted in the Western Cape, South Africa. *AIDS Care*, 25(2), 194-201. doi:10.1080/09540121.2012.689810.

Mandiwa, C., Namondwe, B. and Munthali, M. 2021. Prevalence and correlates of comprehensive HIV/AIDS knowledge among adolescent girls and young women aged 15-24 years in Malawi: evidence from the 2015-16 Malawi demographic and health survey. *BMC Public Health*. 2021 Aug 4;21(1):1508. doi: 10.1186/s12889-021-11564-4. PMID: 34348679; PMCID: PMC8335881.

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

McMillan, J. H. and Schumacher, S. 2001. *Research in education: A conceptual introduction*. New York: Longman

Mekgwe, P. 2008. Theorizing African feminism (s). *African feminisms*, *11*.

Merriam, S.B. and Tisdell, E.J. 2016. *Qualitative Research: A Guide to Design and Implementation*. Jossey-Bass, John Wiley & Sons, Inc.

Merriam, S.B. 2009. *Qualitative Research: A guide to Design and Implementation*. San Francisco, CA: Jossey-Bass.

Merriam-Webster Dictionary. Available at: https://www.merriam-webster.com/dictionary/destigmatize. (Accessed on 21 April 2020).

Merson, M. H., O'Malley, J., Serwadda, D. and Apisuk, C. 2008. The history and challenge of HIV prevention. *The Lancet*, *372*(9637), 475-488.

Miller, C.L., Nkala, B., Closson, K., Chia, J., Cui, Z., Palmer, A., Hogg, R., Kaida, A., Gray, G. and Dietrich, J. 2017. The Botsha Bophelo Adolescent Health Study: A profile of adolescents in Soweto, South Africa. *Southern African Journal of HIV Medicine*, 18(1): 1-10.

Mitchell, E. and Bennett, L. R. 2020. Young women’s perceptions and experiences of sexual risk in Suva, Fiji. *Culture, health & sexuality*, *22*(5), 504-519.

Muula, A.S. 2008. HIV Infection and AIDS Among Young Women in South Africa. *Croatia Medical Journal*, 49: 423-435. doi:10.3325/cmj.2008.3.423.

Mwamwenda, T.S. 2014. Education level and HIV/AIDS knowledge in Kenya. *Journal of AIDS and HIV Research*, 6(2), pp. 28-32.

Naicker, N., Kharsany, A.B.M., Werner, L., van Loggerenberg, F., Mlisana, K., Garrett, N. and Karim, S.S.A. 2015. Risk factors for HIV acquisition in high risk women in a generalised epidemic setting. *AIDS Behav*, 19(7): 1305–1316. doi:10.1007/s10461-015-1002-5.

Nnaemeka, O. 2005. *Nego-feminism: Theorising, Practicing and Pruning Africa's Way*. *Signs: Journal of Women in Culture and Society*, 29(2), 357-385.

Noble, H. and Smith, J. 2015. Issues of Validity and Reliability in Qualitative Research*. Evidence-Based Nursing*, 18(2):34-35.

Ntshiqa, T., Musekiwa, A., Mlotshwa, M., Mangold, K., Reddy, C. and Williams, S. 2018. Predictors of male condom use among sexually active heterosexual young women in South Africa, 2012. *BMC Public Health* (2018) 18:1137.

Nwapa, F. 2010. *Women and Creative Writing in Africa. Landmark and New Essays in Literary & Linguistic Theories and Analysis*, F. B. O. Akporobaro, M. E. Sotunsa & S. Iguanre, Princeton (eds.), 357-374.

Nyambe, A., Van Hal, G. and Kampen, J. K. 2016. Screening and vaccination as determined by the Social Ecological Model and the Theory of Triadic Influence: a systematic review. *BMC public health*, *16*(1), 1-15.

Nyirenda, L., Kumar, M. B., Theobald, S., Sarker, M., Simwinga, M., Kumwenda, M., Johnson, C., Hatzold, K., Corbett, E.L., Sibanda, E., and Taegtmeyer, M. 2020. Using research networks to generate trustworthy qualitative public health research findings from multiple contexts. *BMC medical research methodology*, *20*(1), 1-10.

Odimegwu, C., Adedini, S.A. and Ononokpono, D.N. 2013. HIV and AIDS stigma and utilization of voluntary counselling and testing in Nigeria, *BMC Public Health*, 13(1), article 465.

Ogundipe-Leslie, M. 1994. Re-creating Ourselves: African Women and Critical Transformations. Trenton: Africa World Press.

Okoror, T.A., BeLue, R., Zungu, N., Adam, A.M. and Airhihenbuwa, C.O. 2014. HIV Positive Women's Perceptions of Stigma in Health Care Settings in Western Cape, South Africa. *Health Care for Women International*, 35(1), 27-49. DOI: 10.1080/07399332.2012.736566.

Ongowo, E. O., Ngetich, K. and Murenga, H. 2021. A false start: Children of the Street's journey into the Charitable Children Institutions and its policy implications. *Social Sciences & Humanities Open*, *4*(1), 1-10.

Owolabi, R.S., Araoye, M. O., Osagbemi, G.K., Odeigah, L., Ogundiran, A. and Hussain, N. A. 2012. Assessment of stigma and discrimination experienced by people living with HIV and AIDS receiving care/treatment in University of Ilorin Teaching Hospital (UITH), Ilorin, Nigeria. *Journal of the International Association of Physicians in AIDS Care*, 11(2), 121–127.

Pannetier, J., Lelièvre, E. and Le Coeur, S. 2016. HIV-related stigma experiences: Understanding gender disparities in Thailand. *AIDS Care*, 28(2), 170–178.

Parker, C., Scott, S. and Geddes, A. 2019. *Snowball Sampling*. SAGE Research Methods Foundations. doi:10.4135/.

Parker, R. and Aggleton, P. 2003. HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. Soc Sci Med. 2003 Jul;57(1):13-24. doi: 10.1016/s0277-9536(02)00304-0. PMID: 12753813.

Parlindungan, P. 2018. Identifying and Formulating the Research Problem. Available at: https://www.researchgate.net/publication/329179630_Identifying_and_Formulating_the_Research_Problem (Accessed on 25/12/2019).

Parton, N. 2003. Rethinking professional practice: The contributions of social constructionism and the feminist 'ethics of care'. *British journal of social work*, *33*(1), 1-16.

Patton, M.Q. 1999. Enhancing the quality and credibility of qualitative analysis. *Health Sciences Research, 34,* 1189–1208.

Peltzer, K., Parker, W., Mabaso, M., Makonko, E., Zuma, K. and Ramlagan, K. 2012. Impact of National HIV and AIDS Communication Campaigns in South Africa to Reduce HIV Risk Behaviour. *The Scientific World Journal*, 2012, 1-7.

Pettifor, A.E., MacPhail, C., Bertozzi, S. and Rees, H.V. 2007. Challenge of evaluating a national HIV prevention programme: the case of LoveLife, South Africa. *Sex Transm Infect*, 83, Supplement 1: 170-4. Medline: 17327261 doi:10.1136/sti.2006.023689.

Peltzer, K. and Pengpid, S. 2019. 'Prevalence And Associated Factors Of Enacted, Internalized And Anticipated Stigma Among People Living With HIV In South Africa: Results Of The First National Survey.' HIV AIDS (Auckl). 2019; 11: 275–285.

Piot, P., Karim, S. S., Hecht, R., Legido-Quigley, H., Buse, K., Stover, J., Resch, S., Ryckman, T., Møgedal, S., Dybul, M., Goosby, E., Watts, C., Kilonzo, N., McManus, J., and Sidibé, M. 2015. *Defeating AIDS—advancing global health. The Lancet, 386(9989), 171–218.* doi:10.1016/s0140-6736(15)60658-4.

