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Acceptability and willingness among young people in Soweto to use at-home HIV test.

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A research reported submitted in partial fulfilment of the requirements for the degree of Master of Arts in Psychology by Coursework and Research Report in the Faculty of Humanities, University of the Witwatersrand, Johannesburg, 2020.

Declaration

I declare that this thesis, titled ‘Acceptability and willingness among young people in Soweto to use at-home HIV test’ is my own unaided work. It is submitted for the degree of Master of Arts by Coursework and Research Report in Psychology, at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any other degree or examination at any other university.

Signature: _____ Date: _____

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ACRONYMS AND ABBREVIATIONS

AIDS- Acquired Immunodeficiency Syndrome

ARV- Antiretroviral

DOH- Department of Health

FDA- US Food and Drug Administration

HBM- Health Belief Model

HCT- HIV Counselling and Testing

HIV- Human Immunodeficiency Virus

HIVST- HIV self-test

HPCSA- Health Professions Council of South Africa

MSM- Men having sexing with men

NHLS- National Health Laboratory Services

PMTC- Prevention for mother-to-child Transmission

SAPC- South African Pharmacy Council

UNAIDS- United Nations Programme on HIV/AIDS

USA- United States of America

VCT- Voluntary Counselling and Testing

WHO- World Health Organization

Abstract

HIV testing among young people aged 15-24 remains at sub-optimal levels in South Africa. To increase HIV testing, the World Health Organization (WHO) recommends that an at-home HIV test be made widely available in all countries. In 2017, the South African Pharmacy Council approved the availability of an over-the-counter HIV home test kit in South African pharmacies. However, little is known about the knowledge and use of HIV home test kit among young South Africans. In this study, I conducted 15 in-depth interviews with young males and females aged 18-24 years old in Soweto, Johannesburg. Participants were first asked to share their experience with testing for HIV, their views about the benefits of testing, and their perceived HIV risk. Participants were then showed a video of the HIV home test (as a demonstration of how it works) and were asked to provide feedback on whether or not they would find it easy to use. All of the participants that were interviewed had previously tested for HIV. The interview data revealed that the majority of the participants were not aware of the HIV home test but they expressed their willingness to use it. However, some raised concerns about the absence of HIV counselling and suggested that a toll-free number be made available should one need to speak to someone regarding the test. Additionally, young people were willing to purchase the HIV home test at an affordable price ranging from R25-R100 from their local pharmacies, retail stores, or for free from their local clinic. All participants agreed that the HIV home test would improve the uptake and frequency of HIV testing among young people in South Africa. This study suggests that an HIV home test kit has the potential to increase HIV testing rates among young people. There is a need for increased awareness around the availability of the HIV home test kit. Further consideration should also be given to ensuring the affordability of the HIV home test kit for young people in South Africa.

Key words: Acceptability, Health belief model, HIV home test, HIV self-testing, South Africa, Young people

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CHAPTER 1: Introduction

This chapter introduces the reader to this research report, providing insight and background information that is relevant to its conceptualization. This chapter provides a short history of the at-home HIV test and where South Africa is in terms of selling the HIV home test kit over-the-counter. This chapter also highlights some of the salient reasons as to why young people do not get tested for HIV and why there is a need for more innovative ways of testing for HIV in order to improve the uptake as well as contribute to meeting the United Nations HIV/AIDS programmes (UNAIDS) 90-90-90 targets (UNAIDS, 2014).

1.1 Research Aims

This study aims to investigate the acceptability and willingness among young people living in Soweto in using the HIV home test kit. The aims of this study include the following:

- To understand the reasons young people (between ages of 18-24 years) do not test for HIV.
- To facilitate the engagement of young people in using at-home HIV test kit that has the potential of improving/increasing the frequency of testing in young people.
- To explore the perceptions of young people of the HIV home test kit.
- To increase awareness of the at-home HIV test kit that is available in South African pharmacies among young people living in Soweto.

1.2 Background

The United Nations Programme on HIV/AIDS (UNAIDS) defines HIV self-testing as an activity where an individual with the desire to know their HIV status collects a sample of their oral fluid or blood, carries out the test and interprets the test results in private without the help of a healthcare worker (UNAIDS, 2014). There is limited literature on where and when the HIV home test was first developed. However, research shows that the HIV home test has been available on the online market through online stores in the United States of America since 1996 (Ibotoye et al., 2014). It was only in July of 2012 when the US Food and Drug Administration (FDA) officially approved the first ever HIV home test to be sold over-the-counter (Ibotye et al., 2014). In 2014, the United Kingdom also lifted the ban on HIV

home testing, however, no manufacturer is producing it as yet. In November of 2016, the World Health Organization (WHO) advised that the HIV home test that enables users to find out their HIV status in private and in the comfort of their own home, be made available in all countries to increase accessibility to HIV testing (WHO, 2016). The Director-General of the WHO, Dr. Margaret Chan, argued that the HIV home test kit would allow a large number of people to test for HIV and to know their HIV status (WHO, 2016). However, in spite of the abundant research showing the benefits and effectiveness of the HIV home test kit, in addition to the approval from the WHO, pharmacies in South Africa were still prohibited by the South African Pharmacy Council (SAPC) from selling the HIV home test to the public over the counter. This ban was initially published in 2004 (SAPC, 2016). The SACP banned pharmacies from selling the HIV home test for two main reasons. The first concerns the damaging implications a positive result could have on the public while the second concerns the absence of the important pre- and post-test counselling which would not be accessible when conducting at-home testing. However, in 2016, following a decision taken by the council in May of 2015, the SAPC has since lifted this ban. While the SAPC agreed that tests be sold over the counter, it has emphasised that pharmacists should guide customers in using the test (SAPC, 2016).

HIV counselling and testing are a crucial part of public health efforts in order to fight the impact of the HIV pandemic in South Africa. The South African government and international donors have made large investments to increase access to HIV counselling and testing services (Rooyen et al., 2013). One of the major efforts undertaken by South Africa was the launch of the HIV counselling and testing campaign in 2010. This ambitious campaign aimed to have 15 million South Africans tested for HIV in 12 months (Health-e News, 2010). However, despite the large investments and the rise in numbers for HIV testing, the number of South Africans who are aware of their HIV status still fails to meet international standards. Van Rooyen et al., (2013) discovered that men, in particular, are reluctant to approach healthcare institutions for HIV counselling and testing services. Results obtained by van Rooyen et al., (2013) further revealed that privacy, confidentiality and healthcare workers' attitudes are major concerns in healthcare facilities. In addition, testing for HIV still requires one to 'come to the service' which can be time-consuming. This can hinder the seeking out of HIV testing services (Ntsepe et al., 2014)

1.3 Rationale

Young people between the ages of 15-24 years are at a higher risk of contracting HIV and are unequally affected by HIV in comparison to other population groups (Moodley, 2019; Avert, 2018). In 2016 alone, 610 000 young people between the ages of 15-24 years were infected with HIV (Hosek & Pettifor, 2019). Moreover, one-third of all new global HIV infections occur among young people aged 15-24 years; the majority of them located in Sub-Saharan Africa (Hosek & Pettifor, 2019; Ridgeway, Dulli, Murray, Silverstein, Dal Santo, Olsen, de Mora & McCarraher, 2018). Half the number of HIV-positive young people between the ages of 15-19 years, are found in South Africa, Nigeria, Mozambique and Tanzania (Avert, 2018). Hosek and Pettifor (2019) add that girls in Sub-Saharan Africa, aged between 15-19 years are four to five times more at risk of HIV infection than their male peers.

According to the 2018 report by Statistics South Africa, HIV prevalence among young people between the ages of 15-24 years has declined from 6.7 % in 2002 to 5.5 % in 2018. The annual progress report for 2017/2018 by the Gauteng province reported that HIV prevalence in young people aged 15-24 years has remarkably dropped in contrast to other provinces (Gauteng Department of Health annual report, 2018). The Gauteng province is currently in fifth place in the country's overall ranking of HIV prevalence (DOH, 2018). The State of the Provincial Healthcare System: Spotlight on Gauteng (2018) reported that the City of Johannesburg, City of Ekurhuleni and the City of Tshwane have the highest burden of HIV in the province. The City of Johannesburg has a population of 5 172 937 people where 12.9 % of them are living with HIV. Soweto, which is under the City of Johannesburg metropolitan, "is an urban township located 15km southwest of the City of Johannesburg" (Rooyen et al., 2014, pg. 2). Soweto has a number of townships in an area of $63km^2$ (Rooyen et al., 2014).

The goals of UNAIDS are to provide HIV treatment to all of those who are infected and to end the AIDS epidemic by 2030 (UNAIDS, 2016). To help end the AIDS epidemic, UNAIDS has set 90-90-90 treatment targets, one of which is ensuring that by 2020, 90 % of people infected with HIV will know their HIV status. Mphaya, Roos and Ehlers (2008) are of the view that before treatment and care for those living with HIV can occur, individuals must first be aware of their HIV status. Being aware of your HIV status leads to behavioural change, obtaining treatment, care and support (Mphaya et al., 2008). Additionally, knowing your HIV status limits the chances of infecting others (Mphaya, Roos & Ehlers, 2008).

Previous research in South Africa has identified barriers preventing young people from using HIV testing services. These barriers include the negative attitudes shown towards patients by healthcare workers and the lack of confidentiality with test results as young people often reside in the same areas as the nurses at their local clinics (MacPhail et al., 2009). These findings are similar to the results obtained by Mphaya, Roos and Ehlers (2008) which identified the lack of confidentiality of test results, privacy, and long waiting time as barriers identified by young people to testing for HIV. Kabiru et al., (2011) pointed out lack of privacy, long waiting times, and lack of confidentiality of test results as barriers preventing young people from seeking HIV testing services. According to Young, Hlavka, Modiba, Gray, Van Rooyen, Richter, Szekeres and Coates (2010), the close proximity of the testing stations to the home or school also acted as a barrier when seeking out testing services. It is therefore important that more innovative ways of testing be explored. The use of the HIV home-test kit would potentially enable young people to test for HIV without concerns as to the confidentiality of their test results and long waiting times while in the comfort of their own home (MacPhail et al., 2009). However, little is known about the knowledge that young people have about the HIV home test kit and their willingness to use it. For this reason, this study will investigate if young people are willing to make use of the HIV home test kit in order to improve both the testing for HIV and the frequency of testing.

1.4 Structure of the Report

This research report is divided into five chapters which include: the introduction, literature review, research methods, findings and discussion and conclusion.

Chapter one presents a general introduction to the full report which includes background information to this research study. The justifications for conducting this research and focusing on this specific study topic are outlined. The aims and research questions of the study are also presented here.

Chapter two presents the literature that is relevant to this study. In this chapter, the prevalence of HIV among young people in South Africa, HIV testing, the at-home HIV test kit and its benefits and limitations are discussed amongst other things. Since the focus of this study is on young people, the literature review will also address the risky behaviours in which young people engage that places them at a higher risk of contracting HIV. Stigma, as a barrier

to HIV testing, will be detailed in this chapter. Lastly, the theoretical framework used in this study will also be presented.

Chapter three focuses on the methodology used in this study to answer the research questions and a detailed outline of how the research was conducted. This includes details of the study sample and the sampling procedures conducted. This will be followed by the data collection tool used and the data collection procedures. Thematic analysis, which is the method used to analyse data, is discussed along with the six steps that were followed in this study.

Chapter four presents the findings of this research study in addition to a thematic analysis. Major themes identified from the data will be presented along with direct quotations to illustrate the acceptability and willingness among young people to use the HIV home test kit.

This chapter also includes an integrated discussion of the research findings in relation to the literature review. The Health Belief Model will also be applied to allow for a rich interpretation of the research findings.

Chapter five presents a summary of the main findings of the study and the conclusions that are drawn. This chapter also details the limitations of this research study, its contribution to existing knowledge as well as recommendations for future research in this area.

CHAPTER 2: Literature Review

2.1 Introduction

This chapter presents a review of literature on the history of HIV/AIDS in South Africa including South Africa's first response to the pandemic and the treatment response. This chapter also explores HIV in the South African social context and the stigma attached to the disease. Additionally, literature on young people and the factors influencing their decision-making is also presented in the chapter. Furthermore, HIV testing & counselling, including available testing services and the different testing tools used, are outlined here. This is followed by HIV home testing, what it is and its development as well as the benefits and limitations of this test. Lastly, this chapter explores the Health Belief Model (HBM) theory to understand if young people in South Africa would accept and subsequently use the HIV home test.

2.2 History of the HIV pandemic in South Africa

The HIV/AIDS pandemic in South Africa has evolved to become the biggest challenge in public health. The HIV pandemic in South Africa was first known to be found among gay men as well as in individuals receiving unsafe blood transfusions (Karim & Karim, 2005). According to Whiteside and Sunter (2000), the first identified cases of AIDS in South Africa was in 1982 when the South African Medical Journal reported two cases of AIDS in male homosexuals (Karim & Karim, 2005). In the next 8 years, AIDS was known to be a pandemic exclusively found in white homosexuals (Whiteside & Sunter, 2000). McNeil (2012) adds that the AIDS epidemic peaked in the mid-1980s when male homosexuals were being diagnosed with opportunistic diseases related to AIDS.

By 1989, an increased number of male homosexuals were being admitted to HIV clinics while the number of visits from heterosexuals began rising. Towards the end of 1989, the discovery of HIV among heterosexuals in South Africa was confirmed through several studies (Karim & Karim, 2005). In a similar vein, Whiteside and Sunter (2000) add that

AIDS began rising in 1990 and the disease started spreading among other groups. It became evident between 1990-1994 that the rate of HIV transmission among heterosexuals was exceeding the rate of transmission among homosexuals. Therefore, from the early 1990s, transmission among heterosexuals began to emerge as the dominant mode of transmission that led to the concomitant HIV epidemic in new-borns and young children through mother-to-child transmission (Karim & Karim, 2005).

2.2.1 The prevention and treatment response

In the 1980s through 1990s, there was limited understanding with regards to how HIV was transmitted. As a result, the public healthcare sector responded by giving people free condoms as well as a 'safe sex' education programme accompanied by stigma, fear and other factors of a social and behavioural nature (Simelela & Venter, 2014). Attempts to educate the public were further hindered by the controversies around the 'Sarafina II' play and the virodene scandals (Simelela & Venter, 2014). The aim of the 'Sarafina II' play, a costly musical that was meant to tour South Africa spreading the anti-AIDS message to the illiterate, was to teach the public about the dangers of unsafe sex (Daley, 1996). Virodene, which was a drug developed in South Africa, was alleged to work quickly, promised rapid weight gain and the reversal of terminal cases of AIDS. However, the virodene researchers did not get approval from either the Medicines Control Council (MCC) or ethics clearance from the University of Pretoria (Myburgh, 2007).

According to Simelela and Venter (2014), this controversial stage was followed by a number of trials examining the effectiveness of antiretrovirals (ARVS) given to pregnant women and their neonates (Prevention of mother-to-child transmission (PMTCT). After a piloting approach declared by the South African government was concluded, there was enough scientific evidence proving that ARVs were effective in reducing HIV transmission from mother-to-child and it was thus to be implemented immediately (McNeil, 2012).

The decision to rollout PMTCT came at the peak of civil society's clash with then President Thabo Mbeki over his AIDS denialism. Civil society disputed Mbeki's policy in the highest court with the argument that the refusal to provide nevirapine for the prevention of mother-to-child transmission was a violation of the constitution (Malan, 2016). "The Pretoria High

Court ruled that 'a countrywide PMTCT programme is an ineluctable obligation of the State'" (Simelela & Venter, 2014, pg. 249). According to Malan (2016) Mbeki and his then Minister of Health, Manto Tshabalala-Msimang, restricted the use of donated Nevirapine which prevented the transmission of HIV from mother-to-child and also refused funds from international organizations. Harvard researchers showed that this delay resulted in the deaths of more than 330 000 South Africans and has led to 35 000 children being born HIV-positive (Boseley, 2008).

2.2.2 The development of the ART programme

Beginning of 2002, a joint Health and Treasury Task Team was established by the South African government to look into options around increasing the HIV treatment response outside of the limitations of prevention of mother-to-child transmission (Simelela & Venter, 2014). Meanwhile, clinicians in the joint task team secretly developed HIV treatment protocols that comprised of ART for adults and children (Simelela & Venter, 2014). When the cabinet received the final report from the Joint Health and Treasury Task Team, they declared their position on the casual link between HIV and AIDS (Government ZA, 2002). Following this report, the National Department of Health received a mandate from government to urgently develop a precise plan for executing the ART programme nationwide (Government ZA, 2002).

Eventually, on 1 April 2004, ARV programmes commenced at various service stations nationwide. However, according to Simelela and Venter (2014), these service stations required accreditation through passing an intense examination consisting of 23 different criteria. At the same time, then Minister of Health, Manto Tshabala-Msimang, pushed a campaign for alternative treatment based on nutrition and palliative care (McNeil, 2012). Tshabalala-Msimang urged HIV-positive individuals to eat African foods such as lemons, garlic and beetroot as an alternative to ARVs. Additionally, she publicly continued to suggest that ARVs were poisonous (McNeil, 2012). Still, by 2005, only 23 % of HIV-positive patients were receiving treatment and less than 30 % of pregnant women were receiving nevirapine (The New York Times, 2008). Chigwedere and colleagues found that the Health Minister's obstruction of life-saving treatment resulted in the deaths of more than 330 000

people between 2000-2005 (Boseley, 2008). Additionally, 35 000 babies were born HIV-positive which could have been easily prevented by treatment (Boseley, 2008). It can be argued that this alternative campaign by the Health Minister had a negative impact on the attitude and perceptions of the treatment among people living with HIV. It also contributed to the stigma attached to HIV that is still present till this day.

2.2.3 New administration

In 2009, the new government normalised the response to HIV (Simelela & Venter, 2009). This is evident in the many campaigns that were launched in response to the fight against HIV in South Africa. For example, the HIV Counselling and Testing (HCT) campaign was launched with the aim of normalising discussions around HIV in South Africa (Avert, 2011). This initiative functioned through door-to-door campaigns and billboard advertisements to create awareness of the freely-accessible testing and counselling services in health facilities as well as to address myths and reduce stigma surrounding the disease (McNeil, 2012). At the same time, there was a campaign to provide voluntary male medical circumcision which started in the province of KwaZulu-Natal following evidence that the procedure lowered the risk of HIV transmission from women to men by up to 60% (McNeil, 2012). Evidence shows that steady progress has been made in fighting the HIV pandemic, however, more work still needs to be done particularly among high-risk populations including young people between the ages of 14-24 years.

2.3 Social Context of HIV prevalence in South Africa

Under the Apartheid government, South Africa was designed in a way that only benefited the white minority population (Whiteside & Sunter, 2002). According to Whiteside and Sunter (2002), this was achieved by subjecting South Africa to social engineering that controlled where one lived and worked. Government policy stated: “Bantu are only temporarily residents in European areas for as long as they offer their labour there. As soon as they become, for some reason or other, no longer fit for work or superfluous in the labour market, they are expected to return to their country of origin.” (Harrison, 1982, p. 183) This social engineering led to the breakdown of traditional family structures which ultimately changed sexual relationships (Squire, 2007).

South Africa's social engineering under the Apartheid system meant that adults, particularly men, moved to urban areas to work in factories and mines that were owned by white people. Men working in the mines lived in single-sex hostels and were not allowed by law, to bring their wives and families (Whiteside & Sunter, 2002). Squire (2007) adds that domestic and migrant workers started sexual networks that were made up of partners in urban or mining areas as well as partners back home in the rural areas. Whiteside and Sunter (2002) argue that forced migration manufactured a tradition of urban and rural wives and contributed to the increase in prostitution. During this time, there were limited services to healthcare which meant that several diseases, such as sexually transmitted diseases (STDs) went untreated. According to Squire (2007), limited healthcare facilities were available to provide HIV education or give STI treatment. Gender inequality had an impact in the spread of HIV because women had limited economic resources which forced them into sexual relationships with men for survival (Whiteside & Sunter, 2002).

2.3.1 Poverty

Kalichman et al., (2005) argues that a substantial number of the world's HIV infections are in parts of the world that are ravished by poverty. Mafune (2015) also supports this view where he argues that poverty plays an important role in the spread of HIV/AIDS. Mafune (2015) describes it as a 'disease of poverty' because of how it disproportionately affects the poor while simultaneously worsening the toll of poverty. According to Barnighausen et al., (2010), women from low socio-economic backgrounds are particularly at a high risk of transmitting HIV. Women from low socioeconomic backgrounds might be financially dependent on their male partners which compromises their capacity to negotiate condom use in heterosexual relationships or places them in a position to sell sex for money. Mabaso et al., (2018) concurs with this view and adds that the majority of South African families are affected by poverty and because of this deprivation; adolescent girls and young women are often under pressure to fend for themselves and contribute financially or materially to support their families.

Additionally, older partners might also provide financial and material benefits which add to the young women's inability to negotiate condom use. Gilbert and Walker (2002) are of the view that the main determinants of an individual's health status are poverty, vulnerability to HIV and high fertility levels. Furthermore, the health and wellbeing of people are compromised because of poor nutrition, lack of access to quality healthcare, poor sanitation, lack of basic needs, and violence (Kalichman et al., 2005). The link between HIV infection

and poverty is the result of poor and limited healthcare facilities, large social density, substance abuse and transactional sexual partners.

