

EMPOWERING WOMEN THROUGH HIV PREVENTION PROGRAMMES

By

THIRUSHA RAMBARATH

Submitted in accordance with the requirements for

the degree of

MASTER OF ARTS

in the subject

PSYCHOLOGY

at the

UNIVERSITY OF SOUTH AFRICA

Supervisor: Keit Shirinda-Mthombeni

Date: November 2020

DECLARATION

DECLARATION

I declare that **“Empowering women through HIV prevention programmes”** 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 have not previously submitted this work, or part of it, for examination at Unisa for another qualification or at any other higher education institution.

T Rambarath

Signature

(408-535-27)

(Thirusha Rambarath)

04th February 2021

Date

ACKNOWLEDGEMENTS

I would like to acknowledge and thank the following persons for their assistance, guidance and motivation in finalising my dissertation:

Mrs Keit Mthombeni-Shirinda, my supervisor: Words cannot describe my appreciation towards you for the guidance, unconditional support, encouragement, mentorship and for being a key player in my research journey. Thank you for your patience and understanding, especially during my pregnancy and my baby's tender moments. This has given me strength, inspiration, understanding and motivated me to never lose hope no matter how difficult it was. I gained vast knowledge of the research process, collating data, literature and writing skills. You have been a guiding pillar during this journey. Thank you for being my mentor. I am forever grateful for your teachings.

Vanessa-Lynn Neophytou, my editor: I thank you for all the assistance, understanding, motivation and guidance, your experienced research and higher-level writing skills provided me with a great amount of knowledge. Thank you for being an inspiration to me.

Diven, my loving husband: Thank you for all that you do. You were my strength during this journey. You made numerous sacrifices and always tried your best to assist me in every way possible. Thank you for your unconditional love and support, understanding and mostly for shouldering many responsibilities in caring for our little one.

Diyara, my beautiful 18-month little angel: Mummy loves you so very much and apologies for not being able to spend as much time as I could with you.

Nancy and Cecil, my parents: Thank you for my upbringing and for always being there to love, support and encourage me and for taking care of my little one.

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Kuaressa and Prenessa, my sisters: Thank you for all the love and support throughout the years.

Nerisha, my mother-in-law: Thank you for always being there ready to help and assist me in every way possible, especially in taking care of my little one.

Rachel and Krish: Thank you for always being there as a helping hand and for having a remarkable influence in my upbringing.

The Verulam Regional Hospice Association, my work colleagues: Thank you for all the guidance, experience, support and prayers that you have showered upon me during my research at the hospice.

ABSTRACT

In South Africa, women are the most affected and vulnerable group to HIV and have shouldered most of the caretaking responsibilities. The current study aimed to empower women through HIV prevention programmes, particularly those living with HIV. A qualitative research design was adopted, and an interpretative phenomenological approach (IPA) was used in this study. The researcher used in-depth interviews with seven black and three Indian participants aged between 36 to 58 years old. A purposive sampling technique was used to select the participants. The findings indicated that the women faced many challenges in their lives. They experienced challenges, socio-economic, psychological as well as emotional ones. Despite these challenges, the women were able to cope. However, their coping strategies need to be enhanced. Cultural barriers were not a problem for the women in this study. The theoretical framework adopted in the study comprised models and theories with the social-ecological and feminist theories being the most applicable. Recommendations for future research as well as for the Department of Health (DoH) and the Health Professions Council of South Africa (HPCSA), were provided to facilitate HIV prevention programmes to reduce the spread of HIV.

Keywords: Empowerment, Antiretroviral (ART), HIV, Coping strategies, Prevention programmes

LIST OF ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome ABC
ABC	Abstinence, Be faithful, Use a Condom'
CBO	Community-based Organisations
CCP	Center for Communications Program
DHET	Department of Higher Education and Training
DMPA	Depot Medroxyprogesterone Acetate
DoH	Department of Health
DSD	Department of Social Development
GBV	Gender-based violence
GEM	Gender Empowerment Measure
HEAIDS	Higher Education Training HIV/AIDS
HPCSA	Health Professions Council of South Africa
HPV	Human Papillomavirus
ICDM	Integrated Chronic Disease Management
ILO	International Labour Organisation
IPA	Interpretative Phenomenological Analysis
MMC	Medical-Male Circumcision

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NCD	Non-Communicable Diseases
NDoH	National Department of Health
NGO	Non-Governmental Organisations
PEPFAR	President's Emergency Plan for AIDS Relief
PHC	Primary Health Care
PrEP	Pre-Exposure Prophylaxis
SANAC	South African National AIDS Council
SEM	Social-Ecological Model
SES	Socio-Economic Scores
STDs	Sexually Transmitted Disease
STIs	Sexually Transmitted Infections
TVET	Technical and Vocational Education and Training
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNDP	United Nations Development Programme
USAID	United States Agency for International Development
VCT	Voluntary Counselling and Testing
WHO	World Health Organization

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CHAPTER 1

GENERAL ORIENTATION

1.1 Introduction

This chapter provides an orientation of the study. It includes the background of the study, the significance of the research problem, the purpose of the study, the objectives of the study, the research questions and the research design and participation. The structure of the dissertation is provided towards the end of the chapter.

1.2 Background of the Study

According to the United Nations Programmes on HIV and AIDS (UNAIDS, 2014c), the sub-Saharan region has more people living with HIV than the rest of the world, with 72% of the global total of HIV-related deaths occurring in that region. Worldwide 38 million people lived with HIV in 2019 (HIV gov, 2020). Furthermore, 1.7 million people were infected with HIV in 2019 (UNAIDS, 2020c).

Although there has been a 23% reduction in new HIV infections since 2010, the decline in preventing transmission is still rather slow (UNAIDS, 2020b). According to UNAIDS (2020a), globally, the transmission of HIV to women and girls had lowered a lot (27% since 2010), with slightly less new infections among women and girls (48% women compared to 52% men and boys) and in southern Africa, a 38% reduction since 2010. Nevertheless, these translate into high numbers of people who live their lives managing a chronic illness, on daily medication, suffering the effects of stigma and discrimination. In sub-Saharan Africa, adolescent girls and young women aged 15–24 years are particularly vulnerable to being infected by HIV (Karim & Baxter, 2019). Of concern is that in this region, out of the total HIV infections, 80% are girls aged 15–19 years (Karim & Baxter, 2019).

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According to UNAIDS (2017), South Africa was regarded as the third highest country with new HIV infections in southern Africa; it had around 7.7 million people living with HIV in 2018 (UNAIDS, 2019). According to HSRC (2018), 20.4% of people in South Africa live with HIV, with the incidence varying across provinces ranging from 12.6% in Western Cape to 27% in KwaZulu-Natal. This means that one in five people in SA lives with HIV. Refer to Table 1 for percentages of HIV prevalence amongst adults in all the provinces in SA.

Table 1: HIV prevalence among adults, by province

(adapted from HSRC, 2018)

Province	HIV + %
Eastern Cape	25.2
Free State	25.5
Gauteng	17.6
KwaZulu-Natal	27.0
Limpopo	17.2
Mpumalanga	22.8
Northern Cape	13.9
North-West	22.7
Western Cape	12.6

According to SANAC (2017), HIV in South Africa has changed from a crisis with high death rates to one where the benefits of a massive expansion of treatment services and comprehensive coverage are evident. They also report that young women (15–24) have the highest HIV incidence of any age or sex group, and young women in their early 20s account for approximately 2 000 new HIV infections weekly (100 000 of the annual 270 000 new infections) (SANAC, 2017). Makhubalo (2019) notes that South Africa cannot afford to become HIV fatigued “not while adolescent girls and young women in South Africa

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are at the greatest risk of HIV infection” (para. 3). Makhubalo (2019) supports the SANAC’s figures, saying HIV prevalence in young girls is nearly four times higher than their male counterparts.

Paudel and Baral (2015) stated that HIV disease affects both women and men, but men are much better at transmitting the disease to women. Women experienced a greater risk of being HIV positive due to their biological vulnerabilities, sexual practices with men and epidemiological factors (risk of getting the disease), low socio-economic status, and low levels of literacy thus disposed to experience stigma and discrimination with their families, communities and health workers (Paudel & Baral, 2015).

Van Dyk et al. (2017) reported that healthcare professionals face a massive task of eliminating prejudice, discrimination and lack of knowledge to empower communities. People use denial, myths, stigma, prejudice, and blame as a defence mechanism to protect themselves psychologically. For instance, HIV positive people might blame their partners for infecting them or deny their status rather than face what it means. Families and communities fear being infected and may spread rumours, filled with prejudice, to justify staying away from HIV positive individuals. Hence, it is understandable when HIV positive people are in denial or make efforts to distance themselves from others (van Dyk et al., 2017).

Loutfy et al. (2014) stated that HIV transmission was an area of scientific inquiry which consisted of findings and views that require on-going interpretation using qualified medical experts. The consensus expert opinion relating to the possibility of HIV transmission and the nature of the HIV infection was that sexual acts were fundamentally difficult to study (Loutfy et al., 2014).

Loutfy et al. (2014) reviewed three decades of the most relevant, reliable medical and scientific evidence relating to HIV and HIV transmission and concluded it was a

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manageable chronic illness. Individuals who are now HIV positive who receive care are no longer dying of AIDS but rather from the same conditions as those who are HIV negative, with their main causes of death being liver, heart, lung disease and other non-AIDS-related cancers (Loutfy et al., 2014).

HIV/AIDS has transformed from a life-threatening emergency “to a manageable chronic disease” (WHO, 2017, p. 35). People living with HIV are often the best advocates for social and behaviour change and should be included in developing HIV prevention programmes. Women played a key role in response to HIV and should also be included in this phase.

This research aims to prevent the spread of HIV by empowering women through education and prevention programmes by educating them on partner selection, partner reduction, mode of intercourse, and condoms. This will prevent people from being infected or infecting others but also help them become compassionate, caring members of today’s society who are struggling with the aftermath of HIV.

1.3 The Research Problem

In South Africa, the stigma relating to HIV made newly diagnosed individuals fearful of disclosing their status and seeking support and information on HIV. According to the WHO (2015), guidelines have recommended that ARTs be offered to all HIV positive individuals regardless of their CD4 cell count to reduce the risk of transmission. Although there is no cure, Antiretroviral Therapy (ARVs), by lowering the amount of HIV in the body, reduces the chance that an HIV positive individual transmits the infection to an HIV-negative partner (van Dyk et al., 2017).

According to Chandra-Mouli et al. (2015), women constitute half of all persons living with HIV. Stigma and discrimination are key barriers that women living with HIV have to

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face in their everyday lives. Even though women living with HIV face stigma and discrimination, they also feel rejected because of judgements made about their behaviours by families and communities. Women are more likely to be blamed because many societies have different expectations and standards of a women's sexual conduct compared to men. This creates a sense of helplessness and hopelessness since they do not have strategies to handle the situation.

According to Orr and Braithwaite (2012), women appeared to be most affected by HIV and the stigma it carries. Women shoulder caretaking responsibilities and are more vulnerable than men. Families, friends, neighbours, and partners usually rejected many women living with HIV. Therefore, it was crucial to conduct this study to address the challenges which women face by using effective HIV prevention programmes and effective coping strategies in their daily lives.

1.4 The Purpose of the Study

The purpose of this study is to empower women who are living with HIV through effective prevention programmes; to educate women on breaking the stigma and preventing the spread of HIV. The study promotes safer sex with few economic resources, using the principles derived from both prevention and empowerment. This study can strengthen local health systems. Many healthcare delivery systems in resource-limited settings are designed for acute, time-limited care, helping expectant mothers through pregnancy (for example, prevention of mother-to-child-transmission or treating infectious diseases). According to Ramjee and Daniels (2013), the Stepping Stones programme used participatory learning approaches to build communication skills, knowledge, and risk awareness in South Africa. This treatment programme was invested in capacity building for comprehensive chronic health services designed to support individuals across time and assist in promoting behavioural change in women living with HIV (Ramjee & Daniels, 2013).

1.5 The Objectives of the Study

The main objective of this study is to empower and educate women who are HIV positive, to share their experiences of being victims of this disease and prevent re-infections. In order to achieve the main aim, the following objectives were identified:

- To describe and explore the experiences of women living with HIV.
- To explore and describe the challenges faced by women living with HIV.
- To explore the coping strategies used by women living with HIV to cope with their challenges.
- To identify prevention measures pertaining to empowerment required by women living with HIV.
- To identify theories and models that are used as interventions in preventing HIV.

1.6 The Research Question(s)

The questions to be used in this study are as follows:

- What are the experiences of women living with HIV?
- What are the challenges faced by women living with HIV?
- What are the coping strategies used by women living with HIV?
- What are prevention measures (prevent re-infection) used to empower women living with HIV?
- What are the theories and models used as an intervention in preventing HIV?

1.7 Outline of Chapters

Chapter one introduces the study by providing an overview and a brief background of the study. The study describes the research problem aiming to prevent the outspread of HIV. The purpose of the study is to empower WLHIV by using effective prevention

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measures. The study's objectives are to empower and educate HIV-positive women by allowing them to share their experiences to prevent the spread of the disease. Research questions were compiled into an interview schedule (see Appendix E). The research design used was a qualitative research approach with purposive sampling drawn on to select the participants.

Chapter two, the literature review, presents different studies and documents which surveys the body of literature on empowering women through effective HIV prevention programmes. In this study, the concept of empowerment is discussed as it enables understanding of ways to empower and educate women affected by HIV. This section elaborates on women's health and empowerment to focus on various programmes to empower, educate on awareness and provide them with correct information, knowledge and skills that allow them to make decisions. The study on the effects of HIV highlights that the disease has no gender; it affects both men and women but places women at a much higher risk compared to men. The study elaborates the effects of women living with HIV using an integrated approach to health and human rights; this ensures the wellbeing and dignity of women living with HIV. The study's disclosure of HIV focuses on reducing risky behaviours and increasing support and adherence towards ARTs. The study highlights stigma and discrimination experienced by WLHIV to empower them and steps needed to prevent their rights from being violated. The study uses coping strategies to deal with minor or major stresses and natural changes they experience in life. The HIV support groups allowed healthcare workers to provide information to all people living with HIV. Religion and treatment were used as coping strategies and thus discussed. A discussion on the HIV prevention programmes drawn on in the study is provided. These programmes aim to reduce the spread of HIV and highlight the South African prevention measure. They are based on biomedical, behavioural and social/structural approaches. The study uses theories and models in HIV prevention to bring about behavioural change and prevent the

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spread of HIV. The theories and models of HIV prevention provided are from social cognitive theory, social and behavioural interventions, social-ecological model (SEM), and feminist theoretical perspectives.

Chapter three outlines the research methodology in the study. The aim and objectives of the study are to empower women living with HIV through prevention programmes. The study uses a qualitative research design that includes both descriptive and interpretive approaches. The rationale for using a qualitative research approach ensures the research is naturalistic, that is, engaging directly with participants a lot whilst studying everyday life of different groups of HIV-positive women in their natural setting. The study consists of 10 participants, using purposive sampling techniques; the data sources to be obtained by identifying relevant organisation's groups. The data collection techniques are a biographical questionnaire (see Appendix E) and semi-structured face-to-face interviews. The study's data analysis is to be reviewed continuously to seek meaning and understand problems being faced by HIV positive women for effective empowerment. The issues of reliability and validity are essential to evaluate using credibility, dependability, confirmability, transferability and authenticity and reflexivity in the study. The ethical considerations to be used included confidentiality and informed consent. The provision of debriefing, counselling and additional information from the pilot study was made available to all participants in the study should they require it.

Chapter four presented the results. The study elaborates the psychological and emotional experiences of women, such as the feelings of shock, disbelief, panic, fear, worry and challenges faced by women living with HIV. The psychological challenges in the study focus on depression, anger, social and behavioural challenges, and isolation. The socio-economic challenges faced in the study were unemployment, child support and disability grant, cultural barriers in HIV prevention, coping strategies to deal with HIV. The study uses support groups as strategies such as ARV adherence, exercise and prayer. The prevention

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measures used in the study were HIV counselling and testing, prevention through abstinence, ARVs and condom use. A discussion on the effectiveness of these preventive measures was provided.

Chapter five provides the discussion, conclusion and recommendations of the study based on the participant's experiences and the challenges they faced. It also discusses the measures they drew on to move forward and empower themselves. The study elaborates the experiences of women living with HIV and the effects of physical, psychological, financial and social distresses. A discussion is provided on the strategies used in coping with HIV to reduce stressful situations. The knowledge about prevention measures in the study reveals that women experiencing HIV could deal with the difficulties. The study uses HIV counselling and preventive measures to empowering women through HIV prevention programmes. The limitations of the study will be discussed, as well as the recommendations.

CHAPTER 2

LITERATURE REVIEW

2.1 Introduction

This chapter discusses the concepts and theories relevant to this study, beginning with the concept of empowerment then looks at women's health and empowerment. The literature on the effects of HIV and research examining the challenges they face are discussed. These challenges are around disclosure and dealing with stigma and discrimination. This leads to a discussion on women's coping strategies, which are HIV support groups, religion, and treatment. Previous research conducted in the area of women and HIV prevention programmes is discussed. This research reveals that the three approaches used in these intervention programmes are biomedical, behavioural and social/structural. The theories and models of HIV prevention drawn on were social and behavioural, social-ecological, and feminist theory. Social and behavioural have been effective, but it is difficult to change people's behaviour around HIV prevention. The SEM recognises that the individual and the environment in which they live are intertwined. Feminist theory reveals the patriarchal nature of society and problematises gender. Relevant electronic sources and journal articles, as well as books, were used in the review of the literature with a particular focus on the literature and research in South Africa.

2.2 The Concept Empowerment

The term empowerment originated in the women's movement within western feminism, influenced by feminism and individuals in politics (Luttrell et al., 2009). The term has evolved in gender and development, and the US black and civil rights movement, with notions of power and agency, and more recently, structural inequalities, being debated (Luttrell et al., 2009). Empowerment is defined "as a multidimensional social process that

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helps people gain control over their own lives” (Luttrell et al., 2009, p. 1). Chamberlin (1997) offers a working definition of empowerment specific to her research project, which includes having the power to make decisions, access to information and resources, a range of options from which to make choices, not feeling alone; feeling part of a group, and bringing about change in one’s life and the community. In addition, empowerment refers to “increasing the spiritual, political, social or economic strength of individuals and communities” (Behal, 2011, p. 39). The study explored empowerment in women by using prevention programmes to prevent the spread of HIV and to empower these women to live a normal healthy lifestyle.

The definition of empowerment has an agentic meaning. It looks at the individual being able to gain control over their lives, make decisions and effect change for themselves, and increase their strength in deficient areas. Agency is significant as women are considered vulnerable to HIV transmission, more so than men, labelled a vulnerable group in terms of GBV, a label that can be disempowering. Women are agentic, and this must be acknowledged without denying their vulnerability. Women were seen as agentic (and affected by HIV) in this study, and their vulnerability and the measures they took to cope with challenges in their daily lives were explored.

Given the role of gender inequality in the transmission of HIV, the empowerment of women is critical, and they need to be empowered in the area of health, and economically, educationally, socially and politically (Erhardt et al., 2009). Unless structural factors that impact women’s lives are addressed, it will be difficult to empower women as structural factors, such as poverty, directly impact behaviour.

This study draws on the concept of empowerment as a process. Empowerment is not a fixed state with a goal one can simply measure; it can be temporary (Cornwall, 2016). Cornwall (2016) says that a useful way of understanding empowerment is to think of it as a

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journey; different for each woman. Rowlands (1997) defined empowerment as a process whereby women can organise themselves to increase their independence, emphasise their right to make choices and change external conditions, and control resources eradicating their subordination. Her definition shows the difference between 'power over', which is coercive and 'power to', which is the ability to change (Luttrell et al., 2009). Kabeer (1994) suggests that if women are going to improve their ability to control resources and make decisions, the empowerment strategies must build on 'power within'. The United Nations (UN) defines women empowerment as their "sense of self-worth, their right to have and to determine choices; their right to have access to opportunities and resources; their right to have the power to control their lives" (2012, para. 2, p. 8).

According to Yuval -Davis (1994), empowerment has been a central item on the political agenda of all grassroots resistance movements since the late 1960s, whether called black power, raising women's consciousness, or asking for a more general 'return' to the community. Yuval-Davis (1994) viewed women's empowerment as a process needing resources to enable the processes that expand women's ability to make choices.

Mandal (2013) reported that global empowerment for women is a new concept. Empowerment is seen as a modern idea that would not have been possible 200 years ago (Mandal, 2013). In the twentieth century, political empowerment was seen in different countries of the world led by people such as Martin Luther King, Mahatma Gandhi and Nelson Mandela (Mandal, 2013). The empowerment of women is now seen as a global phenomenon since the origin of the UN (Mandal, 2013). This development has attracted students worldwide, and the concept has become a political agenda in numerous countries (Mandal, 2013).

Chaturvedi et al. (2016), in their study about the effect of women empowerment on women's health, highlighted that empowering them leads to better health amenities as

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women's health is so important. The authors found that "better education, employment, and a shift in society's attitude towards women" (Chaturvedi et al., 2016, p. 12) would result in empowerment. Women should be supported and encouraged to have self-confidence. Society also needs to be encouraged to support women by changing how it treats them (Chaturvedi et al., 2016). The study explores women empowerment by using support groups, religious organisations and ARV adherence to encourage women to regain their self-confidence and lead a normal life.

According to Oktem (2015), women are viewed as caretakers of their families, and they take the blame for bringing HIV into a relationship or passing the virus onto their children. Therefore, in this study, women empowerment was explored as well as to encourage women to 'speak out' their experiences, educate the communities, and break harmful cultural beliefs. This would be possible if communities worked together in collaboration to hold various prevention programmes in different sectors such as schools, churches and clinics (Oktem, 2015). Women need to be empowered as they play a crucial role in society; it will give them a position of dignity, equality and power to focus on their health, children's health, and the health of families and communities (Oktem, 2015). The focus of this study explored empowering and educating HIV positive women through prevention programmes in eliminating infections and re-infections of the disease. Knowledge is power, and women have the right to receive information. Women living with HIV need to be provided with the information they need to understand their bodies and sexuality (Oktem, 2015). Women should also be encouraged to use condoms and be provided with skills training on communication about sex and foster inter-partner communication (Oktem, 2015).

In empowering women, the community should ensure that women living with HIV have access to health services and are educated on communicable diseases. There should be social support for women struggling to change existing gender norms by allowing these

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affected women opportunities to meet in groups, discuss their issues, strengthen their organisations, and provide them with adequate resources. Women in this study were allowed to voice their concerns and create a group identity separate from their families. The family ensures that women comply with traditional gender norms.

2.3 Women's Health and Empowerment

According to U.S Mission South Africa (2013), The Department of Higher Education and Training (DHET), the South African National AIDS Council's (SANAC) Women's Sector, with support from the USAID/JHU HIV Communication programme and PEPFAR, were in partnership with Children and People with Disabilities, the Department of Women, the Department of Health and Department of Social Development. The programme was seen as advocacy, a mass media and mobilisation programme that addressed gender inequalities by encouraging women to draw on their inner strength, power and self-confidence to guide their life decisions.

Adeokun et al. (2013) declared their study found that women were less likely than men to make any behavioural change decisions. This tends to confirm the report on the powerlessness of women in reproductive decision-making. They indicated that women's resistance to condom use was about a combination of personal preferences, socio-cultural factors, and partner preference (Adeokun et al., 2013). The idea of condom use goes against current beliefs about relationships, womanhood and family. Basic to women enjoying sex is the idea of trust and fidelity through unprotected sex and fulfilment of family and gender roles through pregnancy and childbearing (Adeokun et al., 2013). In this study, women explored decision making in abstaining from sexual behaviour and the use of condoms.

Empowerment of women to negotiate sexual activity should form part of programmes of AIDS prevention. Therefore, programmes should also look at rape, sexual

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violence, dual protection, breast, cervical cancer, STI screening and transactional sex (Adeokun et al., 2013).

The Women's Health and Empowerment Programme was aligned with the SANAC strategy for HIV prevention amongst girls and young women in South Africa. They focused on reducing HIV incidence and prevalence in women between the ages of 14–24 and drew from the ZAZI (Know yourself) Programme, which is a national campaign of the Department of Women, Children and People with Disabilities Department of Social Development (U.S Mission South Africa, 2013). The focus of these programmes was to educate, create awareness and provide women with correct information, knowledge and skills, allowing them to make knowledgeable decisions in their lives.

Decreasing HIV incidence in young women and girls requires a multi-pronged, multi-level approach. We need to look more broadly at creating an enabling environment for women and young girls to make choices. This will lower their risk and reduce HIV in this population.

2.4 The Effects of HIV on Women

Statistics South Africa (2016) estimated that the total number of people living with HIV from 2002 to 2016 is approximately one-fifth of South African women in their reproductive years. It shows that HIV prevalence among the youth aged 15–24 had declined over time from 7,6% in 2002 to 5,6 in 2016 (Stats SA, 2016). The rate at which South Africa's population was being infected declined from 1,77% in 2002 to 1,27% in 2016 (Stats SA, 2016). According to Statistics South Africa (2016), the risk of an HIV-positive mother passing the disease to her child can be reduced by 5% or less if she has access to effective antiretroviral therapy throughout her pregnancy, delivery as well as breastfeeding. This estimated 77% (69–86%) of pregnant women living with HIV had access to antiretroviral medicines to prevent transmission of HIV to their infants (Stats SA, 2016).