Polit, D.F. and Beck, C.T. 2012. Nursing Research: Generating and Assessing for Nursing Practice. Philadelphia, PA: Lippincott Williams and Wilkins. *Research in Nursing & Health,* 29(5), 489-497.

Quinn, C.R. 2015. General considerations for research with vulnerable populations: Ten lessons for success. *Health and Justice*, 3:1-7. DOI 10.1186/s40352-014-0013-z.

Relf, M.V., Holzemer, W.L., Holt, L., Nyblade, L. and Caiola, C.E. 2021. A Review of the State of the Science of HIV and Stigma: Context, Conceptualization, Measurement, Interventions, Gaps, and Future Priorities. *The Journal of the Association of Nurses in AIDS Care*, *32*(3), 392-407.

Rao, D., Feldman, B. J., Fredericksen, R. J., Crane, P. K., Simoni, J. M., Kitahata, M. M. and Crane, H. M. 2012. A structural equation model of HIV-related stigma, depressive symptoms, and medication adherence. *AIDS and Behavior*, 16(3), 711–716. https://doi.org/10.1007/s10461-011-9915-0

Rothwell, H., Shepherd, M., Murphy, S., Burgess, S., Townsend, N. and Pimm, C. 2010. Implementing a social-ecological model of health in Wales. *Health Education*, 110(6), 471-489.

Rousseau, E., Katz AWK, O'Rourke S, Bekker LG, Delany-Moretlwe S, Bukusi, E., Travill, D., Omollo, V, Morton, J, O'Malley, G., Haberer, J., Heffron, R., Johnson, R., Celum, C., Baeten, J. and Van der Straten, A. 2021. Adolescent girls and young women's PrEP-user journey during an implementation science study in South Africa and Kenya. *PLOS ONE* 16(10): e0258542. https://doi.org/10.1371/journal.pone.0258542.

Rowe, S., Baldry, E., and Earles, W. 2015. Decolonising Social Work Research: Learning from Critical Indigenous Approaches, *Australian Social Work*, 68:3, 296-308, DOI: 10.1080/0312407X.2015.1024264

Savin-Baden, M. and Major, C. (2013). *Qualitative research: The essential guide to theory and practice*, London: Routledge.

South African National AIDS Council (SANAC), 2017. *Let Our Actions Count: South Africa's National Strategic Plan On HIV, TB and STIs 2017-2022*, Hatfield Gardens, 333 Grosvenor Street, Hatfield, Pretoria 0028

Scheibe, A., Van der Merwe, L. L. A., Cloete, A. and Grasso, M. A. 2018. Transgender women outreach workers and their role in South Africa's HIV response. *South African Health Review*, *2018*(1), 69-76.

Schwandt, T. 2000. 'Three Epistemological Stances for Qualitative Inquiry. Interpretivism, Hermeneutics and Social Constructionism' in Denzin, N.K and Lincoln, Y.S (eds), *Handbook of Qualitative Research* (2nd ed.), London: Sage: 189-213.

Segala, F. V., Micheli, G., Seguiti, C., Pierantozzi, A., Lukwiya, R., Odong, B., Aloi, F., Ochola, E., Cauda, R., De Gaetano-Donati, K. and Cingolani, A. 2021. Prevalence of sexually transmitted infections and factors associated with HIV status among vulnerable women in Northern Uganda: baseline results from Pe Atye Kena cohort study. *Mediterranean Journal of Hematology and Infectious Diseases*, *13*(1).

Shamu, S., Khupakonke, S., Farirai, T. Slabbert, J., Chidarikire, T., Guloba, G. and Nkhwashu, N. 2020. Knowledge, attitudes and practices of young adults towards HIV prevention: an analysis of baseline data from a community-based HIV prevention intervention study in two high HIV burden districts, South Africa. *BMC Public Health* **20,** 1249-1258. https://doi.org/10.1186/s12889-020-09356-3.

Shisana, O., Rehle, T., Simbayi, L.C., Zuma, K., Jooste, S., Zungu, N., Labadarios, D. and Onoya, D. 2014. *South African national HIV prevalence, incidence and behaviour survey*, Cape Town, South Africa: HSRC Press (2014).

Simbayi, L. C., Kalichman, S. C., Jooste, S., Cherry, C., Mfecane, S., and Cain, D. 2005. Risk factors for HIV-AIDS among youth in Cape Town, South Africa. *AIDS and Behavior*, *9*(1), 53-61.

Simelela, N. P. and Venter, W. D. F. 2014. A brief history of South Africa's response to AIDS: history of HIV in SA-Progress towards the Millennium Development Goals. *South African medical journal*, *104*(3), 249-251.

Spotlight. 2019. Graphs that tell the story of HIV in South Africa’s provinces. Available at: https://www.spotlightnsp.co.za/2019/08/05/graphs-that-tell-the-story-of-hiv-in-south-africas-provinces/ (Accessed on 20/04.2021).

Stangl, A.L., Earnshaw, V.A., Logie, C.H., van Brakel, W., Simbayi, L.C., Barré, I. and Dovidio, J.F. 2019. The Health Stigma and Discrimination Framework: a global, crosscutting framework to inform research, intervention development, and policy on health-related stigmas. *BMC Medicine*, *17*(1), 1-13.

Statistics South Africa. 2021. Mid-year population estimates 2020. Pretoria. Available at: http://www.statssa.gov.za/publications/P0302/P03022021.pdf. (Accessed on 18/01/2021).

Statistics South Africa. 2004. *Census 2001: Primary tables South Africa. Census ’96 and 2001 compared*, Statistics South Africa, Pretoria, South Africa.

Stein, J. 2003. HIV/AIDS Stigma*:* 'The Latest Dirty Secret.' CSSR Working Paper No. 46. Published. Centre for Social Science Research, University of Cape Town.

Stellenbosch University. Determining-the-Level-of-Risk. Available at: https://www.eng.sun.ac.za/media/sites/7/Determining-the-Level-of-Risk.pdf. (Accessed on 07/01/2022).

Takada, S., Weiser, S.D., Kumbakumba, E., Muzoora, C., Martin, J.N., Hunt, P.W., Haberer, J.E., Kawuma, A., Bangsberg, D.R. and Tsai, A.C. 2014. The Dynamic Relationship Between Social Support and HIV-Related Stigma in Rural Uganda. *Ann Behav Med*., 48(1), 26–37.

Tarkang, E., Pencille, L. and Komesour, J. 2018. The Ubuntu concept, sexual behaviours and stigmatisation of persons living with HIV in Africa: A review article. *J Public Health Afr*. 2018 Oct 1; 9(2): 677. Published online 2018 Oct 10. doi: 10.4081/jphia.2018.677.

Taylor, C. 2005. Levinasian ethics and feminist ethics of care. *Symposium*, 9(2), 217-239.

Temin, M., Milford, C., Beksinska, M., Van Zyl, D. and Cockburn, J. 2021. Inclusive HIV Prevention in South Africa: Reaching Foreign Migrant Adolescent Girls. *Frontiers in Reproductive Health*, *3:629246. doi: 10.3389/frph.2021.629246*www.frontiersin.org.

Teterina, O. 2020. 'Punishment for your sins, the patient as a tourist attraction and exceptionally lower-class issue. HIV-associated stigma perceptions and experiences in Georgia'. (Master's thesis, NTNU).

Tlhako, R.K. 2016. 'Exploring Socio-Economic, Cultural and Environmental Factors Influencing Young Women’s Vulnerability to HIV: A Study in Sunnyside (Pretoria).' Thesis Submitted for the degree of Master of Arts, University of South Africa.