2.3.2 Access to services

The South African constitution states that everyone has the right to healthcare. However, because of distortions in resource allocations, this is a myth for the majority of poor South Africans (Harris, Goudge, Ataguba, McIntyre, Nxumalo, Jikwana, & Chersich, 2011). Coovadia, Jewkes, Barron, Sanders and McIntyre (2009) add that "racial and gender discrimination, the migrant labour system, the destruction of family life, vast income inequalities, and extreme violence have all formed part of South Africa's troubled past and all have inexorably affected health and health services" (p. 817). Factors such as socio-economic status, race, class, and urban-rural location determine access to care with poor black South Africans experiencing the greatest barriers to health-care services. These factors include long distances and high travel costs, long waiting times and queues as well as disempowered patients (Harris et al., 2011). To this day, these problems still persist within the healthcare system and young people are not exempted.

There is lack of access to sexual and reproductive services, especially for young people and this is alarming. In South Africa, there are numerous reports showing the poor quality of care experienced by young people in primary healthcare services, and these include poor reception and treatment from the healthcare workers (Karim & Karim, 2005). Healthcare providers are often rude when serving young people, particularly concerning their sexual and reproductive needs.

It is therefore evident that contextual factors such as physical and living conditions, for example, where one lives, the quality of healthcare services and gender inequality all contribute to the HIV prevalence in South Africa. To this day, many South Africans in particular are still subjected to poor living conditions and a dysfunctional health system.

2.4 HIV Stigma

According to the Oxford dictionary, stigma is a symbol of shame that is associated with a specific circumstance or individual (Stevenson, 2010). Goffman (1963, p. 3) defined stigma

as “an attribute that is deeply discrediting within a particular social interaction”. According to Moughan -Brown (2010) “stigma refers to a social process through which individuals are devalued on the basis of particular negatively perceived characteristics or status”. HIV is probably the most stigmatised epidemic in the history of medicine. HIV stigma continues to stand in the way of public health efforts for treatment, the prevention of HIV and HIV programmes (Gilbert, 2016). In a similar vein, Moughan-Brown (2010) maintains that stigma deters people from being tested and hinders access to treatment and care. Stigma serves as an obstacle to taking and adhering to treatment and discourages disclosure to sexual partners. Gilbert (2016) argues that HIV stigma is still prevalent thirty years after the discovery of the pandemic.

HIV related stigma deters people from testing, lowers their risk perception and perceived susceptibility to HIV and discourages those who are already infected from disclosing their HIV status to their sexual partners, family and friends. All of these factors contribute to new infections and further the spread of HIV in addition to deterring young people from accessing the life-saving treatment that is widely available and easy to access in South Africa (Gilbert & Walker, 2016).

Goffman (1963) argues that there are three different types of stigma, namely: stigmas of the body, stigma of character and stigmas associated with social collectives. Relating Goffman’s three different types of stigmas to HIV, it is clear that more than one attribute and sometimes all three can be experienced simultaneously (Gilbert, 2016). Gilbert (2016) asserts that people infected with HIV are often blamed for it and some people are of the view that HIV could be avoided if people behaved morally. Secondly, even though HIV is manageable, it is still however a long term, incurable infection, and even worse in countries like South Africa where not all those who are infected, have access to antiretroviral treatment. Gilbert (2016, p.10) argues that stigma is fuelled by “fear, ignorance, anxiety, denial, shame, taboo, racism, xenophobia, moral judgments and by misleading metaphors such as death, punishment, crime, war, horror and otherness”. One of the main contributing factors to the rampant HIV-related stigma in South Africa was its association with death (Gilbert, 2016). When ART rollout was introduced in 2004, it brought hope that there would be a decline in stigma and it was assumed that with the increasing access to treatment and the increased number of people living with HIV and not dying, levels of stigma would decrease (Gilbert, 2016). However, evidence shows contrasting views.

According to Herek (2002) stigma generally decreases as the disease becomes better understood and as treatment becomes widely available and accessible. However, this does not seem to be the case in South Africa. Based on research findings, a conclusion was reached that "programs that promote widespread HIV testing and discussion of HIV/AIDS as well as education regarding universal access to ARVs, may reduce HIV/AIDS-related stigma and discrimination" (Gilbert, 2016, p.12). Moughan-Brown (2010) concurs with this view and adds that the availability of effective treatment is a contributing factor to the reduction of stigmatising attitudes and behaviours towards any diseases. Nationwide surveys have reported a decrease in HIV-related stigma. However, Gilbert (2016) argues that that is not the case on the ground. Gilbert asserts that despite the rollout of HIV treatment, stigma continues unabated, and is often in more subtle forms. Gilbert (2016) goes on to argue that HIV-related stigma has become another "dirty secret", which poses a problem to its measurement because it is almost impossible to measure a hidden truth.

There is little known about the stigma that may come when expecting a positive HIV diagnosis among HIV negative individuals, especially among the population at high risk (Starks, Breslow, Parsons & Golub, 2013). Anticipated HIV stigma is described as a belief that a positive HIV diagnosis will come with stigmatization, either interpersonal or internalized. Research shows that even the HIV-negative individuals can be affected by the negative consequences associated with living with HIV. According to Starks et al., (2013), HIV-related stigma and anxiety are barriers to HIV testing which means that people fear testing for HIV because of the fear of being stigmatized should they be HIV-positive.

2.5 HIV in relation to Adolescents and Young People

2.5.1 Who are young people?

Both the terms 'adolescent' and 'young people' are put to use in this chapter where adolescent is defined as a stage of development which starts from puberty up to young adulthood (Karim & Karim, 2005). Youth, on the other hand, refers to ages 10-24. The term 'young people' is made up of a wider group that can include men and women up until their early thirties. According to the World Health Organization (WHO), 'young people' are between the ages of 10-24 years.

Shaffer and Kipp (2010) define adolescence as a time of transition marked by high levels of mobility, instability and change. “Adolescence is a time of experimentation and risk, often leading to heightened vulnerability, as young people make the transition to greater social and psychological independence” (Shaffer & Kipp, 2010). Peer pressure and socio-cultural norms contribute to the progression of the adolescence stage. Sexuality is a common area of experimentation and exploration starting from the teenage years going forward. The arrival of puberty comes with physiological changes accompanied by the appearance of sexual expression as well as the desire to experiment. During this period of transition, young people are most vulnerable because of their emotional and physical development, age, inexperience and financial dependence.

2.5.2 Adolescent and young people’s risky behaviour

Adolescents and young people engage in various risky behaviours which can potentially have unfavourable medical and social consequences. The various risky behaviours that young people engage in include smoking, drinking, early sexual debut and drugs. According to Karim and Karim (2005), a number of social, behavioural and situational factors making young people vulnerable to HIV/AIDS influences engaging in risky sexual practices. Ratele and Duncan (2003) add that certain biological or developmental factors also make young people vulnerable to HIV infection in the same way that the broader social context, as discussed above, does. For a significant number of youth in South Africa, these factors include poverty, unemployment and access to quality education. Shaffer and Kipp (2010) also add that adolescence is a time of exploration and experimentation where sexuality is big part of development and transition. The high rate of HIV infection in the general population puts young people at a higher risk by simply being sexually active. Additionally, young women and men have unique characteristics of sexual partnerships which expose them to contracting HIV. For example, young women have the tendency to have sexual partners who on average are three to five years older than them (Karim & Karim, 2005). Young men, on the other hand, have the tendency to have multiple sexual partners which puts them and their partners at a higher risk. Other risk factors include infrequent or inconsistent use of protection and high levels of sexual coercion, especially around sexual initiation (Karim & Karim, 2005).

Research findings show that drinking alcohol, substance abuse and engaging in risky sexual behaviours are a sign of problem behaviour among young people and these behaviours differ

(Wade & Brannigan, 1998). According to Brown et al (1991) risky behaviours serve a psychological need for adolescents. For example, young people engage in risky behaviours because of the pressure from their peers and the need to belong in a peer group. Belonging in a peer group, argues Wade and Brannigan (1998), boosts their self-esteem. DiClemente, Hansen and Ponton (2013) also add that risk-taking serves multiple purposes for young people; it is a way of dealing with anxiety, frustration or feeling inadequate. Brown, DiClemente and Reynolds (1991) emphasise the struggle for autonomy that is almost inherent at a young age. They argue that young people struggle for autonomy while searching for their identity. Risky behaviour is therefore used as a way of resisting adult authority.

2.5.3 Cognitive development

Brown et al (1991) asserts that young people lack the capacity to separate their "unique emotional reactions and those common to all people" (p. 55). For example, a young person would believe that they themselves will not acquire HIV from having unprotected sex despite knowing that other people acquire HIV from having unprotected sex. The perception that they are not susceptible to HIV makes engaging in risky sexual behaviours more likely (Brown et al., 1991). In a similar vein, Karim and Karim (2005) also add that young people, particularly, do not perceive themselves to be vulnerable to HIV infection and this prevents them from taking preventative measures This occurs as a result of the need to explore as well as lacking the cognitive capacity that is required in the consistent engagement of safe sex. The cognitive immaturity of young people has a huge impact on their risk perception (Brown et al., 1991).

2.5.4 Social media influence

The media landscape has been, over recent years, changing at a rapid pace with new types of media and various platforms for distributing content. Media contents can now be consumed on computers, MP3 players, cell phones and television. The portability allows users to view content in various settings at a time that's most convenient for them throughout the day (Collins, Martino & Shaw, 2010). Young people are absorbing and engaging with this new media using social networking sites, smartphones and instant messaging and these have become a big part of their daily lives (Collins et al., 2010).

Most research on the effects of media use focuses on television. Consuming media through television remains the most commonly used medium and platform by young people and

previous research shows that television contains a considerable amount of sexual content (Bleakley, Hennessy, Fishbein & Jordan, 2008). According to the social learning theory and the social cognitive theory, screen-media exposure results in the "cognitive acquisition of behaviours along with their expected social, emotional, and cognitive consequences" (Collins et al., 2010, p. 6). The use of media has the potential to shape or influence young people's perception of sex and sexuality during the crucial time in their social and sexual development.

In a study conducted in Soweto, South Africa, investigating the perceptions of sexual behaviours and attitudes of adolescents, it was found that parents strongly believed that television programmes and music videos were normalizing indecent behaviour by showing alcohol use, drugs and pornography. They were particularly concerned about the effect the media has on young people (Dietrich, Khunwane, Laher, de Buryn, Sikkema & Gray, 2011). A study conducted in the United States of America with adolescents found a correlation between talks about sex, visual depictions of sex and early sexual initiation and increased frequency of sexual behaviour (Collins et al., 2010).

2.6 History of HIV testing in South Afri

Healthcare in South Africa is made up of two sectors, mainly the public sector which caters to over 80% of the population as well as the private sector that serves the middle- and upper-class population, mainly through medical aid (Gous, Berrie, Dabula & Stevens, 2015). The National Health Laboratory Service (NHLS), the biggest pathology service in South Africa, is responsible for diagnostic testing in the public sector. The NHLS is a national public entity that was established by the merging of various public-sector laboratory service providers as well as different Provincial Departments of Health laboratories. South Africa has witnessed swift progress in HIV diagnostic technology since the mid-1980s when HIV antibody tests first became commercially available (Karim & Karim, 2005). The HIV diagnosis methods over the years have improved the care of people vulnerable to HIV infection (Smith, Clayton, Pike & Bekker, 2019) and today, a variety of antibody tests are produced both internationally and locally (Smith et al., 2019).

2.6.1 HIV diagnostic tests

The most commonly used HIV test in South Africa is the ELISA antibody test (Whiteside & Sunter, 2000). ELISA or EIA is an enzyme-linked immunosorbent assay test that detects and determines antibodies in your blood (Kinman, 2017). According to Kinman (2017) the ELISA test is commonly used as a screening tool before more advanced tests are done. ELISA is used to assess if an indvidual has antibodies associated with conditions that are infectious such as HIV (Kinman, 2017). Iweala (2004) defines antibodies as proteins that are produced by the body in response to harmful substances known as antigens.

The different types of tests used for diagnosing HIV differ in their levels of sensitivity (Karim & Karim, 2005). According to Iweala (2004), HIV diagnostic tests work by detecting antibodies created against various HIV proteins or by looking for the whole virus such as HIV p24 antigen or HIV RNA. I-base (2016) also adds that HIV tests detect three different elements namely: proteins on the surface of the virus (antigens/Ag) like protein 24 known as (P24); an immune response to the virus (antibodies/Ab) and genetic material from the virus (HIV RNA or DNA) (i-base, 2016). The primary aim of most HIV diagnostic tests is to detect the HIV virus as early as possible, therefore reducing the length of the window period (Iweala, 2004).

The most commonly used methods to collect blood specimens to detect the antigens/antibodies or HIV RNA/DNA include venepuncture and finger pricks. However, this invasive approach of collecting blood samples is often found to be unpleasant. As a result, different HIV tests that use saliva or urine have been developed (Iweala, 2004). Saliva and urine collection are found to be less painful when compared to blood collection.

2.6.2 HIV Counselling

Voluntary counselling and testing (VCT) is the commonly used method of testing in various parts of Africa (Matovu, 2011). VCT provides patients with two counselling sessions. The first session is conducted before taking the test and the second session is conducted after taking the test (Akhiwu, 2011). According to Kartikeyan, Bharmal, Tiwari and Bisen (2007), VCT is a process where a patient undergoes counselling so that they can make a better informed decision regarding testing for HIV. The aims of VCT are to help people understand their HIV diagnosis, whether negative or positive, address the accuracy of the test results and the consequences of HIV tests, and to help those who cannot read or interpret their HIV status (Akhiwu, 2011). Counselling focuses on the infection (HIV), the disease (AIDS), the testing kit as well as changing behaviour.

2.6.3 Facility-based voluntary HIV counselling and testing (VCT)

Public health efforts to prevent the spread of HIV include offering VCT, where one is tested for HIV in a confidential setting (Botma, Motiki & Viljoen, 2007). VCT services are known to be effective in the fight against HIV through offering contact centres where one obtains information, guidance and referral for treatment (Francis, 2010). Meursing and Sibindi (2000) add that HIV counselling and testing are designed to allow an individual to make good use of their results whether positive or negative.

The process of VCT begins with an individual receiving counselling to prepare them for a positive diagnosis. The individual will be counselled again after receiving their result, and if the results are negative, the counsellor will encourage the patient to remain safe (Botma et al., 2007). In the case of a positive result, the patient is provided with continuous emotional & psychological support and gets further medical intervention and treatment where they are guided in how to live a healthy lifestyle (Botma et al., 2007). Furthermore, they are encouraged to take extra precaution not to spread the virus to others by practicing safe sex and by disclosing their HIV status to sexual partners (Botma et al, 2007).

2.6.4 Community-based testing

To increase the uptake of HIV testing, the public health sector decided to move away from the traditional facility-based HIV testing services (HTS) approach where one has to actively seek HIV testing (Avert, 2019). The need to improve HIV testing uptake fostered the adoption of new testing approaches that do not require one to first acknowledge their own risk and then come forward on their own to test for HIV (Avert, 2019). This was achieved by moving HIV testing services from health facilities and away from healthcare providers to community-based testing services delivered by trained lay providers (Avert, 2019; Meehan, Beyers & Burger, 2017).

Community-based HIV testing services provide HIV testing on a mobile basis (using mobile vans and tents) as well as stand-alone facilities (fixed-sites) (Meehan et al., 2017). While both health facility-based and community-based testing services have been successful in identifying HIV-positive individuals and linking them to care, young people in particular are still not accessing and making use of these facilities in high enough numbers (Avert, 2019).

2.6.5 Access to HIV testing remains low

While efforts have been made to improve HIV testing uptake, and new ways of reaching the people are continuously being developed, access to HIV testing in South Africa still fails to meet the universal standard of access to HIV testing. The National HIV Testing Services Policy document of 2016 shows that HIV testing numbers remain low. Negin et al., (2009) argue that areas with high HIV prevalence such as Sub-Saharan Africa still rely on traditional ways of testing. For example, individuals have to present themselves to the services, therefore making it hard to reach a large number of people, especially the already hard-to-reach population. The low testing numbers , especially among young people, are a barrier to implementing the WHO's recommendation that everyone diagnosed with HIV must be on treatment (WHO, 2016). Late HIV diagnosis is still one of the major issues faced by the public health sector (Tek Ng et al., 2012). Harichund, Karim, Kunene, Simelane and Moshabela (2019) argue that testing numbers remain suboptimal because of barriers related to patients and the health system.

2.7 Barriers to HIV testing

2.7.1 Lack of confidentiality

Available literature illustrates the barriers to accessing facility-based or community-based HIV testing services that are most common among young people. In his study, Francis (2010) found that the main concerns out-of-school youth had in accessing testing services was being seen by someone that knows them or family relatives who might report having seen them using HIV testing services. A study by Strauss, Rhodes and George (2015) found similar results where adolescents in the study showed concerns about being seen making use of the testing services with the fear of being discriminated against, judged, as well as experiencing community stigma surrounding sexual practices. MacPhail, Pettifor and Coates (2008) found that young people avoid testing services because of the lack of confidentiality in testing facilities where the healthcare workers are known to gossip among themselves and also within the communities where they live. Matseke, Peltzer and Mohlabane (2016) also maintain that lack of confidentiality in healthcare facilities and VCT settings act as barriers to accessing HIV testing services. A particularly important finding from Strauss, Rhodes and

George (2015) is that the locations of the testing services do not necessarily mean convenience. What is more important is confidentiality.

Concerns regarding confidentiality resulted in 43 % of participants in a study conducted by Francis (2010), stating that if they wanted to access VCT services, they would choose a site that is less likely to compromise their confidentiality. This means that they would go to a VCT site or health facility that is far from home or, if they could afford it, go to a private doctor. Study results in Matseke, Peltzer and Mohlabane (2016) showed that more than 50 % of the VCT clients showed concerns about being seen by others at the VCT site. This result corroborates the findings of Bwambele, Ssali, Byaruhanga, Kalyango and Karamagi (2008) who found that the chances of men accessing HIV testing services were small because of concerns of being recognised by people known to them.

In addition to concerns over confidentiality, young people showed a lack of trust in healthcare workers and a concern over the privacy of the VCT site, stating that how they react would compromise the confidentiality of their test results. According to Botma et al (2007), reactions of patients to an HIV-positive result involves various emotions such as shock, denial, disbelief and helplessness to name a few. Lack of trust in healthcare workers and their attitude are also some of the barriers reported in Peltzer, Matsheke, Mzolo and Majaja (2009).

The efforts by young people to shun gossiping neighbours and relatives, stand in the way of accessing VCT services by making it more difficult and expensive for them (Francis, 2010). This undermines the efforts by the public health sector to making access to VCT free and friendlier. Additionally, these barriers work against the goal of increasing HIV testing uptake among young people because they force them to seek VCT far from home, which makes it less likely that they will actually seek these services. The fear young people have of being seen using HIV testing services might be an indication that stigma and prejudice still exists.

2.7.2 Personal barriers to testing for HIV

Adding to the contextual barriers discussed above, Strauss, Rhodes and George (2015) also maintain that there are barriers that exist on the personal level. Strauss, Rhodes and George (2015) argue that young people's behaviour can influence their attitude towards testing and their desire to test. For example, young people who perceive themselves to be at high risk because of practicing risky sexual behaviour and therefore expect a positive HIV diagnosis,

are most likely going to avoid testing. In a similar vein, Matseke, Peltzer and Mohlabane (2016) add that a fear of the diagnosis or uncertainty around HIV status can act as barriers to HIV testing. In a study conducted in South Africa, learners reported that they would rather avoid undergoing HIV testing than finding out that they are HIV-positive (Strauss, Rhodes & George, 2015). Fear of a positive diagnosis was also found to be associated with concerns over ARVs because of their potential side effects and decreased quality of life (Strauss, Rhodes & George, 2015).

2.7.3 Poor HIV counselling

Others barriers identified in the literature include limited counselling space and shortage of counselling staff (Matseke, Peltzer & Mohlabane, 2016). MacPhail, Pettifor and Coates (2008) sited mistrust of the counselling quality as a barrier to accessing counselling and testing services. Participants in a study conducted by MacPhail, Pettifor and Coates (2008) showed doubt in the ability and training of the healthcare workers to deliver satisfactory counselling during VCT. MacPhail, Pettifor and Coates (2008) also noted that healthcare workers were more likely to cause nervousness and unease instead of creating a safe atmosphere for testing.

While it might be expected that making VCT easily accessible to young people through community-based services (using mobile vans and tents) for convenience, would increase the uptake, it is evident from the above discussion that confidentiality is more important to young people. This shows that confidentiality rather than convenience drives young people's decision to access testing.

2.8 HIV home test

2.8.1 What is HIV home test?

HIV self-test is described as any form of HIV testing where one collects their saliva or blood to perform a simple, rapid test where they will be the first to know of their HIV status (Mavedzenge, Baggaley & Corbett 2013). Johnson et al., (2017) define HIV self-test as "a process in which a person collects his or her specimen (oral fluid or blood) and performs a test and interprets the results, often in private or with someone they trust" (p. 1). The WHO (WHO, 2016) describes the HIV self-test as an oral fluid or blood-finger-pricks test that one

can use to find out about their HIV status in the comfort and convenience of their own home. Therefore, it is evident that HIV self-test kit is emerging as a crucial tool with the potential to improve the uptake and frequency of testing for HIV, especially among young people (Lyons et al., 2019).