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According to Paudel and Baral (2015), HIV was a disease that had no gender affecting both women and men. However, women were at a much higher risk of being HIV positive due to their biological vulnerabilities, dominant sexual practices of males, low socio-economic status, cultural factors and epidemiological factors (Paudel & Baral, 2015). They indicated that HIV affects women differently compared to men because women are more vulnerable to the disease due to their economic dependence on men, lack of education, poverty, exposure to sexual exploitation, coercion and rape (Paudel & Baral, 2015). Men are much more efficient at transmitting HIV to women than women are to men (Paudel & Baral, 2015). The study explored women living with HIV facing biological vulnerabilities, socio-economic status and cultural factors.

Dellar et al. (2015) reported that young women aged 15–24 years in the southern African region contributed nearly 30% of all new infections. In South Africa, this percentage translates to 113 000 new infections in young women per year, which is more than 4 times the number contributed by their male counterparts (Dellar et al., 2015). The WHO (2017) reported that HIV was not only driven by gender inequality but also establishes gender vulnerability, leaving women more vulnerable to its impact. This led to the provision of sexual and reproductive health interventions for WLHIV grounded in principles of gender equality and human rights. The interventions had a positive impact on their quality of life, and it was also a step towards long-term improved health status and equity.

According to Odimegwu and Somefun (2017), societal norms and gender-power relations influence behaviour, which allows for positive or negative changes. For instance, in different societies, norms and beliefs of suitable roles for men and women are enforced by that society's institutions and practices, such as marriage, polygamy, and female genital mutilation (Odimegwu & Somefun, 2017). This determines the extent to which men and women can control various aspects of their sexual lives, for example, when they have sex

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and if condoms are used. The study explores the effects of vulnerability towards women leaving men to have more power to make decisions.

Femininity prescribes gender roles for women as being passive in sexual interactions and uninformed of sexual matters. This passivity limits their ability to access information on the risk of sex and the ability to negotiate condom usage. Masculinity prescribes men to be sexual risk-takers condoning multiple partners, which, without adequate protection, increases their vulnerability to HIV. The unequal power balance between men and women results in unequal access to HIV information, resources and services (Odimegwu & Somefun, 2017). In this study, condom usage is looked at by the participants, as discussed in the findings.

Atukunda et al. (2017) stated that ethnic socio-cultural identity and historical perceptions were strongly related to how specific groups behave in their current environments. Their study looked at how Ugandans living in the UK had the lowest condom usage (Atukunda et al., 2017). This revealed that although many people may view condom usage as essential to prevent HIV, socio-cultural resistance was still a challenge among black ethnic groups and needed to be considered in designing effective programmes (Atukunda et al., 2017). Their study found stigma attached to condoms linked to pregnancy and relationships outside marriage (Atukunda et al., 2017).

Lys and Reading (2012), in the study conducted on young women in the North-West territories in Canada, highlighted that models developed for sexual health education respected and integrated diversities and differences in the population. They specified that health promoters should improve the content and delivery of sexual health education; improve communication on sexual health education between parents and adolescents; help young women empower themselves regarding sexuality and sexual issues; and normalise youth sexual health and sexuality (Lys & Reading, 2012).

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Odimegwu and Somefun (2017) indicated that risky sexual behaviours involved the number and types of partnerships, sexual acts, and sexual orientation. Other risky sexual behaviour elements included early age at first sexual intercourse, unprotected sexual intercourse with 'at risk' sexual partners, and untreated STDs. These behaviours have implications in the prevention of HIV and other STIs. They mentioned that to ensure a decline of HIV and other STIs, further research on youth sexual behaviour causes is important (Odimegwu & Somefun 2017). In this study, the researcher explored the number of intimate relationships the participants had interacted in and the period of these relationships. This indicated how they had discovered HIV and if they were able to identify the infected partner.

2.5 The Effects on Women Living with HIV

According to WHO (2017, p. 2), "an integrated approach to health and human rights lies at the heart of ensuring the dignity and wellbeing of women living with HIV". Oliveira et al. (2015) indicated that the status of being HIV positive is a constant threat, both physical and psychological, which affects women's social relations with people. There is always the fear of the unknown, leading to denial and fear. Another effect of HIV is the fear of new relationships due to stigma and prejudice from communities. The physical effects of HIV are discussed below.

2.5.1 Physical Effects

According to Oliveira et al. (2015), women reported that social and personal responsibilities increased after the HIV positive status diagnosis. They indicated that the disease brings in the responsibility of taking care of themselves in ensuring they have extended life care. Although this responsibility prevented the spread of HIV and also protects their partners from the infection, it becomes a strenuous exercise for them. Their bodies are no longer strong enough to carry all the duties they once performed as they tire

easily. In this study, the physical effects were explored by women living with HIV and measures they used to enable them to remain healthy physically.

Being HIV can affect the sexual health of women as follows:

- Decreased sexual desire;
- Stress that may inhibit sexual function;
- Infertility (WHO, 2006).

McIntosh and Rosselli (2012) indicated that women who know their way of HIV transmission was through sexual intercourse create a stigma against sex, have a decreased sex drive and loss of libido, and have demonstrated a sense of regret for not taking prevention measures. An HIV positive status compromises one's sexuality, and the emotional and social consequences associated with this diagnosis are a challenge (McIntosh & Rosselli, 2012). The discovery of an HIV positive status is a traumatic experience and can cause pain. The person may start to lose their appetite due to the medication's side effects, losing weight in the process (McIntosh & Rosselli, 2012). The study explored the feelings of participants on their first discovery of being HIV positive.

2.5.2 ARV Drugs Side Effects

De Jesus et al. (2017) stated that the lack of information about HIV treatment directly affects individuals because the side effects are unknown before the beginning of the treatment. ARV drugs are known for side effects such as severe lack of appetite, diarrhoea, cough, hormonal problems and gastrointestinal complications (Schiller, 2004). The poor state of the economy, neglect and lack of support from family and community members, lack of appetite, and drug reactions all contribute to the high incidence of the acute effect of HIV in PLHIV. The adverse effects of drug treatment interfere with them taking care of themselves and their quality of life. The regime of complying with treatment takes over the

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person's life. It is challenging to keep up with treatment, going to the clinic regularly, taking all the medication (a large number of tablets with side effects).

Eisinger and Fauci (2018) indicated that other effects were associated with drug toxicities, such as inconsistent adherence to complex treatment regimens, drug resistance, tablet fatigue, and limited access to treatment by women living with HIV/ADS. The success of highly active ART for AIDS (HAART) depends on maintaining high rates of patient adherence to drug treatment. Analysing factors associated with adherence are perceived by women living with HIV as crucial for improving health policies and practices to improve the treatment effectiveness (Eisinger & Fauci, 2018). There has been an increase in the number of PLHIV receiving ART. This means that treatment regimens and strategies need to be renewed all the time to ensure access to ART, rapid diagnosis, ensuring people stick to treatment and medication and stay in care (Eisinger & Fauci, 2018). In this study, the researcher explored the effects of ARVs on HIV positive women and the way in which ARVs affected their lifestyle.

2.5.3 Trust Issues

Oliveira et al. (2015) highlighted that among the effects caused by the diagnosis of HIV positive status was the development of feelings that pervade the lives of women living with HIV, for example, trust, anger, fear, and guilt. Trust is the basic factor in a loving relationship without which they will not work. Trust in relationships was considered critical to ensure that women could have support. Relationships have levels of intimacy based on trust. If there is no trust, women are scared of being rejected by their partners. Some women's partners resented them because they believed they infected them (Oliveira et al., 2015). Other women's partners do not accept that they are HIV positive and do not support them (Oliveira et al., 2015). Women in this study explored their feelings on trust as well as methods of support during this process.

2.5.4 Fear and Anger

Pauldel and Baral (2015) highlighted research that found that an HIV positive status brought anger to women as it changed their daily routine. They could not accept their situation; they lost confidence and did not want to engage in sexual relations with their partners (Pauldel & Baral, 2015). They were also scared that people in the community would find out their positive status, so they did not want to socialise (Pauldel & Baral, 2015). Fear of discrimination makes it difficult for women to take their medication (ARVs) as they should because they cannot go and fetch it at the clinic (Pauldel & Baral, 2015). The study explored the feelings of women living with HIV and the strategies to help them overcome their fear and anger.

McIntosh and Rosselli (2012) indicated that discovering an HIV positive status was a traumatic experience that caused distress mostly associated with the fear of death, fear of rejection by the partner, rejection by family, rejection by society, stigma, and prejudice. Fear weakens the ability of individuals, families, and societies to safeguard themselves and provide support. Internalised stigma is also harmful to PLWHIV's mental wellbeing with fear of discrimination, breaking down their confidence to get help (UNAIDS, 2014).

2.6 Challenges Faced by Women Living with HIV

2.6.1 Disclosure of HIV Status

Disclosure is an important area regarding empowering women because knowledge of one's status and of one's partner and children allows a woman to make decisions. In a broader perspective, disclosure is important because it ties into prevention strategies linked to stigma. Disclosure is gendered: it is different for women and men.

HIV status disclosure is vital to any discussion on HIV because of its potential for HIV prevention, and gender shapes it as well (Obermeyer et al., 2011). Disclosure means

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opening up, talking about status and ending stigmatisation. Disclosure is telling someone that you are living with HIV. Obermeyer et al. (2011) conducted an electronic search of databases for journal articles and abstracts which looked at HIV disclosure by adults living with HIV sharing their status and found it can help relieve the stresses of being HIV positive. It is crucial to decide whom to tell and how to break the news since it can be difficult. The study's findings on disclosure showed that it is difficult to disclose one's status, and few people keep their HIV status a secret (Obermeyer et al., 2011). Obermeyer et al. (2011) stated that disclosure levels were high, but lower levels had been recorded in certain populations, especially in those that tested positive during prenatal care. Here is an indication of the gendered component of the disclosure.

First, it must be noted that the focus was on HIV groups to gain a better understanding of their circumstances that favour or hinder disclosure (Obermeyer et al., 2011). Second, disclosure is much higher in high-income countries (Europe and the United States) than in middle-income countries (Obermeyer et al., 2011). Lastly, women accepted disclosure (from others) and appeared to disclose more easily than men, unless married and/or pregnant (Obermeyer et al., 2011).

A study conducted on HIV status disclosure among post-partum women in Zambia revealed that disclosure of an HIV positive status to sexual partners amongst couples had a significant implication for the health of those living with HIV, their sexual partners and public health (Maman et al., 2014, cited in Hampanda & Rael, 2018). Status disclosure is associated with improved social support and reduced feelings of anxiety and stigma (Hampanda & Rael, 2018, p. 1652). A gendered component to disclosure was also revealed, backing up the study cited previously. The study in Zambia showed it was challenging for WLHIV to disclose their status, especially those that feared violence from their partners (Hampanda & Rael, 2018).

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Dessaiegn et al. (2019), in their study on HIV disclosure to sexual partners among individuals receiving care in Addis Ababa, indicated that disclosure was associated with reduced anxiety, fewer symptoms of depression, increased support and strengthening of relationships. Disclosure also entails potential risks, for example, loss of financial support, abandonment, blame, emotional and physical abuse, discrimination, and disruption of family relationships (Dessaiegn et al., 2019).

In their study, Colombini et al. (2016) reported that HIV disclosure for WLHIV in Kenya was a major reason for stress; they were afraid of their male partner, stigma, discrimination, violence, and abandonment. Several women were less likely to enrol in HIV care due to such stressors. Nevertheless, for many women living with HIV, an HIV-positive status disclosure can lead to either an extension of former violence or new conflict specifically associated with an HIV test (Colombini et al., 2016). Disclosure of an HIV-positive status by individuals to family members, co-workers and/friends is important for ensuring social and emotional support. It is also important for individuals with an HIV-positive status to disclose to all their sexual partners for HIV prevention. It is crucial for pregnant women to disclose their HIV-positive status to their sexual partners to adopt safer sexual behaviours to prevent re-infection if they are both HIV-infected and avoid infecting the HIV-negative partner (Shiyoleni, 2013).

Genet et al. (2015) highlighted that disclosing one's HIV status should be a personal choice; however, in a sexual relationship, this ought to be a legal requirement. Whether or not the partner acquires HIV, or whether or not prevention methods were used or the person living with HIV meant any harm, criminal charges may be faced if one's partner accuses them of not disclosing their status in a sexual relationship. Disclosure of an HIV-positive status has a significant role in the prevention and control of HIV. It indicated that the failure of people being infected with HIV and not disclosing their positive status could

expose their sexual partners and other relatives that have close contact with them to the virus (Genet et al., 2015).

Genet et al. (2015) further stated that the disclosure of an HIV status could have different effects on sexual partners. It could motivate partners towards Voluntary Counselling and Testing (VCT). Disclosure can reduce risky behaviours and increase support and adherence to ART (Genet et al., 2015). However, there are negative consequences, as well. A positive status could cause blame, discrimination, abandonment, depression, loss of economic support, and family relationships could be upset (Genet et al., 2015). This could be why some patients may not disclose their HIV-positive status. This can also have a negative effect on women's treatment outcomes which would have improved in more recent years.

Paudel and Baral (2015) stated that it is evident that millions of HIV-infected persons have been rejected by their family, friends and partners. Thousands have lost their lives, and thousands have not been able to live their lives to the fullest. Despite the burden of this disease, the world is paying less attention to the issues raised by women living with this disease (Paudel & Baral, 2015). The current study looked at disclosure and how participants felt opening up to their loved ones and partners. Stigma and discrimination are some of the challenges faced by WLHIV and are discussed below.

2.7 Stigma and Discrimination

According to UNAIDS (2015), the HIV stigma and discrimination recognises prejudice with negative attitudes and brought upon abuse directed to people that were HIV positive. In "35% of countries with data available more than 50% of men and women report discriminatory attitudes towards people living with HIV" (UNAIDS, 2015, p. 25). Stigma and discrimination render people more vulnerable to being HIV positive (UNAIDS, 2015).

Women infected with HIV face stigma and discrimination based on whether they have HIV

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or not, and on top of that, their gender, age, race, socio-economic status, sexual orientation, gender identity or other grounds (AVERT, 2020). Stigma and discrimination can occur in different ways in healthcare settings, such as stopping people from accessing health services. HIV-related discrimination in healthcare remains an issue, for instance, in “denial of health services, inadequate and poor quality of care” (UNAIDS, 2015, p. 25). Healthcare professionals can help people who are HIV positive with information on prevention and care and provide life-saving information on preventing the spread of the virus (AVERT, 2020).

According to Paudel and Baral (2015), HIV-infected women’s lives are not easy. They endure profound physical and psychological consequences. Women were seen to bear a ‘triple jeopardy’ impact of HIV since the persons infected with HIV were mothers of children, carers of partners, parents or orphans with HIV AIDS. However, it was seen that women living with HIV are at a higher risk of living with a painful and very shameful life of illusions. UNAIDS (2017) suggested that using specific programmes that emphasised the rights of PLHIV in eradicating stigma were well-documented. People living with HIV should be aware of their rights and be empowered to take action if these rights are violated. In March 2016, The UNAIDS and WHO’s Global Health Workforce Alliance launched an Agenda for Zero Discrimination in Healthcare settings (UNAIDS, 2016a). This works towards a world where everyone (everywhere) could receive the proper healthcare requirements they needed with no discrimination. This was in line with The UN Political Declaration on Ending AIDS (UNAIDS, 2017).

People living with HIV at the workplace experience stigma from their employers and co-workers. These experiences include social isolation and ridicule or experiencing discriminatory practices, such as the refusal of employment or termination.

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HIV had a huge impact on the workplace, organisations' efficiency, workers' productivity and the overall economy. According to Twinomugisha et al. (2020), the HIV disease brought about a decrease in productivity, causing a significant increase in staff turnover. Due to related deaths and illness, this has influenced the increase in cost in the workplace. Stigma and discrimination were frequently affecting societies (Twinomugisha et al., 2020). The International Labour Organisation (ILO) made a "pledge to overcome stigma and discrimination in the workplace" (Twinomugisha et al., 2020, p. 1.). The study on exploring HIV-related stigma and discrimination at the workplace in southern Uganda revealed that many employees were in support of HIV testing at the workplace (Twinomugisha et al., 2020). Similarly, a study in Nigeria showed that employees supported several HIV activities in the workplace, such as VCT and counselling (Twinomugisha et al., 2020).

According to Hammarlund et al. (2018), stigma was a complex construct that comes from many sources and can manifest as a barrier in several ways. "Perceived social stigma is one type of stigma in which a person recognises and believes that their society holds prejudicial beliefs that will result in discrimination against them" (Corrigan et al., 2015, cited in Hammarlund et al., 2018, p. 115). Perceived social stigma can also act as a barrier to the extent that those to whom substance users turn to for help have negative responses, even revulsion (Hammarlund et al., 2018).

Paudel and Baral (2015), in a meta-synthesis of reports, examined the issue of discrimination in women living with HIV stating that HIV stigma was linked with rejection from friends, family, society, feelings of doubt and loss, anxiety, low self-esteem, fear, depression and suicidal thoughts. Their study revealed that women living with HIV lived with panic and the painful effects of stigmatisation and discrimination, including social rejection with denial, including violence in families and community (Paudel & Baral, 2015). Self-stigma and fear of a negative community response can impede efforts to address the HIV

epidemic. Negative self-judgement resulting in shame, worthlessness and blame represents an important but overlooked part of living with HIV. Self-stigma affects a person's ability to live positively and have a good quality of life and be able to follow through with their treatment plans (UNAIDS, 2017). The current study explored stigma and discrimination and the effects it has had on women living with HIV. It has been emphasised that women experience higher levels of discrimination from societies because of their gender. Different factors have been identified that were challenges to women living with HIV. These factors are discussed below.

2.7.1 Biological Risk Factors.

Abbai et al. (2016) indicated that many adults living with HIV are women, and the infections occurred mainly through heterosexual transmission. According to Dellar et al. (2015), the per-coital act towards HIV incidences indicated adolescent girls and young women's rates are high, but this does not explain behavioural risks. Young women become infected with HIV after experiencing a few coital encounters illustrating that in young girls, infection is equal to sexual intercourse for the first time (Dellar et al., 2015). They further stated that potential biological factors increased the behavioural risk resulting in vulnerability which caused more infection in younger women than men and older women (Dellar et al., 2015).

According to Ramjee and Daniels (2013), women were at a greater physical risk of contracting HIV than men. This was because women have a greater mucosal surface area exposed to pathogens and infectious fluid for longer periods during sexual intercourse and are likely to face increased tissue damage. In addition, cells beneath the surface of the cervix are particularly vulnerable to HIV infection, especially during adolescence and during a woman's first pregnancy, or due to infection with human papillomavirus and chlamydia (Pebody, 2009). Most young women are at a much higher risk due to immaturity of the

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cervix, which has not acquired enough thickness to be an effective barrier preventing bacteria from entering the vagina (Jacobs, 2013). Young women are also more vulnerable to infections during their menstrual cycle when sex hormones in the female tract are suppressed (Ramjee and Daniels, 2013). This is because, during the second phase of the menstrual cycle, the immune system is suppressed, increasing infection risk (Boutot, 2018). Young women were particularly high risk due to cervical ectopy, which helps greater exposure of target cells to damage and bacteria in the vagina (Ramjee & Daniels, 2013). Cervical ectopy is the erosion of the cervix caused by normal hormonal changes, a benign condition, in adolescents, in pregnancy, and women taking oestrogen (Jones, 2016).

A study conducted on adolescent girls and women in key populations illustrates biological factors that “create the perfect storm of conditions” (Dellar et al., 2015, p. 67). Young women are much more susceptible to HIV infections than older women, with biological factors illustrating the age vulnerability (Dellar et al., 2015). They also reported high levels of genital inflammation that increased consistently in reported HIV cases, especially in young women with an immature cervix with a greater proportion of genital mucosa exposed to HIV and disposed to infections (Dellar et al., 2015). Young women are more at risk than young men for increased HIV infections if one considers STIs, contraceptives use, and many other bacterial diseases associated with increasing infections (Dellar et al., 2015).

Hormones, for example, progesterone, play a role in a woman’s biological vulnerability to HIV infection (Baeten et al., 2007). This was backed up by Ramjee and Daniels (2013), who highlighted that progesterone in women plays a role in biological vulnerability to HIV infection as it contained depot medroxyprogesterone acetate (DMPA) – injectable contraception placing women at a higher risk for HIV.

2.7.2 Socio-Economic Factors.

According to Ramjee and Daniels (2013), nearly all southern African countries have faced slowing economic growth, which has influenced spending on social services in the last two decades. This has further impoverished African populations, with increases in unemployment rates and decreased social services provisions, including education and health services. This reflected the deterioration in health care services, education and other social services, which brought upon loss of prevention opportunities in HIV (Ramjee & Daniel, 2013).

Pascoe et al. (2015) highlighted that the disproportionate numbers of those affected with HIV lived in the poorest areas of the world; however, HIV is not always concentrated amongst the poorest populations in these areas (Dinkelman et al., 2007; Gillespie et al., 2007; Wilson & Halperin, 2008 cited in Pascoe et al., 2015, p. e0115290). The socio-economic position and HIV may also change over time, with a somewhat higher HIV prevalence shifting from the urban wealthy into much impoverished and more rural populations. Raymond et al. (2014) stated the relationship of poverty and low socio-economic status towards HIV infection and its consequences was unclear, therefore obstructing an attempt in developing effective prevention interventions. Some poor populations have a lowered prevalence risk for HIV than predicted by their socio-economic scores (SES). Predominantly poverty, access to resources and prevention measures with complex relationships presents a challenging public health problem.

Poverty plays a major role in rendering people vulnerable to HIV. Poverty is linked to HIV in a complex way, such as through gender inequality. As Wu (2019) points out, poverty contributes to “life disruption and exposure” to a dangerous environment (p. 39). The low economic rate had been associated with earlier sexual experiences. Further causes of HIV transmission are lower condom use at last sex act, having multiple partners and engaging

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in sexual activities, first sex act being non-consensual, having transactional sex to sustain livelihoods, and young girls being coerced into sexual activities with older men to sustain their survival (UNAIDS, 2017). In addition, women were prone to increased risk due to poverty, unemployment and financial reliance on their sexual partners.

According to Pascoe et al. (2015), socio-economic factors acts as a distal determinant of infections. Distal being national, cultural, legal factors that indirectly have an influence on health. Women who are poor are mostly economically dependent on men. The need for constant economic support may be a reason for early marriages and make it difficult for women to insist on safer sexual practices effectively. HIV risk becomes a low priority among people's daily concerns in poverty conditions. The poorest women may have to choose the behaviour that puts them at risk of infections such as intergenerational and transactional sex, earlier marriages and relationships that expose them to violence and abuse (Pascoe et al., 2015).

Young people with limited access to education, lack of opportunities, and bleak prospects may turn to sex as a way to pass the time (UNAIDS, 2017). UNAIDS reported findings that men were not only the only ones that had multiple partners, but women also sought sex from several partners for financial gain, placing them at an even greater risk of HIV infections and re-infections (UNAIDS, 2017). Women were prone to increased risk of HIV infection due to poverty, unemployment and financial reliance on their sexual partner. They also sought sex from several partners for financial gain, placing them at an even greater risk of HIV and re-infections, as mentioned earlier (UNAIDS, 2017). The study explored the effects of HIV and the impact it has had on them financially.

2.7.3 Psychosocial Factors.

Stigma is one of the most damaging social phenomena concerning psychosocial factors. In the study conducted on people living with HIV, it was found that stigma

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negatively affects their health outcomes, including lower visit adherence, non-optimal medication adherence, overall lower quality of life, and higher depression (Turan et al., 2017). Although research has documented the negative effects of stigma Turan et al. (2017) stated that some researchers tried to classify specific mechanisms and examine pathways through which PLHIV processed and experienced stigma relating to HIV, which affects their health outcomes.

Violence and gender inequity in relationships have been associated with increased HIV in women (Karim & Baxter, 2016). Rape and other forms of sexual violence increased women's risk of infection and re-infection, with some women remaining in sexually abusive relationships for economic reasons. Sexual abuse may well be socially constructed realities that women are resigned to experience in their lifetime. According to Karim and Baxter (2016), research has shown the links between HIV, gender inequity, and gender-based violence (GBV) and what lies in the patriarchal nature of society. The study conducted on the dual burden of gender-based violence and HIV in adolescent girls in South Africa shows that IPV and HIV are intertwined, and efforts made to eliminate GBV/IPV could improve sexual and reproductive health encounters as well as HIV amongst adolescent girls. GBV and HIV require substantial rethinking on a structural level, and a rethinking of masculinity and femininity, with an emphasis that places values on the rights of women.