Treves-Kagan, S., El Ayad, A.M., Pettifor, A., MacPhail, C., Twine, R., Maman, S., Peacock, D., Kahn, K. and Lippman, S.A. 2017. Gender, HIV testing and stigma: The association of HIV testing behaviors and community-level and individual-level stigma in rural South Africa differ for men and women. *AIDS Behavior*, 21(9): 2579–2588. doi:10.1007/s10461-016-1671-8.

Treves-Kagan, S., Steward, W. T., Ntswane, L., Haller, R., Gilvydis, J. M., Gulati, H., Barnhart, S. and Lippman, S. A. 2015. Why increasing availability of ART is not enough: a rapid, community-based study on how HIV-related stigma impacts engagement to care in rural South Africa. *BMC public health*, *16*(1), 1-13.

Trochim, W. M. K. and Donnelly, J. P. 2007. *The Research Methods Knowledge base (3rd ed.).* Atomic Dog Publishers.

Turan, B., Hatcher, A.M., Weiser, S.D., Johnson, M.O, Rice, W.S. and Turan, J.M. 2017. Framing Mechanisms Linking HIV-Related Stigma, Adherence to Treatment, and Health Outcomes. *Am J Public Health*, 107(6): 863-869.

Turan, B., Budhwani, H., Fazeli, P., Browning, W., Raper, J., Mugavero, M. and Turan, J. 2017. How Does Stigma Affect People Living with HIV? The Mediating Roles of Internalized and Anticipated HIV Stigma in the Effects of Perceived Community Stigma on Health and Psychosocial Outcomes. *AIDS Behaviour*, 21(1), 283–291. doi:10.1007/s10461-016-1451-5.

Turan, J. M., Miller, S., Bukusi, E. A., Sande, J. and Cohen, C. R. 2008. HIV/AIDS and maternity care in Kenya: how fears of stigma and discrimination affect uptake and provision of labor and delivery services. *AIDS care*, *20*(8), 938-945.

Tuohy, D., Cooney, A., Dowling, M., Murphy, K. and Sixsmith, J. 2013. An overview of interpretive phenomenology as a research methodology. *Nurse Researcher*, 20(6), 17–20. doi:10.7748/nr2013.07.20.6.17.e315.

Ugarte, W. Högberg, U. Valladares, E. and Essén, B. 2013. Assessing knowledge, attitudes, and behaviors related to HIV and AIDS in Nicaragua: a community-level perspective. *Sex Reprod Healthc.* 2013 Mar;4(1):37-44. doi: 10.1016/j.srhc.2012.11.001. Epub 2012 Nov 19. PMID: 23427932.

UNAIDS. 2020. AIDSinfo: Country Factsheet. Available at: https://aidsinfo.unaids.org/ (Accessed on 17/11/2021).

UNAIDS. 2020. 2020 Global AIDS Update – Seizing the moment – Tackling entrenched inequalities to end epidemics. Available at:

https://www.unaids.org/sites/default/files/media_asset/2019_women-and-hiv_en.pdf (Accessed on 21/03/2021).

UNAIDS. 2019. "Women and HIV: A Spotlight on Adolescent Girls and Young Women." 20 Avenue Appia, 1211 Geneva 27, Switzerland.

UNAIDS. 2018. South Africa Overview. Available at: https://www.unaids.org/en/regionscountries/countries/southafrica (Accessed on 23/12/2019).

UNAIDS. 2016. 2016 United Nations Political Declaration on Ending AIDS sets world on the Fast-Track to end the epidemic by 2030. Available at: https://www.unaids.org/en/resources/presscentre/pressreleaseandstatementarchive/2016/june/20160608_PS_HLM_PoliticalDeclaration (Accessed on 03/04/2021).

UNAIDS. 2014. Reduction of HIV-related stigma and discrimination: Guidance note, Joint United Nations Programme on HIV and AIDS, Geneva, Switzerland, 2014.

UNAIDS. 2008. Report on the Global AIDS Epidemic. Geneva: UNAIDS.

UNICEF. 2009. Communication for Development (C4D) Capability Development Framework, UNICEF and 3D Change. Available at: https://www.unicef.org/cbsc/files/Module_1_SEM-C4D.docx. (Accessed on 16/11/2019).

UNISA. 2016. Policy on Research Ethics. Available at: https://www.unisa.ac.za/static/corporate_web/Content/Apply%20for%20admission/MD/Documents/Policy%20on%20Research%20Ethics%20-%20rev%20appr%20-%20Council%20-%2015.09.2016.pdf. (Accessed on 12/01/2020).

Uys LR. 2000. Confidentiality and HIV and AIDS in South Africa. *Nursing Ethics*, 7(2), 158–166.

Van Dyk, A.C. and van Dyk, P.J. 2003. To know or not to know: Service-related barriers to voluntary HIV counseling and testing (VCT) in South Africa. *Curationis*, 26(1), 4-10. doi: 10.4102/curationis. v26i1.1289. PMID: 14509113.

Van Wyngaard, A. and Whiteside, A. 2021. AIDS and COVID-19 in southern Africa. *African Journal of AIDS Research*, *20*(2), 117-124.

Visser, M., Makin, J. and Forsyth, B. 2009. HIV and AIDS Stigma in a South African Community. *AIDS Care*, 21(2), 197–206. doi:10.1080/09540120801932157.

Visser, M. 2018. Change in HIV-related stigma in South Africa between 2004 and 2016: a cross-sectional community study. *AIDS Care*, 30 (6), 734–738. doi:10.1080/09540121.2018.1425365

Visser, M., Makin, J., Vandormael, A., Sikkema, K. and Forsyth, B. 2009. HIV and AIDS stigma in a South African community. *AIDS Care*, 21(2), 197–206. doi:10.1080/09540120801932157.

Voltelen, B., Konradsen, H., & Østergaard, B. 2018. Ethical considerations when conducting joint interviews with close relatives or family: an integrative review. *Scandinavian Journal of Caring Sciences*, *32*(2), 515-526.

Vukoičić, J. 2013. Radical feminism as a discourse in the theory of conflict. *Sociological discourse, Year 3,* 5, 33-49.

Wakeel, F., and Njoku, A. 2021. Application of the weathering framework: Intersection of racism, stigma, and COVID-19 as a stressful life event among African Americans. *Healthcare*, 9(2), 145.

Wamoyi, J. Stobeanau, K. Bobrova, N. Ambrasky, T. and Watts, C. 2016. Transactional sex and risk for HIV infection in sub-Saharan Africa: a systematic review and meta-analysis. *Journal of the International AIDS Society*, 19:20992.

Wathula, J. 2016. Gender inequality dynamics in the prevention of a heterosexual HIV epidemic in sub-Saharan Africa. *Afr J AIDS Res* (AJAR), 15(1), 55–66. https://doi.org/10.2989/16085906.2016.1150310

Wiles, R., Crow, G., Charles, V. and Heath, S. 2007. Informed Consent and the Research Process: Following Rules or Striking Balances? *Sociological Research Online*. DOI: 10.5153/sro.1208.

Winter, SF. and Winter, SF. 2018. Human Dignity as Leading Principle in Public Health Ethics: A Multi-Case Analysis of 21st Century German Health Policy Decisions. *Int J Health Policy Manag*, 7(3), 210–224.

Wood, L. and Irons, C. 2017. Experienced stigma and its impacts in psychosis: The role of social rank and external shame. Psychology and Psychotherapy: Theory, *Research and Practice*, 90(3), 419–431. doi:10.1111/papt.12127

World Bank. 2019. New country classifications by income level: 2019-2020”. Available at: https://blogs.worldbank.org/opendata/new-country-classifications-income-level-2019-2020 (Accessed on 18/11/2019).