2.8.2 History of HIV home test

HIV self-testing was first introduced over 20 years ago but it was never implemented until recently (Mavedzenge et al., 2013). The World Health Organization in 2016 passed a resolution that HIV self-test kits be made available in all countries in order to improve HIV testing and the frequency of testing (Smith et al., 2019; WHO, 2016). This resolution suggests that there is a shift in policy and policy makers are open to adopting flexible methods, with less emphasis on pre- and post-test counselling (Mavedzenge, et al., 2013). This is evident in the decision taken by SAPC in 2017 to lift the ban and allow South African pharmacies to sell the HIV home test over the counter.

The adoption and implementation of the HIV self-test over traditional methods of testing came with challenges, criticism and controversies from healthcare professionals as well as policy makers (Mokgatle & Madiba, 2017). The Health Profession Council of South Africa recognises the availability of over-the-counter HIV home test kits in South African pharmacies, but have warned pharmacies to be aware of the potential abuse of the testing kits (HPCSA, 2016).

South Africa took a while to put the HIV home test kits on the market despite evidence showing its feasibility and effectiveness due to concerns over the absence of HIV counselling when testing from home (Radio 702, 2017). Deputy Executive Director of the Wits Reproductive Health and HIV Institute at the University of the Witwatersrand, Johannesburg Francois Venter raised concerns of unmanaged suspense and the possibility of committing suicide because of the absence of pre- and post-test counselling (Radio 702, 2017). Myers et al., (2013) argues that HIV self-testing is not a new concept. Myers et al., (2013) are of the view that HIV self-testing was first introduced in mid-1980s but due to concerns about the accuracy of test results or the potential increase in suicide attempts after a positive diagnosis, self-testing was never encouraged. Myers et al., (2013) further add that there were concerns over the safety and effectiveness of testing in the absence of supervision by a healthcare professional.

Speaking on Talk Radio 702, the Registrar of SAPC, Amos Masango, said that pharmacists should give customers more information when they purchase the test kits. He further added that pharmacists should emphasise to people that the test is for screening and should confirm results with a professional healthcare provider (Radio 702, 2017). Moreover, pharmacists must practically guide patients on how to use the HIV self-test kit. Francois Venter added "it is not a magic bullet that will solve all our problems, but it will allow people to take control of their own health rather than solely be at the mercy of a health system that is not always efficient, friendly, or geographically accessible" (Daily Maverick, 2016). Mokgatle and Madiba (2017) argue that the major concerns over the HIV self-test are based on vague and unfounded fears since HIV self-test is a fairly recent development in South Africa.

According to Smith et al. (2019) HIV self-testing is there to complement the already existing traditional methods of testing for HIV and can be used to curb existing barriers to testing. This is evident in the latest national HIV testing guidelines in South Africa, where it is clearly stipulated that HIV self-testing should be considered as an alternative approach to the available testing methods and should not be used to confirm HIV diagnosis (Harichund et al., 2019). Mokgatle and Madiba (2017) also add that HIV home tests are accepted nationwide as a crucial addition to the already existing testing methods.

2.8.3 Benefits of the HIV home test

HIV self-testing is recognised as a tool to improve HIV testing uptake and allow people who would not otherwise visit healthcare facilities to know their HIV status (Tek Ng et al., 2012; Smith et al., 2019). This is in alignment with the view of the World Health Organization (2016) that HIV self-testing is a strategy to advance access to testing. According to Myers et al. (2013), HIV self-testing has the potential to improve the frequency of testing among those who are vulnerable to new infections and allows sexual partners to test together. Smith et al. (2019) add that the confidentiality that the HIV self-tests affords its users will provide relief to those who would otherwise not visit healthcare facilities because of real and perceived barriers, particularly young people. The HIV home test has the potential to increase HIV testing rates and the frequency of testing because of the privacy, convenience, and anonymity it affords to its users (Myers et al., 2013). According to Lyons et al. (2019), the HIV home test affords the user total control, as confidentiality is guaranteed. Furthermore, members of community who belong to the marginalized groups such as sex workers, men having sex with men (MSM) and adolescents will be given a chance to test in private, in a place of safety and

with dignity (Lyons et al., 2019). The World Health Organization (WHO) predicted that improving HIV testing and access to treatment could reduce new infections by 95% over 10 years (WHO, 2016).

Lyons et al. (2019) shows that HIV self-testing is able to reach hard-to-reach key populations such as those who have never tested as well as those who do not test frequently. This study further showed that despite existing testing services, self-testing was able to reach a significant number of people testing for the first time in Senegal. Ritchwood et al. (2019) found that young people in rural areas of South Africa preferred HIV self-testing over traditional methods of testing. This finding is consistent with research conducted in Senegal where acceptability was overall high and that there was no significant difference in acceptability between first-time testers and those who test frequently (Lyons et al., 2019).

Mokgatle and Madiba (2017) investigated the acceptability of HIV self-testing among college students in Gauteng and Northwest province. They found that 87.1% of the participants considered the HIV self-testing acceptable and 84% reported that they would use the HIV self-testing with partners. Furthermore, a South African-based study on men having sex with men (MSM) found that HIV self-testing was acceptable among this population. A number of observational studies and systematic reviews also showed HIV self-testing as an acceptable approach in different contexts, including groups at high risk of HIV (Ritchwood et al, 2019). Ritchwood et al . (2019) found that the factors attributing to the high acceptability of the HIV self-testing was its ability to overcome critical barriers such as confidentiality, privacy, convenience and control over who to disclose HIV status to. Similarly, Mokgatle and Madiba (2017) found that being sexually active, having multiple sexual partners, and having been tested for HIV was linked with high acceptability of HIV self-testing. Ritchwood et al. (2019) found that being able to complete the test independently and the test being user friendly, were the main drivers for accepting HIV self-testing. Study participants in Ritchwood et al. (2019) were confident that they could independently administer the test and reported that they would prefer to use the HIV home test next time when they wanted to test.

2.8.4 Limitations of HIV home test

Despite the overwhelming acceptability of the HIV self-testing, some concerns still exist. Some of the concerns expressed, particularly by young people is the potential for a false positive or a false negative result (Ritchwood et al., 2019). This concern was also highlighted in Harichund et al. (2019) as a potential challenge with the unsupervised administering of the

test. The cost of the HIV self-testing kit was highlighted as a potential barrier in Mokgatle and Madiba (2017), particularly in poor rural areas and townships in South Africa. Findings in Ritchwood et al. (2019) also highlighted concerns over the cost of the HIV self-testing kit. Young people in the study expressed concerns about their ability to purchase the test, citing high youth unemployment rates in South Africa. Mokgatle and Madiba (2017) study conducted in Gauteng and North-West showed that despite the students being from poorly resourced areas, 75% of them reported that they are willing to pay for the HIV self-testing kit while only a small number of them were not willing to pay for the HIV self-testing kit.

Despite the potential to overcome the current barriers of VCT, the lack of counselling is a potential challenge to using HIV self-testing kits (Harichund et al., 2019). Though study participants in Ritchwood et al. (2019) expressed approval of HIV self-testing because of the privacy and confidentiality it provides, a number of participants reported concerns about the lack of emotional support when testing alone. There was a lot of uncertainty among the study participants on how young people would react should they get a positive result. Mokgatle and Madiba (2017) argue that lack of face-to-face counselling, which is considered an important part of all VCT/HCT models in South Africa, is the reason why there is still doubts around HIV self-testing. In Harichund et al. (2019), regular testers who are familiar with HIV counselling still expressed a need for counselling to prepare them should they receive a positive diagnosis. "However, counselling was not universally required among some HIV naïve testers and regular testers" (Harichund et al., 2019, pg. 4).

2.9 Psychosocial effects of screening for disease prevention and detection

The role of public health, in any country, is to identify and solve community health problems and screening for diseases is an important part of those efforts (Croyle, 1995). Screening for diseases in clinical or community contexts is a means of identifying populations who have an increased risk for disease or who show early signs of disease (Croyle, 1995). Croyle (1995) postulates that identifying individuals who are at risk allows the public health sector to target those who will benefit the most from early intervention. Stoate (1989) argues that screening for disease results in either benefit or no effect. However, this is dangerous because it neglects the third possibility, which is harm.

2.9.1 Changes in psychological distress

One of the biggest victories in the fight against AIDS has been the development of serological tests that detect HIV antibodies before the development of physical symptoms (Croyle, 1995; Jacobsen, Perry, & Hirsch, 1990). The use of these tests has had a dramatic effect in reducing HIV transmission. Additionally, the use of serological tests continues to have significant medical benefits, hence testing for HIV regularly is advocated for. Knowledge of HIV status could result in behavioural change, start of treatment and care and reduces chances of transmitting HIV (UNAIDS, 2010). However, as with any other disease screening, HIV antibody testing can lead to great social, psychological, and behavioural effects on the individual (Croyle, 1995).

According to Perry, Jacobsberg, Fishman, Weiler, Gold and Frances (1990) there are a number of psychosocial stressors that affect the population at high risk of HIV, however, a big contributing factor to the distress experienced is the fear of HIV infection. Similarly, Croyle (1995) adds that people fear testing for HIV because of the anticipated distress following a positive result. Evangeli, Pady and Wroe (2015) argue that fear of HIV testing is associated with the fear of a HIV positive diagnosis, shown in the two studies that they completed. Additionally, the study in Perry et al. (1990) further suggests that uncertainty about one's HIV status can have an emotional toll.

Individuals who tested HIV positive may remain asymptomatic for years; nevertheless, they are left to deal with the prospect of eventually falling into serious illness leading to death (Croyle, 1995). In addition, HIV/AIDS is still associated with immorality and is therefore stigmatized (Gilbert, 2016). This stigmatization may manifests in forms of alienation from friends & family and discrimination (Gilbert, 2016). With all of this, it is worth noting how the emotional and psychological effects of being diagnosed with HIV may outweigh any potential benefits associated with screening for HIV antibodies, especially because there is no cure (Croyle, 1995).

A study was conducted using a sample of physically asymptomatic gay/bisexual men, intravenous drug users and heterosexuals with partners at risk. In this study, the participants received pre and post-test counselling and were evaluated 2 weeks before getting their results and 2 and 10 weeks after receiving their results. The report of this study shows that both seronegative and seropositive participants did not differ in the levels of anxiety, depression or clinical ratings of depression 2 weeks before receiving results and 10 weeks after receiving

results (Croyle, 1995). There was a significant decline in anxiety, depression and global distress at 10 weeks after receiving results in both groups compared with initial values. Those who tested negative showed a decline in clinical ratings of depression 10 weeks after receiving results, whereas those who tested positive did not show any significant changes (Croyle, 1995).

A similar study conducted in Perry et al. (1990) where a psychological assessment of physically asymptomatic people at risk of HIV both before and after receiving their results showed that seronegative participants had a remarkable decrease in various measures of distress after receiving their results. Furthermore, seronegative participants of the study reported relief immediately after notification of results and during the follow-up session (Perry et al., 1990).

2.10 Theoretical framework

The Health Belief Model (HBM) was developed in the early 1950s by four social psychologists working at the United States Public Health Services. The idea behind HBM was to gain insight as to why people fail to adopt disease prevention strategies or to undergo screening for early detection of diseases. Conner and Norman (2002) add that this theory was developed in order to explain, predict and influence health-related behaviour. Buldeo and Gilbert (2015) define HBM as psychosocial framework that aims to describe health behaviour. Buldeo and Gilbert (2015) are of the view that HBM is "determined by an individual's personal beliefs or perceptions about a disease and the options available to decrease its occurrence." (p. 209)

The HBM theory is based on the premise that the attitudes and beliefs that people have determine their health behaviour/actions (Rosenstock, Stretcher, & Becker, 1998). Additionally, Stretcher and Rosenstock (1997) assert that, HBM also proposes that people take preventative actions when they have certain beliefs about the recommended preventative actions. The HBM model provides the foundation for prevention-based interventions studies in public health areas such as smoking, substance abuse, obesity, sexual risk taking and HIV/AIDS (Corner & Norman, 1996).

The HBM is taken from psychological and behavioural theory which states that the two components of health-related behaviour are; firstly, the desire to avoid an illnesses or disease or to recover if one is already sick and secondly, the belief that adopting a particular health

behaviour will prevent or cure illness/disease. Essentially, one's course of action lies on the perceived benefits and barriers to carrying out that health action (Wayne, 2018). This model is commonly used to understand health behaviour in public health and psychology and it has provided a point of departure for prevention-focused interventions and research in areas such as substance abuse, smoking, obesity, sexual risk taking and HIV/AIDS.

Initially, the health belief model was of the view that health-related behaviour is influenced by the presence of four factors, namely: perceived susceptibility, perceived severity, perceived benefits and perceived barriers (Rosenstock, Stretcher & Becker, 1998).

2.10.1 Perceived susceptibility

Perceived susceptibility to an adverse health outcome is described as one's personal perception of the risk of contracting a disease (Rosenstock, Stretcher & Becker, 1998). For example, to which extent does one believe that they are at risk? Personal feelings of vulnerability to a certain illness or disease vary from person to person meaning that the higher the perceived risk, the higher the chances of adopting behaviours to reduce the risk.

2.10.2 Perceived severity

Perceived severity refers to one's perception of the seriousness of acquiring an illness or disease (Rosenstock, Stretcher, & Becker, 1998). One would evaluate the consequences that may follow after acquiring an illness or disease. Consequences include medical (e.g. death, disability) and social (e.g. family life, social relationships). McCormick-Brown (1999) argues that while perceived severity mostly relies on medical knowledge or information, it can also be influenced by the perceptions one has about the effects the disease would have on their life. For example, most people do not perceive flu to be a serious illness, but for someone who is self-employed having flu and staying at home as a result would mean loss of income. This shows how perceived seriousness may differ from person to person.

2.10.3 Perceived benefits

Perceived benefits of a given preventative actions in order to curb the adverse health outcome; this refers to an individual's perception of the effectiveness of different actions designed to minimise the risks of acquiring an illness or disease. At this stage, one would consider both perceived susceptibility and perceived benefits. This means that people only

adopt the recommended health behaviour/action if they think that it will be beneficial for them. Simply put, people adopt healthy behaviours if it will benefit them by reducing the chances of getting a disease. For example, young people would test frequently for HIV if they believed that testing will lead to early detection, therefore start treatment early. It is evident that perceived benefits play a crucial role in decisions to adopt prevention behaviours such as screening for disease.

2.10.4 Perceived barriers

Perceived barriers refer to the obstacles to perform the designed preventative action, which often includes costs (Rosenstock, Stretcher, & Becker, 1998). This refers to the various barriers or negative consequences that can stand in one's way of performing a particular health related action which leads to a cost/benefit analysis. One would weigh the benefits of a health behaviour against the fact that it might be costly, have adverse side effects (psychologically and physically), might be time-consuming or inconvenient. For example, perceived barriers for young people in South Africa in using the HIV home test may include costs.

2.10.5 Self-efficacy

A fifth factor was later added to this model in order to improve the challenges of changing unhealthy behaviour as well as to improve the theory's predictive ability (Conner & Norman, 2002). This is called self-efficacy (Bandura, 1977), which refers to one's confidence in their ability to perform the desired preventative actions. Conner and Norman (2002) define self-efficacy as the measure to which one believes that they can take preventative actions. It is one's confidence in their ability to successfully perform the recommended health related action. Generally, people do not try to do something new unless they are confident that they can do it. For example, young people will not use the HIV self-testing kit if they are not confident that they can carry this out without the supervision or help from a trained healthcare professional.

Perceived susceptibility as well as perceived severity combine to provide the motivation for health-related action, whereas one's preferred course of action is determined by the cost-benefit analysis of weighing the benefits against barriers.

The HBM theoretical framework is appropriate for this study because it contains a blend of emotions, habits, social conditioning and personal preferences to study health behaviour. The

focus is on young people's personal experiences and preferences in order to make sense of their health behaviour. This framework will allow us to suggest if whether the HIV home test has the potential to improve HIV testing. Moreover, it will tell us if young people are willing to use the HIV self-testing kit. It will also give an idea of young people's self-efficacy in correctly administering the HIV self-testing kit without supervision. Additionally, it will give an understanding of the potential barriers young people might come across in adopting this action, thus potentially uncovering effective methods of distributing the HIV self-test kits to young people.

Despite the HBM framework being the most used frameworks in public health, it has its limitations. The HBM does not explain actions that are carried out for reasons that are unrelated to health, for example, social acceptability (Conner & Norman, 2002). Taylor et al. (2006) assert that HBM is not sufficient in predicting behaviour. They are of the view that HBM's explanatory power is insufficient when compared to other social cognition models like the Theory of Reasoned Action (TRA), which was shown to be more fitting to predict health behaviour than the HBM. Other critiques have argued that little is known about the relationship among the HBM constructs. For example, it is not clear whether they all predict behaviour or if some of the constructs mediate the relationships to behaviour (Glanz, Rimer, & Viswanath, 2015).

Even with these limitations, the HBM framework has been useful in predicting and influencing behaviour change across various diseases, including HIV. As the critics have argued that the HBM is not clear if all constructs predict behaviour, I argue that the HBM should be adapted with each study to be most effective. For this particular study, the HBM was not adapted, however, we are aware that some constructs were more powerful than others in explaining and/or predicting behaviour. Therefore, the emphasis should be placed on the constructs that were most useful instead of trying to fit in each of the constructs, especially when dealing with intervention studies like this one.

2.11 Conclusion

This review of literature had broadly explored HIV/AIDS in South Africa, following a timeline from when HIV/AIDS was first identified, and the treatment response over the years. The role of social contexts such as age, gender and migration in driving the transmission and spread of the disease, were also explored in this chapter. This chapter also presented factors that are specific to young people that make them vulnerable to HIV infection. A discussion of

HIV testing and counselling, including HIV self-testing was presented. Lastly, a discussion on the HBM theoretical framework with the various components used for understanding health behaviour was presented.

CHAPTER 3: Research Methodology

3.1 Introduction

This chapter presents the research questions that informs this study. It further goes on to give a description of the research paradigm, including the research design that was used, the process followed in participant selection, the sampling criteria, the sampling process and the methods used in collecting and analyzing data. To ensure rigor, Guba's model of Trustworthiness of qualitative research is discussed, followed by a reflexive piece detailing how the researcher experienced the process and how the researcher might have influenced the findings of this study. Ethical considerations that were considered are discussed.

3.2 Research Questions

The following research questions informed the study:

- What do young people know about the at-home HIV self-testing kit?
- What is the willingness among young people to use at-home HIV self-testing kit?
- What are the perceptions among young people about using the at-home HIV self-testing kit?
- What is the perceived role of HIV counselling in the case of at-home testing for young people in Soweto?

3.3 Research Paradigm

This study is located within an interpretivist research paradigm. According to Goles and Hirscheim (2000), the interpretivist paradigm searches for explanations and meanings within one's consciousness and subjective experiences (Goles & Hirscheim, 2000). Terre Blanche and Durrheim (2006) add that the interpretive paradigm entails understanding the world from subjective experiences and studying those subjective experiences as reality. This study is

aligned with the interpretive approach as it aimed to look at the different views that young people hold regarding home-based HIV testing and how they interpret this. The meanings that young people attach to the HIV self-testing kit is of paramount importance for this study and will help to adequately answer the larger research question which is, whether young people accept HIV self-testing as an alternative method of testing or not. Interviews were used as a form of collecting data to gain the subjective experiences of young people living in Soweto about the HIV self-testing kit.

3.4 Research Design

A qualitative research design was used for this study. Qualitative research design aims to describe and understand actions and events from the research participant's perspective (Babbie & Mouton, 2001). A qualitative research design was used for this study, which is aimed at "describing and understanding actions and events in greater details from the point of views of the research participants" (Babbie & Mouton, 2001, p.270). This study used the qualitative research design because its aim was to explore and explain the willingness and acceptability among young people of using an HIV self-testing kit. This allowed the researcher to unpack the meaning young people associate to testing for HIV and using HIV self-testing kits (Leavy, 2014). Qualitative research design was more appropriate because it allowed for description and interpretation of young people's experiences and what meaning they attached to these experiences (Greenstein, Roberts & Sitas, 2003).

This research design allowed the researcher to gain an understanding of young people's view about testing for HIV, and if they are willing to use alternative methods of testing such as the HIV self-testing kit. Looking at the research questions for this study, the qualitative design was found to be more compatible than a quantitative design. This is a relatively new and exploratory area of HIV research in which the researcher seeks to discover and understand the different aspects of young people's perceptions of the at-home HIV self-testing kit.

3.5 Participants

As this research study's focus is on young people in Soweto, the research participants from whom the data was gathered were young people between the ages of 18-24 years old who

resided in Soweto. The researcher attempted to get a diverse group of young people which included participants of different ages, genders and sexual orientation.