According to Karim and Baxter (2016), women who have experienced physical or sexual violence by their partners have increased rates of adverse health outcomes, including short- and long-term physical, psychological and social impacts. In South Africa, women with violent or controlling male partners were more likely to acquire HIV compared to women who had not experienced partner violence. GBV is regarded as a major problem in South African communities and is exacerbated by unemployment, poverty and alcohol abuse. They further indicated that women's social and economic dependence on their male counterparts puts them at a greater psychosocial disadvantage and heightens the risk of

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HIV (Karim & Baxter, 2016). Failure to negotiate safer sex, after having many sexual partners, early sexual debut, premarital sex and even unsafe marital sex all increased the risk of HIV infection (Karim & Baxter, 2016).

The WHO (2017) reported a correlation of forced sex with the risk of HIV infections. Being HIV positive does not preclude women from further sexual abuse and violence, even within a marital relationship. Women remain silent about rape, violence and other injustices as feelings of shame, stigma and discrimination, whether real or perceived, often keep women from reporting their experiences of violence. Often survivors of violence are not effectively supported by health and public services. Women have the courage to share their stories and are able to give courage to other women that are unable to speak of their injustices. These women are empowering themselves in doing this and empowering other women. Olley et al. (2017) stated that depression also remains a major psychological drawback in HIV infection, and it could persist when interventions are not begun. In other studies, they pointed out that several psychosocial factors such as self-esteem, stigma, social support and discrimination have been consistently associated with depression (Olley et al., 2017). The study explored the psychosocial influences affecting women living with HIV and coping strategies utilised in overcoming depression by keeping a stable mental state.

2.7.4 Cultural Factors

Kemboi et al. (2011) highlighted that the impact of culture on sexual behaviour was complex at both individual and societal levels. People's control over their sexual lives and choices is, in turn, shaped by gender-related values and norms defining masculinity and femininity. Some cultural factors have shown significant and somewhat increasing risks for HIV in cross-type generational relations; these relations have at least a 10 year age gap between partners (Kemboi et al., 2011). Young females have relations with older men as

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sexual partners referred to as a 'sugar daddy'. For young women, this is a sign of prestige amongst peers, a way for them to pay for their daily living, education and luxuries (Chelala, 2013). Family pressure encourages young females to seek relationships in the belief that these will improve the family's financial situation (Chelala, 2013). The study explored the cultural background of women living with HIV, indicating if there were cultural beliefs preventing them from leading a normal life with HIV.

Mampane (2018) mentioned that in South Africa, the label 'blesser' and 'blessee' phenomenon had been salient through media since 2016. Transactional sex means older, richer men (blessers) enticing younger women (blessees) using money and expensive gifts for sexual favours. The study conducted on transactional sex and HIV in the rural areas revealed rural women were silenced and not allowed to report their cases or speak about their marital rape, IPV and GBV; and in addition, this study identified marital rape, IPV and GBV as a high risk in HIV infection (Mampane, 2018). Poverty is prevalent in rural areas and has compelled women to engage in transactional sex to survive, earning a living (Mampane, 2016, cited in Mampane, 2018. p.2).

According to Nandoya (2014), men and younger women get into different relationships, such as marriage, polygamy, early marriage, multiple sexual partners. Older men are more sexually experienced and are prone to HIV infection, which is then passed on to younger women (Nandoya, 2014).

Mampane (2018) stated that women often are limited in speaking out or unable to negotiate the use of condoms in their sexual encounters. Power relations and inconsistent condom use between men and younger women due to financial and material exchange for sex are often characterised by a continuous change in sexual partners and inconsistent condom usage (Mampane, 2018).

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According to Nandoya (2014), a study in Kenya stated that the Turkana community struggled with early marriages between older men and younger women in the name of their parents receiving cows as wealth. Great respect is shown to elders, which makes it difficult for young women to reject or oppose older men placing young women at a disadvantage in requesting condom use (Nandoya, 2014).

Culturally defined values are determined and reinforced through traditional practices. These cultural practices, norms, values and traditional influences are important determinants in the HIV vulnerability for both men and women. Cultural factors could also be used to prevent the spread of HIV. The reluctance by men of all ages to use condoms is one of the primary catalysts of the HIV epidemic. The wider the gap between men and women in sexual relationships, where the man is older (than the woman) and providing financially, the less likely he is to wear a condom.

According to Nandoya (2014), harmful cultural practices, which include widowhood related-rituals, female genital cutting, and sexual cleansing, increases the risk of HIV. These types of practices are, however, justified in the name of culture and traditional values. Whilst cultural values and traditions are important to communities, it is crucial that an individual's health is not compromised.

Kemboi et al. (2011) indicated that common cultural factors influencing the widespread of HIV include polygamy and wife inheritance. In polygamous relationships, partners that become infected are more likely to spread the virus to their other partners. Polygamy, which is still a common practice in most parts of Africa, is particularly risky if men are allowed to have many wives, and if condoms are not used, or if wives seek extramarital relationships. If any partner becomes infected, the others are at high risk of infection during the window phase (Kemboi et al., 2019). In some regions in countries such as Kenya, wife inheritance is the practice where the brother of the deceased 'inherits' his

brother's wife (Chelala, 2013). If the brother died of HIV-related illness, thus infecting his widow, whom he has inherited, this would spread the infection. Customs also state that after a husband has died, the widow is 'unclean' and must undergo a cleansing ritual by having sexual intercourse soon after the death of her husband, even if he died from AIDS (Chelala, 2013).

2.8 Coping Strategies for Women Living with HIV

Greenaway et al. (2015) defined coping as a necessary process that was important to adaptation and survival and illustrates how people deal with and learn from stressful situations. Coping mechanisms were strategies that people employ to deal with minor or major stress and natural changes that they experience in life. People are not always able to cope with the difficulties that they face, as not all coping mechanisms are equally effective. Some use emotion-oriented coping, and avoidance-oriented coping when encountering a difficult, stressful, or upsetting situation (Skinner & Zimmer-Gembeck, 2016).

Akintola et al. (2013) indicated that emotion-focused coping was when the individual uses strategies such as denial, anger and impatience, which causes considerable stress for them as it does not solve their problem. Avoidance-oriented is the avoidance of a problem that may be used to maintain hope and optimism, but it may also be used to deny both facts and the implications of the truth. It is generally used when individuals believe they are unable to change a stressful situation (Akintola et al., 2013). Coping strategies are explored in this study as a coping mechanism for women living with HIV. Below are some of the coping strategies used by women living with HIV.

2.8.1 HIV Support Groups

Bategana et al. (2015) indicated that some HIV programmes use support groups to allow healthcare workers to provide information to all people living with HIV. The first

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support groups were HIV post-test clubs, supporting clients who tested positive for HIV. The WHO (2013) initiated interventions through support groups to address retention and adherence of people living with HIV that receive ART. The WHO and the PEPFAR promoted peer support groups which were facilitated by trained people living with HIV to address their special needs. These groups served to allow sharing of experiences, reducing stigma/discrimination, encouraging disclosure, improving self-esteem and coping skill, psychosocial functioning, medication adherence and improving retention in HIV care (WHO, 2013). Support groups are generally offered and supported by non-governmental organisations (NGOs), community-based organisations (CBOs) and civil society that convene health facilities in the community (WHO, 2013).

Pauldel and Baral (2015) indicated that coping with the multidimensional and complex effects of stigma and discrimination was never easy for women, especially where their social status was low. Women that are HIV positive have different needs that are best addressed through support groups (Pauldel & Baral, 2015). Support groups are associated with reducing anxiety, loneliness, isolation and depression (Pauldel & Baral, 2015). They offer a space for WLHIV to deal with and express their suppressed feelings in the company of women going through similar situations. This facilitates sharing of strategies for dealing with the disease. They learn strategies to securely disclose their HIV status and build a network of friends (Pauldel & Baral, 2015). The women meet new friends with whom to socialise and provide emotional support to each other. Women in these support groups become empowered to educate and value themselves in taking small steps to improve their lives both physically and emotionally (Pauldel & Baral, 2015). Support groups in this study were explored by women living with HIV as a coping strategy.

2.8.2 Religion as a Coping Strategy

Themes in the literature view religion as a source of support, a barrier or facilitator to treatment, a coping strategy, a palliative in AIDS care (Szaflarski, 2013). According to Ndiaye (et al., 2009), reports suggest that in Africa, religion is linked to HIV disclosure among women. More specifically, in their study in Burkina Faso and Mali, they found that women who viewed religion as important disclosed more frequently, but social support was not linked to disclosure (Ndiaye et al., 2009). Disclosure is relevant for prevention programmes.

A study in the South-eastern U.S. with a sample of black, predominantly Christian women with HIV revealed that 95% considered spirituality important (Dalmida et al., 2012). According to Oliveira et al. (2015), women believe that religion helped them overcome barriers imposed by HIV through finding the will to live and the meaning of life, evaluating the idea of death and redefining personal relationships. Religiosity seems to benefit the fight against disease because it offers comfort and a feeling of strength among infected people. It facilitates accepting the disease and relief from fear (Oliveira et al., 2015). The spiritual comfort from religiosity minimises the biopsychosocial impact of HIV infection (Oliveira et al., 2015). Therefore, nurses should understand women's religious dimension and recognise it as an assistant in the therapy process (McIntosh & Rosselli, 2012). During the planning of assistance, they should consider it to improve the quality of life according to these women's reality (McIntosh & Rosselli, 2012).

According to Kremer and Ironson (2014), HIV-positive people used spirituality to cope with life's usual events on top of HIV-related stress, e.g., facing death, stigma, poverty, limited healthcare. Spirituality is a connection to a higher presence independent from religion, institutionalised spirituality (Brown, 2012). Brown (2012) stated that religion and spirituality were closely woven into the South African public and private life. Scriptures

teach that God as the father of the family, provides, protects, comforts, and has authority (Brown, 2012).

The church plays a role as a coping strategy because all Christians are seen as one system (Brown, 2012). If one is dysfunctional, the whole system is affected. In a fellowship of believers, if people were burdened, the whole church shared the burden and carried it together (Brown, 2012). The church showed empathy and sought comfort in providing for the poor or affected by HIV (Brown, 2012). Prayer in cultures was explored as a coping strategy in this study.

2.8.3 Treatment as a Coping Strategy

Paudel and Baral (2015) stated that women view treatment as essential in maintaining their health. Treatment using coping strategies where the stigma and discrimination come from many areas. i.e. it is complex, is difficult to put into effect, especially for women from a low socio-economic background (Paudel & Baral, 2015). These women have unique needs which can be addressed through support groups (Paudel & Baral, 2015). This facilitates women in sharing strategies to securely disclose their HIV status by building a network of friends and family to provide emotional support (Paudel & Baral, 2015). These women try to focus their attention on other aspects, trying to adjust to the presence of HIV in their lives. Those who follow up the drug treatment regime cope well with the disease (Paudel & Baral, 2015). Women who accept their HIV-positive status represent the will to live and create life prospects for the future. The study highlights that women faced higher levels of discrimination from society due to being women (i.e. their gender) and that the rejection and discrimination have extended to treatment by health care professionals (Paudel & Baral, 2015). Thus we see that stigma comes from many areas, it is complex and difficult to address, making support groups so important for women. The study further asserted that to achieve a greater quality of life, the adherence in treatment for

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women has to go through a behaviour change that involves adaptation (Paudel & Baral, 2015).

Adherence to treatment encourages psychological adjustment and appropriate care during HIV infection, preventing any living conditions that affect commitment (Dalmida et al., 2017). The process of confronting the new health conditions of women with HIV is directly linked to the expression of their health situation without fears and prejudices that will reflect directly on possible relationships that they may have (Paudel & Baral, 2015).

Dalmida et al. (2017) reported that although there has been major progress in HIV treatment and control, the absence of a cure and continued spread of the virus make it a difficult chronic disease to treat. However, psychosocial factors, including coping, social support, quality of life, have a significant impact on an HIV patient's medical decision-making and treatment adherence (Dalmida et al., 2017). The study conducted was to examine religious and psychosocial factors that correlated and predicted > 90% ART adherence in PLWH (Dalmida et al., 2017). This study revealed that half of PLWH struggled to achieve optimal ART adherence and required support (Dalmida et al., 2017).

The decision to adhere or not adhere to ART depends not only on a patient's medical characteristics but also on the individual's belief about ART, complementary/alternative medicine and spirituality (Dalmida et al., 2017). They further reported that social and psychological factors reflecting emotional adjustment to HIV were related to better medication adherence (Dalmida et al., 2017). Poorer physical functioning was associated with stopping ARTs, whereas working and maintaining a regular daily routine were associated with better adherence. Therefore, those who adhere to ART cope better than those who cannot adhere to the medication (Dalmida et al., 2017). The current study explores treatment as a coping strategy in women living with HIV on a daily basis.

2.9 HIV Prevention Programmes

The aim of HIV prevention programmes is to reduce the risk of HIV transmission. They were implemented to protect an individual and their community or roll out as public health policies. HIV prevention programmes focused primarily on preventing the sexual transmission of HIV through behaviour change. Some researchers say that the 'Abstinence, Be faithful, Use a condom' (ABC) approach is the reason why HIV infection rates have fallen in Kenya, Zimbabwe and Uganda in the 90s (Cohen, 2005 & Green, 2003). Evidence revealed that by the mid-2000s, HIV prevention programmes needed to consider the socio-cultural, economic, political and legal context (UNAIDS, 2014b). This meant that the ABC approach was replaced with programmes of 'combination prevention' (UNAIDS, 2014b).

According to the UN Programme on HIV (UNAIDS, 2014a), the combination of prevention supports a holistic approach through which HIV does not have one (single) intervention (such as the distribution of condoms) but the simultaneous use of interrelated biomedical, behavioural and structural prevention strategies. Combination prevention programmes examine factors specific for each setting, such as levels of infrastructure, local culture, traditions, populations most affected by HIV (UNAIDS, 2014a).

UNAIDS (2016) pointed out that there were effective preventions available and to target people who needed them, and it was necessary to speed up the pace of prevention and treatment approaches to bring HIV to a more manageable level. HIV prevention coverage was not systematic; it was fragmented. Improving services that held back HIV transmission to mother and child had not been the same in other pivotal prevention areas, particularly in financing and instituting programmes for key affected (UNAIDS, 2016).

2.9.1 HIV Prevention Programmes in South Africa

Healthcare is delivered through two modes: horizontal, comprehensive primary healthcare through public healthcare systems and vertical, which select specific interventions (Msuya, 2004/5). Vertical programmes are found more often where poverty predominates, epidemics flourish, and general health services are poor (Elzinga, 2005). Kawonga et al. (2013), in a local study, measured the extent to which general health service (horizontal) managers, exercised authority over the HIV programme's monitoring and evaluation function to explore factors that may influence this exercise of authority.

In 1994 South Africa instituted a national HIV programme run by a national HIV directorate, HIV managers at provincial and district levels, several sub-programmes (e.g., for HIV counselling and testing, prevention of mother-to-child HIV transmission, and ART) coordinated in separate silos, indicating further verticalisation (Kawonga et al., 2013). This shows that chronic disease services are fragmented, with the HIV programme being vertically controlled and administered in a 'silo' within the health system (Kawonga et al., 2013). They concluded that these programmes addressed only a fraction of the need for healthcare, creating duplication, inefficient facility utilisation by recipients, and gaps in care (Kawonga et al., 2013).

The South African National Department of Health (NDoH) commenced the Integrated Chronic Disease Management (ICDM) model (NDoH, 2013). The model uses a diagonal approach to health systems strengthening, integrating the vertical HIV programme with the horizontal general health system. The national pilot of the ICDM model began in three provinces, Gauteng, North-West and Mpumalanga in 2011 (NDoH, 2013). The ICDM model was introduced as a response to the dual burden of HIV and non-communicable diseases (NCDs) in South Africa, one of the first efforts made by the African Ministries of Health (Amehet al., 2017).

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South Africa hopes to expand its partnerships in prevention, particularly in the area of key populations. They continue to partner with the South African NDoH in support of activities targeting high-risk populations. Amet et al. (2017) illustrated that the ICDM model has a health facility, community and population element. In health facilities, services were restructured to improve the operational efficiency and quality of care, and in communities, ward-based primary health care (PHC) outreach teams provide 'assisted' self-management to promote individual responsibility (Amet et al., 2017). The study on the quality of integrated chronic disease care in rural South Africa to the user and provider perspective illustrated that the rural sub-district of South Africa and study's findings could not be generalised to PHC facilities in the urban and semi-urban areas in provinces in which there were pilot studies.

According to Carmona et al. (2018), The South African National HIV programme had achieved substantial antiretroviral therapy (ART) coverage over the last decade. The coverage expansion was supported by the national strategic plan for treatment, care, support, prevention and surveillance linked with policy and guideline changes, allowing for earlier ART initiation (Carmona et al., 2018). It is anticipated that if the ART scale-up continues, the increase in access to treatment and reduced stigma will lead to treatment initiation earlier in HIV infection (Carmona et al., 2018).

Van Dyk et al. (2017) indicated that although there are many HIV prevention success stories worldwide, sub-Saharan Africa still has challenges. HIV prevention programmes were often not well planned since the focus was often on singular and short-term change. Therefore, it was recognised that for these programmes to be effective, a combined approach to HIV prevention would be necessary and entail a combination of biomedical, behavioural and social/structural approaches (van Dyk et al., 2017). The approaches are, therefore, discussed in detail below.

2.9.2 Biomedical Approach

Biomedical approaches use both clinical and medical approaches to reduce the transmission of HIV, for instance, male circumcision. According to the WHO (2020, para. 3), “the Voluntary medical male circumcision (VMMC) reduced men’s heterosexually acquired HIV by 59%”. VMMC is one of the powerful and cost-effective HIV prevention tools in settings with a high burden of HIV. It was rolled out for HIV prevention among adult men and adolescent boys (15 years and above) who often do not look for healthcare.

WHO (2020, para. 2) stated the updated guidelines “on the safety of prequalified device-based male circumcision methods and on interventions to enhance service uptake among men”. These ground-breaking surgical methods improve safety and make the procedure more comfortable, increasing access and making it more acceptable to young men (WHO, 2020). Male circumcision provides minor protection and is part of a broad HIV prevention programme. Other services include HIV testing, safer sex education, condom promotion, risk-reduction counselling, pre-exposure prophylaxis, and STIs identification and treatment (WHO, 2020).

Morris et al. (2017) highlighted that medical-male circumcision (MMC) was a one-time intervention providing life-long partial protection against HIV and other sexually transmitted infections (STIs), as well as reducing the risk of female-to-male transmission of HIV and development of cervical cancer in women. Van Dyk et al. (2017) stated that MMC reduced the risk of female-to-male sexual transmission of HIV, and it should never be perceived as sufficient protection against HIV. It should be emphasised that male circumcision reduces but does not eliminate the risk of HIV infection (Dyk et al., 2017).

MMC reduces the risk for women, uncircumcised men and eventually, infants. With an increasing number of circumcised males, the rate of human papillomavirus (HPV)

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infections are decreasing in females. This means that MMC does not benefit only males but also their partners or spouses (WHO, 2016).

Another prevention strategy that put South Africa on the map was the ARV roll-out programme. Brown et al. (2014) suggested that ARVs prevention approaches may offer an even greater potential to reduce HIV transmission among high-risk populations. However, before ART can significantly impact the epidemic, all individuals taking the medication need to adhere fully to the medication regime and have suppressed viral loads all the time. They should have the best management for genital-tract inflammation, like STIs, and lower risk-taking behaviour or the idea that they may be less infectious (Brown et al., 2014). Padian et al. (2011) claimed that biomedical interventions should not be put in place alone to be effective but together with behavioural interventions. For example, when a man is circumcised, he will often be tested for HIV and receive counselling and education about condom use and safer sex (Padian et al., 2011). Programmes designed to promote adherence and safer sex among substance users with HIV will continue to be extremely important (Padian et al., 2011). Of importance is to note that for ARV programmes to work, they need to stress the importance of taking all their medication, following the treatment protocols properly and taking care of all their health issues plus, these initiatives have to look at changing people's behaviour.

Raiford et al. (2016) indicated that biomedical and other prevention methods might fail because individuals may not prioritise sexual health when experiencing demands to meet their basic needs such as food, clothing, shelter and employment. Individuals may need structural-level interventions that attend to these needs before or along with HIV risk-reduction education and programming that target reducing transmission and infection, including linkage to and retention in care and treatment (Raiford et al., 2016).

2.9.3 Behavioural Approach

Behavioural interventions address methods to reduce the risk of HIV transmission. For behavioural change to occur, communication forms part of a primary component in combination prevention (UNAIDS, 2016). Coates et al. (2014) indicated that behavioural interventions aimed to reduce the number of sexual partners individuals might have. It also improves treatment adherence amongst PLHIV, increases the use of clean needles amongst people who inject drugs and increases the consistent and correct use of condoms (Coates et al., 2014). The examples of behavioural interventions included providing counselling, handing out information (such as sex education), psychological support, assisting with safe feeding guidelines for infants, reducing stigma and discrimination and assisting with cash transfer programmes (Coates et al., 2014).

UNAIDS (2016) reported a notable pattern of not prioritising and discontinuing combination-HIV-prevention programmes in recent years. Many countries invested in programmes that promoted abstinence and faithfulness, even though they did not show much success in reducing the number of sexual partners, multiples sexual partnerships, age at sexual debut and pregnancy in teenagers (UNAIDS, 2016).

2.9.4 Social/Structural Approaches

Social/structural interventions focus on the aspects that allow individuals or groups to become vulnerable to HIV infection. These aspects are economic, political, social norms, environmental factors and gender roles. UNAIDS (2016) revealed that HIV-related vulnerabilities were driven by inequalities and prejudice ingrained within society's social, legal and economic structures. Gender inequality is created and maintained by social norms that demand culturally appropriate roles and behaviour for both men and women. Gender inequality is structured into hierarchical gender roles with lower levels of education

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amongst women, fewer public roles, lack of family, social and legal support, and lack of economic power.

Heymann et al. (2019) stated that institutionalised economic inequalities keep money, land and other resources out of a women's reach, caused women to be financially dependent. A woman's subordinate status influences her ability to negotiate using a condom with her partner. Also, because women do not have access to basic structures such as transport, it will restrict them from accessing proper healthcare as they cannot travel to clinics. A way of dealing with these structural barriers is to empower people to access HIV prevention services. Empowering adolescent girls and women from groups most affected by the disease gives them rights to receive a high-quality education, enjoy a healthy lifestyle, and take steps to protect themselves. HIV education is a basic tool for the combination-HIV-prevention programme (UNAIDS, 2016).

Structural interventions were (and still are) difficult to administer since it dealt with deep-rooted socio-economic issues that included gender inequality, poverty, and social marginalisation and relied on governments' cooperation to achieve legal or policy reforms. According to UNAIDS (2016), structural issues created gaps in HIV prevention for women facing gender inequalities, and this includes GBV, which worsens their vulnerability to HIV, blocking their access to HIV-related services. The consent required by parents or carers is an obstacle for HIV treatment and sexual and reproductive healthcare services. Adolescent girls and young women who are the key populations also face particular challenges such as violence and human rights violations. Homophobia would be seen as a hurdle to HIV services for gay men and for those men who have a sexual relationship with them. (Bearing in mind that not all men who engage with sex with men are gay). Same-sex relationships, cross-dressing, sex work, and drugs are stigmatised against and in most parts of the world, criminalised, which then obstructs HIV prevention services and increases risky behaviours.

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The stigma and discrimination involving the key populations vulnerable to HIV weaken access to HIV prevention and other healthcare services (UNAIDS, 2016).

Several structural interventions to address these issues were recommended to create awareness that strengthens legislation, law enforcement, and programmes that end intimate partner violence (UNAIDS, 2016). First, world union, country partnering to implement harsh punishment to offenders and voluntarily allow for individuals to feel at ease to disclose their experiences; second, increase educational regimes for young girls to access secondary education so that they can seek appropriate employment that creates self-independence; third, provide basic financial training and entrepreneur programmes to empower women on how to be financially independent as well has to control their finances to sustain their families (UNAIDS, 2016).

Women need to be empowered on their rights to remove third-party permission, which stops them from gaining access to sexual reproductive health services. Education, supportive care and counselling need to be available for women to know and understand their status (UNAIDS, 2016).

In line with this, in June 2016, the South African government launched the three-year She Conquers campaign to decrease HIV infections, improve overall health outcomes, and develop opportunities for adolescent girls and young women to determine their future (Subedar et al., 2018). The campaign shifted from disease transmission and associated stigma to a narrative of power, including programmes on sexual and reproductive health, HIV testing, GBV, positive parenting, tertiary education and employment (Subedar et al., 2018).