World Health Organisation. Global HIV Programme: HIV data and statistics. Available at: https://www.who.int/teams/global-hiv-hepatitis-and-stis-programmes/hiv/strategic-information/hiv-data-and-statistics (Accessed on 17/11/2021).

World Health Organisation. Vulnerable groups and key populations at increased risk of HIV. Available at: http://www.emro.who.int/asd/health-topics/vulnerable-groups-and-key-populations-at-increased-risk-of-hiv.html (Accessed on 12/01/2020).

World Bank. 2019. New country classifications by income level: 2019-2020”. Available at: https://blogs.worldbank.org/opendata/new-country-classifications-income-level-2019-2020 (Accessed on 18/11/2019).

Yin, R. 2018. *Case Study Research and Applications: Design and Methods Sixth Edition*. SAGE Publication.

Young, T. and Wayne, B. 2019. *Contemporary Approaches to Qualitative Research: Andragogical Strategies for Teaching and Learning.* Available at: https://newprairiepress.org/cgi/viewcontent.cgi?article=4099&context=aerc (Accessed on 23 June 2021).

Yuh, J., Ellwanger, K., Potts, L. and Ssenyonga, J. 2014. Stigma among HIV and AIDS Patients in Africa: A critical review. *Procedia - Social and Behavioral Sciences*, 140, 581 – 585.

Zanoni, B., Archary, M., Buchan, S., Katz, I. and Haberer, J. 2016. Systematic review and meta-analysis of the adolescent HIV continuum of care in South Africa: The Cresting Wave. *BMJ Global Health*, *1*(3), e000004.

Zuma, K., Shisana, O., Rehle, T.M., Simbayi, L.C., Jooste, S., Zungu, N., Labadarios D., Onoya, D., Evans, M., Moyo, S. and Abdullah, F. 2016. New insights into HIV epidemic in South Africa: key findings from the National HIV Prevalence, Incidence and Behaviour Survey. *African Journal of AIDS Research*, 15(1): 67–75.

ANNEXURE 1: PARTICIPANT INTERVIEW SCHEDULE

INTRODUCTION

My Name is Mwenda Imenda. I am a master's student at the University of South Africa (UNISA), presently engaged in a research project entitled "Investigating how stigma aids the spread of HIV infections among young women in Johannesburg and possible interventions to ameliorate the problem." I am working under the guidance/supervision of Mr Leon Roets of the Department of Sociology. Overall, the purpose of this study is to investigate how stigma, as a social factor, increases the chances of young women contracting HIV. I would like to ask you questions [on] this topic and [the] interview will take approximately 40 minutes. In case I may forget important points which you may bring up, I would like your permission to audio-record this interview, do you allow me to do that?

Your participation in this research is entirely voluntarily. It is your choice to participate or not to participate. You should not feel forced to participate. You are free to stop participating in the study, should you feel that you cannot continue. However, I'll be grateful if you participate because the success of this project depends on some agreeing to participate. There is no right or wrong answer, it all depends on your personal opinion and/or experience.

INSTRUCTIONS	
What will be covered	
Section A	Biographic details about you the participant
Section B	Interview questions

SECTION A: BIOGRAPHIC DETAILS

1. How old are you?
2. Where do you currently reside and for how long?
3. Who do you currently live with?
4. What is you[r] highest education level?
5. Are you currently employed?

SECTION B: INTERVIEW LEAD QUESTIONS

6. Have you ever heard of the word ‘stigma’?
   - 6.1. If so, what is your understanding of stigma?
   - 6.2. If not, then I’ll explain what the word means. Since the research is not about the meaning of the word, *per se*, explaining what it means will not compromise the aims of the study – rather, it will help ensure that both the interviewer and interviewee are ‘on the same page’, so to speak.
7. Have you ever experienced stigma?
   - 7.1. If yes, what was your experience?
   - 7.2. How did that experience affect you?
8. Do you believe that there is [a] stigma associated with HIV and AIDS?
   - 8.1. Please, explain your answer.
9. Have you ever been tested for HIV?
   - 9.1. If yes, what was your experience? Please, explain.
   - 9.2. If no, why not?
10. Are there some people that you know of who are afraid to test for HIV because of what people might say?
    - 10.1. If yes, why do you think they [may] be afraid of what people may say?
11. Are there some people that you know of who are afraid to go to the hospital, or other health care facilities, to collect their HIV or AIDS medication because of what people might say?
12. Would you trust health care workers to keep your HIV test results secret or confidential?
    - 12.1. Please explain.
13. Would you say that the stigma associated with HIV and AIDS affects women and men equally or in different ways?
    - 13.1. Please explain your answer.
14. In your view or experience, how would HIV stigma affect people’s desire to (a) go for HIV testing, (b) access care and treatment, (c) programmes to stop or reduce HIV-related stigma?

15. How can families assist family members to deal with HIV stigma?
16. Do you know how HIV stigma is being addressed in your community?
    16.1. If yes: Can you please describe the nature and types of such programmes and
    16.2. what were some of the shortcomings of the programme?
    16.3. In your view how can these shortcomings be addressed to strengthen the programmes?
17. Do you know of some people in your community who avoid going to hospitals or clinics, to receive health care or information about HIV or AIDS, for fear of being known or suspected to be HIV positive, or to be suffering from AIDS?
    17.1. If so, what could be done to assist such people not to fear going to hospitals or other health care facilities?
18. How do you think HIV-related stigma could effectively be addressed in your community and in the country as a whole? Please explain.
19. If you tested positive for HIV, do you think people would treat you differently? Please explain.
20. If you tested HIV-positive, would you feel free to talk about your status around people? Please explain.
21. What else, would you like to share with me on the topic of stigma and HIV and AIDS?

ENDING OF INTERVIEW

We have now come to the end of the interview. Please allow me to express my sincere thanks to you for your participation in my study. You have assisted me very much because, without your participation, this study would not have been possible to complete. Once again, thank you very much.

ANNEXURE 2: CONSENT LETTER TO PARTICIPANTS

University of South Africa
Faculty of Humanities and Social Sciences
Department of Sociology

Dear Madam

I am a Master's student at the University of South Africa (UNISA), presently engaged in a research project entitled "To examine how stigma aids the spread of HIV and AIDS among young women in Johannesburg and possible interventions to ameliorate the problem" under the supervision of Mr Leon Roets of the Department of Sociology. The overall, the purpose of this study is to explore how stigma, as a social factor, increases the chances of young women contracting HIV.

To complete this study, I need to conduct interviews of approximately 40 to 60 minutes' duration which will be audio taped in order to verify findings. Your participation in this research is entirely voluntarily. It is your choice to participate or not. You should not feel forced to participate. You are free to stop participating even though you have agreed to participate. As part of this study, the information that you provide will be used strictly for the purpose and objectives of this study. Your details and all the study information will be kept strictly confidential.

There will be no immediate or direct benefit for participating in this study, therefore participants will not receive any form of awards, compensation or incentives for their participation. All information received will be for academic purposes and will be used to gain a deeper understanding about the role that stigma plays in the spread of HIV.

A summary of the research findings will be made available to you on request. Should you wish to contact the researcher please do so at the following address: Miss Mwenda Imenda Cell: 082 814 0791
Email: 67139361@mylifeunisaac.onmicrosoft.com

Thank you.