3.5.1 The sampling approach

Research participants were selected using the following criteria;

- Be between 18-24 years old
- Reside in Soweto
- Have tested for HIV before

Participant no	**Age**	**Sex**	**Sexual orientation**
1	21	Male	MSM
2	21	Female	Lesbian
3	21	Male	MSM
4	20	Male	Gay
5	22	Female	Heterosexual
6	21	Male	Gay
7	24	Female	Heterosexual
8	23	Male	Heterosexual
9	21	Male	Heterosexual
10	20	Male	Heterosexual
11	24	Male	Heterosexual
12	22	Female	Lesbian
13	19	Female	Heterosexual

14	20	Female	Heterosexual
15	22	Female	Heterosexual

A total of 15 participants from Soweto were interviewed. The participants included 8 men participants, where four of them are gay/men having sex with men (MSM) and seven women, where two of them were lesbians. The sampling technique used to access participants included non-probability purposive sampling, as participants had to meet the sampling criteria. According to Neuman (2000), a non-probability purposive sampling technique is used when the researcher is specific with the type of participants needed. Following this, elements of snowball and convenience sampling techniques were used. Lewin (2005) postulates that snowball sampling is when individuals with characteristics of a certain population are used to identify and recruit similar individuals willing to take part in the study.

The researcher asked participants who had already participated in the interviews to recommend people who meet the selection requirements. This is known as the convenience non-probability sampling. The researcher also visited the Baragwaneth Hospital taxi rank, Maponya mall and surrounding areas, and approached young people to recruit the for the study. The researcher took the contact details of those who were interested to arrange for follow up contact. Participants that had shown interest were contacted and had the aim of the study was explained to them. Following their consent to take part in the research study, a date and time for the interview that was most convenient for them was set. While, diverse ages were desired for this study, due to snowball sampling technique, the majority of participants are between the ages of 21 and 22 years.

3.6 Data collection

The data collection method for this research study was through semi-structured interviews. Using interviews as an instrument to collect data aligned with the aim of this study, which was to get the perceptions of young people regarding the use of HIV self-testing kits. Discussions that unfold during the interview talk allows for the rich data to be collected. The structure of the interview is flexible and can take on any direction (Longhurst, 2003). “In

semi-structured interviews are structured, however, the nature of the semi-structured interviews allows for flexibility to ground the sequence in which the researcher will ask the questions listed" (Thomas, 2003). In addition, questions that appeared to be of most interest to the interviewees are explored.

Semi-structured interviews allow the interviewee to clarify their answers if they are not clear to the interviewer. The interviewer also gets the opportunity to probe the information that is provided by the interviewees, in order to get more clear and detailed information. Additionally, the interviewer helps the interviewee with interpreting the questions they were asked. The interviews were guided by a list of questions under different topics (see Appendix D). Questions that were initially not part of the interview schedule were also asked in order to probe based on the interviewee's response to illicit more information. A total number of 15 participants were interviewed individually, with each interview lasting for at least 30 minutes. All the interviews were tape recorded with the consent of the interviewees.

3.6.1 Procedure for data collection

This research study focused on young people who reside in Soweto. To ensure variation in the sexual orientation of participants, while maintaining sensitivity, participants who were gay young men/men who have sex with men and lesbians were identified through recommendations by their friends and those who had already participated in the interviews. Participants were contacted telephonically to arrange for the date and time that was most convenient for them. The interview questions (Appendix D) were in English, however participants were encouraged to respond in a language that was most comfortable for them. The commonly used languages among the interviewees were Isizulu and Sesotho. The interviewer understood all the languages used by the participants, and in some cases the interviewer used the language of the interviewee. All audio recordings were transcribed verbatim.

A tape recorder and a mobile phone (as backup) were used to record the interviews. All recordings were deleted from the tape recorder and mobile phone after being securely stored on a password protected computer. All recordings will be destroyed from the computer once the study has been completed and graded. Before starting the interview, participants were given the participant information sheet (Appendix A) to read and understand before signing Appendix B and Appendix C for consent. The interviews lasted 30 to 50 minutes. All

interviews took place in a quiet, private room at the Perinatal HIV Research Unit at Baragwaneth Hospital in Soweto.

3.7 Data Analysis

After interviews were transcribed, a thematic analysis was conducted using themes identified in the literature review (chapter 2) and themes that were identified from the data. Braun and Clarke (2006) define thematic analysis as "a method for identifying, analysing, and reporting patterns (themes) within data" (p. 79). The function of a thematic analysis is to organize your data into meaningful details (Braun & Clarke, 2006). Furthermore, thematic analysis allows for a flexible approach to the collected data and enables delivery of data that in a detailed and multi-faceted manner (Braun & Clarke, 2006).

The researcher first established what the concept of a theme means in the context of this study. Braun and Clarke (2006) assert that a theme represents something important about your data regarding the research question. A theme also refers to subject matter that keeps recurring (Vaismoradi, Jones, Turunen & Snelgrove, 2016). In addition to this, the researcher also identified themes that are divergent from the rest of the themes. After a theme was successfully identified, the researcher followed the six steps identified by Braun and Clarke. The six steps include: (1) Familiarising yourself with your data; (2) Generating initial codes; (3) Searching for themes; (4) Reviewing themes (5) Defining and naming themes and (6) Producing the report.

To help with the process of becoming familiar with the data, the researcher read and re-read each transcript individually while also allowing themes to manifest on their own. Additionally, some themes were taken from already existing literature on young people, risky behaviour, HIV testing and HIV self-testing kits. Once the researcher was more familiar with the transcripts, single words, phrases, or paragraphs that stood out were highlighted. Additional notes and remarks next to the highlighted words or phrases were added to indicate under which group those phrases will be allocated to.

Once familiar with each transcript, a list of codes was created and allocated into groups according to their similarities to identify themes (Braun & Clarke, 2006). Re-occurrence of particular codes did not necessarily equate to a theme. What was chosen as themes was based on their relevance to the research questions. Moreover, an attempt to identify unsuspected, hidden or contradictory connections across the data set was made to identify themes. The

flexible nature of thematic analysis allowed the researcher to determine what counts as a theme and what does not, while following a set out guideline (Braun & Clarke, 2006). As the researcher was busy with this process, additional comments and notes were added to make more sense of the summarised transcripts. This process is in line with steps two and three of Braun and Clarke's (2006) six steps.

In order to organise the long list of themes, the summaries of transcripts were reviewed again, and sub-themes were identified (Braun & Clarke, 2006). This stage resulted in having a more succinct understanding of the data. While this process took place, the researcher became more immersed with the data until the researcher was able to start with the discussion. After listing all themes and sub-themes, the researcher carried out a thematic analysis. To interpret the data, the researcher relied on the existing body of knowledge. Extracts from the findings that supported, differed, extended or challenged the information that already exists in literature were used to make arguments about the research questions (Braun & Clarke, 2006). This final stage involved considering and applying the Health Belief Model theoretical framework to the themes.

3.8 Ensuring Rigor

Guba's (1981) model identifies four aspects of trustworthiness, namely; (a) truth value, (b) applicability, (c) consistency, and (d) neutrality. According to Krefting (1990), these strategies are important to researchers because they assist in designing ways in which they can increase rigor for their qualitative studies. Rigor is equally important for readers to use as a tool of evaluating the value of the findings of qualitative research.

The truth value establishes the confidence of the researcher based on the research design, participants and context (Krefting, 1990). A qualitative research design, which aligns with the aim, was chosen for this study. The study design provided for a detailed description and interpretation of the acceptability and willingness among young people in Soweto to use the HIV self-testing kit. Furthermore, it allows for the adequate answer to the study research questions as it allows for descriptive information and understanding of the perspective of others. Another method of ensuring rigor prescribed by Guba's 1981 model is through transferability. When the researcher has provided sufficient descriptive data that will allow for comparison, then the question of transferability can be addressed (Krefting, 1990). The researcher is confident in the data collected for this research study because of the relatively

large number of interviews conducted with a diverse group of young people. Various opinions and perspective were gathered from the interviews and the researcher was able to sufficiently answer the research questions.

Another criterion from Guba's 1981 model is consistency of the data (Krefting, 1990). According to Krefting (1990), data is consistent if the findings are the same in a replicated study with the same study participants or the similar context. The researcher solely relied on the information provided for by the study participants and a reflection piece of how the researcher might have influenced the finding is discussed. The last criterion of Guba's 1981 model is neutrality. Neutrality is the extent to which the findings are as a result of conditions of the research and not ulterior motives or perspective. In addition, triangulation was used to ensure the rigor of the study. To ensure triangulation, the researcher and supervisor assessed against one another their interpretation of the data. Krefting (1990) refers to this strategy as triangulation of investigators. This occurred between the researcher and the supervisor where diverse approaches were used in analysing and interpreting the data. In addition to this, theoretical triangulation was used where a theory was used in the interpretation of the data.

3.9 Ethical considerations

This study had to address a number of ethical issues because human participants were used. Firstly, the aim of this study was explained and all participants were aware that taking part in this study was voluntary. The researcher asked for the participants' consent. The informed consent for conducting the interview (Appendix B) and consent for audio recording the interview (Appendix C) were signed. Both consent forms included explanations of what they were consenting to. The researcher made sure that all participants understood everything on the participant information sheet by asking them to explain what they understood from the information sheet. The researcher reiterated to the participants that they could withdraw from the study at any time and could decide not to answer any questions they were not comfortable with.

While the confidentiality of participants was guaranteed, participants were informed that anonymity could not be guaranteed because of the nature of collecting data through interviews. No risks or benefits were anticipated with participating in this study, and this was explained to the participants. Issues which emerged that were sensitive i.e. the loss of a loved

one from HIV, were carefully dealt with. When 3 participants experienced distress as a result of talking about sensitive issues such as the loss of a parent due to HIV/AIDS and rape, the audio recorder was paused, and participants were asked if they were comfortable to continue with the interview. Referral information for free counselling services was given to participants who needed it.

Tape recordings of interviews and transcripts were secured in a password protected computer and only accessible to the researcher and the supervisor. These recordings and transcripts will be later destroyed. The names of the participants were not recorded or used in the research report. However, participants were informed that direct quotations from the interview would be used. No revealing information is provided in the study, participants are referred to as 'participant' plus a unique number to assist the researcher with data analysis and interpretation. The participants were informed that the results of the study would be presented in the form of a research report form to be submitted to the Faculty of Humanities, University of the Witwatersrand, Johannesburg, for examination purposes.

3.10 Reflexivity

According to Harvey (2017), researchers are participants in a social life; therefore, they can be seen as socially similar to their participants in general ways. I shared a few characteristics with my participants that they were able to identify with. We are black and in the same age group. My participants are all from Soweto, a township in the South of Johannesburg and I also grew up in a township which is similar to Soweto in terms of culture and language. I was eager to make ensure that my participants are aware of our shared similarities. For example, while race was obvious, I made sure that I spoke using township slang when introducing myself to them so that they are aware that I grew up in a similar context as them. In addition to this, I would also mention my age when introducing myself.

Harvey (2017) argues the participant and researcher's shared experiences, of any kind, enable the participant to identify with the researcher. Because of these experiences, I went into the research with the idea that my participants are going to feel comfortable to share intimate stories or experiences if they felt understood by me. While this proved to be correct in most instances, our differences were also obvious. Being a university student, with my level of education, and being associated with an institution such as the Perinatal HIV Research Unit (PHRU), my participants were intimidated.

Our differences and similarities played different roles in the data collection process. While our similarities made participants to be open and trusting with their information, our differences made them to put me in a pedestal and they thought I had the powers to make the changes that they want as young people in the context of HIV. For example, in so many instances with different participants, they assumed that I designed the HIV self-testing kit. This was evident when they would tell me what to do regarding the HIV self-testing kit. They would say things like 'Make the HIV home test to be available for free in the clinics' and 'you must change the way they do counselling at the tents'. Some of my participants belonged to a minority group, the LGBTQI community. Because they are often discriminated against or 'othered', I discovered that they often needed reassurance from me that their participation will not in any way disempower them. Some of them took the opportunity during our interview to vent about all the frustrations they have with the public health sector, how their needs are not catered for and how healthcare workers often treat them differently. I realised that they identified me as an advocate for their needs. I felt helpless in that situation because I knew there is nothing I can do for them.

My interview schedule was developed in English but I am conversant with several African languages. Because of this, I emphasised to my participants before recording that they are free to speak in any language they are comfortable with. However, because I was continuously asking and responding in English, most of my participants responded in English; interchanging with their home language and this seemed to have an impact in the research from early on. I felt this limited them in how deeply they expressed themselves. It is possible that my participants may have elaborated further had the interview schedule been adjusted to suit their language preference. In instances where I felt like I could get more out of their responses, I tried probing in the language they were comfortable with. However, this was not always successful as responses remained brief. Brief responses from participants may also be attributed to the intimate and sensitive nature of some of the questions.

Going into this research, bearing in mind my research topic, I did not anticipate physical and emotional exhaustion because I thought my research topic was not, in any way sensitive in nature. However, to my surprise I was left physically and emotionally exhausted after a few of my interviews. This happened when topic about loss of parents and family members due to HIV/AIDS and living with People Living with HIV (PLWH). One participant spoke about her mother who died because of HIV/AIDS and how taking care of her younger brother who

is living with HIV (because of mother-to-child transmission) has been difficult for her. She cried, and in that moment, I did not know what to do except to stop the audio recording. It was in that moment where I realised that I was not prepared for my participant's emotional responses, which appeared more often than I expected. Harvey (2017) states, "collecting data can be emotionally intense for, and demanding on researchers, especially when the topic of research is of sensitive nature". It is evident that I did not expect this emotional labour from collecting my data on HIV self-test. This made me to realise that I had completely forgotten how HIV/AIDS has had a devastating impact on South Africa. No part of South African society can claim to have escaped the devastating effects it has had on all the levels of social fabric, from an individual level to family and community. The devastating effects are still felt even to this day, as there are those who were left orphaned and had to head households.

Harvey (2017) believes that it is important for researchers to pace their interviews to allow time to process emotions. However, I did not anticipate that the data collection process to be emotionally draining. In addition to this, I did not pace my interviews to allow enough time in between interviews to process my emotions and this was largely due to the pressure of time. I was behind and I had to finish data collection as soon as possible. Because of the time pressure, I found myself conducting three interviews in per day. There was no time for me to have a moment of reprieve in between my interviews, to see where I can probe more or what I can ask differently because I always had to rush to the next interview. Because of both emotional and physical exhaustion, I did not give some of the interviews my best and therefore I could not get the best out of my research participants.

As I started reflecting on the data collection process after completion, I realised that I sometimes stepped out of my role as a researcher, not because I felt forced by participants towards this, but I did it when I felt the need and when I wanted to. I consciously chose to share personal stories with participants. I voluntarily shared my personal experiences related to participant's stories. I did this at times when I felt like they needed to know that I could relate to their stories, mainly because of our shared similarities. Additionally, I felt privileged that they trusted me with sensitive information that they would not otherwise share it with anyone else.

3.11 Conclusion

This chapter presented the study research questions, the research paradigm and research design used for this study. This chapter also discussed the participants of the study, including, how they were recruited, and the sampling criteria used. The data collection tool and the procedure of how the data were collected were also explained in this chapter. The researcher also further discussed how data for this study was analysed. The researcher provided a rationale for every method used in this study. Rigor to ensure the quality of qualitative research was briefly discussed with an overview explaining the strategies used to ensure the rigor of the study. An overview of the ethical considerations and steps that were followed to ensure fair treatment of the research participants was provided. The researcher also provided a reflexive piece of the data collection process. The next chapter presents research findings taken from the data collected.

Chapter 4: Findings and Discussion

In this chapter, findings analysed using thematic analysis are presented and discussed. Five primary themes from the Health Belief Model are described and explained in this chapter. There are three themes outside the HBM, namely; HIV testing and recommendations made by participants. Findings are based on interpretive paradigm and therefore, the focus was on young people's subjective experiences on HIV testing and their acceptability and willingness to use the HIV self-testing kit. A discussion of the findings is provided to explain young people's views and attitude towards the HIV home test and testing in general. This discussion incorporates the description and positioning of the findings based on existing literature with my own interpretations of the findings.

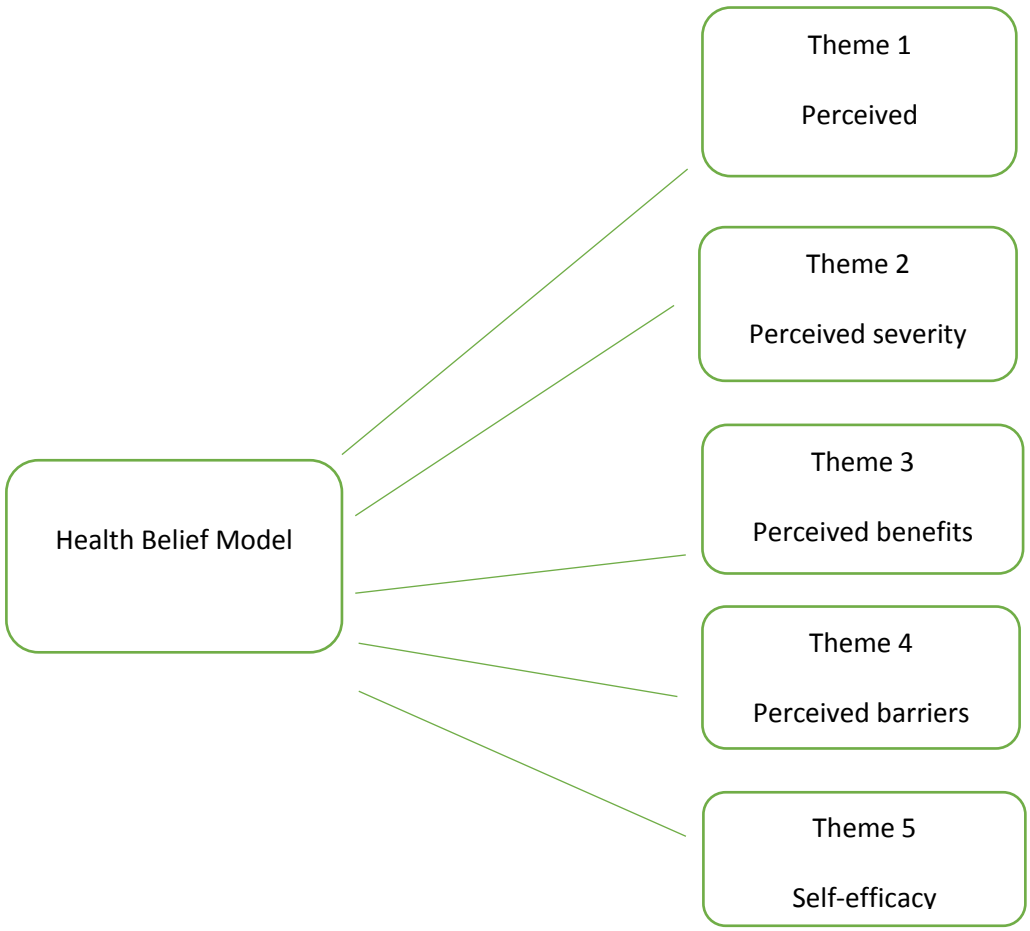


Figure 1. Presented in this figure are five key themes taken from the Health Belief Model (HBM).

As displayed on the diagram above, five key themes taken from the Health Belief Model (HBM) were identified. (1) Theme 1: Perceived susceptibility; (2) Theme 2: Perceived severity; (3) Theme 3: Perceived benefits; (4) Theme 4: Perceived barriers; (5) Theme 5: Self-efficacy. These are presented in sections 4.1 to 4.5.

4.1 Theme 1: Perceived susceptibility

The first component of the HBM model refers to personal feelings of vulnerability to a certain illness or disease. Three sub-themes emerged under the theme 'perceived susceptibility' as seen in figure 2 below.

Figure 2, presents three sub-themes identified in relation to Theme 1: perceived susceptibility.

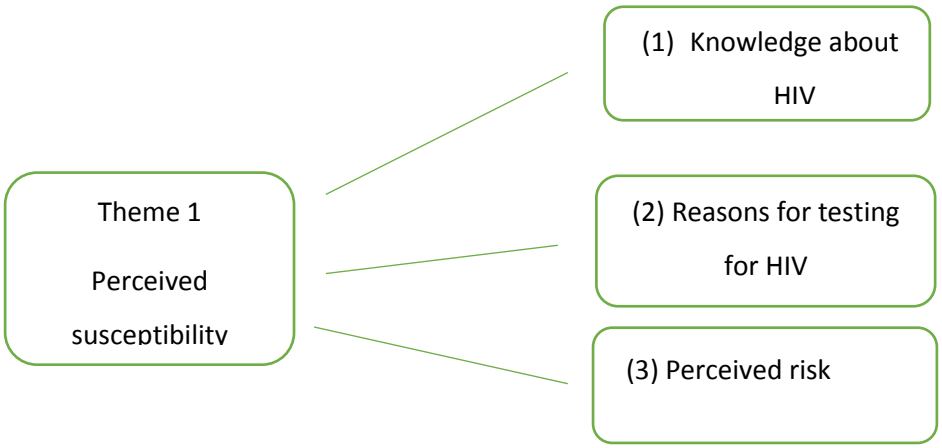


Figure 2. The three sub-themes related to Theme 1: perceived susceptibility

As shown in figure 2 above, perceived susceptibility (Theme 1) was explained in terms of the following three sub-themes: (1) knowledge about HIV; (2) reasons for testing for HIV; (3) perceived risk. These sub-themes are presented from sections 4.1.1 to 4.1.3

4.1.1 Knowledge about HIV

Young people's knowledge about HIV was tested by asking them what they know about HIV. We believed that what they know about HIV will tell us about their personal feelings of vulnerability to the disease. Most participants answered that it is a disease and have shown understanding of how this disease is transmitted.