In 2019, HEAIDS rebranded into Higher Health, adopting health and social development programmes at its partners comprising 6 public universities and 50 technical and vocational education and training (TVET) colleges (Higher Health, 2020). These

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programmes responded to widespread challenges confronting students, including GBV, psychological stress, substance use and maintaining sexual health. The model for delivering healthcare on campuses was based on the idea that students must take charge of their wellbeing. There were areas in the model: HIV prevention and treatment; TB prevention and treatment; sexual and reproductive health; GBV, mental health; alcohol and substance abuse prevention; gender diversity and human rights; and disability and human rights (Higher Health, 2020, p. 9). Given young women's vulnerability to HIV infection, Higher Health focused on young women. This was through the PEPFAR-sponsored DREAM, an initiative which recognised that straightforward, practical steps could empower young women reducing their possibility of being infected by HIV (Higher Health, 2020). A grant from the Global Fund for teenage females and young adult women at TVET colleges allowed a cohort from 10 colleges to test regularly, link to ARTs if positive, and for the majority who are negative, there is counselling on HIV prevention methods, including condoms and pre-exposure prophylaxis (PrEP), along with contraception and sexual reproductive health services (Higher Health, 2020).

2.10 Theories and Models of HIV Prevention

This study's theories and models are based on behavioural change interventions that aim to lower the spread of HIV. Each behavioural model has a unique but limited number of theoretical methods that have determinants. These methods and behavioural prediction roles guide development for an effective behavioural change. The theories used in this study are as follows: social cognitive theory, social and behaviour interventions, social-ecological intervention and feminist theories.

2.10.1 Social Cognitive theory

Dilorio et al. (2000) showed that social cognitive theory had been broadly used to explain health behaviours, with only one construct in this model, self-efficacy being well

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established. They explained that the role of other social cognitive constructs had not been looked at much in the research conducted on HIV prevention (Dilorio et al., 2000). Their study looked at the social cognitive-based model for condom use among college students. The findings that self-efficacy was directly related to condom use behaviours indicated support of the condom use model (Dilorio et al., 2000). Thus, the study was positive as it contributes to research that can prevent HIV through condom use through understanding people's behaviour. Because in this study, it was discovered that people had anxiety about themselves, but the anxiety was not related to using condoms.

Bandura (1997) stated that self-efficacy is people's beliefs, mentioning their capabilities to produce designated levels of performance areas; this allowed them to exercise their influence of events that could affect lives. Individuals with high self-efficacy believe that they have the power to influence and even control their environment, while people with low self-efficacy believe that failure results from low ability (Peeler & Jane, 2006). There are many reports of interventions that have led to an improvement in teenagers self-efficacy concerning responsible sexual behaviour (Lawrence et al., 1990).

Olem et al. (2014) highlighted that many foundations of cognitive behavioural therapy, such as identifying and changing negative thoughts, improving adaptive coping skills, and problem solving are appropriate when dealing with the difficulties in medication compliance and improving health outcomes. People changing their beliefs about a chronic health condition and its treatment can help improve motivation to become actively involved in care, and providing specific skills can improve observance of treatment regimens (Olem et al., 2014).

The attempts to slow the HIV epidemic worldwide have led to a clearer understanding that the battle is not merely about using condoms or adherence to medication. Rather, HIV risk and AIDS care involve complex behaviours influenced from

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multiple levels, individual's knowledge, attitudes, emotions, and risk perception, to power dynamics between partners, accessibility of services, economic inequalities, criminalisation of vulnerable groups, and policies that make HIV a priority health issue (Kaufman et al., 2014).

Although a lot has been done in the last two decades to counteract HIV stigma, it remains a significant obstacle to public health worldwide and a huge problem in HIV treatment, prevention, and support (Han et al., 2018). Research has documented high levels of stigma, leading to physical and psychological pain, reduced economic income, increased alienation from family and friends, resistance to HIV testing, and non-disclosure of HIV status to sexual partners (Han et al., 2018). The profound negative effects of HIV stigma have resulted in calls for more social support to reduce HIV stigma associated with lower levels of mood disturbances and depression, better adherence to ART, and less high-risk sexual behaviour (Han et al., 2018).

Olem et al. (2013) indicated that there is a critical need to increase HIV treatment adherence to improve HIV prevention. Starting treatment at the right time and complying with it can significantly reduce the viral load on both an individual and a community level. To prevent new infections, a reduction in both individual and community viral load can reduce the likelihood of HIV transmission following exposure. For those who already have the virus, compliance has a positive impact on increasing people's life spans (Olem et al., 2013).

These skills need to be identified early and modelled accordingly. According to Bandura's (2002) social cognitive theory, an individual notices something external and after repetition he/she begins to internalise and copy it; they are rewarded for that behaviour, and learning is internalised. However, this theory was not applied in this study because it only focuses on one construct, which is self-efficacy. The other constructs are not attended to. According to theorists of cognitive behavioural therapy, knowledge on its own does not and

cannot lead to behavioural change; people need cognitive, behavioural and social skills (Cherry, 2020).

2.10.2 Social and Behavioural Interventions

According to Pantalone (2014), cognitive and behavioural interventions have also been shown to be effective in improving health behaviours. They have worked well to increase the use of barrier protection, focusing on skills training, increasing self-efficacy, and applying problem-solving strategies. Also, they worked well to improve medication adherence and cognitive strategies to reduce the dysfunctional thinking that can get in the way of pill-taking, and problem solving to make sure that there are doses of medicines on hand, to prevent new HIV infections and to improve the medication adherence- and thus, to extend the lives of people currently living with HIV (Pantalone, 2014).

Changing people's behaviour towards HIV prevention is extremely difficult, but it can lead to a decrease in HIV. There are various methods such as abstinence or delaying sexual debut, condoms, safe sex, monogamy, reduction in the number of partners, and VCT. However, abstinence is not an option for many women. Rao et al. (2007) revealed in their study on stigma and social barriers to medication adherence that PWLHIV illustrated that total adherence was necessary for favourable health conditions. They also indicated that youth adherence is poor in active anti-retroviral therapy (HAART). Furthermore, they said there is little research that explains why youth experience difficulty in sticking to treatment (Rao et al., 2007). There are many published reports of HIV-related health behaviour change interventions that aim to and do, decrease unprotected sex across populations as well as other interventions that increase medication adherence; many of these interventions have worked well (Pantalone, 2014).

According to Bello et al. (2017), alcohol misuse is one of the critical factors underlying the remarkable vulnerability to HIV infection in many parts of sub-Saharan

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Africa, especially in urban settings. Across the sub-continent, alcohol was linked with HIV risk via unprotected sex, multiple sexual partnerships, transactional sex, and sexual violence (Bello et al., 2017).

Rehm et al. (2017) also supported the idea above by indicating that alcohol had psychoactive effects, resulting in poor judgement, dampen reasoning skills, and reduce one's sense of responsibility. Alcohol alters the brain's gamma-aminobutyric acid receptors, and it changes the body's serotonin levels, resulting in disinhibition – reducing anxiety about the consequences of one's actions; therefore, the assertions about alcohol and sexual behaviour causality was strengthened by studies demonstrating links between drinking contexts and the likelihood of sexual risk behaviours (Rehm et al., 2017). Cherish et al. (2014) emphasised that alcohol abuse in Africa is characterised by irregular episodes of heavy drinking, frequently in the form of weekend bingeing. These drinking patterns affect the decisions people make about sex, condom use, and the ability to negotiate condom use. Studies have demonstrated that women with heavy episodic drinking patterns were more prone to use condoms inconsistently and incorrectly, experience sexual violence and acquire STIs (Cherish et al., 2014).

Society conveys many messages on HIV prevention. The use of a condom as a prevention measure assumes that women can negotiate condom use with their partners. In some instances, women do not support condom use because it will prevent them from having children. Social, cultural and environmental norms play a role in behavioural change for HIV prevention and STIs (Cherish et al., 2014).

UNAIDS (2018) reported that few HIV policies, services for HIV prevention, or research projects adequately address the harm caused by alcohol-HIV. This is surprising as southern Africa have massive HIV and alcohol burden regions; however, lower alcohol use regions have lower HIV rates. For example, South Africa has the largest number of HIV-

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infected people (estimated 5.6 million) and the highest consumption of alcohol per drinker globally (UNAIDS, 2018). In South Africa, the burden attributed to alcohol excluded the effects on HIV acquisition or disease progression, owing to a lack of consensus, unsafe sex and harmful use of alcohol rank first and third in disease burdens estimates around alcohol-HIV causal links.

Although alcohol has been identified as one of the factors that contribute to people not being able to change effectively, there are other barriers that might seem to block progress towards behaviour change. For instance, an individual's good intentions to change behaviour may be undermined if they become discouraged and disheartened by perceived obstacles. An individual's attitude towards a given behaviour always depends on the belief about the advantages and disadvantages of the behaviour. According to van Dyk et al. (2017), individuals are likely to change behaviour only if they perceive the new behaviour as effective, beneficial and feasible in practice. They are prepared to alter their behaviour if they believe that behaviour is beneficial. For example, if the behaviour will decrease their risk of infection and if they know that they have social support from family, friends as well as the community.

Research into the prevention of HIV infection identified a lack of communication skills as one of the most significant obstacles in the way of behaviour change (van Dyk et al., 2017). People find it difficult to ask partners to use condoms, especially if they do not know their partners well. They are also often afraid that the partner may think that they have AIDS. Women, in many cases, do not have the power to negotiate condom use with their husbands or partners (van Dyk et al., 2017).

Raiford et al. (2016) stated that the economic strains, coupled with low education and employment, can impact personal resources available for basic needs. As a result, women often report significant levels of stress and lack of social support, which are

associated with a reduced likelihood to engage in health-protective behaviours (Raiford et al., 2016). Unsupportive sex partners and peers lead to the giving up of all attempts at safer sex. Van Dyk et al. (2017) pointed out that people often do not use condoms because they do not want to offend their sex partners due to fear of rejection. They stated that people often give up attempts to use condoms if they find it stressful to initiate or maintain the behaviour (van Dyk et al., 2017). Condoms are often associated with infidelity and a lack of trust in the partner; hence it is difficult to manage the partner's refusal to use condoms.

2.10.3 Social-ecological Model (SEM)

The SEM recognises the entwined relationships between individuals and the environment in which they live (Gombachika et al., 2012). The model looks at the “complexities and interdependences between socio-economic, cultural, political, environmental, organisational, psychological, and biological determinants” (Gombachika et al., 2012, p. 2). It recognises that it is up to the individuals to establish and sustain changes in their lifestyle required to “reduce risk and improve health, individual behaviour is influenced by factors at different levels” (Elder et al., 2007, cited in Gombachika et al., 2012, p. 2). The levels as depicted in Figure 1; are relevant to the study because an individual's behaviour is influenced by each level, such as the networks they belong to, the institutions and the community in which they are located, the national health policy of the country. Thus, programmes designed around SEM constructs could be key to improving health outcomes.

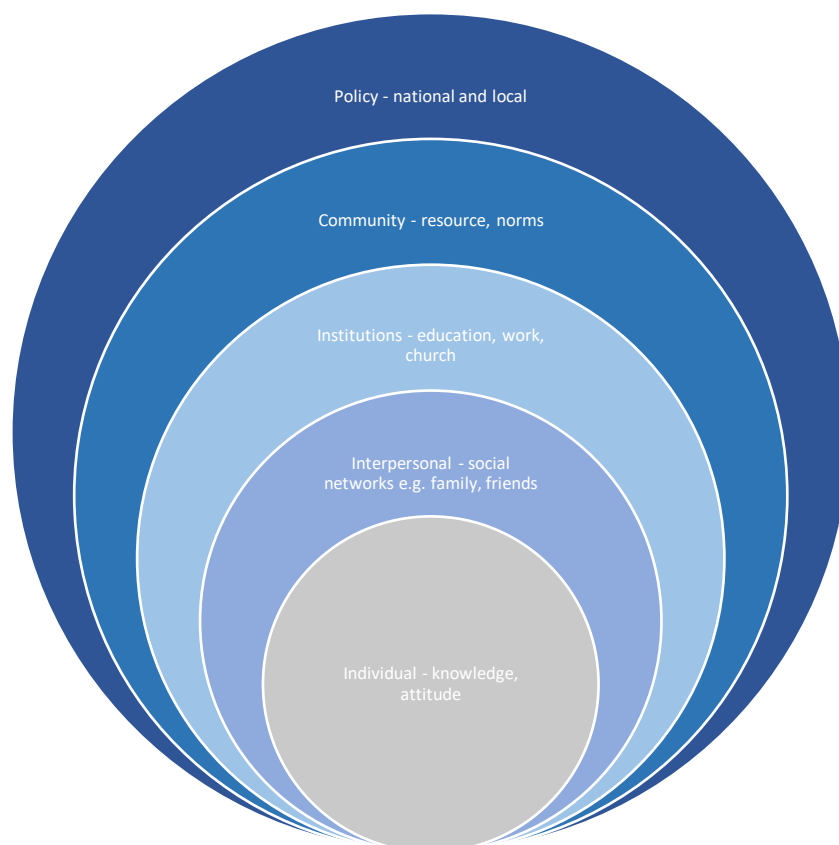


Figure 1: Social-Ecological model (SEM)

(Source: adapted from McLeroy et al., 1988)

Baral et al. (2013) developed the modified SEM calling it the MSEM comprising five layers of risk for HIV infection as depicted in Figure 2.

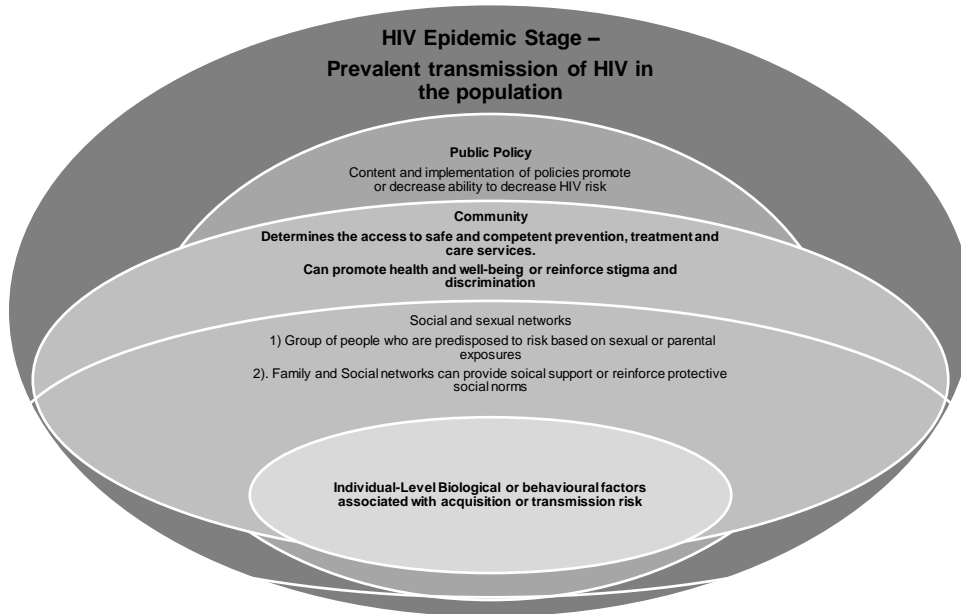


Figure 2: Modified SEM for HIV risk in vulnerable populations

(Source – Baral et al., 2013)

The MSEM modifies the SEM by modifying the levels of risk as well as adding the level of the HIV epidemic to it, and is based on the assertion that individual-level risks do account for the spread of disease but cannot account for the population-level epidemic dynamics (Baral et al., 2013). Because the SEM takes the individual within the whole of society into account systematically, including policy and its implications, it is a valuable approach. SEM is recognised as a methodical and coordinated approach for understanding and reducing a vulnerable population’s risk of disease (Oetzel et al. 2006, Gregson, 2001, cited in a Mahadevan et al., 2014, p. 89). The social-ecological model was applicable to this study because it considered the complex interplay between individuals, relationships, community, and societal factors. It allows people to understand the range of factors that put individuals at risk for HIV/AIDS or protect them from experiencing the disease.

2.10.4 Feminist Theory

The study has adopted the position of women and girls that are particularly vulnerable towards HIV, although it is not only due to their biology (sex and gender that is differentiated) but to the social construction of gender in a patriarchal society. Feminist theory is the lens through which society is viewed as patriarchal in which men have primary power, control resources and access to the resources and oppress women. Patriarchy means the manifestation and institutionalisation of male dominance over women and children in the family and the extension of male dominance over women in society in general (Lerner 1989). It does not imply that “women are either totally powerless or totally deprived of rights, influence, and resources” (Lerner 1989, p. 239). Thus, patriarchy describes the institutionalised system of male dominance.

Walby has defined “patriarchy as a system of social structures and practices in which men dominate, oppress and exploit women” (1990, p. 20). It is a system, not a natural biological entity. Following from this is the concept of sex, as in male and female, where men and women may be biologically different. Gender, which is the social construction of man and woman, such that men are viewed as active, and women passive, men occupy public spaces, such as paid work, with women in private spaces such as the home. Gender is “socially constructed, produced and reproduced through people’s actions; for example, dynamic and possible to change” (Ekström et al., 2004, p. 8). Gender is “‘the social product’ that we attach to notions of biological sex” (Kang et al., 2017). But there is an acknowledgement in this study that women have agency and are not merely passive beings that are acted upon as power shifts continuously. As women have inequitable access to resources in society as it is patriarchal, they experience marginalisation, stigma further compounded by the intersections of race, sexuality, class, age and other categories. Before exploring how the identity categories mentioned (race etc.) intersect, the concept of

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gender is looked at more in-depth. Because the distinction drawn between sex and gender is not so clear cut.

We understand that sex and gender are different and that gender is determined by sex. Butler (1990) unpacks the familiar binary distinctions between sex and gender by problematising them. She questions if we can refer to a given 'sex' and 'gender' by looking at how gender needs to be reformulated to encompass the pre-discursive power relations of 'sex' as a category (Butler, 1990, p. 7). Butler suggests that "sex is as culturally constructed as gender" and concludes then gender and sex are the same saying sex is a cultural norm because sex is no longer treated as something that is determined by the body (Butler, 2011, p. xii). Butler (1988) conceives gender as performative. Gender "is real only to the extent that it is performed" (Butler, 1988, p. 527). Butler views gender as socially constructed through performance; it is subject to small changes and keeps creating itself. To understand performativity, we need to think of performative as performance in a theatre in front of an audience. Gender is a performative repetition of acts associated with male or female (Butler, 1988). However, these actions have been socialised over generations to seem natural. There is no gender if there is no performance. As she says, "... gender proves to be performative ... gender is always a doing ..." (Butler (1999, p. 33). So, the term 'woman' is problematic as there are so many types of women it is not possible to find something common that is 'woman'. Gender is thus an unstable identity (Butler, 1999). Having problematised gender and shown that the category is complex, the next paragraph returns to the idea of how the categories of identities intersect.

Feminist theories have an understanding of how categories intersect such as age and race through a framework of intersectionality, which is valuable for understanding women who live with HIV and AIDS, as well as their empowerment. Intersectionality coined by Crenshaw in 1989 is useful for looking at how women intersect with age, race, socio-economic levels. Intersectionality came out of the black feminist movement, and is rooted in

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black feminist scholarship, an approach that focuses on multiple historically oppressed populations (Bowleg, 2012). Intersectionality, as a theoretical framework, states that: “multiple social categories (e.g., race, ethnicity, gender, sexual orientation, socio-economic status) intersect at the micro-level of individual experience to reflect multiple interlocking systems of privilege and oppression at the macro, social-structural level (e.g., racism, sexism, heterosexism)” (Bowleg, 2012, p. 1267).

In relation to this study, being HIV positive looks at one analytical category (the HIV status regarding health). However, the social category of gender and of race is critical to consider if one looks at the lived experiences of an HIV-positive black woman in terms of employment. In addition, where the social categories of age, being young or old, socio-economic status, being rich or poor, intersect with race and gender, then they must be considered but not as if they are added on to one’s identity but where they intersect for the individual. These social categories, race, gender etc., are not “independent and undimensional but rather multiple, interdependent and mutually constitutive” (Collins, 1995, Crenshaw, 1991, Cuadraz & Uttal, 1996, cited in Bowleg, 2012, p. 1270). Women have many identities and hold them simultaneously, a mother, a worker, a daughter, HIV-positive. When looking at empowering women who are HIV positive, it is important to acknowledge and recognise their lived experiences at the intersection of their multiple identities.

Gender is significant from the perspective too, because historically, women have been viewed as vulnerable and passive victims of the HIV epidemic. The US journalist Gena Corea covered the absence of women when the AIDS epidemic occurred in her book, *The Invisible Epidemic* (1992) (Gunnarsson, 2020). Historically women were invisible when the disease first broke out; women were marginalised and excluded from responding. However, women struggled to change this and fought for money for research about how HIV affected them (as women) (Psychology and AIDS Exchange Newsletter, 2018). If

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prevention and empowerment are going to be successful globally and locally, then women must be taken into account; their subordination, their structural inequality, and they have to be acknowledged as agentic actors in prevention processes and programmes. It is beyond the scope here to trace the journey of women activists responding to the AIDS epidemic. However, as this is a local study, it is significant to note that South Africa was another important site for feminist responses to AIDS. As apartheid was brought to an end in 1994, the women's movement was strong with health being critical as evident in media projects such as the journal *Agenda* and *Speak* magazine (Gunnarsson, 2020). Furthermore, the Treatment Action Campaign (TAC) was founded in 1988 by activist Zackie Achmat alongside 10 other activists. The first issue TAC took on was to confront the South African government for not making sure that mother-to-child-transmission (MTCT) prevention was available to pregnant mothers (Giliomee & Mbenga, 2007).

Male and females are biologically different, as stated earlier. Biologically women are more vulnerable to HIV infection than men given the composition of the female genital tract. Pregnant women may suffer discrimination from counsellors, telling them not to continue their pregnancy due to their HIV status. These are just two examples of the biological factors that do not affect men but have a negative impact on women. However, gender, as feminist theory has shown us, is socially constructed, prescribing norms and rules for behaviour and is also important to consider in this study. This is because gender determines how and what men and women are expected to know about sex, sex behaviour, pregnancy and STDs. Research has revealed that social constructions of ideal femininity for women are sexual innocence, virginity and motherhood, with female ignorance of sexual matters being a sign of purity which means that knowledge of sexual matters signals easy virtue (UNAIDS, 1999).

On the global scenario, women are more vulnerable than men for HIV transmission because of their biological as well as socio-cultural characteristic. An understanding of

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patriarchy and the social construction of gender, idealised notions of femininity and masculinity show women's socially constructed vulnerability. If something is socially constructed, it can also be changed.

In this study feminist theory was adopted to understand how women (through their sex and gender) are viewed much more vulnerable toward HIV biologically, financially and socially. Gender is seen as a 'social product' produced through a person's actions. The study's use of feminist theory illustrates that these participants are agentic and have multiple identities which they hold simultaneously, such as a mother, daughter, sister, worker and a person affected by HIV. The focus in the study remained on empowering women by allowing them to share their experiences, challenges, coping strategies and prevention measures and using these tools to not only empower themselves but to others as well. The researcher aims to ensure that the research will empower the participants by documenting their views and ensuring social change by presenting their results.

Social-structural issues that affect women differently from men are depicted in Figure 3. In addition, some relevant to this study are discussed in more detail under challenges faced by women living with HIV and AIDS, such as access to resources (education, employment), as this impacts on empowerment.

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Figure 3 : Structural issues affecting women

(Source - author's own)

Feminisation of poverty is critical to understand as women's power inequalities render them especially vulnerable to HIV infection (Wathuta, 2016). Globally, many healthcare services are for married women with children and do not meet the needs of adolescent girls and young women that are single (UNAIDS, 2020b). When resources are available, research has found problems with the provision and access of them by young women. For instance, a study's finding in Soweto, South Africa, found young women's experiences towards service providers attitudes were unsupportive; plus, they had to deal with power dynamics in relationships, communication issues with parents and community members, all of which served to prevent them from acquiring information and obtaining the required service despite knowing where to receive assistance (Lince-Deroche et al., 2015).

Feminist theory has opened up the categories of sex, gender and intersections of identities. Gender roles and ideal forms of femininity reveal women's positions (and men) in

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society regarding knowledge, such as sex, access to education, and resources in general. Gendered roles are further clarified by looking more closely at ideal forms of masculinity and femininity. Connell (1983, 1987, cited in Jewkes & Morrell, 2010) described the existence of multiple configurations of masculinity hierarchically organised and structured along the lines of gendered domination (men over women, powerful men over less powerful men, adult men over younger men). Hegemonic masculinity was refined by Connell and Messerschmidt (2005) to be “a culturally idealised form”. Thus, hegemony refers to a “cultural dynamic through which a male group sustains a leading position in social life” (Connell, 2005, p. 77).

This model conceives that the relationships among male individuals consist of four categories of masculinity: hegemony, subordination, complicity and marginalisation. These are relationships of dominance and subordination, and in South Africa, they are also racialised, and we need to take culture into account. However, it is not within the scope of this thesis to develop this line of thought further. Masculinities are multiple, fluid and dynamic and hegemonic positions are not the only masculinities available (Jewkes et al., 2015). Masculinities are constructed in ways that reflect poverty or power, regional cultures and neighbourhood dynamics; it is evident that subordinated men across the world are actors as well as acted upon (Jewkes et al., 2015).

Connell (2005) points out that masculinity is a relational concept, i.e., masculinity does not exist except in contrast to femininity. Connell also described emphasised femininities characterised by compliance with women’s subordination and an orientation towards accommodating men’s interests and desires (Jewkes & Morrell, 2010). In other words, women ‘agree’ with the unequal structuring of relations, do not challenge these relations, and ultimately collude in the unequal distribution of gender power with men (Jewkes & Morrell, 2010). Some forms of femininity do resist this but are sanctioned by society through marginalisation or stigmatisation, for instance, the treatment of lesbians.

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Understanding hegemonic masculinity and emphasised femininity lends insight into why men and for this study, why women behave the way they do, which in turn will inform empowerment programmes. For instance, one example of a black African hegemonic masculinity is found in the Zulu concept of *isoka*, an idealised heterosexual, virile man, who is desired by women, and whose prodigious sexual successes are the envy of other men (Hunter, 2005, cited in Jewkes & Morrell, 2010). South African masculinities endorse characteristics of physical strength, courage, toughness and an acceptance of hierarchical authority, but most of all, they demand that men can exercise control (over women and other men) (Morrell, 1998 cited in Jewkes & Morrell, 2010). This leads to violence being seen as acceptable by men, and often by women, as long as it is not too extreme. Other practices which flow from hegemonic masculinity involve sexual and other forms of risk-taking (Jewkes & Morrell, 2010).

2.11 Conclusion

This chapter discussed empowerment, the effects of HIV on women and the challenges they faced. It then provided a discussion on various coping strategies, HIV prevention programmes and the approaches informing them. Finally, the theories and models of HIV prevention were provided. In the following chapter, the research methodology will be discussed in detail.

CHAPTER 3

RESEARCH METHODOLOGY

3.1 Introduction

The chapter outlines the research design used in the study. It takes an in-depth look at the methodology, including the study design, population, sampling, data sources, data collection techniques and data analysis used. The issues of validity and reliability, and ethical considerations are also discussed. The main purpose of the study was to empower women through prevention programmes to reduce the spread of HIV, opportunistic infections and re-infection.

3.2 Aims And Objectives

This study set out to empower women living with HIV through prevention programmes, empower and educate HIV-positive women, share their experiences of being victims of this disease, and prevent re-infections. It also explored the effects of HIV as well as the challenges faced by women living with HIV. Further, this study determined the type of support needed to help women living with HIV cope with their challenges.

3.3 Research Design

The study was carried out within the qualitative research approach, using a qualitative descriptive and exploratory design. This study used a qualitative research design to empower women through effective HIV prevention programmes. According to Durand and Chantler (2014), a research design is more than just the data collection method (such as interviews). It refers to the logic of how the data would be collected. According to Silverman (2016), research designs depended upon cool, rational assessment of alternatives. These methods cannot always be 'right' or 'wrong', only more or less

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appropriate. The approach was suitable for this study and had many implications for the research design. It had various consequences for data sources, data collection techniques, data analysis, reliability and validity, sampling techniques, key terms and ethical procedures (Silverman, 2016).

According to Sitorus (2012), qualitative research methods often engage in answering the whys and how of human behaviour, opinions and experience of information which is difficult to obtain through quantitative orientated data collection methods. Qualitative researchers ensure to provide an in-depth and understanding of research in the social world whereby participants learn from their social and material circumstances through experiences, history and perspective about their social and material circumstances, their experiences, perspectives and histories. These practices transformed the world and turn the world into a series of representations, including field notes, interviews, conversations, photographs, recordings and memos to the self.

Qualitative research comprises the use and collection of a variety of empirical materials such as introspection, personal experience, life story, cultural factors, artefacts, interviews as well as observational, historical and interactions that describe the routine and problematic moments which provides meaning to the lives of individual's (Rutledge, n.d.). The research design plan describes how, when and where data will be collected and analysed. This design process helped the researcher to structure her approach in conducting the research in order to meet the objectives of the study. The context was empowering women through HIV prevention programmes, and the targeted population were women aged 18 years and older. The design fitted the study since it was used to explore the effects and challenges of women living with HIV.

According to Durand and Chantler (2014), qualitative research had a relativist-starting point as the aim was to explore how people understand events and phenomena.

Qualitative researchers started by assuming that there were different possible and legitimate understandings. Qualitative researchers are interested in multiple social realities, and they try to avoid assuming that their view of the world is valid and rationale. The study used a descriptive and interpretive approach that is analysed through qualitative methods discussed below.

3.3.1 Descriptive Research

According to Singleton and Straits (2017), the objective of the descriptive study, as the name implies, is to describe some phenomenon. The nature of the description, however, differs considerably from exploratory research. A descriptive study is much more structured. Descriptive research was used in the study to describe the phenomenon through interviews with HIV-positive participants, sharing their experiences with this illness. The researcher used data-gathering techniques, field research and content analysis. This presented a picture of specific details of a situation, social setting, or relationship as well as classifying the different types of risk that these participants face on a daily basis.

3.3.2 Interpretive Approach

IPA is an approach to qualitative analysis with a particular psychological interest in how people make sense of their experience (Smith & Osborn 2015). IPA requires the researcher “to collect detailed, reflective, first-person accounts from research participants” (Larkin & Thompson, 2012, p. 102). It provides an established, phenomenological focused approach to the interpretation. The interpretative approach was used in this study. The researcher conducted interviews that comprised open-ended and in-depth questions to understand how people experienced life being HIV positive. The aim was to explore the feelings of women living with HIV and empower them with skills to live a safer lifestyle. Face-to-face interviews were conducted empathically and in a natural environment. Furthermore, qualitative research allowed the researcher to reflect on her subjective

contribution to this research, rather than attempting to minimise researcher bias. The qualitative approach acknowledges that we are not removed from the contexts we study. In the section below, the study discusses the rationale for using a qualitative research approach.

3.4 The Rationale for Using a Qualitative Research Approach

Qualitative research methods were developed in the social sciences to enable researchers to study social and cultural phenomena. Qualitative researchers study people in their natural settings, to identify how their experiences and behaviour are shaped by the context of their lives, such as the social, economic, cultural or physical context in which they live. Therefore, qualitative research also seeks to embrace and understand the contextual influences of research issues (Silverman, 2016). According to Toews et al. (2017), qualitative research aims to understand people's experiences and perspectives which could influence how healthcare and social interventions are conceptualised, developed and implemented.

The research was naturalistic and attempted to study everyday life of different groups of people and communities in their natural setting. This allowed for selected in-depth issues, openness and detailed experiences as they identify and understand the categories of information that emerge from the data. This determined how people living with HIV unfolded in real-world situations, without manipulation, to the study phenomena as interrelated wholes rather than split up into subtle predetermined variables.

3.5 Research Participants

The population in this study refers to all women living with HIV who attend a support group at the Verulam Regional Hospice. This is a non-profit organisation that caters for HIV patients. A convenient sample comprising 10 participants from different race, economic and

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social groups who met the following criteria were selected: females who were between 36 and 58 years and HIV positive so that they could share this life-changing event. The researcher selected 10 participants from the Verulam Regional Hospice Association (a few more participants were included in case some decided to terminate the voluntary study). The selected 10 participants in the study consisted of the additional participants. The study had accepted 10 participants that spoke fluently and understood English. Women who were mentally or physically unable to participate in an interview due to their level of illness were excluded in the interest of doing no harm.

The study used a biographical questionnaire to obtain how HIV affected different races, religions, financial status, dependants, current partner relations and the period of the relations (see Table 1). Regarding race, seven participants were black, three Indian. Out of the ten, the study's participants belonged to four different cultural groups. This indicated each participant's cultural beliefs and barriers withstanding their prevention measures. In terms of religion, the study has indicated that most of the participants were Christian, Shembe, Zulu, and Islam.

All of the participants in the study have children, three with children over the age of eighteen, whilst others had children that were younger and were dependent on them. Three participants had two dependents, three participants had three dependents, and one participant had four dependents. The financial status of an HIV woman indicates whether or not the virus has made an impact on them financially. Most of the participants, i.e., seven were unemployed, two were employed whilst one worked part-time.

The study uses the relation period to indicate the participant's last relationship's time period. Seven of the participants were in a relationship, whilst three indicated they were not in a relationship. Two participants were in a relationship of zero to ten years, four in a

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relationship of a ten to twenty-year period, and three in a twenty to thirty-year period. One participant was in a relationship of a thirty-to-forty-five-year period.

Table 2: Biographical Information of Participants

Category	Category	No of participants
Age group	36–58 years	10
Race	Indian	3
	Black	7
Religion	Christian	7
	Shembe	1
	Zulu	1
	Islam	1
No. of dependents (children)	0	3
	2	3
	3	3
	4	1
Financial status	Employed	2
	Part-time employment	1
	Unemployed	7
Current relationship status	In a relationship	7
	Not in a relationship	3
Length of relationship	0–10 years	2
	10–20 years	4
	20–30 years	3
	30–45 years	1

Note: Total no. of participants 10

3.6 Sampling Technique

The study used the purposive sampling technique, which is referred to as an expert or judgemental sample. The main objective of the purposive sample is to focus on

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characteristics of interest within the population to produce answers to the research questions. This provides the study with logic that can be assumed to be a representation of the population. This technique was acceptable, and the judgement of the researcher was used in selecting participants that were affected by HIV.

The researcher used HIV-positive women from the Verulam community that fitted the research criteria which needed to be reached in empowering women through prevention programmes alternative. Specific selection criteria were used to recruit participants. The study was conducted in the Verulam community, an organisation that cares for HIV patients. The study focused on racial groups: Indians and Blacks from different socio-economic backgrounds and religions. A letter was written to the manager of the organisation, and an appointment was made according to the availability of the manager. All information was treated confidentially. This form of sampling used in the study, purposive sampling, offered much more robust, less tenuous inferences than inconvenience sampling. However, such inferences were dependent on the researcher's judgement. To understand more about the researcher's judgement, it means that, according to Singleton and Straiths (2017), the researcher relies on his/her expert judgement to select units that were 'typical' of the population. The researcher uses a strategy to identify important sources of variation in the population, thereafter, selecting a sample reflecting this variation.

3.7 Data Sources

The study was conducted by identifying relevant organisations, clinics and social groups. The managers were contacted telephonically and by email since they were identified as gatekeepers. These gatekeepers were informed about the process that would take place during the study. The researcher began observing and interacting with participants for a period of eight weeks. During the observation, researchers consider what they observed and refine or focus on ideas about its significance (Hessie-Biber, 2010).

Detailed interviews were conducted with each participant, and narration was documented on the participant's experience.

3.8 Data Collection Technique

According to Durand and Chantler (2014), qualitative research methods are characterised as those aiming to explore the meaning that produced non-numerical data. The data was collected using in-depth interviews with 10 participants who met the data collection criteria. In order to enhance the stability of the study, interviews had to be conducted with participants with similar experiences. Observations of stability were seen in the interviews of participants. Qualitative data is also produced by a range of data collection techniques. The data in this study was collected through a biographical questionnaire as well as semi-structured face-to-face interviews. The biographical questionnaire was used to gather the biographical information of the participants. The semi-structured interviews were used to gather information from 10 HIV-positive participants who volunteered to participate in the study. The researcher administered the questionnaires shortly before all the participants had been interviewed. Questionnaires were self-completed in the presence of the researcher. In an empathetic manner, interviews were conducted in a quiet room with no distractions at a hospice for approximately 45 minutes each.

An interview schedule was developed and compiled based on information obtained from the literature reviewed. The schedule was then used to provide the researcher with a set of predetermined questions used as an appropriate instrument to engage the participants (see Appendix E). The semi-structured interviews consisted of open-ended questions so that participants would feel free to open up and share their experiences. Interview questions were structured to obtain their experiences of how they became HIV positive, and how the disease had affected their lives, both socio-economically and psychosocially (see Appendix E). This allowed the researcher to record all participants

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interviews with the intention to concentrate on experiences rather than writing down notes. Confidentiality was advised before the interviews, allowing participants to be open and share their experiences openly.

Participants were informed that the interview would be audio-recorded, after which they signed a consent form that gave the researcher permission to audio record the interview (see Appendix B). An audio recording provides details at a level of accuracy that will not be possible by recalling information from memory alone. It is also better than note-taking alone as the researcher can maintain greater eye contact with the participants while using this method (Durand & Chantler, 2014). All participants were interviewed in English, and interviews were transcribed verbatim onto a disc. Participants were educated on key concepts such as 'empowerment' and 'prevention' to ensure that the interview is valid.

3.9 Data Analysis

Durand and Chantler (2014) highlighted that it would be much more useful to access data from more than one source for data analysis. The data was analysed using IPA as this is used to understand how people make sense of their experiences. According to Duran and Chantler (2014), the aim of IPA was to explore how people understand events and phenomena. Qualitative researchers start by assuming that there are different possible and legitimate understandings of the same phenomenon. The following steps were used during data analysis:

3.9.1 Familiarisation and Immersion

Mabuza et al. (2014) pointed out that during qualitative data, the researcher should make themselves familiar by reading the observational notes, transcript and by listening to the tapes. During this study, the recordings of the 10 participants were transcribed by the researcher; she made herself familiar with the qualitative data as a whole by reading the

transcripts, observation notes and listening to the audio tapes. The transcripts of interviews were read and had been reviewed several times whilst considering the following questions: 'Who is telling?', 'Where is this Happening?', 'When did it happen?', and 'Why?' (Assarroudi et al., 2018). These questions guided the researcher to receive and immerse the amount of data enabling her to extract related meaning (Assarroudi et al., 2018; Elo et al., 2014). In this study, the clarity and accuracy of data were obtained by the researcher listening to the participant's recordings and by reading the observation notes for the rigour of the research.

3.9.2 Development of Themes

A list of codes is created based on the familiarisation process mentioned above and organised into categories. The development of themes involves gathering main categories from existing theory and previous research, alongside the emergence of new main categories through an inductive approach. The theoretical definitions of categories must be objective and accurate (Assarroudi et al., 2018; Mayring, 2014). The researcher closely examined the data to identify common themes, topics, ideas and patterns of meaning that came up repeatedly. The development of themes enabled the researcher to organise her data into manageable pieces that can be interpreted with ease in the next step. While the themes were induced, the researcher also took into consideration other themes that were naturally underlying the documents and data. Thus the findings will be discussed under main themes and sub-themes, drawing on the literature review as well.

3.9.3 Coding

According to Assarroudi et al. (2018) and Mayring (2014), coding rules are a description of properties in main categories that are developed based on theoretical definitions. In this study, coding enabled data to be organised into manageable 'bites' to continue into the next step. Once all coding has been completed, it was easier to combine

rather than separating without reanalysing the coded text; therefore, these codes were arranged closer to the data and not defined broadly

According to Assarroudi et al. (2018), coding rules contribute to a clear overview between main categories. In this research study, the aims and objectives of the study initiated the development of codes and categories from the data (an inductive process) collection. The objective of the study provides an overall structure of the study's categories. Codes and categories should be developed from the data (an inductive process). The text was marked with all the codes that were being applied to it by highlighting the passage and noting the code used in the margin. The information was gathered to form a common core of experience as told by the study's participants.

3.9.4 Charting

This step indicates data to be re-arranged into charts. This brings together all data with similar codes, bringing it together in one place. The study used a table to categorise participants' ages, race, religion, number of dependants, financial status, length of relationships, and relationship status.

3.9.5 Interpretation and Checking

According to Mabuza et al. (2014), the aims and objectives (of the study), as well as interpretation (of the data), is necessary. This refers to the way in which respondents define characteristics of key concepts, or how patterns in data suggest explanations, and how emerging themes can be organised in types of cases. In the interpretation of data, it is necessary to pay particular attention to 'deviant cases' that can contradict the main findings of the study. However, deviant and contradictory experiences are seen as rich information sources that allow for further understanding and should not be discarded (Mabuza et al., 2014). The detailed descriptions of the study's sampling, data collection, analysis and the

participant's characteristics were presented. Comprehensive and specific checklists were developed for reporting qualitative data analysis (Assarroudi et al., 2018; Elo et al., 2014).

3.10 Trustworthiness in Research

Trustworthiness or rigour of a study alludes to the level of interpretation, confidence in data, and methods used to ensure quality in the research study (Connelly, 2016, cited in Polit & Beck, 2014). Qualitative research is written with clarity, and the process employed allows the reader to access the scientific rigour of the study (Mabuza et al., 2014).

Amankwaa (2016) outlined the formation of trustworthiness protocols and procedures by noting characteristics of rigour, the process used in documenting rigour and a timeline. This process is necessary in order for a study to be recognised as worthy of consideration by the readers. According to Silverman (2016), the scientific rigour of a research study is essential to evaluate its value. Positivists generally questioned the trustworthiness of qualitative research because their concepts of validity and reliability cannot be addressed in the same way as naturalistic work (Silverman, 2016).

These five criteria are very important for trustworthiness (verification): credibility (for internal validity), dependability (reliability), conformability (objectivity), transferability (external validity) and authenticity. As a researcher with experience in working with people with HIV and interviewing skills, the following criteria will be used in this study:

3.10.1 Credibility

Mabuza et al. (2014) stated there are many study designs and reports affecting the credibility of the research. Credibility recognises the checking of transcriptions, sufficient engagement with phenomenon interest, research methods, emerging themes with informants, debriefing with a supervisor or a mentor and peer scrutiny of the process and triangulation (Mabuza et al., 2014).

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The effects of triangulation indicate more of a holistic overview of the phenomenon of the study and prevent the immoderate reliance on a single data collection method (Mabuza et al., 2014). Triangulation is described as “the process of corroborating evidence from different individuals, types of data or methods of data collection” (Mabuza et al., 2014, cited in Anfara et al., 2012, p. 3).

According to Cope (2014), the researcher describes his or her experiences as a way of verifying research findings with the participants in order to enhance credibility. Credibility reflects participants' views or the truth in data. This is an interpretation and representation of them outlined by the researcher (Cope, 2014, cited in Polit & Beck, 2012). According to Lincoln and Guba (1985), qualitative research consists of credibility, which allows for adequate submersion in the research setting; in order to enable recurrent patterns, they would have to be identified and verified. Thus, an important strategy is to spend an extended period of time with the participants allowing the researcher to check perspectives and allows the participants to become accustomed to the researcher (Lincoln & Guba, 1985). The importance of intense participation is discussed, suggesting that enhanced research findings are through intimate familiarity and the discovery of hidden facts (Lincoln & Guba, 1985). Within the planned research, credibility increased through employing a well-established data collection method: recording interviews and their various transcripts to confirm that the result of qualitative analysis was accurate as obtained from the participants' perspective (Creswell, 2013).

To ensure accurate data collection to contribute to the credibility of this study, the researcher built a rapport with the participants to obtain honest and open responses. She also familiarised herself with the participating organisations before data collection to better understand the organisations and assist the study's participants. Each participant was given the opportunity to refuse participation in the study at any given time. The qualitative study used methods of observation, and detailed audit trails were used to support credibility.

3.10.2 Dependability

Mabuza et al. (2014) indicate similar findings should be expected if the study were to be repeated. Qualitative studies focus on “the range of experience rather than the average experience” (Mabuza et al., 2014, cited in Jootun et al., 2009, p. 3). Mabuza et al. (2014) highlight that the best supporting way of dependability in research is ensuring that methods are described in sufficient detail so they could be replicated by another person else an audit trail with a step-by-step process with limitations to be discussed.

Dependability is viewed as a type of constant stability of data over conditions of the study (Connelly, 2016, cited in Polit & Beck 2014). According to Connelly (2016), illustrated procedures on dependability included audits trails, process logs and debriefing with colleagues. According to Guba (1981), the dependability criterion relates to the consistency of findings. Many qualitative methods are tailored to the research situation. Therefore, dependability can also be enhanced through triangulation to ensure that the weaknesses of one method of data collection were compensated by the use of alternative data-gathering methods (Guba, 1981). One can enhance stability over time by repeated observations of the same event and re-questioning participants about major issues. These are similar strategies to enhance credibility. In this study, the dependability of the data was enhanced through documentation that would be well-kept and transparency in the methodology, data analysis and conclusion. The study’s dependability was achieved by the researcher through data analysed from the recordings and the checking and rechecking of the transcripts to the recordings and observational notes. The themes developed were also checked against the study’s aims.

3.10.3 Confirmability

Confirmability is seen to be neutral with its findings that could be consistent and repeated (Connelly, 2016, cited in Polit & Beck 2014). This enables the reader to ensure

the results are based on the data and not the preference of the researcher (Mabuza et al., 2014).

Connelly (2016) stated that qualitative researchers should keep detailed notes and analysis of all decisions. The study's notes are reviewed by a colleague or a discussion in peer debriefing sessions with a qualitative researcher. This, however, prevents biases by using one person's perspective on the study (Connelly, 2016).

Guba (1981) noted that an investigator should provide documentation for every claim or interpretation from at least two sources to ensure that the data support the researcher's analysis and the interpretation of the findings. The researcher provided an audit path by keeping all research information and recording the steps taken from the start of the research to the event and reporting of the findings. This allows for transparency in the study. The study's aim is to confirm accurate findings and to determine the interpretation is supported by data in the research study. The researcher then kept all evidence of data and analysis to ensure confirmability. Confirmability was also enhanced through peer debriefing, data triangulation, reflection and bracketing of preconceived ideas and views that enhance the accurate collection and interpretation of data.

3.10.4 Transferability

The nature of transferability is the extent to which the findings are useful to people in other settings, which differ from other aspects of the research whereby the reader illustrates how applicable findings are to their situations (Connelly, 2016). Transferability indicates how conclusions in the study can be applied to similar settings. This allows the ability to judge findings that can be transferred depending on the description of the study's selection of participants, setting and the findings (Mabuza et al., 2014, p. 3). Cope (2014) indicates a qualitative study meets the criterion once results have meaning to those uninvolved in the study and its readers can relate to the results with their own experiences.

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The study's transferability was enhanced until saturation was confirmed by an independent coder and by providing detailed descriptions of the research methods and findings and taking field notes in order for the findings of the results to be justified when compared to different researchers' interpretations in a similar setting. The researcher can assist in the transferability of results onto other communities by thoroughly describing the research study's context, participants, settings, and circumstances (Braun & Clarke, 2013).

3.10.5 Authenticity and Reflexivity

The audio recording of the interviews enhanced authenticity. This was supplemented by including verbatim quotes from participants in the description of the findings. The main aim of planned reflexivity is to guarantee the validity of results by lessening the possibilities of researcher bias in the study. Reflexivity can likewise assist the researcher to be aware of how the ideas, opinions, and knowledge the participants brought to the study can be positive. Reflexivity is very significant in subjective research because there are many ways in which the researcher's predisposition could influence the study, from the creation of data-gathering tools to collecting the data, analysing it, and reporting it.

To ensure reflexivity, the researcher examined and consciously acknowledged the assumptions and prejudices she brought to the research, which shaped the outcome. This was achieved through keeping a diary, keeping up an open discourse, and talking with my supervisor (Haynes, 2012).

3.11 Ethical Considerations

The researcher observed all ethical principles outlined by the University of South Africa's (Unisa) research policy and the universal ethics principle (Beauchamp & Childress, 2013) in which more details of ethical considerations are included. Rhodes (2015) indicated that the principles of good medical ethics are seen as illuminating, reasonable, coherent,

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accurate, consistent, measured and informed; this reflects that medical ethics can be used to resolve ethical issues.

Gillon (2015) proposed an intercultural 'moral mission statement' towards the goals of medicine. She stated "the provision of health benefits with minimal harm in ways that respected people's deliberated choices for themselves and that are just or fair to others, whether in the context of distribution of scarce resources, respect for peoples rights or respect for morally acceptable laws" (Gillon, 2015, p. 111).

According to Bernard (2012), the biggest problem in conducting a science of human behaviour was not selecting the sample size or making the right measurement but doing things ethically so that you could live with the consequences of your actions. Although there are several approaches to ethics, there are four widely accepted philosophical principles applied in various ways to determine whether research is ethical (Beauchamp & Childress, 2013). These principles are now discussed.

3.11.1 Autonomy

Autonomy is the freedom and ability to act in a self-determined manner. It represents the right of a rational person to express personal decisions independent of outside interference and to have these decisions honoured (Beauchamp & Childress, 2013). The principle of autonomy sometimes is described as respect for autonomy (Beauchamp & Childress, 2013).

3.11.2 Autonomy and Respect for the Dignity of Persons

In this study, the research will exclude unfair, prejudice or discriminatory practice, for example, in the selection of participants. The principle that each individual had the right to make his or her own choice, which forms the basis for the practice of voluntary informed consent between the researcher and the participant (Beauchamp & Childress, 2013).

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The researcher respected all the participants' choices; for instance, one made a choice to terminate during the interview process and wished to withdraw from the study. The researcher made arrangements for the participant to receive counselling and gave her telephone details for further counselling should she require more sessions. The participant was contacted a day later, ensuring no harm was done to her. All participants in this study were given freedom of choice to participate voluntarily and to terminate at any time should they feel uncomfortable. Participant's appointments were made telephonically, and with permission, all interviews were conducted in the participant's homes to ensure confidentiality and non-disclosure of their status.