INFORMED CONSENT FORM FOR STUDY PARTICIPANTS

Information sheet

Name of principal investigator: Ms Mwenda Imenda
Name of institution: UNISA
Contact information: 082 8140791

Part 1 Information sheet

Introduction

I am a student at the University of South Africa (UNISA), presently studying for a master's degree in Sociology. As part of my studies I am required to do a research project in fulfilment of the requirements for the degree. The title of my research project is: "Investigating how stigma aids the spread of HIV infections among young women in Johannesburg and possible interventions to ameliorate the problem". I will be supervised by Mr L Roets a lecturer in the Department of Sociology.

Purpose of study

The primary aim of this study is to examine the role that stigma plays in the spread of HIV and AIDS among young women in Johannesburg.

Participant Selection

Participation under this study is restricted to young women aged 18 to 24 years of age, living in Johannesburg from both low- and high-income communities. Participants will be selected using the purposive sampling technique, representing both low- and high-income communities.

Voluntary participation

Your participation in this research is entirely voluntarily. It is your choice to participate or not. You should not feel forced to participate. You are free to stop participating even though you have agreed to participate.

Procedure

If you accept to participate in the study, you can then write down your mobile phone number (10 digits long) on the “certificate of consent” of page 2 of this form. We will contact you at that number and ask to confirm your consent. Subsequently, an appointment will be made for an interview.

Risks

There are no foreseen personal risks in your mere participation in this study, or through the information you provide. However, there is a risk that you may accidentally feel uncomfortable answering certain questions. I do not wish for this to happen, so you can stop your participation at any time if you feel uncomfortable – or choose not to answer questions you may feel uncomfortable to answer.

Confidentiality

The information that you provide will be used strictly for the purpose and objectives of this study. Your details and all the study information will be kept strictly confidential.

Ethics

This study will be guided by UNISA’s policy related to research ethics and will uphold strict ethical standards in adherence to the principles of informed consent, confidentiality and anonymity.

Part 2: Certificate of Consent

I have been invited to participate in research on “Investigating how stigma aids the spread of HIV infections among young women in Johannesburg and possible interventions to ameliorate the problem”

I have understood the purpose and objectives of this study, and I have had the opportunity to ask questions about it. All the questions I asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study.

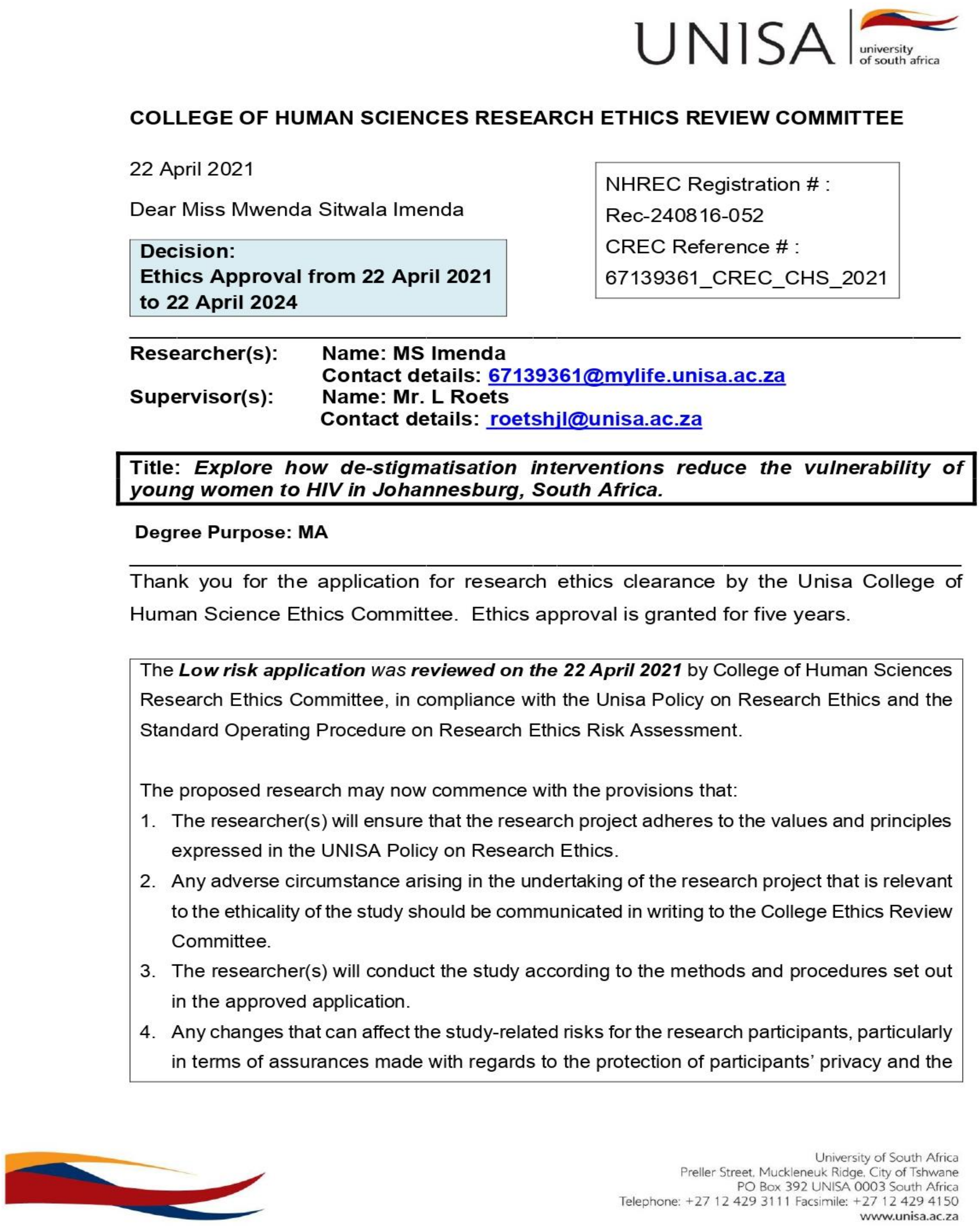
____
Contactable cellular phone number (10 digits long)

____
Name of participant

____

Participant signature

ANNEXURE 3: ETHICAL CLEARANCE FROM THE COLLEGE OF HUMAN SCIENCES RESEARCH ETHICS REVIEW COMMITTEE



UNISA university of south africa

COLLEGE OF HUMAN SCIENCES RESEARCH ETHICS REVIEW COMMITTEE

22 April 2021

Dear Miss Mwenda Sitwala Imenda

Decision:
Ethics Approval from 22 April 2021 to 22 April 2024

NHREC Registration # :
Rec-240816-052
CREC Reference # :
67139361_CREC_CHS_2021

Researcher(s): **Name: MS Imenda**
Contact details: 67139361@mylife.unisa.ac.za
Supervisor(s): **Name: Mr. L Roets**
Contact details: roetshjl@unisa.ac.za

Title: ***Explore how de-stigmatisation interventions reduce the vulnerability of young women to HIV in Johannesburg, South Africa.***

Degree Purpose: MA

Thank you for the application for research ethics clearance by the Unisa College of Human Science Ethics Committee. Ethics approval is granted for five years.

The ***Low risk application*** *was* ***reviewed on the 22 April 2021*** by College of Human Sciences Research Ethics Committee, in compliance with the Unisa Policy on Research Ethics and the Standard Operating Procedure on Research Ethics Risk Assessment.