> I know that it's a chronic disease that you get if you engage in sex without a condom. And touch someone's blood and if you also have cuts or sharing needles and ya… (IDI2, Male, 21)

> It's a sexually transmitted disease, one. And then, okay not only sexually transmitted disease, some people encounter it through accidents, car accidents and stuff. (IDI4, Male, 20)

> And then I just know that you can get it from having unprotected sex, having contact with someone who has it, like via cuts and all that. Participant (IDI15, Female, 22)

In addition to knowing that HIV is a disease and how it is transmitted, participants also emphasized that it is not a death sentence, but rather a manageable disease. They believed that if you take treatment, one can live a long healthy life. This means that participants do not perceive HIV as a life threatening disease. This might have negative implications on how they perceive the seriousness of contracting HIV and how it may affect their lives.

> There's treatment for it like ARVs, it's not a cure but it can make you live longer. (IDI4, Male, 20)

> At first I thought it was a death sentence but then after like seeing my family members sick then they got treated, I was like…it's something you can live with. (IDI8, Male, 21)

> I know that it's incurable, but you can take prescription for it and take medication, but I know that those pills don't cure HIV. (IDI7, Female, 24)

Indeed, as Jones, Modeste, Marshak and Fox (2013) indicate, HIV is transmitted through engaging in unprotected sex, using needles that are contaminated with HIV and through mother-to-child-transmission. However, it is also known that there is no clear indication that HIV knowledge translates to safer sexual practices (Jadack, Hyde, & Keller, 1995). Young people's ability to evaluate their personal risks using the knowledge they have may be limited.

4.1.2 Reasons for testing for HIV

When asked why they test for HIV, an understanding of their vulnerability to HIV was evident in the participants' responses. They all expressed concern about contracting HIV during sexual intercourse, even with their main or regular sexual partner. Common reasons why young people thought they are vulnerable to HIV included alcohol use and having multiple sexual partners.

> It's because of my lifestyle. You know, partying, and a lot of times you are under the influence of alcohol, it's not every time that you are going to use a condom. (IDI1, Male, 21)
>
> …More especially for us young people, we do things, go out at night, chase girls. (IDI8, Male, 23)
>
> He took advantage because we were drinking on that day. First round we used a condom, then I passed out, he took advantage and had sex with me without a condom so that's why I went to test. (IDI13, Female, 19)

Other participants indicated that testing for HIV is a gateway to treatment that can save their lives.

> Because the youth today we sleep around, there's parties, you get drunk and anything could happen so it's better when you know your status so that you can get help as soon as possible. (IDI14, Female, 20)
>
> To know my status, and also if I have it then I can take treatment as soon as possible. (IDI2, Female, 21)

Lack of trust in sexual partner was also mentioned as one of the reasons for testing for HIV. Three participants stated that:

> It was a must for me to do it because I was dating someone whom I didn't know what he was doing before I came into his life. (IDI5, Female, 22)
>
> The guy I had unprotected sex with, he's my boyfriend, we've been together for like three years so the reason why I went to test is because I was suspecting that he's cheating on me. (IDI13, Female, 19).
>
> Cos I have a boyfriend and I don't know what he does so I feel the necessity to test. (IDI14, Female, 20)

Participants were further asked how often they test for HIV in a year. The majority of the participants reported that they test every three months, meaning that in a year they test approximately four times.

I make sure every three months. (IDI2, Female, 21)

Every three months. (IDI5, Female, 22)

After three months. (IDI8, Male, 23)

While majority reported that they test every three months, others reported that they test at least twice in a year, and one of the 15 participants said that they have only tested once.

Maybe in a year twice. (IDI13, Female, 19)

Every after six months. (IDI14, Female, 20)

Maybe once every six months. (IDI9, Male, 21)

Yoooh! I won't lie, it's been a long time, I only tested uhmm once. (IDI10, Male, 20)

It is clear from our findings that young people have access to testing services and this is not necessarily a barrier to them as most have indicated that they test for HIV frequently. However, it is also concerning that the reason why they test frequently is because of continuously engaging in risky behaviours. While HIV early detection is advantageous because it is a gateway to treatment, more needs to be done to encourage safer sexual practices amongst young people.

4.1.3 Perceived risk

To further explore young people's perceived vulnerability to HIV infections, participants were asked if they think that they are at risk of getting HIV. The interview data revealed that young people are well aware that they are at risk and they also appeared to be aware of the factors that put them at a higher risk of being infected with HIV. These factors included: their sexual orientation, engaging in transactional sex and partying. Partying is considered to be a risk factor to young people because they are exposed to excessive alcohol and drug use which impairs their judgement and further exposes them to risk (Katainen, Lehto & Maunu, 2015)

4.1.3.1 Sexual orientation

Sexual orientation was perceived to be a risk factor for some of the participants. Two participants in this study mentioned that they are vulnerable to the risk of getting infected with HIV because of their sexual orientation:

> I think I'm at a huge risk of getting infected because I'm gay as well, so gays are considered high risk people when it comes to HIV. (IDI1, Male, 21)

> I can say that I'm at risk because I'm lesbian and anything can happen to me. It can happen that someone from my Kasie has been eyeing me all along knowing that I'm lesbian, he's HIV, he can do anything." (IDI2, Female, 21)

Gay men and men who have sex with men (MSM) are considered to be a population that is at high risk of contracting HIV. Because of the high prevalence of HIV among this group, the chances of being exposed to HIV are higher (Evans, Cloete, Zungu, & Simbayi, 2016). Additionally, most gay men contract HIV from having anal sex without using condoms. Anal sex is the riskiest type of sex for contracting or transmitting HIV (Evans et al., 2016). Lesbian women are also at high risk of being raped due to stigma and homophobia. This is what is referred to as 'corrective rape' where a woman is raped to "cure" her of her homosexuality (Koraan & Geduld, 2015).

4.1.3.2 Transactional sex

Other participants mentioned their socio-economic status as one of the factors that puts them at a higher risk as young people living in South Africa because they find themselves getting involved in relationships with older men for material possessions.

> Too much! Too much! The reason being is you know youth of today, they like relying on men for money so obviously men want something in return and in most cases they don't use condoms. Poverty, sometimes people just want something to eat so they sleep with older men for money. (IDI7, Female, 24)

> Mmm high risk. For example, I don't have money, I have nothing. A guy with a big car, I don't even know where he comes from, I only see money. He will tell me no; I don't want a condom. Cos I want money, I will do it and then next thing he disappears." (IDI13, Female, 19)

Engaging in sex in exchange for material possessions is common practice in South Africa. Young women in South Africa engage in transactional sexual behaviour because of basic and sustenance needs (Zembe, Townsenol, Thorson, & Ekstrom, 2013). Recent research conducted in South Africa found that women receive money and gifts from their partners (Zembe et al., 2013). In a study by Dunkle, Jewkes, Brown, Gray, McIntryre and Harlow (2004) women reported that they are less likely to suggest condom use due to fear of losing

the material gains. Research shows that transactional sex is associated with increased HIV risk in South Africa as well as globally (Dunkle et al. 2004). Zembe et al. (2013) argue that transactional sex puts women at high risk of contracting HIV because condom use is an uncommon practice in transactional sex. This may be due to women feeling like they are unable to negotiate safer sex practices in conditions of economic gain.

4.1.3.3 Partying

Other participants also reported partying as one of the factors putting them at high risk of HIV. Young people viewed partying as one of the factors that puts them at risk because, in parties, they are exposed to alcohol, drugs and having sexual intercourse with strangers. All of these behaviours combined, reduce the chances of using protection.

> I'm always partying, I'm never home plus I'm a model so I'm always out and meet different people so like the chances of getting sick are too much.(IDI8, Male, 23)

> Yes, cos you see these days, you know parties and I drink a lot. I drink yooh! I was wasted. Okay, if it wasn't for my friends like, if they were not there, I had already decided that I'm leaving with this guy.so like this thing of drinking will put us at risk. (IDI12, Female, 22)

Young people in this study further went on to explain the different risky behaviours that they engage in that puts them at risk of getting HIV. Unprotected sex and substance use were some of the risky behaviours found in the data that put young people at risk of HIV.

> Maybe like I didn't use a condom because I was under the influence of alcohol. (IDI1, Male, 21)
>
> Because I party a lot, sometimes I don't use a condom and I don't mind sharing a guy with a friend, so you know, things like that put me at risk. Because, number 1 I don't like condoms, number 2 I wouldn't mind like getting 5 guys in one night. (IDI3, Male, 21)
>
> And the risk of HIV is high in the times that we live in because there's many drugs and there's this drug called 'bluetooth nyaope', you transfer drugs through another person's blood, that's also risky.

> Ya I can believe that, you see drinking leads to the next thing. And they don't have time for condoms; they don't use condoms, never. (IDI12, Female, 22)

It is evident from the above extracts that young people engage in risky behaviours in situations where their judgement is impaired because of substance use, which in turn

compromises their health. In addition to these risky behaviours that young people engage in that compromise their health, more than half of the participants reported that they have or have had at least two or more sexual partners at some point. Participants were asked how many sexual partners they have, either currently or recently and these were their responses;

> I used to have three [sexual partners]. (IDI1, Male, 21)
>
> I don't know, cause like there's many hey. If one decides to give me a call today and say 'today I just want to be with you. (IDI8, Male, 23)
>
> Currently there's none, previously there was about three or 4. (IDI11, Male, 24)
>
> There's three. (IDI12, Female, 22)

To probe this further, the participants were further asked how often they engage in sexual activities with their sexual partners. For most of the participants, they meet with their sexual partners at least twice a week for sex.

> Three times a week or two times a week. (IDI3, Male, 21)
>
> The other one is my ex but often we have sex so let's say I go to him once a week. Then the other one also once. Then most of the time I go to my partner maybe three times a week. (IDI12, Female, 22)
>
> One [sexual partner] often and then the other one [sexual partner] it's sometimes. With one [sexual partner] I don't use condoms, the other [sexual partner] I don't know him that much so I always use a condom. (IDI13, Female, 19)

On the other hand, three participants did not think that they are at a high risk because they are either not sexually active or because they use protection. When asked how much at risk of being infected with HIV do they think they are, they had the following so say;

> Yeah, 20% I don't think cos I'm not that [sexually active] (IDI4, Male, 20)
>
> I don't think so hey. (IDI9, Male, 21)
>
> No, cos I condomise and I don't just have sex with any individual. (IDI10, Male, 20)

While abstinence is an effective way of addressing HIV/AIDS in South Africa, young people might have a distorted view of their vulnerability to HIV infections. For example, they are

living in a country with millions of people infected with the virus in addition to being part of a population group characterised by high promiscuity (Kahn, 2006).

4.1.3.6 Knowledge on prevention methods

Seeing that the majority of the participants were well aware of their vulnerability, factors contributing to their vulnerability and risky behaviours that compromise their health, young people were asked about the prevention methods they use to reduce their risk. They all mentioned using protection (condoms) as a prevention method. Those living with family members with HIV said they use gloves when they have a cut. Making sure that a needle has never been used before when piercing or injecting drugs as well as Pre-exposure prophylaxis (Prep) were mentioned as prevention methods.

> Using condoms sometimes and using gloves and ensuring that the needle you are about to use has never been used before by someone else. (IDI2, Female, 21)

> Okay, I use gloves if my aunt has a cut or something because there's no one to help her. (IDI3, Male, 21)

> Okay, Prep and then condoms obviously. (IDI4, Male, 20)

> Well…I use condoms all the time cos at first, I did not use, well I did use them but not all the time. (IDI4, Male, 20)

Seeing that they are at a higher risk of getting infected with HIV, participants were asked about the prevention methods they take to ensure that they minimise this risk. Testing for both parties was also reported as a prevention method,

> Condom is number one priority and also testing regularly with your partner. (IDI7, Female, 24)

> Test, for both parties. (IDI11, Male, 24)

While young people know that using a condom during sexual intercourse can minimise their risk of getting HIV, it is evident from their responses that they are not consistent in using condoms which leaves them at risk.

Perceived susceptibility refers to one's personal perception of contracting a disease. The more one believes they are at risk of contracting a disease, the greater the chances of adopting behaviours to reduce the risk (Rosenstock, Stretcher, & Becker, 1998). The findings show that young people have fair knowledge of HIV and how it is transmitted. In an earlier study, Buldeo and Gilbert (2015) employed the HBM to investigate first year students' responses to testing (HCT). Following the HBM, the participants in this study showed a high level of perceived susceptibility when evaluating their chances of contracting HIV through engaging in risky behaviours.

It is also clear that what young people know and what they practice are in conflict. The findings show that young people know that HIV is transmitted through unprotected sex. This is similar to a previous study in South Africa (cited in Jones et al., 2013) that showed an increase in transmission knowledge about HIV among young people. Similarly, another study conducted in Guyana, South America with young people aged 12-20 demonstrated a high knowledge of HIV transmission. However, the findings also showed that despite this knowledge, young people still engage in unprotected sex and they know the factors that put them at a higher risk of contracting HIV For example, in the findings of this study, the participants were aware that partying puts them at risk. The gay participants were also aware that they are at a higher risk of contracting HIV because of their sexual orientation yet they still put themselves in situations that expose them to the risk. Brown, DiClemente and Reynolds (1991) argue that young people do not have the capacity to differentiate between their "unique emotional reactions and those common to all people" (p. 55). This means that young people would believe that they would not contract HIV from having unprotected sex, even though they are aware that HIV is transmitted through unprotected sex. Karim and Karim (2005) argue that this is as a result of young people's need to explore but at the same time, they lack the cognitive ability that is required in the consistent engagement of safe sex.

It is evident from our findings that young people are not consistently engaging in safe sex and as others have mentioned, they do not use condoms with all sexual partners. Brown, DiClemente and Reynolds (1991) argue that young adolescents have low risk perception because of their cognitive immaturity. Findings show that our participants are aware of behaviours that put them at greater risk of acquiring HIV such as substance use, having multiple sexual partners and engaging in unprotected sex, yet they still engage in these risky behaviours. However, this behaviour from the participants cannot simply be attributed to

cognitive immaturity as all of them are above the age of 18. This type of behaviour can be seen as a failure to take personal responsibility in situations of risk. This failure can be attributed to pressure resulting from impaired judgement due to substance use, peer pressure and the urge to engage in destructive sexual practices for pleasure.

In addition to young people's lack of cognitive maturity, there are social factors that make them vulnerable to HIV. The lack of social capital such as schooling, work and employment contribute to sexual risk behaviours among young people (Karim & Karim, 2005). Young participants in the study are unfortunately amongst a group of young South Africans who are unemployed nor at school. According to statistics published in 2018 by Statistics South Africa, out of the 10, 3 million people between the ages of 15-24 years, 32,4% were not in employment, education or training (Statistics SA, 2018).

4.2 Theme 2: Perceived Severity

The second component of the HBM model says that for a person to take a health preventative measure, he or she must believe that the consequences of contracting that disease would be severe. The findings show that young people believe that the consequences of contracting HIV are dire. Six sub-themes emerged under theme 2: perceived severity as seen in figure 3 below.

Figure 3, presents six sub-themes identified in relation to Theme 2: perceived severity.

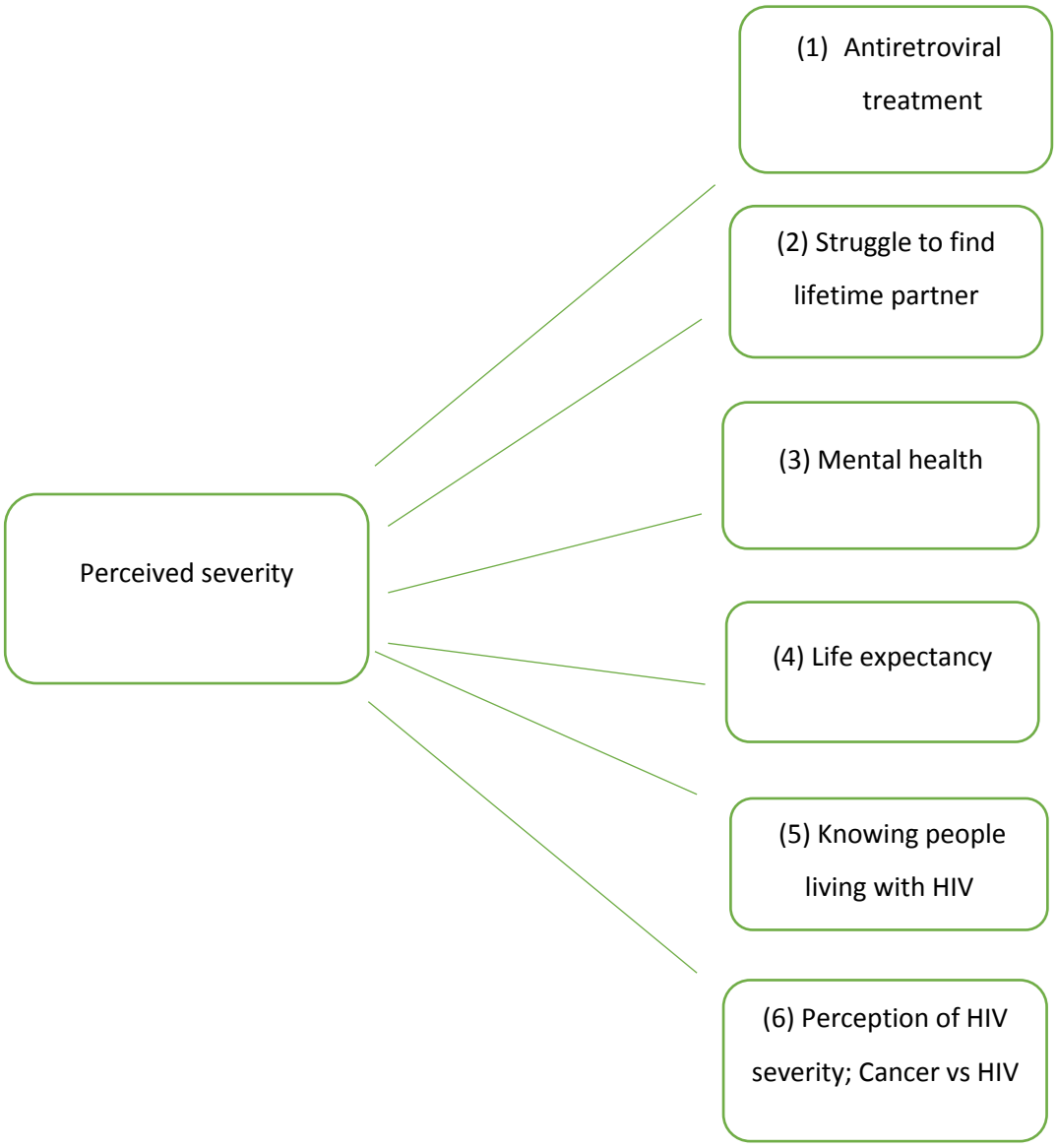


Figure 3. The six sub-themes related to Theme 2: perceived severity.

Figure 3 above shows the six sub-themes that emerged, related to perceived severity: (1) antiretroviral treatment; (2) struggle to find a lifetime partner; (3) mental health; (4) life expectancy; (5) knowing people living with HIV; (6) perception of HIV severity-cancer vs HIV. These sub-themes are presented in sections 4.2.1 to 4.2.6

4.2.1 Antiretroviral treatment

The HIV treatment was identified as a dire consequence mainly because it has to be taken every day. Additionally, others also mentioned the side effects of the HIV treatment, highlighting that the side effects of the treatment can be bad.

> It's difficult more especially cos you have to take pills for the rest of your life, it's too much. (IDI2, Female, 21)

> Okay, once you get infected like ARVs don't treat everyone the same. Others gain weight, others lose weight, others they vomit whatsoever. (IDI3, Male, 21)

> You might lose or you might gain weight. (IDI9, Male, 21)

Being on treatment of any kind can impair vision and have physiological side effects. In the context of HIV, this often results in unintended disclosure of one's HIV status (Katz et al., 2015). This negative attitude towards treatment can lead to treatment refusal, which affects efforts to control and prevent the spread of HIV.

4.2.2 Struggle to find a lifetime partner

The struggle to find a lifetime partner was also reported as one of the worst possible outcome of contracting HIV. They believe that contracting HIV will change the relationship dynamics and reduce the chances of finding a lifetime partner.

> …not finding a partner, not finding a partner very easily. (IDI4, Male, 20)

> It will change a lot of things, because let's say the person who infected me dies, it will be hard for me to move on or telling your new partner that you have HIV. It can make life difficult. (IDI7, Female, 24)

> People won't understand that you have HIV. And it's not everybody who wants a partner living with HIV. (IDI7, Female, 24)

Young people believe that contracting HIV will limit their chances of finding a dating partner. This might lead to non-disclosure to new partners due to fear of being rejected or unwanted. Moreso, these responses indicate that HIV stigma is still prevalent in many communities. According to Moughan-Brown (2010), stigma serves as an obstacle to taking and adhering to treatment and discourages disclosure to sexual partners. Again, not disclosing your status to a new partner will further put them at risk of HIV infection.