3.11.3 Non-maleficence

According to Beauchamp and Childress (2013), the principles of non-maleficence support specific moral rules, such as, Do not kill, Do not incapacitate, Do not cause pain and suffering, Do not deprive others of a good life and Do not cause offence. It must be noted that harm can include wrongs (Macklin, 2015). In this research study, all participants were considered vulnerable due to their HIV status. Participants would be protected against any form of harm, pain and suffering of their experiences. Counselling and sessions for debriefing were made before interviews could take place. The aim of this research study was met throughout the interview process and ensuring no loss of respect or non-judgement toward the participants in the study. Participant's recordings were paused when they became emotional upon sharing their life-changing experiences. Participants were calmed and given time to recollect themselves, as much time as each one needed. The researcher asked if they wanted to continue further, end the interview and reschedule for another time. Participants in this study were protected from harm, pain and suffering, and all participants were contacted a day after the interview to check on their psychological and emotional wellbeing. It was found in the follow-up the next day that all the participants were well, and no further debriefing was required.

3.11.4 Beneficence

According to Rhodes (2015, p. 72), “beneficence is an imperfect duty, the acts of kindness are nice, but optional; it is defined as a duty ensuring clinician’s to be committed in the best interest and good of the patients and society”. Beneficence is the principle that requires taking action by removing harm, preventing harm and promoting good (Beauchamp & Childress, 2013). It also found expression in research ethics in risk/benefit determinations, where the researchers and ethics committees had to consider the relative risks of a proposed study against any benefits that the study might directly bring to the participants or to society. In this study, the participants would be provided with a report of the results should they be interested.

The study’s results allow participants to analyse their experiences in order for them to assess their situation from different perspectives. In this study, the researcher's organisation has a social worker/counsellor who developed a relationship with the participants. This ensured all participants had trust in the researcher and confided in her. In conducting this study, the researcher worked closely with the participants. This allowed her to gain their trust and build up their self-confidence to empower themselves so they are able to educate others experiencing similar challenges.

3.11.5 Justice

Gillon (2015) argued that individualistic concerns on individual autonomy had been given too much weight when it conflicts with justice; this includes concerns for fair distribution in healthcare globally. Gillon (2015) referred to a claim that was given support by Beauchamp and Childress (2013), who had argued that a globalised world brought upon the realisation of protecting and maintaining healthy conditions which are international in nature requiring a justice-based restructuring of the global order.

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This principle emphasises fairness and equality among individuals as both procedural justice and distributive justice form the foundation from which scarce researchers resources are provided in an egalitarian method (Levitt, 2014). Justice, in general, requires people to receive what is due to them and the researcher to treat research participants with fairness and equity during all stages of research. In this study, the objectivity of the participants would ensure neutrality. This allows for participants to share stories without being influenced by personal values or bias from the researcher. They would be treated without prejudice and with complete fairness. In conducting this research, the researcher treated all participants equally and fairly and respected the participants by allowing them to express themselves openly.

3.11.6 Confidentiality

Fleming and Zegwaard (2018) indicated the importance of keeping the participant's anonymous and confidential and providing them with the assurance of protecting their names. Therefore using self-identifying information and statements should be avoided. Confidentiality and anonymity is seen as an important step in protecting participants from any potential harm that could incur (Fleming & Zegwaard, 2018).

According to Neuman (2014), confidentiality is the ethical protection of the study's participants by holding research data in confidence or keeping it secret from the public. This includes not releasing information in a way that permits linking specific individuals to specific responses. A researcher has a 'right' to break confidences in some circumstances but does not have a 'duty' to do so. According to this view, they are permitted, but not obliged, to divulge confidential information.

Durand and Chantler (2014) also indicated that confidentiality meant that information revealed by participants to the researchers should be kept private within certain agreed limits determining what information could be disclosed to a third party. Anonymity

means that the research participants (and potentially organisations and research locations) cannot be linked by name to any information disclosed. Privacy was the researcher's obligation to protect the participant from undesirable interactions. Before conducting the research study, participants were informed that their identity would not be revealed. This allowed them to be able to express themselves freely, knowing their identity will remain anonymous. All interviews had participants names attached to them but were kept with the researcher in a safe place to ensure confidentiality. The research participants' identities were protected, and all information was kept confidential.

3.11.7 Informed Consent

The term 'informed' and 'consent' consists of two important elements requiring very careful consideration (Fleming & Zegwaard, 2018). According to Fleming and Zegwaard (2018), participants should be informed on what will be asked from them, the way in which the data is used and what the consequences would be if they were to arise.

Ethical principles of autonomy and liberty supported informed consent. According to Durand and Chantler (2014), this comprised participants being 'informed' about all key aspects of the research, including the study rationale, methods, outputs, and potential risks or harms, as well as providing 'consent' for their voluntary participation on the basis of reasoned judgement and without coercion. The participant's competence and understanding, voluntariness in participating and freedom to decline or withdraw after the study was started were obtained. The formalisation of the consent in writing for the research participants was provided with clear, detailed and factual information about the study. Informed consent is seen as a contract between both the researcher and the participant (Fleming & Zegwaard, 2018). This included its methods, risks and benefits along with assurances of the voluntary nature of participation and the freedom to refuse or withdraw without penalties (see Appendix A).

3.11.8 Provision of Debriefing, Counselling and Additional Information

According to Singleton and Straits (2017), debriefing served methodological and educational as well as ethical purposes; ideally, it should occur in all studies with human participants, not just those studies involving deception. Debriefing and counselling were made available to all participants of the study should they require it. Debriefing and additional information were given to the participants. Participants were reassured of confidentiality and were informed they could terminate the interview at any time since it is voluntary.

3.12 Pilot Study

The term pilot study is used in two different ways in social science research. Polit and Beck (2013) highlight the feasibility of studies in a small-scale version or trial run, which are done in preparation for major and large-scale studies. In conducting the pilot testing, efforts were made by the researcher to ensure the setting, choice of participants and interview methods were as close to the main study as possible. The researcher used the same criteria for selecting participants as would be used in the main study. The target participants in this study were women who were HIV positive.

The pilot study in empowering women through an HIV prevention programme is a process reflecting all the procedures of the study and validates whether or not the study would be feasible or not. This process suits the qualitative study since it forms part of the interviews and schedules. Pilot testing was done on five participants to ensure this is suitable for the study. The selected participants for piloting did not form part of the selected group. The goal was to validate the instruments and to test their reliability. The study then added new indicators and compared them to the previous measure. Amendments were adjusted to the questionnaire to ensure reliability and validity.

3.13 Conclusion

The aim and objective of this study are to empower women through HIV prevention programmes. This study's research design was both a descriptive and an interpretative approach that included the rationale for using a qualitative research approach, participants, sampling techniques, data sources, data collection techniques, and analysis. The method of data collection used was semi-structured interviews. These were analysed individually to identify emerging themes. Data was reviewed continuously to find meaning in phrases and to understand problems being faced by HIV-positive women for effective empowerment. The researcher used IPA to analyse data after transcription. The resulting analysis of the data was, therefore, phenomenological since it represented the interviewee's experiences of the world and interpretative in that it was dependent on the researcher's view of the world. IPA also allows for interpretation of the data through coding during the analysis process. The aim of interpreting was to develop an organised, detailed, credible and transparent account of the meaning of the data. The research used the concepts of reliability and validity, which include the criteria of credibility, dependability, confirmability, transferability, authenticity and reflexivity. The ethical considerations in the study included confidentiality and informed consent. The provision of debriefing, counselling and additional information was made available to participants in this study. The pilot study used validated whether the study would be feasible or not. The next chapter discusses the research results.

CHAPTER 4

RESEARCH RESULTS

4.1 Introduction

In this chapter, the results of the interviews with the participants are discussed. Biographical details and details about their experiences, challenges, coping strategies, cultural factors and prevention measures are provided.

4.2 Review of the Objectives

Before discussing the results, it was important to review the research objectives. The first objective was to explore the experiences of women living with HIV. The second objective was to explore and describe the challenges faced by women living with HIV in their daily lives. The third objective was to explore the coping strategies used by women living with HIV to cope with their challenges. The fourth objective was to explore cultural factors hindering women from having autonomous decision-making. The fifth objective was to identify prevention measures pertaining to empowerment required by women living with HIV.

The findings of the analysed qualitative interviews are addressed below through themes and sub-themes. The study reported experiences associated with empowering women through an effective prevention programme. An investigation revealed themes such as psychological and socio-economic challenges, coping strategies, and prevention measures discussed in the next section.

4.3 The Experiences of Women Living with HIV

This section presents the results of the experiences of women living with HIV from the first diagnosis and moving forward. Oliveria et al. (2015) mentioned HIV status as being a constant threat, both psychologically and physically.

Theme 1: Psychological and Emotional Experiences

The experiences faced were psychological and emotional. Although many of these participants had different experiences, the ones that stood out were feelings of shock, disbelief, panic feelings; feelings of fear and worry. The themes and sub-themes are discussed in the following section.

Sub-theme: Feelings of Shock.

The HIV-positive status poses a threat psychologically, which can affect social relations (Oliveria, 2015). Women in this study experienced shock and a flow of emotions when they discover that they were HIV positive. Some participants revealed that they were shocked when they received their results from the counsellor. They felt helpless and embarrassed about the matter. Some participants reflected as follows:

“I was shocked, and I felt angry, I felt helpless. I was also very embarrassed. I buried myself into a shell, and I tried not to meet too many people. It changed me a lot” (P7); “I was very sad, shocked, disappointed because I was not expecting this could have happened to me” (P8); “I was shocked, I was nervous, I was scared. I never heard of HIV before” (P1).

It is evident that participants experienced a state of shock when they received an HIV-positive result. This led to them feeling helpless and living a stressful life due to lack of information concerning the disease. Others decided to change their daily routine and isolate themselves from other people.

Sub-theme: Feelings of Disbelief.

Disbelief is experienced by individuals with the inability or refusal to believe or accept something as true. Horter et al. (2017) refer to periods of non-acceptance towards the disease ranging from months to years. This indicated consequences in an individuals mental and physical, which is seen as a barrier in accessing care. Some participants were in denial after hearing their newly found diagnosis and could not believe it had happened to them. Some participants reflected as follows:

“I was very upset and sad. I couldn’t believe it. I was very stressed out. I didn’t want to show my face to anyone. I just didn’t know I could be the one to have this kind of problem”. (P6); I was very sad and stressed. I cried every day thinking I was going to die” (P5). I was very angry, I had a lot of questions, I questioned God why me? Was this the time in my life for this to happen? I could not understand. It took me time, when I finally found somebody that I wanted to settle down with and I had to pick this up. (P9).

It is clear from the findings above that some participants did not believe that they were HIV positive. They could not comprehend that it happened to them; they became sad and started questioning their belief system.

Sub-theme: Panic Feelings.

Panic is a sudden overwhelming fear, a feeling that something bad is going to happen usually experienced by individuals. Jonsson et al. (2013) highlighted that anxiety disorders were common amongst people living with HIV and indicated the importance to treat and recognise anxiety disorders. This has been associated with an increased rate of poor compliance in treatment and high-risk behaviour. Participants in this study experienced this kind of feeling. Some of the participants reflected as follows:

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“I was very sad, stressed, and I cried every day thinking I was going to die” (P5); “I have felt panic, stress and sadness. It will slowly take time to get out of this” (P7); “I felt a sense of intense fear and started sweating, and I cried uncontrollably” (P6); “I started shaking, sweating and I suddenly felt a shortness of breath” (P8); “I have panicked seriously, felt the numbness all over my body and thought I am dying (P4).”

The findings above indicated that the participants never anticipated the results to be positive. Hence, they panicked and felt that they were going to die. The overwhelming fear usually produced irrational behaviour, which typically lasts for some minutes. However, the duration can vary from minutes to hours. Hence one participant indicated that it would slowly take time to get out of this.

Sub-theme: Feelings of Fear.

Fear is a distressing emotion in individuals which is aroused by approaching danger such as being diagnosed with HIV. This fear can occur whether the threat is real or imagined. According to Hlongwane and Madiba (2020), adults living with HIV experience increased fear of rejection and social isolation. The fear of stigma is related to social consequences resulting in the limitation of social contacts and sources of support. Participants in this study feared disclosing their status to families, children and work colleagues; they were uncertain if they would be accepted or rejected. Some of the participant’s responses were as follows: “I was afraid, I feared because the guy I was supposed to have married had passed away within two months of being sick” (P9); “I feared about the people at work, what would they think if they were to find out about my illness” (P3); “I thought how am I going to tell my children, my family and I became so afraid” (P8); “I felt emotional and frightened, I prayed to the Lord because I have children, so I had to accept it there was not much I could do about it” (P4); “HIV has never given me a problem; only I was frightened about the people at work” (P2).

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It was clear that HIV-positive results brought on a feeling or condition of being afraid. Participants in this study felt fear about how to disclose their status to their loved ones and colleagues at work. Some feared for their lives because their partners had passed away, and they thought they would be next.

Sub-theme: Feelings of Worry.

Worry is a state of feeling anxious and troubled over actual and potential problems. Corneli et al. (2014) mentioned that HIV risk was based on specific events or beliefs and behaviour. However, participants in this study did not worry about becoming HIV positive, instead, they were concerned about their children. Some of the participants in this study experienced worry. Some of the responses are as follows:

“I was emotional; I am worried, I pray, I am just worried about my children” (P8); I prayed to the Lord because I have children, So I had to accept it there was not much I could do about it” (P4); “I was worried that I had TB when my results came out, my madam held me and told me not to worry there is nothing with HIV” (P3); I was very sad, disappointed because I was not accepting that this could happen to me. I was emotional I am worried, I pray, I am just worried about my children” (P9).

The findings above indicated that participants were worried about their lives. The participants felt uneasy and were being overly concerned about their situation. Their minds might go into overdrive as they constantly focused on their children’s futures. They constantly worried about what would happen to their children, which caused a tremendous strain mentally and physically.

4.4 Challenges Faced by Women Living with HIV

The findings in this study suggested that women living with HIV have endured many challenges. These challenges occur in their daily living. These challenges are

psychological, social/behavioural and socio-economic challenges. The participants in this study mentioned that being diagnosed with HIV has impacted them financially. In exploring this section, several themes and sub-themes emerged. The sub-themes include the following: Depression and Anger; Isolation; Financial Challenges, Unemployment; Child Support and Disability grants

Theme 2: Psychological Challenges

The discovery of being tested HIV positive is life-changing as one can think that one's whole world is shattered and there is no hope for their future. HIV posed serious psychological challenges such as depression and anger for the participants.

Sub-theme: Depression.

Depression is a state of unhappiness, sadness, difficulty in thinking and concentration, as well as a significant increase or decrease in appetite and time spent sleeping. Jonsson et al. (2013) reported that people living with HIV in South Africa suffered from depression during their illness. Having mild depression can lead to poor health care, inconsistent adherence to treatment regimes as it is more challenging to take one's medicine, see medical professionals regularly, comply with treatment plans, and it can lead to even more severe health problems. Although mild depression might have fewer symptoms than chronic depression, it still impacts people's lives and medical care regimes. Therefore, depression is one of the challenges that some of the participants faced after being diagnosed with HIV. Some of the responses were as follows:

"I get depressed, I have a low self-esteem now, and I am trying to overcome this, I have felt panic, stress and sadness. It will slowly take time to get out of this" (P7); "I feel depressed only when I get angry" (P4); "I feel depressed and stressed because the treatment is on a daily basis" (P2); "I used to take medication at morning and at night now I know I have to take it for the rest of my life" (P10).

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It is clear from the findings that participants felt overwhelmed about the changes that must take place in their lives. Depression can affect a person's thoughts, behaviour, motivation, feelings, and sense of wellbeing. Taking medication for the rest of one's life is a serious challenge.

Sub-theme: Anger.

Anger is a natural but unwanted emotion that everybody experiences from time to time. It involves a strong uncomfortable, and non-cooperative response to a perceived hurt or threat. McIntosh et al. (2015) indicated that negative emotions such as anger and hostility influence the quality and diminish the number of social interactions.

Some of the participants experienced anger when they were first told they were HIV positive and continued to live with anger afterwards. Some of the responses were as follows:

"I feel angry and stressed because the treatment is on a daily basis (P2); "I am so angry, I used to take medication morning and at night now I know I have to take it for the rest of my life" (P10); "I was angry, how could my loved one do this to me?" (P10); "I had mixed emotions. I didn't know how to deal with the children because I was also scared how they would react" (P9); There's nothing wrong with HIV, I am fine, I am only not happy to sit on a wheelchair, It makes me sad/angry I used to do everything myself now I need someone to help me which is something I don't like" (P3).

It is evident that participants were angry about the situation, especially having to take medication daily for the rest of their lives. They were also angry because they did not know how to disclose their status to their children. Anger took a toll on both their health and their relationships. Therefore, it is important to deal with anger in a positive way.

Theme 3: Behavioural and Socio-economic Challenges

The participants presented one of the behavioural factors, which is isolation, as a challenge. Isolation is a condition of being alone or isolating oneself, especially when the situation makes one feel unhappy. They further revealed that socio-economic factors presented a major challenge for HIV-positive women. Socio-economic factors, such as finances, unemployment, access to grants, were challenges experienced by the participants. These will be discussed under the relevant sub-themes.

Sub-theme: Isolation

Hlongwane and Madiba (2020) reported that individuals isolate themselves after finding out their HIV status. This results from not having information about the disease and how to deal with being HIV positive. Social isolation was used as a way of avoiding rejection due to their HIV-related symptoms. Participants in this study felt embarrassed and did not know how people would react to knowing their status. Some participants felt that by isolating themselves, they would feel better (apart) since they did not want to be judged or rejected by their loved ones. Participants responses were as follows:

“I just want to cry all the time, I become quiet and want to stay in a quiet corner. Just wonder what other things I am going to face each day” (P6); “Families can also bring you down, once you tell one person in the family everyone comes to know, this used to bring me down and make me emotional” (P9); “I buried myself into a shell, and I tried not to meet too many people. It changed me a lot” (P7).

It is clear from the findings that participants resorted to isolation when they encountered rejection from their family members. Living in isolation is difficult because humans are social creatures; however, the participants felt that they are not getting support

from others. They isolated themselves from others in order to prevent the fear of rejection.

Sub-theme: Financial Challenges

The study revealed that financial challenges presented a challenge for HIV-positive women. According to Chetty and Hanass-Handcock (2016), financial challenges in constraining households are viewed as a barrier to accessing central services, causing them difficulty in obtaining employment. One participant said, “I depend on my child support grant because nobody will employ me” (P8).

Other participants reported their financial experience as follows:

I feel sad only when I get angry. When I don't have money or when I don't get paid. I work on a contract basis. Sometimes I don't get paid on time. That affects me, my children and my family (P4).

There are challenges, I have two children they are depending on me, and I am only receiving a child support grant. I feel very stressed every day because the child support grant is not enough to buy food and to transport me to go collect my ARVs. The child support grant I am getting is very little. I am not able to work because I am not strong to go work. I am very weak (P5).

It was clear that the participants did not only suffer psychologically and emotionally; however, they also suffered financially due to their health conditions. Some of the participants were unable to hold steady jobs. This made it difficult for them to support their children financially.

Sub-theme: Unemployment

Diraditsile and Ontetse (2017) highlighted that unemployment is viewed as an issue globally, affecting women more than men, although the experience and consequences of unemployment affect people differently based on their age and gender. The study reflected that unemployment brought upon a major challenge for HIV-positive women. The effects of HIV on physical and mental functioning can make maintaining regular employment difficult.

Patients with HIV infection may also find that their work responsibilities conflict with their healthcare needs. Due to some of the participant's ill-health, they could not hold steady jobs. Some of the responses were as follows. One participant said, "I am unable to work because I am not strong to go to work; I am very weak" (P5). Others responded as follows:

I was really sick, I lost my job because I was sick all the time and I could not keep my job going, I had to go to the hospital all the time, I had to go for treatment, and I was only dependent on the social grant (P6).

"I don't have money or when I don't get paid, I work on a contract basis. Sometimes I don't get paid on time that affects me, my children and my family" (P4).

The findings above indicated that participants could not get employment due to their ill-health. Although people should not be discriminated against due to their HIV status, it is difficult for the participants because they are constantly sick and fragile. Therefore, it is not easy for them to concentrate at work and be determined to work efficiently.

Sub-theme: Child Support and Disability Grant

The study reflects that child support and disability grants provide financial relief for HIV-positive women. The child support grant is aimed at lower-income households. Some

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of the participants were single mothers and relied on this grant for their children's needs.

Some of the responses were as follows:

"There are challenges, I have two children, they are depending on me, and I am only receiving a child support grant" (P5). "I depend on my child support grant, and nobody will employ me" (P8).

According to the South African Government (2020), the child support grant is a social grant for children under the age of 18 to assist single parents that do not earn an income of more than R 52 800.00 per year or a couple's combined income which is less than R 105 600.00 per year.

The disability grant is a social grant to assist people between the ages of 18–59 with a physical or mental disability (South African Government, 2020). To qualify for this grant, an individual must be a South African citizen, permanent resident or refugee living in South Africa during the application (South African Government, 2020). An individual who is sick (and unfit to work for a period longer than six months) must have a medical examination by a state doctor who will assess the degree of the disability (South African Government, 2020). A permanent disability grant does not mean the individual will receive the grant for life, but that it will continue for longer than 12 months. Some of the participants who were too ill to work had applied for a disability grant. Some of the responses were as follows:

"I was really sick, I lost my job because I was sick all the time, and the company could not keep me" (P4); "I has to go to hospital all the time, I had to go for treatment, and I was only dependent on the social grant" (P6).

Whilst some participants affected by HIV found it difficult to cope financially, other participants found it much easier to cope with assistance from their disability grants. Whilst

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others were well enough to hold on to steady jobs. Some of their responses were as follows:

No, it hasn't affected me I am still working. I didn't have any pain; I was all right.

They told me I have HIV, until now I still take medication, I have no pain. I only suffer with my diabetes. I never had a problem with the HIV (P2).

"I am fine, I receive a disability grant, I am only not happy to sit in a wheelchair. I used to do everything myself now I need someone to help me, which is something I don't like" (P3); "When I think of my children, I believe in God, it has helped me, it has affected me the only thing I can do is pray and to be strong" (P4).

It is evident from the responses above that participants living with HIV reported experiencing a range of positive and negative challenges associated with different socio-economic factors. A positive factor was experiencing financial relief by receiving a disability grant. However, this was only a temporary measure as once the recipient's health was restored, the grant was stopped.

4.5 Coping Strategies Used by Women Living with HIV

This study mentioned women living with HIV had found coping strategies in order to live a life being HIV positive. The participants in this study suggested coping strategies applied to assist these included cultural barriers in HIV prevention, support groups to deal with HIV, ARVs adherence, exercise, support care, and prayer.

Theme 4: Coping Strategies to Deal With HIV

The study reflects the coping strategies used in dealing with HIV-positive women. The participants with HIV in this study used different methods to cope with their illness. Some of these coping strategies entailed support groups, ARVs adherence programmes,

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exercise, supportive care and prayer. Poor coping strategies contribute to poor disease management, such as adherence issues, missing medical appointments, and increased morbidity and mortality risks.

Sub-theme: Support Groups

This study drew on the support groups that assist HIV-positive women. Support groups are for a group of people with common experiences or concerns who provide each other with encouragement, comfort and advice. Both WHO and the PEPFAR promote peer support groups facilitated by trained PLHIV to address the distinct needs of PLHIV and their partners (OGAC, 2013; WHO, 2008). These groups' purpose is to share experiences, encourage disclosure, reduce stigma, improve self-esteem, coping skills and psychosocial functioning, and support complying with medication regimens and improved retention in HIV care (Haberer et al., 2010). According to WHO (2013), groups will be more effective if formed around specific populations such as men who have sex with men, pregnant women, adolescents, or couples in conflicting relationships (WHO, 2013).

All of the participants in this study attended the Verulam Regional Hospice for Supportive Care. Some of the participant's responses are as follows:

"I am coping because I am attending The Verulam Hospice support group and the social worker comes to visit me at home to give me counselling and sometimes a little food hamper" (P5); "I am in hospice, and I do work voluntarily, and I meet people there that are very helpful and are supportive" (P7); "I speak to my neighbour, and I speak to hospice" (P1); "Hospice is the best thing that ever happened to my life, I have learnt a lot especially on how to care for myself" (P9).

Participant's responses revealed that a support group played a major role in assisting the participants to cope with their HIV-positive status. Participants in this study

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were selected from the community support group because it is not easy to find people who can and will communicate freely about their HIV-positive status.

Sub-theme: ARVs Adherence as a Coping Strategy

The study reveals ARVs adherence is used as a coping strategy for HIV-positive women. According to Hlongwane and Madiba (2020), various approaches towards coping were engaged in their study, such as accessing support, not feeling cheated by the HIV disease, and applying trust in ARTs to enable adherence. In their study, participants had a strong sense of trust and believed that they could live a healthy life due to the ART treatment (Hlongwane & Madiba, 2020). In the current study, participants were seen by hospice once a week to monitor their ARVs. In addition, participants in this study went to clinics or hospitals to collect their ARVs. Some of the responses were as follows:

“I used to take many ARV’s before, but now it has changed, and I only take one” (P2); “I take my ARVs” (P1); “I have nurses visiting me at home, they encourage me to take my ARVs, and I prefer to abstain, and this is helping me” (P5).

The findings indicated that the participants were adhering to their medication. They were monitored by nurses through home visits. This was important in assisting them to cope with their challenges. As they communicated openly in a support group, they were encouraged to get their medication on time at the clinic and/or hospital.

Sub-theme: Exercise as a Coping Strategy

The study looks at exercise as a coping strategy for HIV-positive women. Exercise is used to improve health, maintain fitness and is important as a means of physical rehabilitation. Jagers and Hand (2016) conducted a literature review since the year 2000 on the health benefits of exercise for PLWHIV, with studies consistently showing physiological and psychological improvement. However, in this study, the focus is on

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exercise as a coping strategy. Gomes-Neto et al. (2013) reported that ART had converted HIV infection into a chronic disease causing several comorbidities. In addition, HIV-related disabilities decreased exercise capacity and the impairment in daily activities; thus, exercise was a key strategy used by HIV positive patients especially since it increases aerobic capacity, muscle strength, flexibility and the total functional ability in patients with HIV (Gomes-Neto et al., 2013).

Participants in this study exercised to maintain a fitter body. Some of the responses were as follows:

“I have been doing exercise, I have joined yoga, and I tried to eat healthier” (P7);
“Hospice teaches us how important exercise is for us” (P9).

It is clear that participants also saw exercise as one of their coping strategies. Exercising is a physical activity that is planned for conditioning any part of the body. It was noteworthy that participants had joined some form of activities to exercise to maintain a healthy lifestyle. This was noted because people who are sick become discouraged and lose interest in doing their daily routines, never mind taking on extra activities.

Sub-theme: Supportive Care as a Form of Coping

A supportive system in HIV is required to reduce HIV stigma to contribute to a more positive HIV lifestyle. The support received from families, friends and health care workers was seen as a source of comfort, which was critical in overcoming their diagnosis (Hlongwane & Madiba, 2020). This study reflects supportive care as a form of coping for HIV-positive women. Support from family and friends was vital. They are pillars of support, especially in difficult times. Participants responses were as follows:

“I have family and friends, I try to talk more to close friends confidentially. Those that will keep my status in confidence and talking does help a lot and sharing with close family”

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(P7); “My family had given me support” (P3); “I speak to my neighbour, and I also speak to hospice” (P1); “Staying strong by praying and going to church” (P4); “Attending the Verulam Regional Hospice for support groups” (P5).

The findings indicated that participants in this study surrounded themselves with family and friends for support and comfort in both times of joy and distress. A strong network of supportive family and friends enhanced their mental wellbeing.

Sub-theme: Prayer as a Coping Strategy

Szaflarski (2013) reported that spirituality and religion assist people in coping with stigma and discrimination as well as other stressors. The utilisation of the power of praying focuses on improving individual outcomes through accessing spiritual, social support for people living with HIV (Szaflarski, 2013). The study uses prayer as a coping strategy for HIV-positive women. Participants in this study had a strong belief and faith in God during a time of crisis. Some of the responses were as follows:

“I am strong. I always pray, I go to church, I just keep on going” (P4); “Going to church and family support, I pray, and I go to church, I also have a good supportive family” (P8); “I ask God every day to help me in all my problems” (P6); “I have drawn closer to God and have spiritually built myself up” (P9).

Some of the experiences are indicated below:

I try to pray about it, and I ask God to help me every day. To help me with my children, I am the sole supporter, and they still very small. I have to support them. I have no support from anyone. So I ask God every day pray about it that he can help me in all these problems. The Verulam Hospice helps me a lot, and they always counsel and advise me. They help us with porridge (P6).

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“Attending The Verulam Hospice to see the social worker for counselling and food parcels” (P5); “Hospice has taught a lot makes patients feel good and special” (P9).

The responses above indicated that the participants had found various coping mechanisms to deal with being a victim of HIV. All these women found spirituality as a healing process. Prayer is spiritual communion with God or an object of worship, as in prayer, giving thanks, and confession.

4.6 Measures Applied in Preventing HIV Re-Infections

The finding of this theme illustrated measures in preventing HIV. The participants emphasised methods applied in preventing HIV through HIV counselling and testing, prevention through abstinence, prevention through ARVs, prevention through condom use and revealed their effectivity.

Theme 5: Prevention Through HIV Counselling and Testing

The study uses prevention through HIV counselling and testing as factors in HIV-positive women. Prevention counselling in HIV is a vital mode for behavioural interventions since there is no available vaccines or curative treatment. It deals with many issues such as psychological, medical and social. Some of the participants' responses were as follows:

“I have a nurses visiting me at home, they encourage me to take my ARVs, and I prefer to abstain” (P5); “The Verulam Hospice helps me a lot they advise and counsel me” (P6); “The hospice teaches us many things which we can teach others about eating healthily, how make oneself feel good and special” (P9).

It is clear that the participants received counselling from the hospice. They also received counselling about taking their medication. However, some of the participants

preferred to abstain in order to prevent re-infection. Counselling is effective as a coping method for these participants in assisting them to prevent HIV.

Theme 6: Prevention Through Abstinence

According to Hlongwane and Madiba (2020), older HIV positive persons are more likely to experience difficulties in sexuality and intimacy, especially older women experiencing menopausal symptoms. Menopause can impact one's sexual feelings of desire. The study uses prevention through abstinence for HIV-positive women. Abstinence is a practice of abstaining from something: The practice of not doing or having something that is wanted or enjoyable.

Some of the participants responses are as follows:

"My boyfriend and I spoke about it, and he knows I am not happy, this is why we are not intimate and chose to abstain" (P3); "I just feel I want to abstain from all this and not to indulge in any relationship with anybody; it is the best way" (P6); "I don't have a partner; I am abstaining" (P9); "No boyfriend due to abstaining" (P1); "I have nurses visiting me and encouraging me to take my ARVs, but I prefer to abstain" (P5).

The responses indicated that some of the participants in this study chose to abstain from sexual encounters to reduce re-infection and the spread of HIV. This method was effective for them. Two participants had chosen not to engage in relationships in order to abstain.

Theme 7: Prevention Through ARVs

Quaife et al. (2016) reported that HIV prevention continued to move forward due to emerging evidence indicating ARV drugs can be used for HIV prevention. Quaife et al. (2016) reported that the HPTN 052 trial determined the potential to decrease HIV positive

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persons by suppressing viral loads, which led to developing treatment as a prevention programme. This indicated ARVs oral pre-exposure prophylaxis (PrEp) has a high degree of protection from HIV through different population's worldwide (Quaife et al., 2016). The study uses prevention through ARVs for HIV-positive women. ARVs is a treatment that suppresses or stops a retrovirus. One of the retroviruses is HIV that causes AIDS. All participants in this study were taking their ARVs daily to be healthier. Participants responses were as follows:

"I have nurses visiting me at home, they encourage me to take my ARVs, and I prefer to abstain" (P5); "I used to take many ARVs before, but now it's changed, and I only take one" (P2); "I take my tablets" (P1).

The participant's responses indicated that they chose to take their ARVs to reduce re-infection and the spread of HIV. They also received counselling from the nurses about ARVs adherence when they do home visits.

Theme 8: Prevention Through Condom Use

The use of prevention through condom use is practised in the study for HIV-positive women. This is applicable to those participants who do not use the method of abstinence. In the South African setting, ARV based prevention products such as male and female condoms assess condom use as the only product to protect against STIs, HIV and unwanted pregnancies (Quaife et al., 2016). Some of the participants in this study used condoms to prevent re-infection, pregnancies and the spread of HIV. Some of the responses were as follows:

"My partner and I use condoms, this prevention measure is helping me" (P2); "My partner and I use condoms" (P4); "We are using condoms" (P10).

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These three participants spoke of condom usage. Some of the participants previously had talked of abstaining from sexual intercourse and felt this would prevent re-infection to others and themselves. However, these three participants (P2, P4 and P10) felt condom usage would stop them from being infected and prevent HIV from spreading. Except for abstinence, latex condoms are the most effective methods for reducing the risk of infection from the viruses that cause AIDS, other HIV-related illnesses, and STDs.

4.7 Cultural Barriers in HIV Prevention

The study reveals that cultural barriers did not influence HIV-positive women regarding ARVs. This is offset against anecdotal and empirical evidence showing that many people in Africa, from different ethnicities and regions, engage in cultural practices that impede HAART adherence (Ondwela et al., 2019). A local study of 18 participants in the Vredenburg regional hospital who did not take their ARTs found simultaneous use of concoctions from traditional healers while on ARTs (Azia et al., 2016). Participants came from various cultural groups and religious backgrounds and, therefore, were asked if anything in their culture or religion prevented them from taking their ARVs. Their responses were as follows:

“There is no cultural barrier that prevent me for taking the ARVs” (P1); “None at all” (P10); “No, nothing” (P2); “No cultural barriers” (P3); “No, none” (P7); “No” (P5).

None of the women who participated in this study faced cultural barriers in making decisions concerning their health. They all took their medication to control their CD4 counts on their own accord.

4.8 Are These Prevention Measures Effective or Not?

The study reveals prevention measures, which are effective or not concerning HIV-positive women. The participants reported that their chosen prevention measure was

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helping them prevent the spread of HIV and re-infection. Some of the participants responded as follows:

“We abstain it is one of my prevention measure” (P3); “My partner and I are using condoms this is helping me” (P2); “My partner and I use condoms this is definitely helping” (P7); “I just feel, I want to abstain from all this and not indulge in any relationship with anybody it is the best way” (P6).

All participants agreed that the prevention measures they chose were favourable for them, and there was no alternative measure they needed in order to empower themselves because they only knew the ones they mentioned.

4.9 Conclusion

The aim of this research study was to prevent the spread of HIV by empowering women through educational prevention programmes. The review of objectives was first, to explore the experiences of women living with HIV; second, to explore and describe challenges in their daily lives; third, to explore coping strategies used to cope with their challenges; fourth to explore cultural factors hindering women from having autonomous decision making. The final objective was to identify prevention measures in empowerment. In this study, women living with HIV experienced psychological and emotional experiences such as feelings of shock, disbelief, panic feelings, fear and worry. The challenges women faced in this study were psychological, such as anger, social/behavioural, isolation, and socio-economic. Some of these women’s financial challenges were unemployment, child support and disability grants, and cultural barriers in HIV prevention. The coping strategies used to deal with HIV in the study were support groups, ARVs adherence, exercise, supportive care and prayer. The prevention measures used to prevent HIV re-infections through HIV counselling and testing, adherence, abstinence, ARVs, condom use was

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discussed and whether these prevention measures were effective or not. Chapter five follows to explore the discussion, conclusions and recommendations of the study.

CHAPTER 5

DISCUSSIONS, CONCLUSIONS AND RECOMMENDATIONS

5.1 Introduction

The purpose of this study was to empower women through effective prevention programmes. This was done by encouraging them to break the stigma and prevent them from spreading HIV as well as other infections to others. The participants were encouraged to share their experiences of being victims of this disease and prevent re-infections. The current study attempted to explore the experience and challenges faced by women living with HIV in their daily lives. It also looked at the coping strategies used by women living with HIV to cope with their challenges. The study further explored if cultural factors hinder women from having autonomous decision-making. The prevention measures pertaining to empowerment required by women living with HIV were also explored. The study was based on understanding the experiences that the participants have undergone and how they had used challenges to move forward and empower themselves by using measures that work for them. Lastly, the limitations were described, and possible recommendations for further studies were made.

5.2 Experiences of Women Living with HIV

UNAIDS (2014a) highlighted that South Africa has the largest HIV burden than many other countries in the world. Statistics South Africa (2016) estimated that the total number of people living with HIV from 2002 to 2016 were approximately one-fifth of South African women in their reproductive ages. Women that have been affected with HIV faced many physical, psychological, financial and social distresses. The women who reported their HIV status at work usually face stigma and discrimination. Many HIV-positive women did not further their studies, have low education and are at risk for employment loss.

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However, pregnant women living with HIV had access to antiretroviral medicines to prevent the transmission of HIV to their babies (UNAIDS, 2016).

According to Oliveria et al. (2015), women living with HIV had many negative experiences, including increased social and personal responsibilities after an HIV-positive diagnosis. The disease brings the responsibility of taking care of themselves. It becomes difficult for them to adjust to the new routine. It is evident from the findings that HIV had an impact psychologically on women infected by HIV. The virus changed their lives and also affected the lives of their families. Participants in this study reported psychological challenges and different emotions ranging from shock, disbelief, panic, fear and worry. They did not dwell on physical challenges.

McIntosh and Rosselli (2012) highlighted that lack of understanding regarding the disease leads to rejection and social isolation. Some of these women experienced fears of rejection, stigma, depression, anxiety and the feeling of hopelessness. All participants in this study showed signs of fear, depression and helplessness. Women who experience fear and anxiety are at a greater risk for poor ARV adherence, leading to treatment relapse (McIntosh & Rosselli, 2012). However, through support groups at the hospice and attending regular healthcare visits, participants in this study managed their condition. Participants were empowered with skills to manage the disease, and they started accepting their illnesses to live their everyday life.

In this study, we saw how some participants were intertwined with society, i.e., their community. This study recognises that participants have the right to acquire knowledge on HIV and receive treatment. In addition, participants are required to attain support from their family, friends and close loved ones.

5.3 Challenges Faced by Women Living with HIV

According to Oliveria et al. (2015), the HIV-positive status poses a threat both physically and psychologically which also affects social relations. This brings about trust issues, anger, denial and fear of the unknown that could prevent them from new experiences. Other challenges faced were loneliness, anger, anxiousness and depression. These negative feelings contribute to much stress in women who are HIV positive. Motivation and psychosocial empowerment are needed to support women living with HIV to access health care services in order to improve quality of life and cope with the stigma and discrimination to prevent self-isolation and substance abuse.

UNAIDS (2017) indicated that stigma and discrimination cause people to become more vulnerable to the disease because it hampers them from getting help and information. Those infected with HIV continue to face stigma and discrimination. This can manifest itself in many ways, for example, in the workplace, healthcare system, community, and family. The participants in this study did not experience any discrimination from their local clinics. They also did not experience any from the workplace, but this is not revealing as many were unemployed. However, some of them experienced stigma and rejection from their family members. They therefore resorted to isolation where they wanted to be alone and not communicate with others in the family. They were also unable and unwilling to share their emotions with others. The social-ecological model indicates that community environments can either promote health and wellbeing or be a source of stigma. Stigma affecting populations at risk for the acquisition and transmission of HIV is often visible at the community level in limiting the uptake of HIV prevention, treatment, and care services. Therefore, for interventions to be effective, strategies need to begin at the community level. Interventions cannot focus on the individual as separate from their community. Baral et al. (2013) emphasised that strategies for interventions should be implemented across society and not on an individual level.

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Olley et al. (2017) indicated that people might be reluctant to discuss anything (meaningful) but only share superficial matters. An individual might feel emotionally isolated despite having a social network. Even though relationships are necessary for their wellbeing, they can trigger negative feelings and thoughts; therefore, people use emotional isolation to protect themselves from distress (Olley et al., 2017). The social-ecological model highlights that social and sexual networks comprise interpersonal relationships including family, friends, neighbours and others that directly influence health and health behaviours in multiple ways. It was, therefore, suggested that interventions to reduce HIV should also focus on social networks. This goes back to community versus the individual, as discussed previously. These family and social networks can provide social support and reinforce social norms and behaviour that serve as protective factors and reduce HIV transmission risks (Baral et al., 2013).

UNAIDS (2017) claimed that poverty was another driving force of HIV transmission. Women affected with HIV have difficulties with socio-economic opportunities resulting in poverty. Women are susceptible, and therefore lack of awareness in various fields increases women who have HIV. Women were considered more vulnerable than men since women in rural and urban areas have limited exposure to media and education, which inhibits their access to information. The participants in the study faced financial challenges as most of the women were unemployed and relied on social grants. Some of the participants in the study were supported by their families.

Low economic rates had been associated with earlier sexual experiences where women engage in transactional sex to sustain livelihoods (UNAIDS, 2017). Young women are coerced into sexual activities with older men to sustain their survival instead of furthering their studies. Women were prone to increased risk due to poverty, unemployment and financial reliance on their sexual partners (UNAIDS, 2017). Although some of the participants were able to work to sustain themselves, seven of them were unemployed.

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Some of the participants in this study had a low education; due to this; they could not find work. Some of the participants sought child support for their children who were below the age of 18. Others made use of child support grants to support their families. This is a serious challenge because the grant is to help parents with the costs of the basic needs of their child and not to be extended further. The grant was not meant to replace other sources of income but intended to bridge the gap in the cost of living.

Although several participants reported experiencing negative challenges associated with the socio-economic factors, only three reported that they could get well and held steady jobs. They were also able to support themselves because they had a disability grant, although it lasts for only six months. Azia et al. (2016) reported that some patients deliberately discontinued taking their ARTs to enable them to lower their CD4 counts and become very sick. The patients then used their low CD4 count and the severity of their sickness to persuade the doctors to qualify them for a disability grant. This is also a challenge because the client is expected to recover after six months with the correct adherence to ARVs medication. Eisinger and Fauci (2018) indicated that ARV adherence is the extent to which a client's behaviour concurs with the prescribed health care regime as agreed through a shared decision-making process between the client and the healthcare provider. The success of ARVs depends on the maintenance of high rates of patient adherence to drug treatment.

Kemboiet et al. (2011) indicated that cultural factors had been reported as one of the challenges faced by women living with HIV. Some cultural factors show increased risks to the spread of HIV. Some young women sought older men to pay for their daily expenditure, luxury lifestyle and education which they could not afford. Family pressure also encouraged women to pursue relationships for financial stability. Azia et al. (2016) indicated that a culturally related factor found to negatively affect adherence to ART was the simultaneous use of concoctions from traditional healers while on ART. According to Azia et

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al. (2016), the respondents in their study used concoctions prepared by traditional healers for cleansing their bodies internally as well as taking ART medication. Although all of the participants in this study were culturally oriented, they did not have any barriers. Due to modernisation, these women understood that they have a right to make decisions concerning their health; hence, they were not affected by their culture in this regard.

Madiba and Ngwenya (2017) reported that while married women, in general, are vulnerable to HIV infection, married and cohabiting older women in rural communities are at a significantly higher risk of HIV infection compared to their counterparts in urban communities. Liu, Li and Huijun (2013) indicated that women living in rural areas are marginalised and disempowered and face geographical barriers in terms of accessing HIV knowledge and services. These dynamics serve to push women into the private sphere of the household and to exclude them from full participation in public life. Feminist theory points out that gender inequality exists for women in a heterosexual marriage and that women do not benefit from being married. Indeed, these feminist theorists claim that married women have higher levels of stress than unmarried women and married men.

However, in South African society, women need to become empowered through education and awareness since they play a vital role in society; this provides them with dignity, equality and power (Oktem, 2015). Most women follow cultural traditions, although being away from rural areas and now living in urban areas, some have converted religions. Most of the participants in this study belonged to Christianity and did not have any barriers that disallowed them from taking their ARVs.

The status disclosure was associated with improved social support as well as reduced feelings of anxiety and stigma (Azia et al., 2016). Several patients reported that they discontinued accessing the ART clinic because they were afraid their status could be unintentionally disclosed if they were seen queuing up at the ART clinic regularly (Azia et

al., 2016). However, HIV disclosure to sexual partners is a major source of stress for women living with HIV (Hampananda & Rael, 2018). In the current study, the disclosure of status was not easy regarding families, as participants were struggling to disclose their status to their children. They did not discontinue accessing their medication at the clinic, and they were also attending support groups in the local clinic.

Azia et al. (2016) reported that the two therapy-related factors that hindered ART adherence were side effects and feeling better after commencing treatment. It is important to address the issue of not having enough information on ARVs, and their side effects if the health system for HIV-positive women is to improve. In this study regarding the side effects of the disease, two participants faced paralysis; however, one participant did recover. The one participant had been paralysed for over a decade due to the side effects of the ARVs. She had come to terms with it. She had learnt to manage her (dis)ability and said she had accepted it. All participants were monitored by the hospice ensuring all medications were taken correctly.

The participants from this study in reference to cultural barriers did not have any barriers hindering them from using prevention measures. They were empowered through support groups and attended regular visits to the health clinics. They came to accept their diagnosis, although some may not disclose their status to everyone. However, their immediate families were aware of their status.

5.4 Strategies Used in Coping with HIV

Greenaway et al. (2015) indicated that coping was a basic process that is important to adapt in survival, and the process in which people deal and learn from their situations makes them stronger. The types of strategies people use for minor or major stressors are natural changes in life. Religion and support groups are some of the strategies used as a coping strategies. Many of the women affected in this study coped effectively with their

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illness and continued to lead a normal meaningful life; some found it difficult to manage other stressors associated with their current illness. Some of these strategies used were to reduce stressful situations. Every individual has different encounters, and not all can cope with these difficulties. Social-ecological models are used to explain the complex associations between social (e.g. social networks) and structural (e.g. access to care) factors, individual practices, the physical environment and health (Baral et al., 2013). Some of the participants used different strategies in coping, such as meditation, prayer, attending support groups or spending time with their loved ones. They employed networking as a coping strategy with institutions such as health care facilities, cultural institutions and by joining support groups in the community for counselling and supportive care and engaging in health care clinics in adhering to treatment.

Poor coping strategies contribute to poor disease management, such as adherence issues, missing medical appointments, and increased morbidity and mortality risks. Inadequate coping strategies for psychosocial stressors may lead to depressed affect, increased psychological distress, hostility/further social isolation, reduced social support utilisation, high-risk sexual behaviour, high prevalence of comorbid psychiatric problems, diminished quality of life and alcohol and/or drug abuse (Makhado & Davhana-Maselesele, 2016). The findings in this study reveal that women with HIV are able to deal with the difficulties they face. This was because they received support from healthcare workers and peers in the support group to which they belonged. Some of them preferred to meditate and spend time with their families. Some HIV-infected individuals can effectively manage their care and lead fulfilling lives.

Although the women in this study were able to cope, the healthcare workers must assist them in developing responsible and effective coping skills that will enable them to prevent and manage HIV infection and help them enhance their lives on various levels. Different life skills are relevant for behaviour change and a better quality of life, which are

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the development of strong and positive self-esteem and self-awareness. They should believe in their right to make their own choices and the ability to handle peer pressure. The women should be able to take responsibility for themselves and others in the community. The skills also include effective communication. Van Dyk et al. (2017) indicated the condom promotion programmes often failed because people were advised to use condoms but were not given guidance on how to communicate with their partners on this issue. Negotiation skills are also important in persuading the partner to practice safer sex and to use condoms (van Dyk et al., 2017).

Vyas et al. (2014) indicated that previous studies have also identified prayer as a facilitator to medication adherence. Those who regularly attended religious services and prayed, and meditated were able to adhere to the medication (Vyas et al., 2014). Dalmida et al. (2017) confirmed findings from previous studies that life-changing religious experiences (prayer) lead to a better understanding of ARV's adherence. Prayer was frequently reported as a facilitator to medication adherence, and in one study, its influence was similar to or above the doctor's recommendation to adhere (Konkle-Parker et al., 2008). The difference in findings may be due to the frequency of prayer and whether medication was combined into one with prayer (Vyas et al., 2014). However, no known studies have compared ART adherence rates or percentages based on the frequency of religious attendance or prayer (Vyas et al., 2014).

5.5 Knowledge About Prevention Measures

Given that women are at a higher risk for HIV infection than men, it is crucial that women be given knowledge about how to prevent themselves from being infected. According to UNAIDS (2017), the global HIV epidemic for women remains at a much higher risk for HIV infection than men. In addition to being at a higher risk, they face additional burdens. Azia et al. (2016) stated that substance abuse such as alcohol, smoking and other

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drug abuse places women at a greater risk for domestic violence, STDs including HIV and other adjustments and mental problems. Azia et al. (2016) found that most of the respondents in their study started drinking heavily and smoking while on ART and reported that heavy drinking and smoking hindered them from taking their ART as prescribed.

Substance abuse in patients taking ART has been noted to have far-reaching consequences on their ability to adhere to therapy. This was because it makes it difficult for them to receive any form of social and family support, which can motivate them to adhere correctly to therapy. In the current study, all participants said they understood the dangers of substance abuse; therefore, they refrained from alcohol abuse, drug abuse and smoking. All participants in the current study stated that they did not engage in risky behaviour, such as drinking and taking drugs, when they encountered challenges in their lives.

Knowledge of contraception is a crucial contributing factor to contraceptive use. In this study, the participants had knowledge of contraception, and it is clear from their experiences they were aware of other alternative methods, including abstinence. All participants received education and training from their supportive organisation that monitored their health and provided them with on-going counselling. According to Genet et al. (2015), VCT can reduce risky behaviours and increase support and adherence to ARTs.

According to Lammer et al. (2013), HIV knowledge has increased on two levels, First, in the awareness of existence and transmission in which HIV was promoted and second, in the way prevention of infection with HIV was communicated. The well-known ABC was incorporated in most prevention campaigns around the world. Condoms are now widely available at all healthcare facilities free of charge. The HIV knowledge gap between females and males in HIV prevention campaigns focuses on improving HIV knowledge amongst women since this ensures more progress in females. The knowledge of condom use is available to all participants in this study as they attended the hospice where this knowledge was shared. Given that women are vulnerable, there needs to be a continued

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emphasis on the ABC approach, the dangers of unprotected sex and assumptions must not be made that women's lives are static, as relationships end and new ones are formed (new strategies for sexual relations such as abstinence or condom use have to be negotiated). Thus counselling needs to remain on-going. This is also backed up by Lammer et al. (2013) who said that not all HIV prevention campaigns had addressed the dangers of unprotected sex. Feminist theories that focus on gender inequality recognises that women's experience of social situations is not only different but also unequal to men's. Feminist theorists have shown patriarchy places women in the private sphere (for e.g. in the household) thus limiting them. This is the sexual division of labour operating in both the public and private domains which need to be altered for women to achieve equality in marriage, the workplace and other areas in society.

Carmona et al. (2018) highlighted that prevention programmes in HIV reduce the risk of transmitting HIV. The programmes are aimed at protecting the individual and rolling out health policies to prevent the further spread of HIV. South African National HIV programmes had achieved substantial ART coverage. It supports the national strategic plan for treatment, care, support, and prevention for early ART initiation. They further indicated that these programmes recognise that to be effective, a combined approach to HIV would be necessary if it entails the combination of different factors that have been identified and need to be taken into consideration when empowering and educating women who are affected by HIV. According to the findings, participants are aware of condoms as a prevention measure. They also have more information concerning the use of ARVs and how to manage the symptoms. They are also aware of changing their risky behaviour as a prevention measure; hence they opted for abstinence and using condoms every time they have sexual activities.

According to Scheibeet et al. (2012), access to HIV prevention and reproduction health commodities such as lubricants, condoms and contraceptives is critical. People

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should be aware of VCTs, as well as treatments for HIV and other STDs in their communities. The participants in this study were aware of some of those services because they were attending support groups, and they went to the clinic for their medication. A multisectoral approach is necessary to attend to the needs of HIV-infected women. VCT cannot be expected to meet all the psychosocial needs of HIV-infected women and families. Although some of the participants were aware of those prevention measures, their sexual partners did not agree with them as they refused to use condoms. Thus, some participants decided to abstain from sexual activities. Therefore, it is imperative that community-based programmes and services should be available to address stigma, violence, sexual coercion, HIV risk behaviours and other issues related to prevention, transmission and behaviour change.

The participants indicated that the prevention measures that they knew were favourable for them. They only knew the ones they were utilising; hence thought there was no alternative measure they needed to empower themselves. The healthcare workers should advise those who are in relationships to encourage their partners to go for MMC to reduce the spread of the disease.

5.6 Empowering Women Through HIV Prevention Programmes

Van Dyk et al. (2017) indicated that for HIV prevention programmes to be effective, a combined approach to HIV prevention should be followed; a combination of biomedical, behavioural and social/structural approaches. The participants in this study reported that they were aware of HIV counselling and testing as a prevention measure. It is important to emphasise that psychosocial support and counselling services must be developed and run by people in their own communities to meet their particular socio-cultural needs.

Healthcare professionals should encourage women on how to begin new relationships after being diagnosed HIV positive by guiding them on the prevention of the

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virus and the importance of follow-up treatment. Some participants in this study are already practising abstinence and using condoms to reduce re-infection and the spread of HIV. All the participants chose to take ARVs as one of the prevention measures. Although they are able to manage their condition, it would be imperative to also empower them with skills to boost their self-esteem, assertiveness, make good decision-making and reduced stigma. That would lead to treatment initiation earlier in HIV infection because they will be more positive. Participants have a right to know their status, to ensure their patient's rights are met, and to receive their ARVs and adhere to treatment.

Van Dyk et al. (2017) indicated that an individual thinks of behaviour consequences before performing a particular behaviour. If any participants in this study have behaviours in their lifestyle that put them at risk, they should be encouraged to change their lifestyle to avoid relapse. The only way to do this is for them to think for themselves and assess whether the behaviour they want to change is positive or negative. This can be done with the help of a counsellor. However, they might want to change the behaviour, only to find that factors affect their willingness to change the behaviour. This is where healthcare workers can play a role by helping people focus on what is in their control to change. If healthcare workers want to be successful in developing sexual behaviour change programmes, they must focus on behaviour that the individual can control. The women should be assessed to find out their strengths and weaknesses in performing a particular behaviour. Therefore, programmes should be tailored to empower them with the necessary skills to deal with situations beyond their control. Health professionals should develop programmes that should promote an active lifestyle and reduce the spread of the disease. It is important for individuals to alter health-related behaviour according to the perceived severity of the threat to their health. The programmes should concentrate on promoting prolonged healthy behaviour by making distinctions between lapses and relapses in an attempt to encourage individuals to maintain healthy lifestyles (van Dyk et al., 2017).

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In 2007, the AIDS Law Project, known as the ALP, was started by non-governmental public lawyers seeking justice and equality of treatment for PLHIV. This law project provided an array of services and programmes consisting of “legal services, human rights and health, policy advocacy and communication and capacity-strengthening” (Duger et al., 2014, para. 2. p .52). Therefore, the use of specific programmes that emphasise the rights of people living with HIV is a well-documented way of eradicating stigma. As well as being made aware of their rights, people living with HIV can be empowered to take action if these rights are violated. Stigma should be reduced in the workplace through HIV education and reducing the cost of ARVs. Due to stigma, employees are more likely to take a day off work. If this is resolved, they will be more productive in their jobs. Thus, women need to be empowered on their rights at the workplace.

Women should be aware of programmes that end partner violence and encourage women to voluntarily feel at ease to disclose their experiences. Women and young girls should be encouraged to access secondary education so that they are able to seek eligible employment that creates self-independence. Women should be provided with basic financial training and to empower them on how to be financially independent. Entrepreneur programmes should be available for women in order for them to control their finances and sustain their families (UNAIDS, 2016).

Women in relationships should be encouraged to involve their partners in prevention programmes. Health care professionals should encourage the couple to create new ways of dealing with their sexuality and relationship because communication between them may not be easy. This requires professionals to encourage couples who have HIV to have an open conversation without prejudices.

Morris et al. (2017) highlighted that MMC is a one-time intervention but provides life-long partial protection against HIV and other STIs and has many medical benefits such as

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protection against several diseases as well as reducing the risk of female-to-male transmission of HIV and development of cervical cancer. Morris et al. (2017) and van Dyk et al. (2017) spoke of the benefits of MMC in reducing HIV transmission. Van Dyk et al. (2017) stated it reduced the transmission of HIV from men to women by about 60%. This shows that MMC does not only benefit males but also their partners/spouses (WHO, 2016). The findings indicated that seven of the participants are in a relationship; therefore, they should encourage their partners to go for counselling and testing as well as circumcision as the benefits are stated above.

Although the participants in this study reported that they were not affected by cultural factors, their male partners have a critical role to play in HIV prevention. Their position enables them to either promote or hinder behavioural change as well as HIV prevention and care in general. Therefore, their involvement in a community's response to HIV is important. Nandoya (2014) indicated that cultural factors could also be utilised to influence the prevention of HIV in the community. Involving women in HIV control activities includes taking a gendered approach to interventions. Thus, involving both men and women in HIV programmes facilitates involvement and participation in designing prevention programmes. Social networks have also played a vital role in influencing HIV prevention programmes. Programmes should encourage local leaders, healers and male religious leaders to use their influence and promote positive images of masculinity and male behaviour for promoting HIV prevention: men as fathers caring for their family, and men with a sense of responsibility and reliability towards themselves and their partners. Healthcare workers should try to identify the obstacles that stand in the way of safer sex practices and to help people to overcome these obstacles.

5.7 Limitations of the Study

A few notable limitations were established in this study. These limitations were as follows:

- The study focused on one organisation that deals with HIV and AIDS patients. This organisation was located in the KwaZulu-Natal province of South Africa (Verulam). Therefore, the results may not be generalised to women living with HIV outside these organisations, areas and regions.
- The study consisted of a relatively small sample; the number of those who participated in the study was minimal; 10 women were interviewed. This may limit the generalisability of findings in the study.
- This study was time-consuming as it took 8 weeks to interview 10 participants from different townships and the CBD since the researcher had to be transported to visit participants.
- Interviewing women from different cultural backgrounds was challenging. Some of these women were not open to express their experiences due to fear of stigma.
- Accessibility to participants was challenging as they were visited in their homes to maintain identity disclosure.
- One participant from this study had passed on after the interviews presenting a challenge because the researcher could not visit her to verify the results (note – cause of death was not HIV-related).

5.8 Conclusion

The finding of this study indicates a need to encourage women empowerment, especially towards women who have been living through challenging experiences. The ongoing persistence of high levels of low education, stigma, discrimination, inequalities, and unemployment contribute to the spread of HIV disease. This study showed that most

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women living with HIV could achieve optimal ART adherence. However, they require support from their families. ART adherence rates vary among women living with HIV and may be based on age, and religious belief. Therefore, these factors should be assessed and considered in the treatment plan as healthcare providers collaborate with patients and other members of the care team, including mental health providers, social workers, and pastoral counsellors.

Challenging stigma, discrimination and denial in the context of HIV requires commitment at all levels, including government institutions, NGOs, CBOs, communities and individuals. HIV is much more than a health problem. It touches human conditions, human security, human rights and social and economic development. A human rights framework is essential to encourage a reduction in HIV-related stigma and discrimination.

Cultural factors were not a challenge in this current study. However, it is masculinity that blocks the use of effective prevention methods; hence some participants resorted to abstinence, and that may further create problems in a relationship. HIV prevention campaigns might be more efficient if women are empowered to have bargaining power which can be addressed with a campaign focus on men and forms of masculinity. Therefore, when diversifying prevention campaigns, it would be important to know which types of knowledge are relevant for males and females, respectively.

5.8.1 Recommendations

The following recommendations represent the perception of the results made.

Recommendations to the Department of Health And HPCA

It was recommended that organisations such as clinics, hospices and other institutions should specialise in programmes that facilitate HIV prevention programmes to reduce both the spread of the disease and other opportunistic infections. Clinics and

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hospices should provide educational, prevention measures on contraceptives and ensure that they are easily accessible. These prevention programmes should target youth and older age groups. Individual counselling should be made possible for those who want to remain anonymous.

5.8.2 Recommendations for Future Studies

The following recommendations, arising from the study, will form a foundation in future studies relating to empowering women through prevention programmes. The results in this study suggest that further studies in prevention programmes will be worthwhile in empowering women.

Some of these participants reported experience could be used as the basis for healthcare services and social services for women with HIV, advocating government involvement in reducing the number of people infected by HIV. It is recommended that future research should focus on the following aspects:

1. Exploring the impact of GBV among women living with HIV in South Africa.
2. Exploring psychosocial challenges of women living with HIV in rural communities in South Africa.
3. Exploring prevention measures that are user friendly without disclosing the person's status.

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APPENDICES

Appendix A: Informed Consent

Informed Consent Form

Title: Empowering Women Through HIV/AIDS Prevention Programmes

Researcher: Thirusha Rambarath (Doorasamy)

The research being carried out is to empower women using educational prevention measures. The study aims to empower, those who have difficulty in understanding their diagnosis and how to help them to adjust to their illness and to take prevention measure in not spreading the virus.

I understand that sharing my experiences is heart breaking. I am aware that the interview will require approximately 60 minutes of my time and that the interview will be recorded by the researcher.

I have read and understood the purpose and procedure of the study. I also agree and promise to keep information shared by others confidential. I understand my participation is voluntary, I have the right to withdraw at any time, before and during the study. I have been informed that the researcher will be available to answer any questions during the research and I have received her contact details.

I give full consent to participate in this study and I have been made aware that my identity will be kept confidential throughout this study. The researcher, transcriber and the supervisor will be the only ones that have access to the recordings of the interviews.

I have been given a copy of the participant information sheet.

Name: _____

EMPOWERING WOMEN THROUGH HIV PREVENTION PROGRAMMES

Age: _____

Contact no: _____

I, _____ do wish to participate in this study.

Participant's signature

Date:

Researcher's signature

Date:

Interview date _____

Time _____

Cut here for the participant.....

Researcher: Thirusha Rambarath (Doorasamy):

Tel: XXXX

Interview date

Time

Appendix B: Interviewer Recording and Consent Form

Interview & Recording Consent Form

I, _____ consent to being interviewed by Thirusha Rambarath (Doorasamy) for the research entitled **Empowering Women through HIV/AIDS Prevention Programmes**.

I understand that participation is voluntary and that:

- I may refuse to answer any uncomfortable questions or withdraw from the study at any point.
- The interview will be recorded and part of my responses may be quoted.
- My responses are confidential and no information identifying me will be included in the research report.

Participant's signature

Date

Researcher's signature

Date

Thirusha Rambarath (Doorasamy)

Appendix C: Organisation Letter of Appeal

Dear (Name of Manager)

My name is Thirusa Rambarath (Doorasamy). I am currently completing a research report towards my Master's Degree in Psychology at the University of South Africa. The research being carried out is to empower women using educational prevention measures. The study aims to empower HIV-positive women, who have difficulty in understanding their diagnosis and how to help them to adjust to their illness and to take prevention measure in not spreading the virus. The research will contribute to the discipline of psychology in gaining understanding as to the complexities that destruct the lives of HIV-positive women.

I hereby seek permission to access clients at your organisation that are living with HIV and that are willing to participate in this study. All participants that volunteer will remain anonymous while their experiences will be known. Each interview will have a time frame of approximately 60 minutes. Interviewees may refuse to disclose any information that they are uncomfortable with, they also have an option of withdrawing from the study at any given time without no consequences.

Debriefing will be made available should the participant require it. Debriefing and information will be provided to the organisations selected. Interviews will be recorded and later transcribed. The recordings will be kept locked in a secure place. The transcripts will be included in the final study. Participant's names will be removed from the study, if anyone requires finding of this study a report will be given after the research has been completed.

You are in no way compelled to participate in this study. Should you have any inquiries, please do not hesitate to contact me. It is necessary for me to seek your permission first and I trust you will give me this opportunity to begin my study.

Kind regards

EMPOWERING WOMEN THROUGH HIV PREVENTION PROGRAMMES

Thirusha Rambarath (Doorasamy)

Cell No: XXXX

Email: tiffyd4@gmail.com

Supervisor: Mrs K Shirinda-Mthombeni

Office Tel Number: 012 4298317

Email: shirik@unisa.ac.za

Appendix D: Participants' Information on Study

My name is Thirusha Rambarath (Doorasamy). I am a Master's student at the University of South Africa. I am completing a study toward my Master's of Arts Degree in Psychology.

You are invited to take part in empowering women through HIV/AIDS prevention programmes.

The study aims to empower HIV-positive women, who have difficulty in understanding their diagnosis and how to help them to adjust to their illness and to take prevention measure in not spreading the virus.

The reason behind your participation towards my study is to share your experiences and challenges which is valuable to this study. Your participation is voluntary. Should you pursue to participate in this study, you are welcome to leave the study at any time without permitting a reason.

All information obtained during this study will be confidential. The interviews will be recorded with your permission. An interview and recording form will be required for you to complete. Once information is recorded we will thereafter transcribe this information. Please note that your identity and contact details will not reflect in this study.

Your participation is of great importance and will assist society that are experiencing the similar difficulties that you have been through. This will empower you to understand your diagnosis, better prevention measure, better coping skill and living a good normal life.

This study is being supervised by Mrs K Shirinda-Mthombeni, who is a lecturer at the University of South Africa. Her contact details are: Office Tel Number: 012 429 8317 and Email: shirik@unisa.ac.za

EMPOWERING WOMEN THROUGH HIV PREVENTION PROGRAMMES

Should you have any further inquiries regarding this study, please contact me: Thirusha Rambarath (Doorasamy), Cell No. XXXX or email me: tiffyd4@gmail.com.

Thank you for your time and patience and for participating in my study. I hope this study empowers you and gives you an opportunity to empower others.

Kind regards

Thirusha Rambarath (Doorasamy)

Supervisor: Mrs K Shirinda-Mthombeni

Office Tel Number: 012 429 8317

Email: shirik@unisa.ac.za

Appendix E: Interview Questions

Biographical Details of participants

Participants Number: _____

Age: _____

Race: _____

Religion: _____

Financial Status: _____

Dependants: _____

In a current relationship: _____

No of relations: _____

Period of relations: _____

Interview Questions

I will be interviewing women who are living with HIV in order to understand the current dilemmas which they are facing.

- a) How did you feel for the first time when you were told that you were HIV positive? and how did it affect your life?
- b) What are the psychological challenges that you were faced with?
- c) Being diagnosed with HIV, did it have an impact on you financially?
- d) What are your current coping strategies in overcoming this illness?
- e) Are there any cultural barriers preventing you from making autonomous decisions?
- f) Do you have any prevention measures in place to prevent HIV or preventing re-infections, if so, what are they?
- g) Are these prevention measures helping you?

If not, would you want to be empowered with better prevention measures and education on HIV/AIDS?

Appendix F: Ethical Clearance

Ref. No: PERC-17068



Ethical Clearance for M/D students: Research on human participants

The Ethics Committee of the Department of Psychology at Unisa has evaluated this research proposal for a Higher Degree in Psychology in light of appropriate ethical requirements, with special reference to the requirements of the Code of Conduct for Psychologists of the HPCSA and the Unisa Policy on Research Ethics.

Student Name: Thirusha Doorasamy **Student no.** 40853527

Supervisor: Ms. Keit Shirinda-Mthombeni **Affiliation:** Department of Psychology, Unisa

Title of project:

Empowering Women through HIV/AIDS Prevention Programmes

The proposal was evaluated for adherence to appropriate ethical standards as required by the Psychology Department of Unisa. The application was approved by the Ethics Committee of the Department of Psychology on the understanding that –

- All ethical requirements regarding informed consent, the right to withdraw from the study, the protection of participants' privacy and confidentiality of the information, should be made clear to the participants and adhered to, to the satisfaction of the supervisor;
- If further counseling is required in some cases, the participants will be referred to appropriate counseling services.
- Any and all formal procedures that need to be followed to gain access to the participants and to obtain information for the purposes of research, as required by the cultural structures of the community, have been adhered to, and that the relevant authorities are aware of the scope of the research.

Signed:

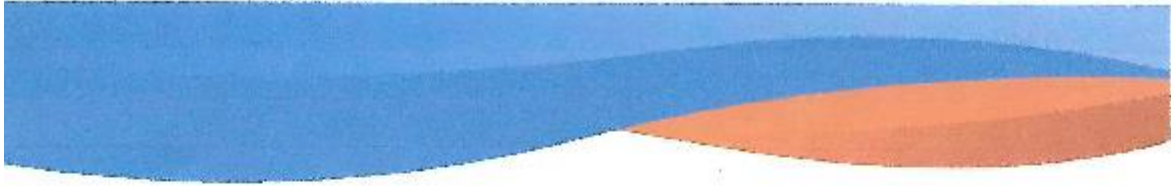
A handwritten signature in blue ink, appearing to read 'M. Papaikononou', enclosed in a hand-drawn oval.

Prof. M Papaikononou

Date: 2017-11-01

[For the Ethics Committee]
[Department of Psychology, Unisa]

Appendix G: Editing Certificate



01 August 2021

Declaration of editing

I declare that I have edited the thesis of Ms Thirusha Rambarath entitled 'Empowering women through HIV prevention programmes'.

My involvement was restricted to language usage and spelling, completeness and consistency, referencing style of the references in the thesis and reference list, formatting of headings, table captions, automated page numbering and automated table of contents. I did no structural re-writing of the content. After my language editing, the author has the option to accept or reject suggestions/changes prior to submission.

This thesis was duly edited by me using track changes. I make no claim as to the accuracy of the research content. It is not the responsibility of the editor to check for plagiarism. I am not accountable for any changes made to this document by the author or any other party subsequent to my edit.

Signed *Vanessa Lynn Neophytou* at *Durban* this *01* day of *August* 2021

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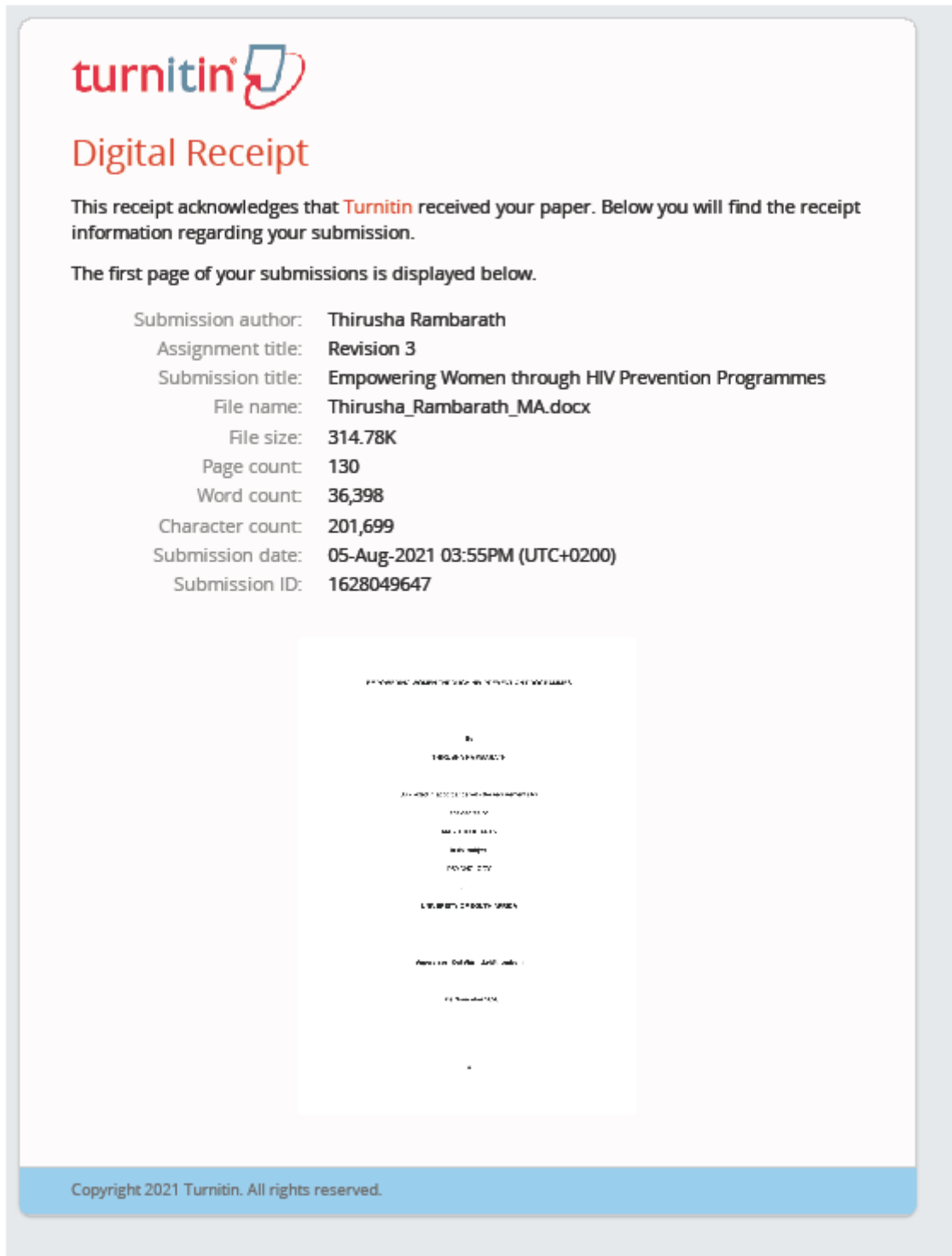
Vanessa-Lynn Neophytou
Associate Member

KwaZulu-Natal Branch: Events Coordinator
Membership number: MED001
Membership year: March 2021 to February 2022

073 276 8899
vanessalynnneophytou@gmail.com

www.editors.org.za

Appendix H: Turnitin Report



The image shows a Turnitin Digital Receipt. At the top left is the Turnitin logo. Below it is the heading "Digital Receipt". A paragraph states: "This receipt acknowledges that Turnitin received your paper. Below you will find the receipt information regarding your submission." Another paragraph says: "The first page of your submissions is displayed below." A list of submission details follows: Submission author: Thirusa Rambarath; Assignment title: Revision 3; Submission title: Empowering Women through HIV Prevention Programmes; File name: Thirusa_Rambarath_MA.docx; File size: 314.78K; Page count: 130; Word count: 36,398; Character count: 201,699; Submission date: 05-Aug-2021 03:55PM (UTC+0200); Submission ID: 1628049647. Below this is a preview of the first page of the document, which contains the title "EMPOWERING WOMEN THROUGH HIV PREVENTION PROGRAMMES" and other text that is mostly illegible due to low resolution. At the bottom of the receipt area, there is a blue bar with the text "Copyright 2021 Turnitin. All rights reserved."