The proposed research may now commence with the provisions that:

1. The researcher(s) will ensure that the research project adheres to the values and principles expressed in the UNISA Policy on Research Ethics.
2. Any adverse circumstance arising in the undertaking of the research project that is relevant to the ethicality of the study should be communicated in writing to the College Ethics Review Committee.
3. The researcher(s) will conduct the study according to the methods and procedures set out in the approved application.
4. Any changes that can affect the study-related risks for the research participants, particularly in terms of assurances made with regards to the protection of participants' privacy and the

University of South Africa
Preller Street, Muckleneuk Ridge, City of Tshwane
PO Box 392 UNISA 0003 South Africa
Telephone: +27 12 429 3111 Facsimile: +27 12 429 4150
www.unisa.ac.za

confidentiality of the data, should be reported to the Committee in writing, accompanied by a progress report.

5. The researcher will ensure that the research project adheres to any applicable national legislation, professional codes of conduct, institutional guidelines and scientific standards relevant to the specific field of study. Adherence to the following South African legislation is important, if applicable: Protection of Personal Information Act, no 4 of 2013; Children's act no 38 of 2005 and the National Health Act, no 61 of 2003.
6. Only de-identified research data may be used for secondary research purposes in future on condition that the research objectives are similar to those of the original research. Secondary use of identifiable human research data require additional ethics clearance.
7. No fieldwork activities may continue after the expiry date **(22 April 2024).** Submission of a completed research ethics progress report will constitute an application for renewal of Ethics Research Committee approval.

Note:

*The reference number **67139361_CREC_CHS_2021** should be clearly indicated on all forms of communication with the intended research participants, as well as with the Committee.*

Yours sincerely,

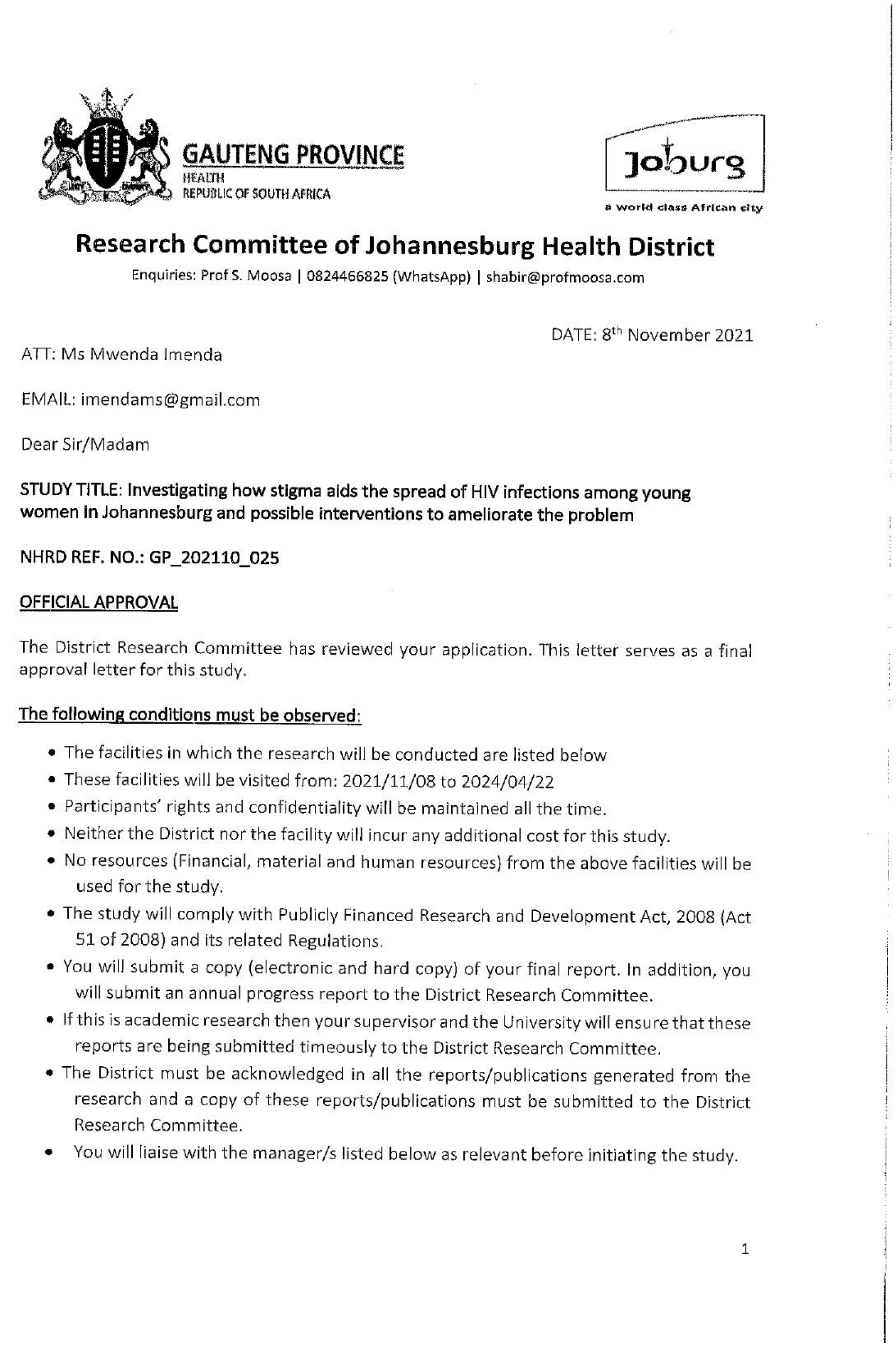
Signature : pp

Prof. KB Khan
CHS Ethics Chairperson
Email: khankb@unisa.ac.za
Tel: (012) 429 8210

Signature : PP AHMudzusi

Prof K. Masemola
Exécutive Dean : CHS
E-mail: masemk@unisa.ac.za
Tel: (012) 429 2298

ANNEXURE 4: PERMISSION FROM THE RESEARCH COMMITTEE OF THE JOHANNESBURG HEALTH DISTRICT



GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

Joburg
a world class African city

Research Committee of Johannesburg Health District
Enquiries: Prof S. Moosa | 0824466825 (WhatsApp) | shabir@profmoosa.com

DATE: 8th November 2021

ATT: Ms Mwenda Imenda

EMAIL: imendams@gmail.com

Dear Sir/Madam

STUDY TITLE: Investigating how stigma aids the spread of HIV infections among young women in Johannesburg and possible interventions to ameliorate the problem

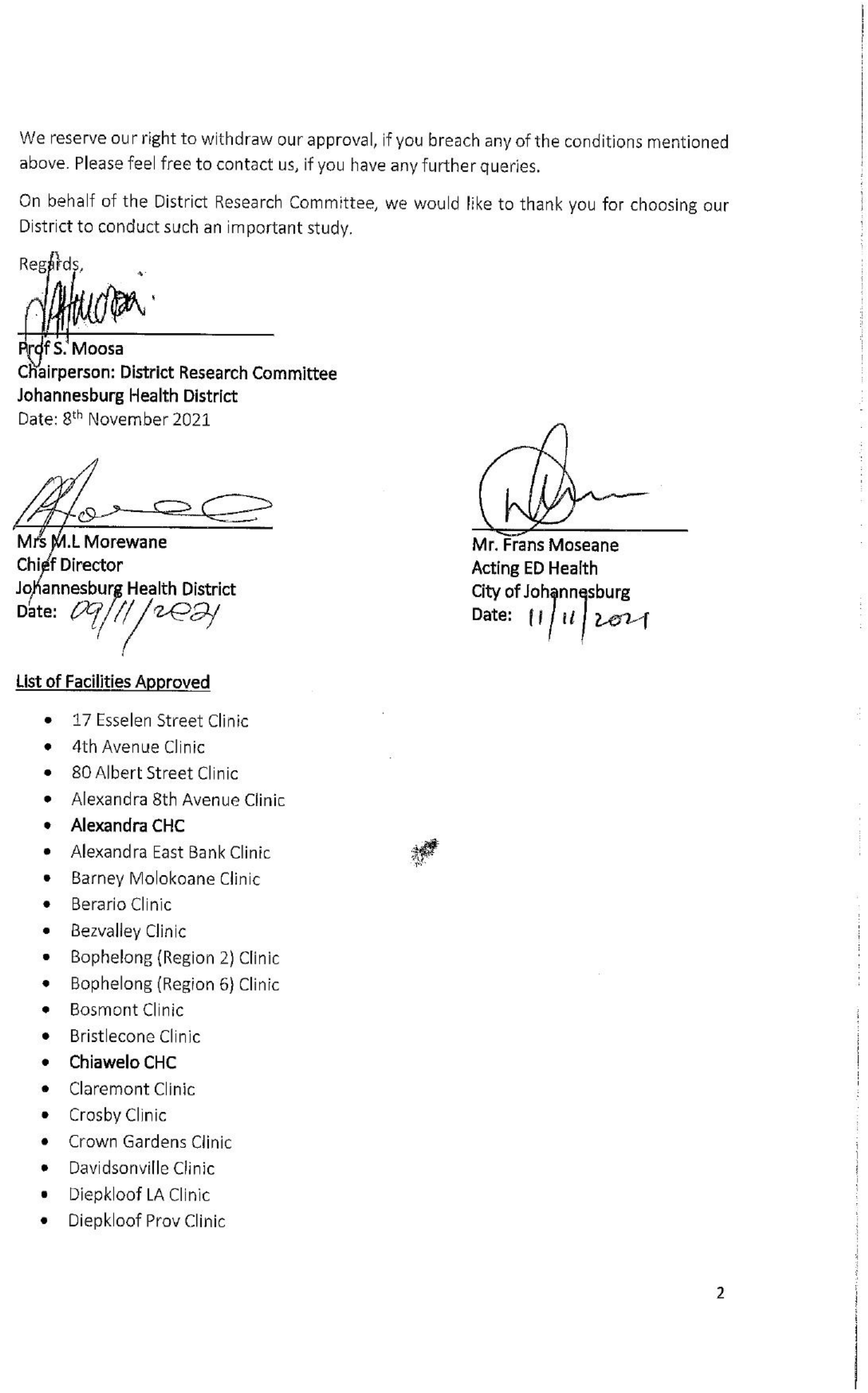
NHRD REF. NO.: GP_202110_025

OFFICIAL APPROVAL

The District Research Committee has reviewed your application. This letter serves as a final approval letter for this study.

The following conditions must be observed:

- The facilities in which the research will be conducted are listed below
- These facilities will be visited from: 2021/11/08 to 2024/04/22
- Participants' rights and confidentiality will be maintained all the time.
- Neither the District nor the facility will incur any additional cost for this study.
- No resources (Financial, material and human resources) from the above facilities will be used for the study.
- The study will comply with Publicly Financed Research and Development Act, 2008 (Act 51 of 2008) and its related Regulations.
- You will submit a copy (electronic and hard copy) of your final report. In addition, you will submit an annual progress report to the District Research Committee.
- If this is academic research then your supervisor and the University will ensure that these reports are being submitted timeously to the District Research Committee.
- The District must be acknowledged in all the reports/publications generated from the research and a copy of these reports/publications must be submitted to the District Research Committee.
- You will liaise with the manager/s listed below as relevant before initiating the study.



We reserve our right to withdraw our approval, if you breach any of the conditions mentioned above. Please feel free to contact us, if you have any further queries.

On behalf of the District Research Committee, we would like to thank you for choosing our District to conduct such an important study.

Regards,

Prof S. Moosa
Chairperson: District Research Committee
Johannesburg Health District
Date: 8th November 2021

Mrs M.L Morewane
Chief Director
Johannesburg Health District
Date: 09/11/2021

Mr. Frans Moseane
Acting ED Health
City of Johannesburg
Date: 11/11/2021

List of Facilities Approved

- 17 Esselen Street Clinic
- 4th Avenue Clinic
- 80 Albert Street Clinic
- Alexandra 8th Avenue Clinic
- **Alexandra CHC**
- Alexandra East Bank Clinic
- Barney Molokoane Clinic
- Berario Clinic
- Bezvalley Clinic
- Bophelong (Region 2) Clinic
- Bophelong (Region 6) Clinic
- Bosmont Clinic
- Bristlecone Clinic
- **Chiawelo CHC**
- Claremont Clinic
- Crosby Clinic
- Crown Gardens Clinic
- Davidsonville Clinic
- Diepkloof LA Clinic
- Diepkloof Prov Clinic

- Diepsloot South Clinic
- **Discoverers CHC**
- Ebony Park / Kaalfontein Clinic
- **Edenvale Hospital**
- Eikenhof La Clinic
- Eldorado Park Ext 2 Clinic
- Eldorado Park Ext 9 Clinic
- Elias Motsoaledi Clinic
- Ennerdale Ext 8 Clinic
- Ennerdale Ext 9 Clinic
- Eyethu Yarona Clinic
- Finetown Clinic
- Florida Clinic
- Glenanda Clinic
- Green Village Porta Cabin Clinic
- Halfway House Clinic
- Helderkruin Clinic
- Hikhensile Clinic
- **Hillbrow CHC**
- **Itireleng CHC**
- Jabavu/Vusabantu Clinic
- Jeppe Clinic
- Jeppe Street Clinic
- Joubert Park Clinic
- Kibler Park Clinic
- Klipspruit West Clinic
- Kliptown Clinic
- Lawley 2 Clinic
- Lawley Clinic
- Lenasia Clinic
- Lenasia Ext 10 Clinic
- Lenasia Ext 2 Clinic
- **Lenasia South CHC**
- Lenasia South Civic Centre Clinic
- **Lillian Ngoyi CHC**
- Malvern Clinic
- Mandela Sisulu Clinic
- Mayfair Clinic
- Mayibuye Clinic
- Meadowlands Zone 2 Prov Clinic
- Michael Maponya Prov Clinic
- Mid Ennerdale Clinic

- Midrand West Clinic
- **Mofolo CHC**
- Mofolo South Clinic
- Moroka Clinic
- Mountain View Clinic
- Mpumelelo Clinic
- Naledi Porta Cabin
- Nokuphila Clinic
- Noordgesig Prov Clinic
- **OR Tambo Clinic**
- Orange Farm Ext 7 Clinic
- Orchards Clinic
- Orlando Prov Clinic
- Parkhurst Clinic
- Petervale Clinic
- Princess Clinic
- Protea Glen Clinic
- Protea South Clinic
- Rabie Ridge Clinic
- Randburg Clinic
- Rex Street Clinic
- Riverlea Major Clinic
- Rosebank Clinic
- Rosettenville Clinic
- Sandown Clinic
- Senaoane Clinic
- Shanty Clinic
- Sinethemba Clinic
- Sinqobile Clinic
- Siphumlile Clinic
- Sol Plaatjies Clinic
- Sophiatown Clinic
- South Hills Clinic
- **South Rand Hospital**
- **Stretford CHC**
- Thembelihle Clinic
- Thoko Mngoma Clinic
- Tladi LA Clinic
- Tladi Prov Clinic
- Tshepisong Porta Cabin Clinic
- Vlakfontein Clinic
- Weilers Farm Clinic

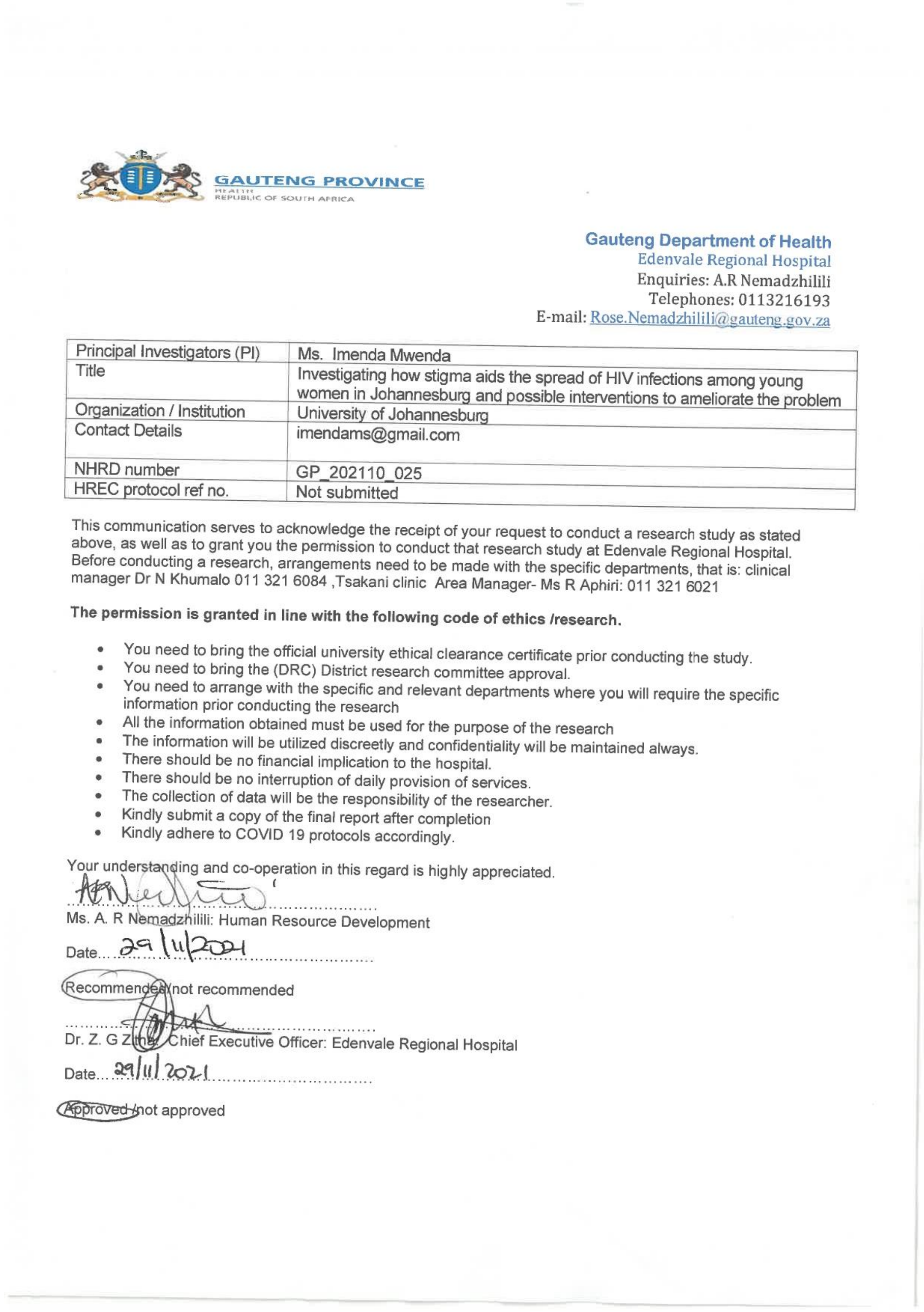
- Weltevreden Park Clinic
- Westbury Clinic
- Wildebeesfontein Clinic
- Windsor Clinic
- Witkoppen Clinic
- Yeoville Clinic
- Zandspruit Clinic
- **Zola CHC**
- **Bhekizizwe Mlangeni Hospital**
- Zondi Clinic

List of Managers

Sub District/ Hospiital	Sub District Manager/ Area Manager	Contact No.	Cell phone	Email
ABCEF	Ms Lombuso Matlala	011 440 1259	082 307 0267	Lombuso.Matlala@gauteng.gov.za
D	Ms Maria Mazibuko	011 674 1200	082 781 9919	Maria.Mazibuko@gauteng.gov.za
G	Mr Peter Mathole	011 213 9603	072 483 6839	Peter.Mathole@gauteng.gov.za
CoJ A	Ms Nelly Shongwe	011 237 8010	082 467 9276	nellys@joburg.org.za
CoJ B	Ms Zanozuko Mbane	011 718 9656	082 551 5804	zanozukom@joburg.org.za
CoJ C	Mr Tebogo Motsepe	011 761 0200	084 655 5420	TebogoMot@joburg.org.za
CoJ D	Ms Busi Phiri	011 986 0164	082 467 9316	busip@joburg.org.za
CoJ E	Mr Vusi Mazibuko	011 582 1504	082 464 9547	VusiM@joburg.org.za
CoJ F	Mr M Monyamane	011 681 8130	082 467 9423	mathibem@joburg.org.za
CoJ G	Ms Olga Kruger	011 211 8936	083 286 0388	olgak@joburg.org.za
Southrand Hospital	Dr N. Maleka	011 681 2002	071 872 6649	Nobantu.Maleka@gauteng.gov.za
Bheki Mlangeni Hospital	Mrs MC Makhetha	011 241 5792	082 768 1069	Makabedi.Makhetha@gauteng.gov.za

Edenvale Hospital	Dr. ZG Zitha	011 321 6157	082 749 3123	Zakhelegoodman.Zitha@gauteng.gov.za

ANNEXURE 5: PERMISSION LETTER FROM THE EDENVALE REGIONAL HOSPITAL



GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

Gauteng Department of Health
Edenvale Regional Hospital
Enquiries: A.R Nemadzhilili
Telephones: 0113216193
E-mail: Rose.Nemadzhilili@gauteng.gov.za

Principal Investigators (PI)	Ms. Imenda Mwenda
Title	Investigating how stigma aids the spread of HIV infections among young women in Johannesburg and possible interventions to ameliorate the problem
Organization / Institution	University of Johannesburg
Contact Details	imendams@gmail.com
NHRD number	GP_202110_025
HREC protocol ref no.	Not submitted

This communication serves to acknowledge the receipt of your request to conduct a research study as stated above, as well as to grant you the permission to conduct that research study at Edenvale Regional Hospital. Before conducting a research, arrangements need to be made with the specific departments, that is: clinical manager Dr N Khumalo 011 321 6084 ,Tsakani clinic Area Manager- Ms R Aphiri: 011 321 6021

The permission is granted in line with the following code of ethics /research.

- You need to bring the official university ethical clearance certificate prior conducting the study.
- You need to bring the (DRC) District research committee approval.
- You need to arrange with the specific and relevant departments where you will require the specific information prior conducting the research
- All the information obtained must be used for the purpose of the research
- The information will be utilized discreetly and confidentiality will be maintained always.
- There should be no financial implication to the hospital.
- There should be no interruption of daily provision of services.
- The collection of data will be the responsibility of the researcher.
- Kindly submit a copy of the final report after completion
- Kindly adhere to COVID 19 protocols accordingly.

Your understanding and co-operation in this regard is highly appreciated.

…………………………………………………………
Ms. A. R Nemadzhilili: Human Resource Development

Date… 29/11/2021 ……………………………………

[✓ Recommended]/not recommended

…………………………………………………………
Dr. Z. G Zitha: Chief Executive Officer: Edenvale Regional Hospital

Date… 29/11/2021 ……………………………………

[✓ Approved] /not approved