4.2.3 Mental health

Another big concern for young people was their mental health that will suffer because of contracting HIV. They believe that living with HIV will affect their mental health, causing depression.

> Yoooh! Depression, like I was telling you about my friend, like now it's as if she's crazy. (IDI13, Female, 19)

> You gonna be depressed, you gonna think that other people are better than you. (IDI13, Female, 19)

> I do know that it could shorten your life, and you undergo depression after finding out that you've got this disease. (IDI14, Female, 20)

Katz et al. (2015) found that adults in Soweto refused treatment because they feared that their mental health will be compromised. The association of HIV and HIV treatment with reduced mental health is dangerous because it has the potential to deter people from seeking the much needed life-saving treatment.

4.2.4 Life expectancy

Others still believed that the consequences of contracting HIV can be deadly. This means that HIV will reduce their years, causing untimely death.

> I think life expectancy decreases. (IDI9, Male, 21)

> It can lead to death and other known and unknown disease can infect you easily. (IDI10, Male, 20)

> The consequences are deadly, that's bottom line. (IDI11, Male, 24)

Even with widely available free HIV treatment, people still associate HIV with death. This could potentially mean that young people do not believe in HIV treatment. This contradicts the responses of others who indicated that one can live a healthy long life as long as they are on treatment.

4.2.5 Knowing people living with HIV

8 out of 15 of the participants had family members who are either living with HIV or who have died from HIV.

> My mom is living with HIV; my dad is living with HIV. A couple of my uncles are living with HIV. (IDI1, Male, 21)

> I've got two people in my household, my aunty and my cousin they've got HIV. (IDI2, Female, 21)

> I have an older sister who is living with HIV and then I had an uncle but unfortunately he passed away. (IDI15, Female, 22)

The rest of the 7 participants knew at least one person in their life who was living with HIV. To see if young people understood the severity of HIV from their close family members, they were asked what they think about people living with HIV. Their responses differed. Responses varied from seeing PLWH as normal, human, and strong. Reference to HIV treatment was also made to emphasise that as long as you are properly taking treatment, you will live a long healthy life.

> I think that they are still the same human beings as I am and there's nothing wrong with them. (IDI10, Male, 20)

> So like for me these people are strong cos like they showed me that you can live with it and live a normal life afterwards. (IDI12, Female, 22)

> I don't think HIV changes how we see people, even if it's your enemy no matter what, it doesn't change the person. (IDI15, Female, 22)

Participant 3 shared a different view by highlighting HIV treatment that serves as a reminder that they are living with HIV.

> I think that they are fine with it but at the same time, no they are not because they are always reminded that they are HIV every day when they take the pills so it's painful in that way, and they don't have a choice. They have to take the pills. (IDI3, Male, 21)

Participant 8 and 11 felt that people living with HIV are partially to blame.

> I don't know how I feel but then they knew that there's HIV, but they didn't protect themselves but then sometimes you don't have to judge a person, maybe they were drunk or drugged… (IDI8, Male, 23)

> So whoever has that it's probably because of stupidity, partially I feel for them because there is a high chance of death if not taken care of, it not treated. (IDI11, Male, 24)

With the high HIV prevalence and history of this pandemic in South Africa, it is not surprising that all the participants know or had lived with an HIV positive person at some point. AIDS denialism by the late health minister Tshabalala-Msimang and former President Mbeki resulted in a large number of deaths due to AIDS related sicknesses (Boseley, 2008).

4.2.6 Perception of HIV severity; Cancer vs. HIV

All the young people interviewed reported that HIV was better than cancer in severity when asked if they would rather have HIV or cancer. Their reasoning was that there is treatment for HIV whereas, there is no treatment for cancer. Even if there was treatment, they probably could not afford it.

> Well, HIV at least it's treatable, you can treat it for the rest of your life but when it comes to cancer, cancer is untreatable sometimes it spreads quickly inside your body." (IDI3, Male, 21)

> I'd rather have HIV, cancer even if you take treatment, you will die. HIV you just take treatment, like flu medication. (IDI13, Female, 19)

> Cancer is painful, ahaa HIV is nothing, it's like flu. That's how we take it these days. (IDI8, Male, 23)

> HIV is better cos of, okay HIV is better compared to cancer because cancer is more of a death sentence. You can be lucky and survive it but the odds are very slim so I prefer like a person with HIV at least they can treat it and can live longer than a person with cancer. Cancer is like, it reacts faster than HIV. (IDI4, Male, 20)

Only one participant differed in their view. For participant 10, there is no difference in severity between HIV and cancer. The only difference they identified is that cancer has a cure while HIV cannot be cured.

> For me cancer and HIV are the same, the only difference is that cancer can be cured, HIV cannot be cured. (IDI10, Male, 20)

The second component of the HBM asserts that an individual must first believe that the consequences of contracting an illness would be severe before they can take preventative measures (Brown, DiClemente & Reynolds, 1991). "It includes an evaluation of the potential consequences that may result from encountering a health problem, including physical harm or interference with social functioning" (Brown, DiClemente & Reynolds, 1991, p.51). Majority of our participants believed that the cost of contracting HIV would be severe because of the potential side effects of the HIV treatment amongst other reasons. Taking ARV treatment, stigma and mental health were severe outcomes mentioned by participants in this study.

The findings of this study are consistent with previous research conducted in Soweto, South Africa, investigating reasons behind adults' treatment refusal (Katz et al., 2015). Participants in this study described treatment in graphic terminology linked to body dysmorphic syndrome. "They change your shape, you will have a huge stomach and your arms look like weight lifters, and you will be ugly and dark in complexion" (Katz et al., 2015, p. 707). A decline in mental and physical health was also mentioned as severe outcomes of HIV treatment. "These tablets change people- they become dark and have nightmares and lose their minds" (Katz et al, 2015, pg. 707). The results also echo findings from a study conducted by Curran et al. (2014) in Kenya. Curran et al. (2014) found that ARVs' side effects posed as a threat because of physical discomfort and inadvertent disclosure of one's HIV status due to physical changes. Early research in South Africa also shows that HIV treatment has often been viewed as representing death which is described as 'nearing the grave'. (Curran et al., 2014; Katz et al., 2015). This is similar to findings as shown above that young people are of the view that contracting HIV will reduce life expectancy, resulting in untimely death.

Additionally, finding a life partner and disclosing one's HIV status to them came out as a severe consequence of contracting HIV. Gilbert (2016) argues that this is a result of the HIV stigma that still exists. According to Gilbert (2016), HIV stigma discourages the disclosure of HIV status to sexual partners. Literature also indicates that HIV stigma is perpetuated by its association with death. Coupled together, it is evident from the findings that the fear of being stigmatized lingers among young people because they believe that acquiring HIV would mean they would be isolated from seeking romantic relationships or even lose potential partners after disclosing their HIV status.

The majority of the participants had family members who were either living with HIV or who had died due to AIDS. From the participants' experiences of knowing PLWH, they believe that PLWH are also normal as people who are not living with the disease and with HIV treatment; they can live a healthy life. There is clearly a difference in how the participants perceive HIV severity when they are concerned and how they perceive HIV severity when others are concerned. Moreover, while aware that there is no cure for both cancer and HIV, participants indicated that cancer is more severe compared to HIV mainly because HIV can be managed with treatment, unlike with cancer where there is no treatment. This shows that while the participants may think that the worst consequence of contracting HIV is taking ARV treatment every day, which comes with adverse side effects, they also appreciate the fact that HIV treatment is available for free to manage it, unlike with cancer where treatment is expensive and inaccessible to the poor.

4.3 Theme 3: Perceived benefits

The third component of the HBM states that people take preventative actions when they believe that the benefits are greater than the costs. 'To know where you stand' was the response from young people when asked about the benefits of testing for HIV. Most young people believed that testing for HIV would enable them to care for themselves if positive or it would give them the confidence to continue to protect themselves against contracting HIV.

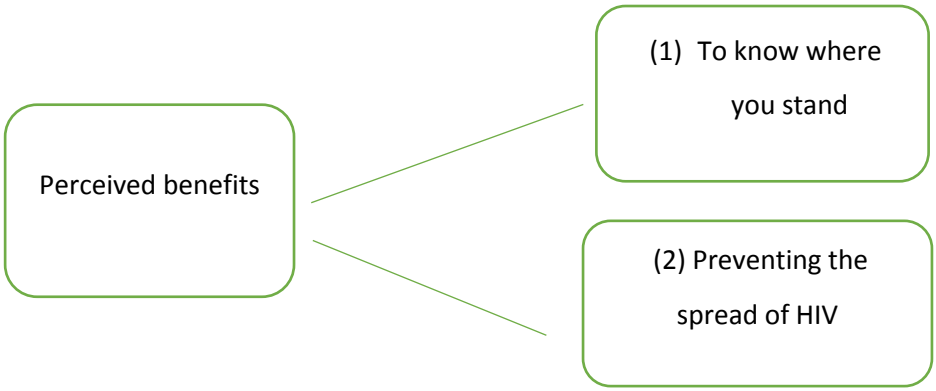


Figure 4. Two sub-themes related to Theme 3: perceived benefits.

Figure 4 shows the sub-themes that emerged, related to perceived benefits: (1) To know where you stand; (2) preventing the spread of HIV. These sub-themes are presented in sections 4.3.1 to 4.3.2.

4.3.1 To know where you stand

Young people in the study indicated that testing allows them to take charge of their health and their future. Testing for HIV allows them to know where they stand so that they can make better decisions regarding their health and their future. The following is what some of the participants had to say about the benefits of testing for HIV.

> The benefits is knowing where you stand and you know that you must always be safe, you understand? And then if only maybe my test came back positive, I know that I must take care of myself. (IDI7, Female, 24)

> You need to know where you stand. (IDI9, Male, 21)

> Benefits are that if you are positive, obviously you gonna start eating healthy, take your treatment, do whatever, exercise and then if…even if you know you are negative then you need to start looking at your life from another side. (IDI3, Male, 21)

> It is important for me, for young people to test in order for them to know where they stand. If they are negative or positive it helps me be free because I know my status and I'll be able to maintain it as a person and live healthy. (IDI10, Male, 20)

The responses above indicate that young people have a sense of agency and want to take charge of their health and future. However, we also know that there are existing barriers, as mentioned in literature, which prevent young people from testing. Moreover, factors such as poverty and poor recreational facilities in their community may prevent them from leading healthy lifestyles.

4.3.2 Preventing the spread of HIV

Although most responses were based on personal benefits, some participants also mentioned protecting others to avoid the spread of HIV as a benefit of knowing your status.

> The benefits of testing for HIV, firstly for one you don't spread it to other people. (IDI1, Male, 21)

> Uhmm at least you are able to protect your partner from being infected. And then, to protect your other family members and people around you, your friends, your relatives…yeah. (IDI5, Female, 22)

As defined above, perceived benefits refer to one's beliefs on the effectiveness of prevention strategies put in place to minimise the chances of acquiring a disease. A previous study by Kabiru, Beguy, Crichton and Zulu (2011) concluded that young males and females tested for HIV mainly because they were concerned about their own status. Similar to the findings in this study, "they need to know where they stand" was the general attitude of young people in a previous study conducted by Francis (2010) among out-of-school young people in a township in KwaZulu-Natal. The results found in Francis (2010), similar to these findings, indicate that young people want to take charge of their health and their future in a way that can be expressed in the mantra "know where you stand" that flowed through all of the participants. Additionally, young females in Francis (2010) mentioned that testing for HIV would allow them to protect their unborn baby. Buldeo and Gilbert (2015) also show that university students are aware of the benefits of knowing their HIV status. These results are an indication that young people have greater agency which is important in the fight for an HIV-free generation.

There is limited literature showing reasons why young people test for HIV (benefits) while there is considerable literature showing reasons why young people do not (barriers). It might be useful for future studies to investigate factors that encourage young people to test for HIV. There has been a lot of focus on why young people do not test; however, the focus should shift to why the few that do test, actually do so. Those reasons could be used to further encourage and promote HIV testing among young people.

4.4 Theme 4: Perceived barriers

The fourth component of the HBM refers to the challenges in performing the prescribed preventative action which often includes costs. Potential barriers to using the HIV home test were discussed with the participants and various sub-themes emerged as a result.

Figure 5, presents four sub-themes identified in relation to perceived barriers of using the HIV home test (Theme 4).

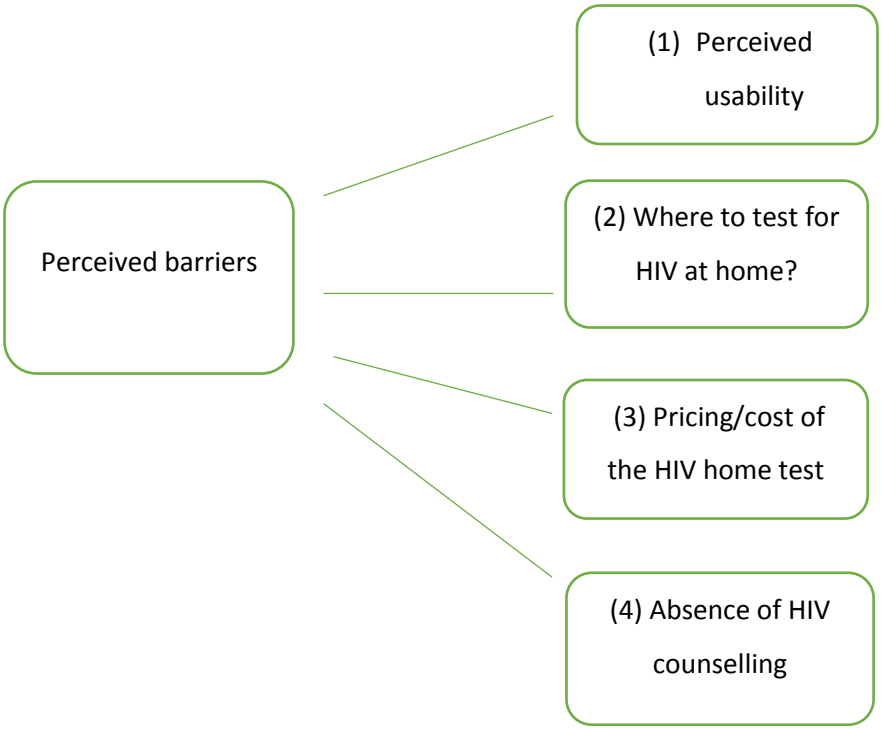


Figure 5. Four sub-themes related to Theme 4: perceived barriers

As shown in figure 5, Theme 4 on perceived barriers was explained in terms of the following four sub-themes: (1) perceived usability; (2) where to test for HIV at home?; (3) pricing/cost of the HIV home test kit; (4) absence of HIV counselling. These sub-themes are presented in sections 4.4.1 to 4.4.4

4.4.1 Perceived usability

To demonstrate how the test is used, participants were shown a 4-minute-long video from YouTube that demonstrated each step of how to use the AtomoRapid HIV test kit that comes with a triggered and sterile safety lancet for blood collection. The kit also included detailed step-by-step instructions on how to use it. As the test was blood-based, two participants reported that they might find it difficult because of the needle or prick.

> I think people might struggle with the thing that you prick yourself with. (IDI1, Male, 21)

> Eish! It's that needle. (IDI3, Male, 21)

This shows that there is a need for both saliva (swab) and blood-based self-tests. The autonomy that comes with choosing which of the two tests to obtain should be given to the user for their comfort so that they feel encouraged to test frequently.

4.4.2 Where to test for HIV at home?

Only one participant mentioned a barrier that other young people might be faced with and that was having a private space to test at home.

> Because they don't want people at home to know. We are too discrete, very secretive. (IDI8, Male, 23)

Finding a private space to test might be a challenge to the majority of young people in South Africa, especially poor young people who live in crowded areas and often in multigenerational households.

4.4.3 Pricing/Cost of the HIV home test kit

Generally, participants in this study were concerned that as young people, with low socio-economic status and unemployment, most of them would not be able to afford to buy the HIV self-test kit.

> And then it would be difficult for me since maybe cos I don't work so it will be difficult for me to purchase the test. (IDI5, Female, 22).

> It [the HIV home test kit] must be free, young people don't have money. (IDI7, Female, 24)

Being aware of the reality of high unemployment faced by young people in South Africa (Statistics SA, 2018), I asked the participants how much they would be willing to pay for the HIV self-test kit or how much they thought they could afford. Half of the participants reported an amount that was R50 or less. The rest of the participants reported amounts ranging from R70-R100, but no one mentioned amounts that were more than this.

4.4.4 Absence of HIV counselling

Despite the high acceptability and willingness to use the HIV home test because of the privacy and confidentiality it affords its users, the absence of HIV counselling raised concerns among some participants because they felt that it was an important component of testing for HIV.

> …I think it's also important for people who are not sure of what they are going to do after their HIV status. (IDI1, Male, 21)

> I feel that counselling is the best process, everybody needs to go through that. Everybody needs to. It's for the best actually for everybody to go through it. (IDI4, Male, 20)

> There has to be someone you know. If you are alone, there is no one to help you. (IDI12, Female, 22)

It was not clear from the findings as to how participants would cope with a positive HIV test result when there is no one with whom to speak. Other participants felt that this would be dangerous because others may act irrationally and choose to commit suicide.

Perceived barriers refer to an evaluation of the level of difficulty in a proposed action (using the HIV home test) or how much it will cost emotionally, socially, psychologically or in monetary value (Conner & Norman, 2002). Aside from the needle or prick, the participants found the HIV home test easy to use and did not raise concerns regarding the validity or accuracy of the test. While the participants found the AutoRapid HIV test easy to use, other studies in South Africa highlight concerns with regards to the validity of the test results. For example, young people in Ritchwood et al., (2019) raised concerns about the chances of obtaining an invalid test result. This is consistent with the findings of Harrichun et al., (2019) where participants highlighted concerns over the accuracy of the test results. This can thus act as a potential barrier to purchasing and using the test.

Findings in Ritchwood et al., (2019) show that while bathrooms or a private bedroom would be the most comfortable space to take the test, participants also noted concerns. Young people reported that these places might not be feasible for young people in their community because majority of them share bathrooms and bedrooms with others, therefore, privacy is limited. While living in shared and often overcrowded conditions might be a reality for millions of young people in South Africa, participants in the study did not seem to have

concerns over this. The participants believed that young people would be able to find a place to test.

Concerns about the costs of the HIV home test are common across several studies in South Africa (Mokgatle & Madiba, 2017; Ritchwood et al., 2019). Despite the fact that young people who took part in the study are in poor-resourced settings, most of them indicated that they are willing to buy the HIV home test for a reduced amount. However, obtaining it for free from their local clinics would be ideal for them. Therefore, we need more studies that will look into how HIV home tests can be effectively distributed to the public, especially young people.

Concerns over the lack of counselling should a person be alone and obtain a positive HIV test result were also raised. The participants noted the important role that HIV counselling plays in clinical settings that are necessary when one receives a positive result. This finding is consistent with previous research with young people in South African rural and township areas. It was not clear from the findings as to how young people would react should they get a positive result. Concerns over lack of HIV counselling were particularly raised by the South African Pharmacy Council (SAPC), healthcare workers and health policy makers. They argue that the unmanaged suspense and subsequently getting a positive result would lead to irrational behaviour and the possibility of committing suicide. However, this argument is not based on empirical evidence but merely on speculation and fear. The HIV home test is a fairly new development in South Africa and no suicide ideation has been reported from other countries where the HIV home test has been available for a long period. Therefore, further research should investigate how counselling services can be provided when using the HIV home test in order to minimise this potential risk.

4.5 Theme 5: Self-efficacy

The last component of the HBM is self-efficacy, which refers to one's perception of being able to perform the necessary health behaviour in order to avoid an adverse health outcome. After watching the YouTube video demonstration of how the HIV home test is administered, all of the participants stated that the test would be easy to administer and that this would be made easier by the instructions on the testing package. Participants showed confidence in their ability to read and understand the instructions on the testing kit package.

> It's gonna be easy because as I see on the video, there are instructions. So it's better when there are instructions. (IDI4, Male, 20)

> It will be much easier. The fact that I've seen the instructions of how to test on my own and uhh. The testing machine. (IDI10, Male, 20)

> It's pretty easy since it comes with the instructions, manual and everything. (IDI11, Male, 24)

> It's very easy, you just need to follow the instructions. (IDI13, Female, 19)

Young people's confidence in their ability to correctly administer the AutoRapid HIV home test was high after watching a video of the blood-based test being used. This finding is consistent with a previous study in South Africa among men who have sex with men (MSM) (Lippman et al., 2018). Since the participants were only shown the blood-based self-test, a comparison of which test was most preferable could not be made. In a study conducted by Ritchwood et al., (2019), participants preferred the saliva-based test because it was painless compared to the blood-based test. On the contrary, MSM in Lippman et al., (2018) preferred the blood-based test over saliva because they felt the blood-based test was more accurate than the saliva-based test. Therefore, young people should be given a choice between the blood-based test and the saliva-based test.

4.6 Theme 6: Testing for HIV

One of the requirements for taking part in this study was to have experience in testing for HIV. This requirement formed an important part of this research. During the data analysis process, four sub-themes emerged that speak to the main theme of 'testing for HIV'.

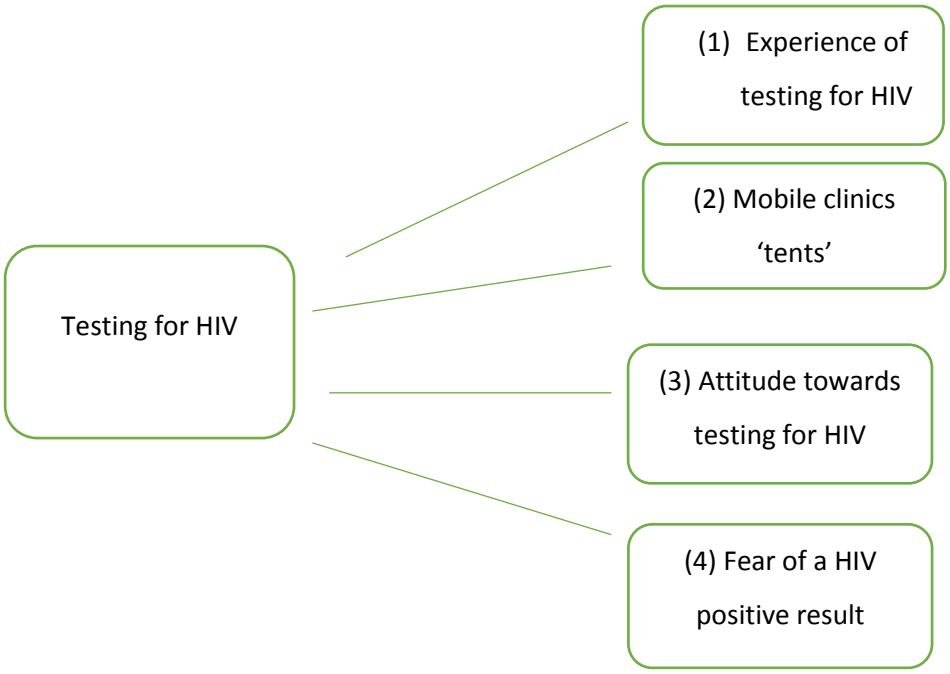


Figure 6. Four sub-themes identified in relation to Theme 6 on testing for HIV

Figure 6 above, shows four sub-themes related to Theme 6 on testing for HIV: (1) experience of testing for HIV; (2) mobile clinics 'tents'; (3) attitude towards testing for HIV; (4) fear of a HIV positive result.

4.6.1 Experience of testing for HIV

The findings show that young people find the experience of testing for HIV to be stressful. The words 'scary' and 'anxious' were used by many of the participants to describe their overall experience of testing for HIV.

> Yoooh! It was stressful. I'm anxious when I know I've done something wrong.(IDI1, Male, 21)

> A lot goes through your mind because you don't know what to expect. The fear, too much stress. (IDI2, Female, 22)

> Before I test, like I always feel nervous because I don't know what to expect, things happen these days, so I don't know. (IDI5, Female, 22)

> At first it was scary because I did it right after I had sex for the first time without a condom… (IDI14, Female, 20)

It is interesting to note that what makes the experience of testing for HIV to be scary, is the fear of the unknown. This entails not knowing what outcome one may obtain; be it a positive result or a negative one. Some of the reasons young people in this study gave for feeling anxious, stressed and not knowing what to expect included having sex without using a condom.

4.6.2 Mobile clinics 'Tents'

The majority of the participants reported that they last tested at the 'tents' in and around their areas which were mobile clinics usually provided by non-profit organizations.

> I tested at those tents, you know those tents by the malls? I prefer testing at the tents. (IDI1, Male, 21)

> Cos like each and every after 3 months they come with their tents, then I went there. (IDI12, Female, 22)

> And then those pop-up tents I go there. (IDI15, Female, 22)

The findings show that young people easily have access to HIV testing services. This also shows that young people do not make use of healthcare clinics but instead prefer the mobile testing services or 'tents', as they refer to them.

4.6.3 Attitude towards testing for HIV

When asked about how they generally feel and think about testing for HIV, some negative attitudes towards testing for HIV were described by participants.

> There's nothing that I like besides knowing my status. (IDI14, Female, 20)

> It scares me, I don't like it. Like its scary and even that tent when you get inside you can feel that atmosphere, it's like you did something wrong. (IDI12, Female, 22)

While others shared negative views about testing, other participants reported that testing is important in order to prevent the spread of HIV. Protecting your partner was also emphasized.

> I feel like everybody should test to prevent the spread of HIV. (IDI1, Male, 21)

> It's very important because what if a guy really likes you and you don't know your status, now you are going to infect him with AIDS. (IDI13, Female, 19)

In addition to protecting themselves, young people were aware that testing for HIV also saves the lives of others.

4.6.4 Fear of a positive HIV result

While still on the subject of testing for HIV, it appeared that the fear of getting a positive result when testing for HIV was a real fear that could possibly hinder chances of being tested.

> "When you get there and realise that there might be a chance that you are HIV positive. (IDI1, Male, 21)

> I don't think at some point I'm ready to get a positive result. (IDI2, Female, 21)

> It's scary shame, what if you are HIV? Where do you even start? (IDI13, Female, 19)

> No, like there is always this fear that 'what if this test is positive?' you know. (IDI15, Female, 22)

It appears that young people do not like testing and find it scary because of the fear of a positive HIV result. However, despite the anxiety and fear of a positive HIV result, the majority of the participants who found the experience to be scary, expressed a sense of relief after receiving their test results.

> You get nervous because you don't know what's coming, you get scared but you get relieved afterwards, it only your results are okay. (IDI7, Female, 24)

> I felt relieved after testing because they came back negative. (IDI2, Female, 21)

> You are relieved at some point; you know where you stand…yeah. (IDI13, Female, 19)

> So you have a sense of relief when you know that you are on the safe side and ((laughs)) you just get to live healthier. (IDI15, Female, 22)

Pre-test stress was high among the participants, particularly because of the fear of getting a positive HIV diagnosis. When talking about either recent or previous experiences of testing for HIV, they mentioned that they were stressed because of the fear of obtaining a positive diagnosis. This finding is similar to a study conducted by MacPhail et al., (2008) where participants expressed distress because of the possibility of getting a positive HIV diagnosis. A study conducted in Nigeria among young people aged 15-24 years indicated that young people feared testing for HIV for fear of being diagnosed as HIV-positive (Yahaya, Jimoh & Balogun, 2010). The fear young people have could be linked to their perceived severity of contracting HIV.

Matseke, Peltzer and Mohlabane (2016) maintain that fear of diagnosis or uncertainty about HIV status can act as a barrier to HIV testing. According to Strauss, Rhodes and George (2015), young people who perceive themselves to be at high risk because of engaging in risky sexual behaviour, therefore anticipating a positive result are less likely to test. However, young people in the study still tested on an average of three times a year despite the fear of getting a positive result. This shows that regardless of the unpleasant experience of going through testing, young people still see the importance of testing for HIV in order to prevent the spread of HIV, as stated by the participants.

There is increased evidence that mobile VCT has been successful in increasing HIV testing among the population at high risk (van Rooyen et al., 2012). This may be true, as the participants cited mobile tents to be the frequently used or last used testing site. This view is supported by a body of existing literature that shows that mobile testing approaches have been successful in reaching young people. However, HIV testing uptake still remains low and could be improved. Young people still remain underrepresented in HIV testing, treatment and care. This proves that there is still room for more innovative ways of testing for HIV that can increase the uptake of HIV testing even further, hopefully pushing it towards the UNAIDS 90-90-90 goal.

4.7 Theme 7: HIV home-test

Study participants were asked questions regarding the HIV home test. They were first asked if they knew about the HIV home test that they could purchase over the counter from their local pharmacy. Three sub-themes were identified from theme 7.

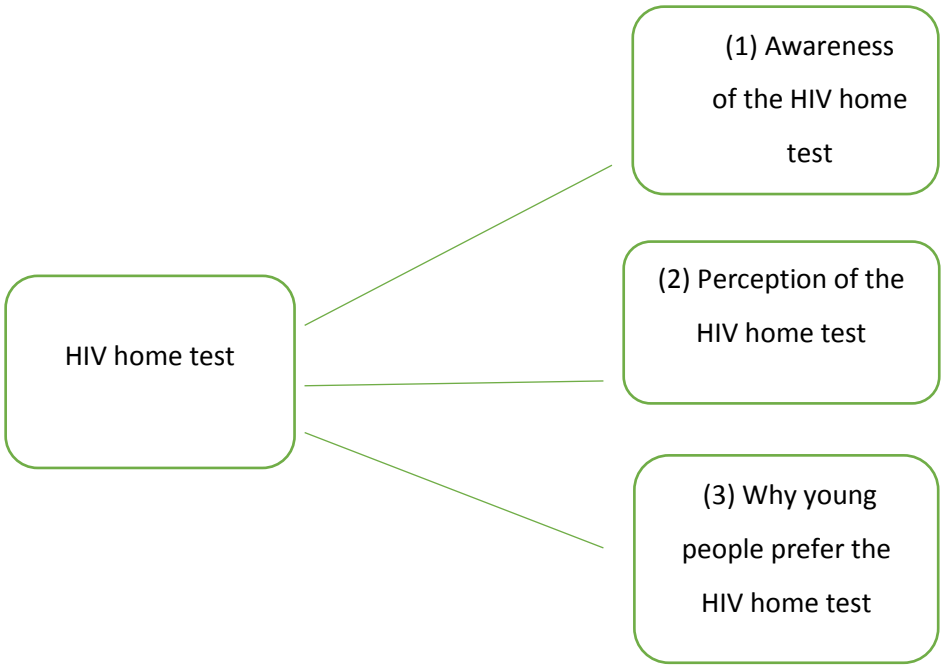


Figure 7. Three sub-themes identified in relation to theme 7 HIV home test

Figure 7 above, shows three sub-themes related to the HIV home test: (1) awareness of the HIV home test; (2) perception of the HIV home test; (3) why young people prefer the HIV home test. These sub-themes are presented in sections 4.7.1 to 4.7.2.

4.7.1 HIV home test awareness

The awareness and knowledge of the HIV home test varied among the participants. The findings show that 5 of the participants did not know about the HIV home test, meaning that they had neither heard of nor used the HIV home test before being recruited to participate in this study.

> I only knew about it [HIV home test] today. (IDI1, Male, 21)

> I don't know anything about it[HIV home test]. (IDI4, Male, 20)

> Well…I've never heard of home HIV test, I've never heard of that. It's actually my first time hearing about it. I didn't know it. (IDI5, Female, 22)

> "Well…I haven't heard about it [HIV home test]. (IDI8, Male, 23)

While the majority of the participants had an idea of what it is or what it does, only one of them had ever used the HIV home test before.

> Well…I know it's similar to the ones we use at clinics or mobile outside where you have to take your blood and then use the liquid then you wait for a certain time for your results to come back. (IDI2, Female, 21)
>
> I know that you are able to test while you are at home and know your results on your own. (IDI10, Male, 20)
>
> I know that you can test at the comfort of your own home. (IDI15, Female, 22)

Only 1 participant out of 15 had ever used the HIV home test. However, the supplier was not healthcare professional or trained personnel.

> I was going to school in the morning, there was a guy by the corner who sells sweets and stuff, he called us and asked if we know this thing. He told us about it and then he demonstrated. He told us to test in the morning when we wake up. He said it works 100%. (IDI7, Female, 24)

Participants stated that the lack of information and awareness of the HIV home test was the reason why they did not know about the test prior to taking part in the study.

> They don't give us more information, obviously a few people know about this thing [HIV home test]. (IDI3, Male, 21)

> It's not something that is raised much, especially in black communities, it's not raised much. No one is talking about it. (IDI14, Female, 20)

> I don't think a lot of people know about it. Like I don't think a lot of people are aware that it's there. (IDI15, Female, 22)

The availability of the HIV home test has been poorly marketed in South Africa according to the findings of this study. One could argue that this might be due to the still existing fears among healthcare workers and public health policy makers of making the test more widely

accessible. This also shows the reluctance from the government and the health department of South Africa.

4.7.2 Perception of the HIV home test

Overall, the results indicate that young people are open to and like the idea of testing at home by themselves.

4.7.2.1 Acceptability of using the HIV home test

Participants reported that the HIV home test would give them more control over the testing process and that was why they would rather use it than going to the clinic.

> I love it! I love it girl because I feel like its stress free. (IDI1, Male, 21)

> I prefer it [HIV home test] because it's better most of the time. (IDI3, Male, 21)

> I prefer home test. I think it's much more better compared to the clinic one. Hence I said going to the clinic, it's a problem so buying one is better. It's like home pregnancy test, people are scared of going to the clinic. (IDI8, Male, 23)

There is high acceptability of using the HIV home test among participants because of the convenience it would afford them and also to avoid the traditional methods of testing.

4.7.2.2 Willingness to use the HIV home test

In addition to liking the idea of testing at home, others also showed their willingness to buy and use the HIV home test.

> I would buy it [HIV home test] definitely, it's my health. (IDI7, Female, 24)

> For myself personally, uhh. I wouldn't mind. (IDI11, Male, 24)

> It's good because most of the time, let me say I don't feel like going to the tent, let me test for me. (IDI3, Male, 21)
>
> Yeah so for me I would go for buying home preg…home HIV test and test for myself, (IDI5, Female, 22)

The willingness to use the HIV home test is demonstrated above by the responses of the participants. Not only did they show acceptability of the test, but they said that they would use the test. Willingness to use the HIV home test showed that there is a need for urgent distribution of the test to this population of young people who are considered to be at high risk and hard-to-reach.

4.7.3 Why young people prefer the HIV home test

Participants stated various reasons why they accept and are willing to use the HIV home test. Three factors that were mostly reported were identified.

4.7.3.1 Privacy

The privacy that the HIV home test afforded users was reported as the primary incentive. Participants reported that they did not want to be seen when accessing HIV testing services by community members.

> I think it's good. At least you are home, you know, your own environment unlike in the streets. Imagine finding out that you are HIV positive from the streets. (IDI7, Female, 24)

> Cos like you see like you have your own privacy. Cos what they are afraid of in the tents is that there are old women and men, they are scared to stand with them in the queue. Cos others do want to test but there's that father from next door their house, then they change their mind to say they will test next time when there is no one. (IDI12, Female, 22)

> You get your privacy, like I said: I want my privacy when I do these things. (IDI14, Female, 20)

The high degree of acceptability and willingness of young people in the study to use the HIV home test can be attributed to the privacy that it affords them. Young people value their privacy and this is often compromised when using existing testing services.

4.7.3.2 Confidentiality

Participants reported that the HIV home test would allow them to have more control over whom they chose to disclose their HIV status to because of the increased confidentiality that the test allowed for.

> It's better because you don't go to the clinic, you're not gonna see people you know in the queue, you do it alone. At the clinic, people see you when you walk out angry. (IDI13, Female, 19)

> I don't have to deal with walking out of the room while people are looking at me and wondering what my status is. (IDI10, Male, 20)

> It's gonna save me time, save me all that stress of going and worrying about my secrete being out. (IDI14, Female, 20)

> I think some it's a situation where they say they don't want anyone else to know my status. Other people feel like confidentiality is key to them. They feel like if someone knows then they will broadcast it to others. (IDI2, Female, 21)

One of the favourable attributes of the HIV home test which was identified by participants is confidentiality. Confidentiality was mentioned by young people as one of the barriers to using facility-based testing services.

4.7.3.3 Convenience

The HIV home test was found to be convenient because it saved time compared to the traditional methods of testing.

> I think it's very convenient because like ya, you don't go to the clinics, you don't go to the hospital, you don't stand in a long line just to get tested. You don't have to like uh uh uh look for tents each and everywhere when you go to the malls and public places just so that you can get tested. (IDI1, Male, 21)

> It will save me much more time than going to those tents. (IDI9, Male, 21)

> One can just buy it [HIV home test] when they are doing their groceries. (IDI12, Female, 22)

Young people require more convenient times and places outside of the health facilities. This might encourage HIV testing often thereby increasing testing uptake and also promoting testing with sexual partners.

4.7.3.4 Alternative to facility-based testing

The HIV home test was also welcomed by young people because it was an alternative to facility-based testing services, which young people do not find friendly to use for various reasons.

> Cause like clinic you get distracted and frustrated cause you see all the sick people, so you also think you gonna end up like them. I know us guys; we don't like this thing of going to the clinic. (IDI8, Male, 23)

> I mean we all like comfort, that's why you find that for the emergency contraceptive, a lot of people would rather go to the pharmacy and pay than going to the clinic. Because there's scrutinization, there's judgement at the clinic and all that. (IDI15, Female, 22)

The attitude of healthcare workers towards young people was also mentioned as one of the reasons why the HIV home test would be a better alternative to facility-based testing.

> I tell them no, I'm dating a girl not a guy. They get shocked and it creates that conflict, and they end up being uncomfortable. (IDI2, Female, 21)

> Especially healthcare workers because on a lot of occasions nurses tend to like have blatant comments about HIV with regards to young people testing for HIV. (IDI1, Male, 21)

> So people would be afraid of testing because of other people around, or the clinics 'the nurses will judge me', let's say you know the nurse. (IDI7, Female, 24)

While there is a fair amount of research studies in South Africa assessing the acceptability of the HIV home test, there is very limited literature investigating the awareness of the HIV home test among young people. The findings of this study show that young people have limited awareness of the HIV home test's availability in South African pharmacies. This may be due to the SAPC's previous ban of the HIV home test. The findings may indicate that there is still reluctance from healthcare professionals and policy makers to make the HIV home test widely known and accessible to the people, particularly the groups considered to be at high risk, namely: young people, men having sex with men and sex workers. There is a growing body of literature that shows that HIV home test is effective in reaching often hard-to-reach populations. It is therefore clear that there is a need for an effective way of distributing the HIV home test to the public to create awareness and thus lead to increased demand.

Overall, the findings show that the HIV home test is acceptable and preferred over facility-based testing services. This finding is consistent with previous studies conducted with young people and men having sex with men (Smith, Wallace & Bekker, 2016; Lippman et al., 2018). Moreover, the participants' feedback on their willingness to use the HIV home test was positive. Most of the participants indicated that they would use the HIV home test as soon as it was made available to them.

As indicated in other research studies in South Africa, the participants particularly preferred the HIV home test over traditional methods of testing because of the home test's ability to address current barriers they are facing with facility-based testing. Young people find the HIV home test favourable because of privacy, confidentiality and convenience. This finding is similar to that of previous studies conducted in rural South Africa and in Cape Town (Ritchwood et al., 2019; Smith, Wallace & Bekker, 2016). In another study on the acceptability and feasibility of the HIV home test, young people between the ages of 16-24 years rated acceptability and usability highly. In a study conducted by Mokgatle and Madiba (2017), also investigating the acceptability of the HIV home test among college students in Gauteng and the North West province, South Africa, the majority of the participants considered the HIV home test acceptable, and others added that they would use the test with their partners. Furthermore, Mogatle and Madiba (2017) found a link between high acceptability of the HIV home test with being sexually active, having multiple sexual partners and having been tested for HIV before. It is evident that making the HIV home test widely available to young people would be beneficial to them as they face real and perceived barriers when visiting healthcare facilities. Additionally, young people would have increased autonomy over whom they choose to disclose their status to as well as the frequency of testing.

Further studies on the awareness and acceptability of the HIV home test are still needed. However, available studies have concluded that the HIV home test has the ability to increase testing uptake, partner testing and increase in the frequency of testing. Therefore, the HIV home test would be useful in facilitating early diagnosis and access to the necessary HIV treatment.

4.8 Theme 8: Recommendations

After noting the potential barriers to the HIV home test, young people made recommendations to bridge the gap between already existing methods of testing and home testing. Three sub-themes emerged from their recommendations.

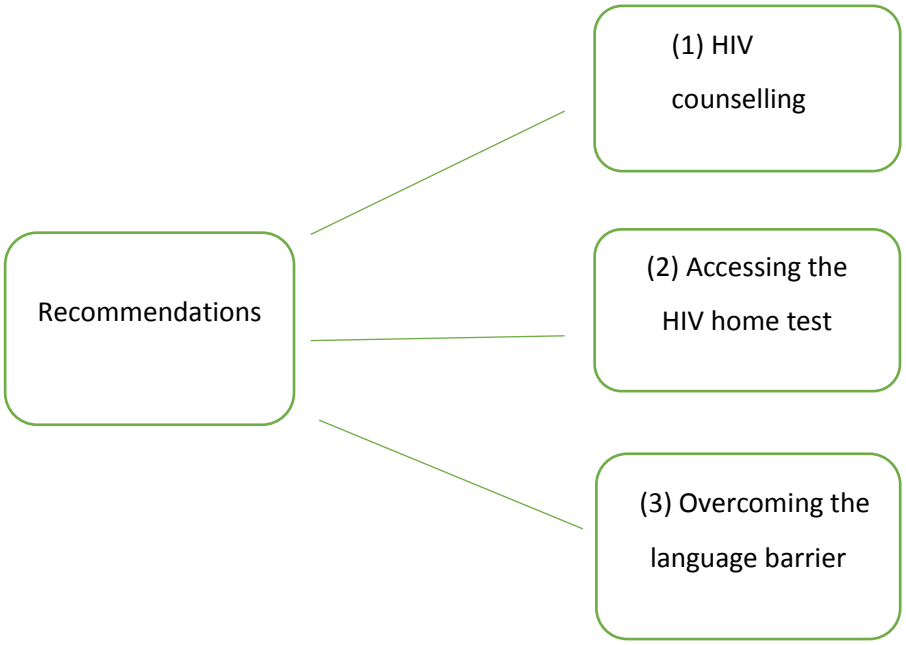


Figure 8. Three sub-themes were identified in relation to the recommendations

Figure 8 above, shows three sub-themes related to the recommendations made by young people: (1) HIV counselling; (2) accessing the HIV home test; (3) overcoming the language barrier. These sub-themes are presented in sections 4.8.1 to 4.8.3.

4.8.1 HIV counselling

Young people are aware of the importance of receiving HIV counselling when testing for HIV. Having been made aware that this important component of HIV testing will be absent when one purchases the HIV home test, these are the recommendations young people then made to address the matter.

> I think also you should like create a website, just a young website whereby people can get counselling, like where there are counsellors who are constantly on the phones and laptops. You should also include that part whereby you remind people that there is free counselling at clinics for anyone who is HIV positive, because they could feel like they are alone. (IDI1, Male, 21)
>
> This home testing thing I was suggesting that it has a toll free number where you can call after receiving your results. If you don't want to talk to someone, just call and then maybe they will ask you questions, and you can answer from your phone. (IDI3, Male, 21)

> It would be better if that pharmacy selling the test has a form of procedure you need to go through before you access it. More of like knowing your details and stuff and then knowing where to refer you if you happen to test positive. (IDI4, Male, 20)

These recommendations could be useful to the public health sector and should be considered because they can assist in planning and preparing the distribution of the HIV home test.

4.8.2 Accessing the HIV home test kit

The results indicated that young people would prefer to access the HIV home test kit at their local pharmacies, local clinics, as well as at supermarkets.

> Local pharmacies like Clicks, Pick n' Pay. (IDI8, Male, 23)

> Pharmacies over the counter. It should be bought over the counter. (IDI11, Male, 24)

> More especially like at the pharmacy, local pharmacies, you see in the township. Maybe you see at Shoprite, there's a pharmacy. Ya, they will find it there. (IDI12, Female, 22)

> Local clinics were also found to be acceptable as a place of accessing the HIV home test.
>
> Uhm local pharmacy is acceptable and your local clinics. (IDI5, Female, 22)

> If it was available at clinics. Okay, just like they give out condoms to at least give these things. (IDI14, Female, 20)

> I think at the clinic, and it must be free. They must hand them out for free at the clinic so we can go get them… (IDI7, Female, 24)

The HIV home test is already available in South African pharmacies; however, findings in the study also showed that young people were not aware of the HIV home test's availability in pharmacies. Young people also indicated that they would be open to accessing the HIV home test through their local clinics.

4.8.3 Language barrier

Two participants raised concerns regarding language. The instructions on the testing kit are written in English, which is a concern because not everyone would be able to adequately comprehend it.

> But I think people should like read instructions perfectly and that I think the instructions should come in different languages for people who…because it's not everyone who can read English. (IDI1, Male, 21)

> Another thing is language, not all of us understand English you know, people would not use it because they can't read the instructions. (IDI3, Male, 21)

Seeing that the HIV home test falls short on some aspects, the participants made recommendations to try and compensate for these shortfalls. One of the concerns expressed by the participants was the lack of HIV counselling when using the HIV home test. Our participants therefore suggested that they have access to telephonic HIV counselling should they feel like they need to speak to someone. This could include a toll-free number that is available for 24 hrs. Testing kits sold at the pharmacies should also be accompanied by more information on the toll-free numbers users can dial should they need help. Additionally, 'live chats' on social media platforms such as Facebook and WhatsApp where young people can chat live to counsellors and ask questions were also recommended by the participants. This will restore young people's confidence and encourage them to use the HIV home test just because they know help is available when they need it.

The participants also recommended that the HIV home test be made available at local pharmacies and supermarkets. The participants preferred these locations because they reported that they were easily accessible to them. This preference may also be due to confidentiality. For example, when doing grocery shopping they can also include the HIV home test in their shopping basket. Local pharmacies in townships are usually found in shopping malls or shopping centres where people shop for a number of items. Therefore, it will not be obvious or apparent to anyone else when young people buy the HIV home test. In local clinics, these tests can be distributed in the same way that condoms are distributed. For example, walking in and out to obtain the test without having to see a healthcare worker. However, this will not be an option for young people in remote and rural areas. Therefore, more studies are needed to investigate a feasible way of distributing HIV home tests for free even to young people in rural South Africa. Another recommendation was having the instructions on the test kit in different languages because others may not understand English. The SAPC can also work with researchers, academics and communications specialists to develop instructions in all 11 official languages. The instructions need to be concise and easy to read.

4.9 Conclusion

This chapter presented the findings analysed using thematic analysis. Five themes taken from the HBM were analysed. Additionally, three themes outside the HBM were analysed. This chapter mainly focused on the participants' subjective experiences. To interpret the findings, the HBM was used. The discussion of the findings included existing literature that is consistent with or contradictory to the findings in this study, in addition to my interpretations and discussion of the findings. A summary of the findings that emerged in this chapter will be discussed in the next chapter, along with conclusions that can be drawn from the study and a consideration of implications for further research.

CHAPTER 5: Conclusion

5.1 Introduction

This chapter presents a summary, conclusions and implications of this research study. Presented first is a summary and discussion of the findings provided in chapter four, in relation to the research questions of this study. A concise understanding of the acceptability and willingness among young people in Soweto to use the at-home HIV test is offered in this chapter. This will then be followed by the strengths of the study and its significance and contribution to existing knowledge. Lastly, the limitations and recommendations for future research will also be outlined.

5.2 Overview of the findings

In the previous chapter, chapter four, a presentation and discussion of the participants' subjective experiences of testing, their acceptability and willingness to using the HIV home test was presented. Overall, young people have a fair knowledge of what HIV is and how HIV is transmitted. Young people also showed awareness of their vulnerability to contracting HIV and factors that put them at risk. Young people in our study also thought that contracting HIV would have severe consequences physically, socially, emotionally and psychologically. However, compared to cancer, they believed that HIV was less severe because there is free treatment available while treatment for cancer is expensive and thus inaccessible to the poor. However, even then, it is not always guaranteed that it will work.

The results showed that most of the participants frequently tested at the mobile clinics. Although participants' experiences of testing were not positive due to the anxiety and fear that comes with waiting for your results, the participants indicated that they still tested for HIV anyway. However, it is worth noting that participants were motivated to test after engaging in risky sexual behaviour. Moreover, participants also viewed testing for HIV as a beneficial process that enables them to have agency over their health and sexual well-being.

The study found that there is limited awareness and knowledge among young people in Soweto about the availability of the HIV home test kit. For many participants, it was their first time hearing of the availability of the HIV home test kit, while some had a vague idea of what it is but did not know that they could purchase it over the counter at South African pharmacies.

The findings indicate that the HIV home test was highly acceptable and young people showed willingness to use the test because it was a better alternative to existing testing services that required them to go to a healthcare facility. The HIV home test was highly acceptable among young people in this study because of its ability to overcome the barriers that they are currently facing with facility-based testing, namely: confidentiality, privacy and convenience. Participants were also confident in their ability to successfully administer the HIV home test as they found it easy to use by observing a YouTube video. Additionally, young people preferred the HIV home test because it would enable them to test frequently and with their partners. Therefore, the HIV home test has the potential to improve early detection as well as early initiation of HIV treatment.

Despite the high acceptability and willingness to use the HIV home test, it still falls short particularly due to the lack of HIV counselling. Even though the participants did not perceive the lack of HIV counselling as a main concern, they noted that this could be a potential barrier to other young people like them. The cost of the HIV home test was a concern. Young people in the study indicated that they may not be able to purchase the test because they were unemployed. This may serve as a barrier to testing for HIV. Being aware that the instructions of the HIV home test kit are in English, they noted that reading and understanding the instructions could be a challenge to others. Another concern raised by one participant was the challenge of having a private space to test without raising suspicion.

Being aware of these concerns, young people made recommendations of how some of these potential barriers could be overcome. Firstly, they recommended that they be provided with avenues where they could get HIV counselling telephonically. For example, a toll-free number available for 24 hours to dial should they feel that they need help. Additionally, they suggested that when they purchased the test, pharmacists should give them details of where they could get help if they needed it. To overcome the cost barrier, young people indicated that they would welcome accessing the HIV home test for free at their local clinics without having to see a healthcare professional. To overcome the language barrier, participants recommended that the instructions inside the kit come in different languages so that young people could choose a language that they are most comfortable with.

The HBM provided a practical framework for this study based on its exploratory and explanatory nature. However, some of the constructs of the HBM were more applicable to this study than others in that responses emerged more on some constructs than they did on

others. For example, perceived severity and barriers yielded more results from the participants whereas perceived benefits and self-efficacy did not yield much insight. This framework made possible the identification of issues specifically relevant to the South African context. For example, South Africa has a poor healthcare system that acts as a barrier to seeking healthcare intervention. The framework limited the study in further exploring the benefits of testing for HIV.

The HIV home test has shown to have the potential to address barriers to HIV testing faced by young people. With the high acceptability and willingness to use the HIV home test, there is thus a need for up-scaling the provision of the HIV home test in order to meet WHO's 2020 targets. The HIV home test offers convenience and privacy to young people and complements already existing testing services. Furthermore, the HIV home test is the solution to existing barriers to testing, especially for young people who are a high risk population. Moreover, the HIV home test should be made available for free beyond its availability in pharmacies so that it can also reach those who cannot afford to purchase it.

There is a need for extensive planning and preparation from the public health sector for the distribution of the HIV home test. Factors that the public health sector should pay close attention to include linking users to healthcare facilities in order to confirm their results and also linking them to care should they be positive. Most importantly is providing HIV counselling to those who might need it. Ways to remotely provide counselling such as providing toll-free numbers or live chats are important to assess when planning and preparing for the distribution of the HIV home test.

5.3 Strengths and contribution to knowledge

This study contributed to a limited body of knowledge. HIV home testing is a fairly new testing strategy in South Africa and it still continues to be under development. Most studies in South Africa on HIV self-testing have only assessed the acceptability of the test, while in this study, the knowledge and awareness of the HIV home test was investigated. Moreover, the views expressed by young people on testing for HIV came from a group that had previous experience on testing for HIV at different testing sites.

This study also highlighted the gaps in existing literature with regards to where the focus of research related to young people and HIV testing should be. This study also contributed to the

limited qualitative research on HIV home testing in South Africa. Additionally, this study also provided detailed and rich views from young people on HIV self-testing. Moreover, the interviewing of a diverse group of young people in terms of age, gender and sexual orientation contributed to distinctive views from young people on HIV self-testing. This further elucidated the complex challenges faced by young people of different sexual orientation with regards to accessing sexual and reproductive health services, as highlighted in the literature.

The researcher's experience with conducting qualitative interviews provided a great advantage to the data collection process. Great focus was given to probing questions in order to gather relevant data and where it was necessary, the researcher delved deeper into certain situations. Further exploration into these situations was beneficial in gaining more detailed information in relation to the topic under investigation. Another methodological strength of this study is the in-depth analysis of the data using Braun and Clarke's (2006) six steps of thematic analysis. This process allowed for flexibility by guiding the researcher with a process to thoroughly engage with the data when interpreting and discussing it.

5.4 Limitations

This study is also associated with a number of limitations. Firstly, methodologically, the study had a small sample size of 15 participants, therefore findings cannot be generalized. The findings cannot be considered to represent those of all young people in South Africa. Secondly, the participants were purposively sampled and thus views and experiences expressed by young people in this study are not generalizable to all young people in South Africa.

While the results of the study are comparable and consistent with previous studies in South Africa, the context in which this study was conducted is different, especially when the broader South African context and its multifaceted elements are considered. The responses from the participants regarding the HIV home test were based on what they were told by the researcher and what they observed from a YouTube video. Therefore, the acceptability and willingness of using the HIV home test by the participants should be interpreted carefully. Providing the participants with the actual AutoRapid HIV home test would have been

beneficial in this regard so that the young people could speak to something that they had actually done.

Contradictions to previous studies conducted in South Africa were also presented in chapter four. For example, the findings indicated that what may be considered barriers to HIV testing among young people in South Africa, were not perceived as barriers by the study participants. Therefore, having a larger and more diverse sample of young people would have been more beneficial.

Using semi-structured instead of structured interviews did not allow for complete uniformity in the manner in which each interview was conducted. This therefore influenced the findings and made more room for researcher subjectivity. Moreover, because this was an interpretive research study, the researcher's interests, biases and knowledge of the existing literature influenced the interpretations made. Therefore, relevant information may have been ignored while giving attention to certain aspects of the data. The quality of the findings along the interpretation and discussion was directed by the researcher's subjectivity.

A further limitation was using an international framework to findings that are context-specific. While the various components of the HBM provided a relevant structure to use in the interpretation of the findings, it did not adequately allow for important contextual issues such as race, socio-economic background and the legacy of historical events whose effects are still felt to this day in South Africa. South Africa's issues due to the legacy of Apartheid are broad and thus applying a framework that was not specifically designed for the South African context may have resulted in limited information that is not necessarily applicable or useful.

5.5 Directions for future research

Various aspects may be explored in relation to this study. Further research with a larger sample of the population considered to be at a higher risk of contracting HIV, can give further understanding of the acceptability and willingness of using HIV self-test. There is no literature in South Africa exploring the ways in which the barriers to using the HIV self-test will be overcome. This aspect therefore requires further investigation among young people.

The findings of this study did not provide clarity on how young people would deal with a positive result when alone at home. While there are not reported cases of suicide after using HIV self-test, further research should continue to investigate how young people think they

would deal with a positive result at home. These findings can contribute to designing effective counselling and support services required by young people.

HIV self-testing is a relatively new strategy in South Africa thus there are no studies on how people will be linked to care in the case of a positive HIV test result. Further studies can investigate how they will link young people to treatment and care initiation after a positive HIV result. Additionally, further investigation into how to adapt and improve the seroconversion sensitivity of already existing testing tools would be beneficial. This will increase the validity of the HIV self-test and young people will thus be confident in using the test.

Further studies should investigate the demand of the HIV self-test, more especially, in resource-limited areas. Furthermore, implementation studies using the HIV home-test such as the AutoRapid, are necessary as the findings of this study indicate that it is a promising alternative way of testing. This will give insight as to how and where to urgently distribute the HIV self-test.

5.6 Conclusion

This chapter presented an overview summary of the research findings as well as the conclusion and implications of the research study. Firstly, a discussion and summary of the findings were presented in this chapter. The research study concluded that there is high acceptability and willingness among young people to use the HIV home test. The strengths of the study, its significance and contribution to existing knowledge were outlined. This was then followed by outlining the limitations of the study and recommendations for future research.

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Appendices

Appendix A: Participant Information Sheet

Good Day

My name is Sonto Gugu Madonsela, a student at the University of the Witwatersrand, Johannesburg studying towards a Master's degree in Psychology. Part of the requirements to complete this qualification requires me to conduct a research project. My research seeks to explore the acceptability and willingness among young people in Soweto to use the at-home HIV test. I would therefore appreciate it if you would participate in this study. Participating in this study is voluntary and all information will be treated confidentially. Participating will require me to interview you as a group for approximately 1 hour and 30 minutes and our interview will be tape recorded. The tape of our interview and the transcript of the tape will also be treated confidentially and will only be accessible to my supervisor and I. After completing this study, the tape and transcripts of the tape will be kept safely by the university in a locked cupboard for three years and will be destroyed after. You are welcome to answer questions that you only feel comfortable with answering and can choose not to answer questions with which you are not comfortable. You are also free to withdraw at any time should you feel uncomfortable; there will not be any consequences. The are no risks or benefits associated with participating in this project. Your name or any information that reveals your identity will not be revealed as you will be referred to as a number throughout the entire study. e.g. participant 005 or participant 002.

If you have further questions or are keen to know the outcome of the study, you are more than welcome to contact me. A summary of the study and the results should be available at least six months after the interview. Find my contact details below the signature.

Thank you for your time. I appreciate your participation. Please detach and keep the slip.

Kind regards

Sonto Gugu Madonsela

870073@students.wits.ac.za

Tanya Graham

tanya.graham@wits.ac.za

Appendix B: Consent (interview)

I, _____ hereby agree to being interviewed by Sonto Gugu Madonsela for her study exploring the acceptability and willingness among young people in Soweto to use the at-home HIV test . I understand that,

- Participation is voluntary
- I can choose not to answer questions I am not comfortable with.
- I can withdraw from the study at any time.
- All the information I provide as well as my identity will be treated confidentially.
- There are no benefits or risks associated with this study.
- My real name will not be used in the study.
- The results of this study will be reported in a form of a research report but my identity will still not be revealed.
- Direct quotations from the interview may be used in the research report, but I will not be identified as I will be referred to by my pseudo name.

Signature _____

Date _____

Appendix C: Consent (Recording)

I, _____ hereby consent for my interview with Sonto Gugu Madonsela to be tape recorded for her study in exploring acceptability and willingness among young people in Soweto to use the at-home HIV test . I understand that,

- The recordings will be highly confidential and only Sonto and her supervisor will have access to them.
- I will be referred to by a pseudonym throughout the entire study and my identity will not be revealed.
- After the completion of the study, the tape will be locked in a safe cupboard in the university and will be destroyed after three years.
- Tapes are kept mainly to facilitate the research being presented or published.
- Transcripts will be destroyed after the completion of this study.

Signature _____

Date _____

Appendix D: Interview schedule

Good day,

My name is Sonto Gugu Madonsela. I would like to thank you for taking the time in participating in my research project. If you give me permission, I would like to record our interview and I assure you that everything you will say will be treated as strictly confidential and only my supervisor and I will have access to the tapes. The tapes and transcripts will be kept in a locked cupboard at the university and will be destroyed after three years. These records and transcripts are only kept to facilitate the publication of the study. Even though I know who you are as I can see you, confidentiality will still be maintained by not revealing your identity or any information that might reveal your identity.

I would like to remind you that you can withdraw from this study at any time should you feel uncomfortable or vulnerable. You can also choose not to answer questions that you are not comfortable with. You can request a feedback sheet on the findings of the study that will come in a form or a one-page summary in about 8 months from now. You can make this request by either emailing or phoning me. My contact details are on the information sheet.

Before we can start with the interview, I firstly need you to read the information sheet. This sheet basically has everything that we have been discussing. If you agree with everything that is there, may you kindly sign the two consent forms for me (Appendix A & B). These forms indicate that you understand everything that we discussed regarding confidentiality, privacy, and feedback.

Thank you, you will let me know when you are ready to begin.

Testing for HIV

1. Tell me about your experiences of testing for HIV?
2. How did you feel before and after receiving your test results?
3. What do you like and what do you not like about testing for HIV?

Perceived HIV risk

4. Tell me what you know about HIV?
5. Do you test for HIV?
6. Why do you test for HIV and how often do you test?
7. Do you think that you might be at risk of getting HIV and why?
8. Tell me about the precautionary measures you have in place to prevent yourself from getting HIV?

Perceived severity

9. Do you know and understand the consequences of HIV infection?

Home testing

10. What do you know about at-home HIV test kit, the HIV test kit that you can purchase at your local pharmacy?
11. Tell me what you think about testing for HIV at home by yourself?
12. Why do you think you, as young person would prefer or would not prefer to use the self-administered HIV test?

Perceived Barriers

13. How easy or difficult do you think it will be for you to use the HIV self-test kit?
14. Do you think it will be easy for young people to access and purchase the HIV test kit?
15. Where do you think this test should be made available for young people?

HIV counselling

16. What have you learnt about HIV counselling?
17. What do you think the importance of HIV counselling is?
18. How do you feel about the absence of HIV counselling when you test by yourself at home?

Perceived benefits

19. Do you think it is important for people to know their HIV status, why do you think that?
20. What do you think are the benefits of knowing your status?

Appendix E: Ethics Clearance certificate

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

HUMAN RESEARCH ETHICS COMMITTEE (SCHOOL OF HUMAN & COMMUNITY DEVELOPMENT

CLEARANCE CERTIFICATE	**PROTOCOL NUMBER: MPSYC/18/001 IH**
PROJECT TITLE:	Acceptability and willingness among young people in Soweto to use at-home HIV test
INVESTIGATORS	Madonsela Gugu
DEPARTMENT	Psychology
DATE CONSIDERED	19/07/18
DECISION OF COMMITTEE*	Approved

This ethical clearance is valid for 2 years and may be renewed upon application

DATE: 19 July 2018

CHAIRPERSON _____
(Dr Peace Kiguwa)

cc Supervisor:

Prof. Tanya Graham
Psychology

DECLARATION OF INVESTIGATOR (S)

To be completed in duplicate and **one copy** returned to the Secretary, Room 100015, 10th floor, Senate House, University.

I/we fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure be contemplated from the research procedure, as approved, I/we undertake to submit a revised protocol to the Committee.

This ethical clearance will expire on 31 December 2020

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES