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Adherence to Antiretroviral Therapy (ART) Amongst black adolescents. A case study on the perceptions of HIV/AIDS adolescent male patients in Ekurhuleni, South Africa

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Adherence to Antiretroviral Therapy (ART) Amongst black adolescents. A case study on the perceptions of HIV/AIDS adolescent male patients in Ekurhuleni, South Africa

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DECLARATION

I, the undersigned, hereby declare that the work submitted in this research report is my own original work and has not been previously submitted to any other university for any academic credit and that all supporting material contained herein have been duly acknowledged.

_____

Bradley Mothusi Monyai

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Abstract and key words

South Africa continues to upscale in the advancement of programmatic interventions towards HIVand AIDS, however, this epidemic is observed to be affecting a high proportion of adolescents and exacerbates critical social, psychological, economic, and educational challenges (Poku & Poku, 2020). In the estimated 7.8 million of South Africans living with HIV, the second highest prevalence rate is considered to be amongst black adolescent males. Within this cohort, adolescent males reported high risky sexual behaviours related to HIV. moreover, in their adolescent-hood, HIV risk factors were correlated with lower levels of HIV and AIDS related information, low rates of viral suppression and condom attitudes. There is a noted inconstant adherence to ART (Anti-Retroviral Therapy) amongst adolescent males. Such being the case, drivers of non-adherence, retention in care that is poor and mental health challenges differs with each adolescent demographic background and the mode of infection. Such notable variances indicates that studies which merge adolescent males and their counterparts living with HIV may blur social, psychological, structural, and clinical experiences of these two diverse sub-populations. This qualitative research study aimed to explore adherence to antiretroviral therapy amongst black adolescent males living with HIV. A qualitative case study design was employed and twelve adolescent males from Ekurhuleni health care facilities were purposely sampled in the study. The data collection method that was used, was a semi structured focus group and face to face interviews whereby an interview and a focus group schedule were utilised. The different themes that emanated from the participant's experiences were analysed using thematic content analysis.

Major findings highlight that, societal stigma profoundly impacts self-perception, leading to a pervasive sense of shame and low self-worth among black adolescent males, influencing their reluctance to disclose their HIV status. The intersectionality of identity, encompassing socioeconomic factors, sexual orientation, and race, intricately intersects with health status, illuminating the challenges faced by economically disadvantaged adolescent males managing a chronic health condition. Moreover, the intricate dynamics of HIV status disclosure within families contribute to adolescent fears of social isolation, exacerbated by poor support for medication routines. Lastly, challenges in healthcare accessibility and patient experience, characterised by discomfort with healthcare facilities and dissatisfaction with human interactions, underscored the need for a more patient-centric approach and comprehensive interventions to address systemic barriers.

Keywords: Adolescent, HIV and AIDS, adherence to ART, retention in care, mode infection.

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Chapter One

INTRODUCTION

1.1 Introduction and background of the study

The years of adolescence marks the commencement of an increase in the prevalence of HIV across South Africa as a country with generalised epidemics. In the face of well- known need for protection against HIV infections and various health risks related to reproduction, sexual debut accelerates with years. Thus, through that agency, age, social and economic status restrict adolescent's access to knowledge and services in low middle-income settings. Hudelson and Cluver (2015) suggest that a volume of adolescents who are sexually active reside in countries that are burdened with high levels of HIV since this period of growth entails experimentation, vulnerability, and new experiences. Too et al, 2021 state that an estimated 84% of young people living with HIV is noted in sub-Saharan Africa. In actuality, United Nations Programme on HIV and AIDS (2021) stresses that half of adolescents from the age of 15 to 19 who are living with HIV in the world reside in six key countries beginning with South Africa, Kenya, India, Nigeria, Tanzania, and Mozambique. Stats SA (2020) estimates that 7.8 million people in South Africa are living with HIV, while adolescents constitute to 18,7% of the overall population. Into the bargain, 70% of adolescents living with HIV have acquired it perinatally and have been living with the virus from birth.

A research study in Mozambique, Kenya, Tanzania, and Rwanda amongst a range of 160 clinics revealed that adolescent males were likely to drop out of care both prior and after being initiated on HIV treatment (Muller, Spencer, Meer & Daskilewicz, 2018). These estimations incorporate both adolescents who acquired HIV perinatally or postnatally through breastfeeding as well as those who acquired it behaviourally. limited studies emanating from low- and middle-income countries with concentrated epidemics propose that HIV prevalence is excessively high amongst adolescent belonging to key populations, particularly adolescent males (Strauss, Rhodes & George, 2015).

According to Casale, Boyes, Pantelic, Toska, and Cluver (2019) This group faces an elevated level of stigma which contributes towards poor access to support and key services for the management of HIV infection. The authors concur that adolescent males have poor retention and adherence outcomes despite being enrolled in HIV treatment and care compared to adolescent females. Age and gender disaggregated data in the coverage of antiretroviral therapy within adolescent males is lacking, this is due to the fact that there is constancy in the number

of perinatally exposed boy children growing into adolescence, which leaves pockets of concerns that the number of adolescents living with HIV and in need of treatment management is likely to persist (Sherr, Cluver, Toska & He, 2018).

This reiterates that virological failure and HIV and AIDS related deaths amongst adolescent males is as a result of distorted access to ART. Retention of male adolescents in care is a challenge. Vreeman, McCoy and Lee (2017) postulates that dealing with the prospects of a treatment that is lifelong can be demoralising, however, for adolescents this comes on top of navigating common challenges of maturity development, psychologically, emotionally, sexually, and physically which when intertwined with social pressures, can also conspire in putting the health of an adolescent male at risk. The population-based survey found that adolescent males on antiretroviral treatment fare worse in achieving viral load suppression (Slogrove, Mahy, Armstrong & Davies, 2017). With this persistent inequality, ending HIV amidst adolescents is unlikely to be possible with adaptations and innovation programming only. It is against this background that the study focused on black adolescent males, with due regard that there is paucity in literature that is concentrated, specifically on this group. The psychosocial development and systems theory were applied as theoretical lenses, underpinning the phenomenon under investigation.

1.2 Statement of the problem

South Africa is presently confronting a diverse weight of diseases, with the HIV and AIDS plague concurring with a significant burden of tuberculosis, adolescent mortality, road injury, interpersonal violence, and suicide. Adolescents in South Africa continue to be prone to HIV and AIDS, while a persisting global number of HIV related deaths is primarily as a result of major mortality amongst adolescents, particularly in the African region (Smith et al, 2018). On a global scale, adolescents and youth constitute an estimated 45% of all recent HIV infections, in addition, the report by the United Nations (2019) asserts that approximately 4 million of recent infections are adolescents between the age of 15 to 24 years. Adolescence commences at puberty until mid-20s and is crucial period of development which sexual debut may be pivoted rapidly (National Academies of Sciences, Engineering, and Medicine, 2019). Cluver et al (2015) found that an estimated 2.4 million of South African youth has lost one or both of their parents or caregivers due to AIDS indicating that perinatal HIV infection is inevitable. Moreover, research by George et al (2020) highlights that there is an acute surge of HIV infections around adolescence as the age of sexual debut. These scholars' postulate that with the exception of perinatal infection, there are other factors exacerbating this increasing rate

such as individual and socio-structural elements intersecting around the lives of adolescents in South Africa, to prompt risks of HIV and poor adherence. For Teasdale, Sogaula, Yuengling, Wang, Mutiti, Arpadi and Abrams (2018) this includes and not limited to poverty, violence, inadequate shelter circumstances and food scarcity. Into the bargain, there is a gendered scope to HIV susceptibility amongst adolescents, studies have, however, indicated that while case finding, and treatment provision programmes are major in South Africa, issues around the provision of treatment and adherence within male adolescent cohort persist (Fritz, Blevins, Lindegren, Wools-Kaloutsian, Musick, Cornell, & Wester., 2017). The study by Kharsany and Karim (2016) corroborates that of Saul et al (2018) where boys and men were found to be likely initiated on ART at a latter age while it is a late stage of infection and had nearly a replicate mortality rate than that of female adolescents and women.

In 2019, 65% of female adolescents living with HIV had access to treatment in relation to 56% of male adolescents living with HIV (Lim et al., 2016). Against this backdrop there is a noted gap demonstrating the need to engage male adolescents in HIV services and retaining them in care. Furthermore, there are discrepancies between male and female adolescents with reference to viral suppression. Due to late testing of male adolescents for HIV, only 47% of this group is virally supressed compared to 58% of their counterparts. A study in the United States of America by Shaw and Amico (2016) revealed that adolescents living with HIV were highly under-represented in the evidence base of interventions relating to adherence irrespective of their various and noteworthy needs therewith barriers.

These scholars concurrently revealed that male adolescents living with HIV are less likely compared to any population be retained in care and have their viral load suppressed. Against this backdrop, remedying HIV in male adolescents calls for young pupils to have access to knowledge and tools needed to make healthful decisions and alleviating their risk of adverse viral suppression, obtaining treatment, and remaining in care. It is therefore mandatory to provide Interventions pertaining to HIV that are attainable and adolescent friendly, yet responsive to their needs. A habitual viral load monitoring can ascertain adolescent patients in need of enhanced adherence support to realise viral suppression and its' correlating individual and public health benefits, in order mitigate the development of drug resistance. Thus, there is a need to focus on perceived reasons to poor adherence. It is therefore relative to explore their areas of concerns, perceptions, nuances and needs, as far as sexual and reproductive health, HIV prevention, treatment services and referral to antiretroviral therapy.

1.2.1 Rationale for the study

Studies in South Africa document that adolescents present a challenge to HIV care programmes as they hold increasing rates of suboptimal treatment adherence and virologic treatment failure (Hogg et al, 2017; Zanoni et al, 2017; De Wet, Akinyemi & Odimegwu (2018). Nonetheless, paucity in the discourses of adolescent males and HIV and AIDS overlooks certainties that adolescent males compared to other young individuals receiving similar therapy, fare worse in reaching meaningful clinical levels of ART adherence, being retained in care, and having their viral loads suppressed. Limited research on adherence amongst black adolescent males living with HIV infection in high prevalence settings warrants this proposed research study, in addition to the researcher's observations as a former Paediatric and Adolescent services coordinator at the Aurum Health Institute, supporting seven health care facilities in Ekurhuleni.

1.3 Primary Aim

The main aim of the study was to investigate antiretroviral therapy (ART) adherence among HIV and AIDS male adolescent patients in Ekurhuleni.

1.4 Overview of the research design and methodology

This research report was positioned within a qualitative paradigm using a case study approach. Semi structured interviews and a focus group were used as a data collection method from twelve (12) black adolescent males who were enlisted by way of non-probability purposive sampling, coupled with snowball sampling (chain effect sampling), which was employed to access participants that were hard to reach within facilities. Into the bargain of using semi-structured interviews and a focus group, direct observation was also used as a complementary data collection method, to primarily investigate aspects of behaviour that are normative, provides insights about how a group thinks about a specific issue, about the range of ideas, opinions and the variability that exist in particular communities regarding beliefs, experiences and practises of adolescent males living with HIV. In the analysis of data, thematic content analysis was utilised.

1.5. Definition of key concepts

Adolescence

According to Sawyer et al (2018) adolescence is a time of life between puberty and adulthood characterised by hormonal changes in the body, the social environment, and the mind which rests on both individual development as well as cultural norms. For Word Health Organisation

(2020) this is a stretching phase that not only entails biological growth and significant social role transitions, but a period where this group experience accelerated physical, psychosocial, and cognitive development which affects their feelings, how they think, make decisions, and interact with the society at large. The World Health Organisation states that adolescence commences from the age of 10 until 19 years, wherein, adolescents develop patterns of behaviour relating to aspects such as physical activities, diet, substance use and sexual acts.

HIVand AIDS

World Health Organisation defines HIV as human immunodeficiency virus which is an infection that effects the body's immune system, particularly white blood cells referred to as CD4 cells. According to Yoshimura (2017) the virus kills the CDV cells and weakens a person's immunity from opportunistic infections such as tuberculosis and some cancers. For Lu et al (2018) when an individual's CD4 count falls below 200, their immunity is critically compromised and leaves them more prone to infections. An individual with CD4 cells count that is extremely low is reported to be in the midst of acquiring AIDS (acquired immunodeficiency syndrome). According to Frimpong, Amponsah, Abebrese and Kim (2017) If the person's CD4 cell count falls below 200, their immunity is severely compromised leaving them more susceptible to infections.

Adherence to ART

Adherence to ART refers to the service user's ability to observe a plan of treatment, take medicine at the prescribed times and frequencies while following restrictions pertaining to foods and other medications (Wallis et al, 2019). Myer and Phillips (2017) adds that adherence denotes the match between the patient's behaviour against the health advice given, of taking the prescription at the right time, in the appropriate dose and in the proper way. This indicates the working relationship between the patient as a service user and the care provider in understanding the plan of care and health management.

Retention in care

Retention in care denotes a range of continued care packages beginning at diagnosis of HIV infection until lifelong services where characteristics such as, being alive and actively on ART, being transferred out to other health care facilities and remaining on treatment (Koss et al, 2017). According to Murray et al (2017) retention in care speaks to sustained, habitual HIV care, initiation and maintenance of antiretroviral therapy leading to overall health for an HIV infected service user and for the prevention of further transmission. Anderson et al (2020)

concur that being retained in care is concerned with receiving an ongoing and regular scheduled care, thus, yields to lower viral loads, increased CD4 cell counts, reduces morbidity and mortality.

Mode of infection

According to Maskew et al (2019) there are mode of infections when it comes to HIV and AIDS, the most common being mother to child infection as well as behavioural infection. mother to child infection is associated with the spread of the virus to the babies breasted by and born to HIV infected mothers. Behavioural infection occurs through sexual contact with an infected individual through the lining of the vagina, penis, or mouth during sexual intercourse (Slowgrove & Sohn, 2018). Other modes of infections in HIV include the contamination of blood through contacts with blood that is infected, nonetheless there is low chance of acquiring the virus during blood transfusions as it is screened prior (Kaplan-Lewis & Fierer, 2015). Additionally, Spiller et al (2015) suggest that another mode of infection includes the sharing of needles, syringes, or drug use instruments with someone that is infected with HIV.

1.6 Theoretical framework(s) underpinning the study.

Psychosocial Development theory

The psychosocial development theory postulates that the environment which people inhibit plays a significant role in adjustment, being self-aware, human development and the establishment of identity. This theory asserts that people progress through stages of development premised on how they adapt to presenting social crises as they influence daily living (Branje & Koper., 2018). For Knight (2017) this theory proceeds from a perspective that human development is influenced by internal psychological factors and external factors presented by the environment at large. Green, Kalvaitis and Worster (2016) purports that both the internal and external factors as social crises inform how individuals respond to the surrounding environment. According to Maree (2020) these factors are considered to have a thorough implication on mental health as well as wellness. The psychosocial development theory is an advancement of Erik Erikson's eight stages of psychosocial development that a healthy person ought to go through from infancy until the late stages of adulthood (Meeus, 2016). Maree (2020) highlights that Erikson recognised identity as consolidated in adolescence and maintained that challenges that takes place at a given stage will shake the synthesis of the whole composition. This theorist argues that the capacity to move effectively across these stages is influenced by both the biological and sociocultural factors, wherein the movement

between these stages is repeatedly reinforced by social crises, that perpetuate the way in which individuals react to the presenting world (Newman & Newman, 2017).

For social work in social development, this theory aids in the analysis of service user's symptomatic behaviour regarding previous experiences of trauma and challenges with present developmental requirements (O'Hare, 2019). Levenson (2017) posits that social workers can use the maturation timetable by Erikson to indicate individual challenges and to assess what services of support would be adequate to remedy them. For Walker and Horner (2020) this viewpoint provides social workers with a collective of indicators that assist in determining how progressively clients deal with crises and differentiate individual difficulties, thereby, providing appropriate supportive services as they proceed through the maturation table as it is a roadmap to meet healthy development.

This examination aligns with this theory, notably the stage of "Identity vs. Role Confusion" during adolescence. In this phase, adolescents actively explore their sense of self and identity, which includes how they perceive themselves in relation to their health condition and treatment regimen. Additionally, the study delves into the "Intimacy vs. Isolation" stage, as adolescents with HIV and AIDS may encounter challenges in forming close relationships due to stigma or apprehension about disclosing their status. Their adherence to ART may significantly impact their ability to establish intimate relationships and foster social connections. By understanding how adolescents in this demographic navigate Erikson's psychosocial stages, valuable insights can be gained into their perceptions, behaviours, and obstacles regarding ART adherence. These insights, in turn, can inform the development of targeted interventions and support strategies tailored to their developmental needs.

Systems Theory

In systems thinking Greene (2017) asserts that there is an existence of various systems that are interdependent, both natural and human made. Becvar and Becvar (2017) argues that the systems theory is rooted in the structure of miscellaneous systems. This theory holds the view that an effective system is attributed to individual needs, expectations and attributes of individuals living in that system. For Germain and Knight (2021) systems are both formal and informal and may allude to family, friends, social clubs as well as public institutions such as schools. McMahon and Patton (2018) concur by stating that the systems theory departs from an interdisciplinary approach to comprehending how an occurrence at a time in a system can directly have a rippling effect on other parts of the system. in addition, these scholars asserts

that people do not exist in isolation but form part and operate within a wide network. An individual's caregivers', parents, friends, economic class, home environment and other aspects all have an influence on how a person thinks and responds (Coady & Lehmann, 2016). Bogo and Vayda (2016) states that families and groups are involved directly with the rationale of solving problems and hindrances that emerge when there is no homeostasis between a person and the system they function within. In social work, Turner (2017) purports that systems theory renders an understanding of how a person's existence in multifaceted systems informs their outcomes as they influence a daily living. Furthermore, the author demonstrates that the theory locates people from a lens of collective existence and how they relate to each other, the society at length and the effects that societal pressures have on individuals. In accordance with Howe et al (2018) social workers intervening from a systems approach seeks to aid or remedy missing or ineffective parts of a system which can correlate to a positive impact on behaviour. Into the bargain Adams, Dominelli and Payne (2017) agree with Hepworth et al (2016) that social workers ought to observe and investigate all of the systems that contributes to an individual's behaviour, welfare and strive to improve those systems by means of positive role model provision, therapy/counselling g, and interventional services to assist in the creation of a supportive systems for a person.

Systems theory emphasises the interconnectedness and interdependence of various elements within a system, highlighting the influence of the environment on individual behaviour and vice versa. In this study, black adolescents living with HIV and AIDS are situated within multiple systems, including their families, communities, healthcare systems, and broader societal contexts. These systems shape their perceptions of HIV and AIDS and influence their adherence to ART. For instance, family dynamics, peer relationships, cultural beliefs, and access to healthcare services can all impact an adolescent's willingness and ability to adhere to treatment. Understanding the complex interactions among these systems is essential for comprehensively addressing adherence challenges and designing effective interventions. By applying systems theory, the study aims to elucidate the intricate web of factors influencing ART adherence among black adolescents with HIV and AIDS, ultimately informing holistic and systemic approaches to support their well-being.

1.7 Limitations and Delimitations of the study

A qualitative study may be conducted with the aim of producing in-depth perceptions, meanings, and understandings, nonetheless, there were possible limitations. Since this study investigated nuances and personal accounts within a chronic disease field, some participants were hesitant to participate due to the fear of stigma. For this reason, participants were taken through the participation information sheet particularly looking at the ethical considerations and how they will be adhered to. Maintaining confidentiality amongst participants in the focus group was a limitation towards the research. In particular, the researcher was limited in guaranteeing confidentiality amongst participants when they are out of the focus group. Thus, the researcher alerted the study participants that the index and narrations given in the focus group should remain confidential. Limitations experienced during the data collection process was due to the data collection method being a qualitative interview and a focus group which were mostly characterised by open-ended questions and led to participants having control on the content of the data. The researcher was not able to be objective when verifying results against participant's responses. Social desirability bias from participants occurred to some extent in the focus group, this denotes the participant's temptation to produce desirable answers (Larson, 2019). The researcher mitigated this issue by consistently maintaining an unconditional positive regard for participants. This involved framing questions and prompting participants to share information in a manner that conveyed acceptance, reassuring them that it was acceptable not to conform to societal expectations in their responses.

The researcher was aware that some of the discussions may provoke psychological emotions and as a researcher it was important to ensure that necessary arrangements were made, this was inclusive of creating a protocol for arranging debrief and counselling for participants with a designated qualified registered Social Worker/ counsellor, from the respective health facilities where they collect their medication.

1.8 Organisation of the report

This research report consists of five chapters. In chapter one, the introductory aspect provides an overview of the study. This is inclusive of a summary that is brief, of the aim of the study, the research design, the methodology and the definition of key terms. Moreover, key features of the theoretical frameworks in which the study was located, followed by the inherent limitations in the research design and the methodology.

Chapter Two is concerned with two sections: The review of literature and elaboration on the two theoretical frameworks that form the foundation of the study. The topics: Adolescent psychosocial challenges related to HVI and AIDS, HIV and AIDS-related Stigma and mental health, Socioeconomic constraints related to ART adherence, Clinical related matters to ART intake, Policy background on adolescent health, Impact of HIV and AIDS on individual health are discoursed at length. The second section speaks to the Psychosocial Development theory and the Systems Theory as theoretical frameworks locating the study.

Chapter Three presents a detailed interpretation of the research methodology which covers the description of the aim, objectives, research approach and design, population, sample and the sampling procedures. In addition to that, provides the research instrument used, the way in which the research tool was pre-tested, methods of data collection and the method of data analysis. A criterion for trustworthiness is scrutinised in conjunction with the ethical consideration that were cohered to, in the process of the study.

Chapter Four Introduces and deliberates on the findings in alignment with the study's objectives. This chapter is divided into objectives, a category of themes with direct verbatim quotes which are findings emanating from the study.

Chapter Five summarises the main findings that were unearthed from the research, draws conclusions, and makes recommendations for the social work practise, social work education as well as further research.

CHAPTER TWO

REVIEW OF LITERATURE AND THEORETICAL FRAMEWORK

2.1 Introduction

Adolescents in sub-Saharan Africa remain at the epicentre of the HIV epidemic, with surveillance data signifying persisting high levels of HIV incidence. In South Africa, adolescent males account for a quarter of all new HIV infections. Compounding the prevalent biological factors, increased recognition of structural determinants has been realised in this cohort. Mwisongo, Mohlabane, Tutshana and Peltzer (2016) broadly asserts that this denotes barriers to or facilitators relating to social, economic, systems, policy, organisational, or other factors of the environment playing a key role in influencing adolescent's HIV-related outcomes. Elements related to HIV and AIDS infection, perinatal vs. behavioural acquisition, time frame since diagnosis and care e.g., availability and access to quality care, service provider-service user relationship, and practices have been observed to be related to ART adherence and viral suppression amongst adolescents (Galea, 2018). Into the bargain, while adherence to ART amongst adolescents has been attributed to individual-level factors, mental health conditions, and structural related support, this group continues to present a heightened risk of viral failure, morbidity, and mortality.

Research findings by Bongfen (2019) demonstrate that paucity in the advancement of psychosocial considerations in health care, particularly HIV knowledge, attitudes, perceived risk, self-efficacy, and social norms associated with the infection additionally results in sub-optimal adherence amongst adolescent males, which has implications for their health and onward transmission. This section will provide a discourse on the following established topics: Adolescent psychosocial challenges related to HIV and AIDS; HIV and AIDS-related stigma and mental health; Socio-economic constraints related to ART adherence; Clinical related matters to ART intake; Policy background on adolescent health; and Impact of HIV and AIDS on individual health.

2.2 Adolescent psychosocial challenges related to HV/AIDS.

There is synthesised evidence suggesting the prevalence of mental health issues amongst HIV and AIDS adolescent patients. Morris and Rushwan (2015) assert that mental health challenges are rife in this cohort and may need to be addressed within a comprehensive HIV care setting. According to Sherr, Cluver, Toska, and He (2018) there is a correlation between poor mental

wellbeing and non-adherence to antiretroviral therapy and other risky behaviors resulting in distorted physical outcomes and a high risk of transmission. Longitudinal studies by Stein et al (2017) in the United States of America and Puerto Rico indicated that amongst HIV and AIDS infected adolescents, symptoms associated with depression and anxiety have been linked with lower adherence to ART, therewith high substance use and risky sexual occurrences. The study by Dessauvagie (2020) revealed that 30- 50 % of adolescent males showed emotional and behavioral difficulties leading from moderate to severe psychological distress. The authors lament that adolescents with anxiety are 40% less likely to have their viral loads suppressed compared to other adolescents. Into the bargain, studies from high-income countries by Vries, Davids, Mathews, and Aaro (2018) concur that adolescents males living with HIV encounter an increased load of mental health needs.

According to this publication HIV adolescents' patients are susceptible to psychiatric hospitalisation compared to the general adolescent population. Bankole et al (2017) agree that the prevalence of psychiatric diagnosis in adolescents exists amongst perinatally infected pupils and transcend to individuals acquiring the infection behaviourally. Similarly, a longitudinal cohort study of adolescents in New York Kim et al (2017) found 60% of adolescents who were born living with HIV to have psychiatric disorders. Into the bargain, the authors narrate that an occurrence of anxiety, mood, and other various behavioural disorders was the same amongst all HIV-exposed populations. Thus, even in settings that are highly resourced and financially standing, this report highlights that there are disparities in comprehensive HIV services in settings such as the United States.

These authors further indicated that black adolescent males were less likely to receive care for mental health symptoms emanating from living with HIV. Mebrahtu (2020) states that children who are born living with HIV may experience neurocognitive complications such as shortfalls in cognitive development, speech, fine motor, and gross motor functioning with significant impact on their quality of life, as they enter the stage between childhood and adulthood, particularly academic achievements, social relationships and risks for use and abuse of substance. According to Guilamo-Ramos, Flores, Randolph and Etogho (2021) black adolescents living with HIV, especially those in developing countries grow and develop in an environment that entails exposure to biomedical, familial, economic, and social factors that prompts their risk of mental health challenges. A European study by Borran, Dashti-Khavidaki and Khalili (2021) revealed that amongst HIV infected adolescent males, 53% was diagnosed with psychiatric disorders while 44% experienced a continuance of depressive disorders.

Cross-sectional studies in low- and middle-income countries suggest that with the existence of mental wellbeing challenges amongst black adolescent males, there is a need to remedy them within support and care systems. In Kenya, the study by Vreeman, McCoy and Lee (2017) found that of the 162 HIV-infected adolescent males, 49% were described to have at least a single psychiatric diagnosis, most common anxiety disorders, suicidality accompanied by major depressive disorders. In Kampala, Uganda a cross-sectional study of adolescents living with HIV reported that 51.2% of black males scored higher in signifying psychological distress, 17.1% narrated to have attempted suicide in the previous year while 30.5% had encountered psychotic symptoms (Mutumba et al, 2016). In the management of HIV, Botswana used a culturally adapted approach to a study involving 692 adolescents living with HIV. This study by Too et al (2021) purports that there is a correlation between psychosocial dysfunction and virological failure, proposing that the is an association between psychosocial functioning and clinical outcomes.

2.3 HIV and AIDS-related Stigma and mental health

Rueda et al (2016) state that HIV-related stigma and individually internalised stigma triggers the risks of suicide ideation and behaviours. For Boivin, Ruisenor-Escudero and Familiar-Lopez (2016) exposure to HIV as an adolescent transcends beyond HIV infection or status of health, the impact of a variety of biopsychosocial experiences should be lamented. There is a link between social exclusion, HIV-related stigma associated with late HIV testing, and poor treatment adherence. Stigmatising aspects of HIV and treatment like lipodystrophy that is observed to cause changes in the body of the infected may additionally drive negative mental health outcomes such as depression and disturbed adherence, in light that, this is amidst a developmental phase where body image and social desirability of “fitting in” are strong reinforcers of behaviour for an adolescent (Engler, Lessard & Lebouche, 2017). According to this study, behavioural HIV-infected adolescents who are prone to a diverse of personal challenges such as low self-efficacy in conjunction with challenges of the milieu have greater issues of acquiring opportunistic infections such as TB and being switched to a different regiment of treatment.

As reported by Vreeman, McCoy and Lee (2017) a mental framework that is positive towards treatment adherence is affiliated with autonomy and control over adolescent wellbeing and health. On the contrary, these authors argue that a mental framework that is negative perceives adherence as a reminder of one’s infection. For Remien et al (2019) this interaction of the psychosocial environment mental health and adherence suggest a critical need for remedying

and identifying risk factors in order inoculate adolescents from mental and emotional health unwellness.

In the South African context, there is paucity in the data on adolescent mental health, in addition, Fisher and Cabral de Mello (2011): Erskine et al (2017) and UNICEF (2018) argues that in such resource-constrained settings, mental health services are insufficient for adolescents and thus not only leads to severe limitations but distortions in the uptake of mental health services. Advances in antiretroviral therapy and preventative medicine confirm the view that HIV and AIDS is now a manageable and treatable infection. With maximum and better adherence to medication, O'Hayer, Bennett and Jacobson (2016) contend that the viral load of a patient can be suppressed below detectable levels, which ultimately reduces negative effects of the infection and transmission. However, these authors affirm that factors such as HIV and AIDS-associated stigma, shame and depression disrupt adherence to medication and standard health care use thereby accelerating vulnerabilities towards opportunistic infections, emergency care, and costs of health care.

2.4 Socioeconomic constraints related to ART adherence.

In the United States of America Singer, Weiser and McCoy (2015) found that adolescents residing in neighbourhood's characterised by high rates of poverty were more likely to have a low CD4 count cell. In this regard, Adolescent patients residing in households and environments with higher rates of unemployment were less likely to be on a current ART prescription. In certain geographical areas in Philadelphia, factors strongly related to poor viral suppression hotspots amongst adolescents' males included residing in economically challenged households and distance to pharmacies (Singer, Weiser & McCoy, 2015). HIV care missed appointments were reported more often by patients from such challenged backgrounds and in countries with a higher prevalence of non-adherence amongst adolescents (Shubber et al, 2015). In this discourse, the authors examine the interconnectedness of structural-level characteristics and HIV infection management within a large, geographically diverse sample of HIV-infected adolescents. Particularly, exploring the interaction of structural-level and individual-level factors as they relate to the use of antiretroviral therapy, consistent appointment keeping, and viral suppression among adolescent males living with behaviourally and perinatally acquired HIV in the US.

Patterns of infection have been shown to vary with the social and economic circumstances of the country affected (Adejumo et al, 2015). These authors argue that poverty remains a

paramount social determinant of HIV and AIDS, transmission, access to Adherence, and ART management. A Study by Singer, Weiser and McCoy (2015) in Southern Africa purports that financial challenges were thematised as the most prevalent accounts of patients missing their doses. Naanyu et al (2020) concur that distance barrier and unavailability of transportation to ART clinics emanated as social circumstances that patients of HIV and AIDS come across. According to Widome, Jansen, Bangerter and Fu (2015) households with less economic means reported having endured two days or more with no access to food. Thus, posit that there is an association between patients holding the view that medication needs to be taken after meals and failure to take medication when there is an unavailability of food. Shabalala, De Lannoy, Mayer and Reis (2016) assert that patients find themselves negotiating between paying for transportation to the facility and utilising the money for pressing home needs such as food. Studies by Jennings, Ssewamala and Nabunya (2016) in Uganda and Tanzania have shown that costs of transport were considered to be the most obstacles towards being adherent to ART.

These authors postulate that the availability of transportation means to attend health-related appointments has been associated with progressive linkage and retention in care for adolescents living with HIV. For Charles (2018) this has implications not only for daily adherence but also retrieval of lost to follow-up patients. Reinforcements of adherence to ART for adolescent males infected with HIV in sub-Saharan Africa were investigated with ethnographic research methods in HIV management sites in Nigeria, Dar es Salaam, Jos, Mbarara, Uganda and Tanzania. These results evidenced that infected adolescents residing in female-headed households, and on routine ART navigate economic impediments through various deliberate strategies focused on prioritising adherence: lending and begging for transport capital, making infeasible choices to allocate resources for treatment and "doing without" (Charles, 2018).

Thus, this reiterates the view that adolescent individuals residing in households that are more structurally disadvantaged, including those living in the absence of food, the recent chronic increasing rates of unemployment and racial segregation leads to a high lack of HIV Adherence amongst adolescents. Research by Kahana et al (2016) and Adolescent Medicine Trials Network for HIV and AIDS interventions (2016) revealed that HIV services both in the United States and internationally were received by individuals with many complex issues related to getting access and utilising ART, as well as challenges of the environment and considerations of resources. Their findings ascertained that food insecurity is associated with lacking access to ART treatment and delayed engagements with HIV service rendering facilities. These findings highlight that structural factors are significant in understanding the reasons for

distorted linkage and retention in care (Kahana, 2016). In addition, the report by Adolescent Medicine Trials Network suggests the importance of developing interventions that are multidisciplinary concerned in addressing the continuation of care. At the core, various discourses posit that a structurally disadvantaged system is negatively impacted by a decreased collective efficacy and social cohesion, therefore, affects the individual's capacity to engage in behaviour that is health-seeking. E.g., being engaged and retained in care (Korotchenko & Anderson, 2020)

Various household-related challenges about adolescent males include instances where biological parents may be deceased due to the infection. On the contrary, in instances where a mother or caregiver is available, may be living with HIV and similarly challenged by the needs of their own infection, psychological factors, treatment regimens and financial burden which amounts to negative influences around adherence (Fields et al, 2017). Amid sociodemographic factors such as conditions of living, discrimination, financial problems, and instabilities in structural social support. Muller, Spencer, Meer and Daskilewicz (2018) argue that the sexual and reproductive health of an adolescent males is firmly associated with their specific social, cultural, and economic standing. Additionally, these scholars concur that apart from regional variations, ART experiences are diversified by age, sex, schooling, migration, and sexual orientation amongst other factors.

Thus, this highlights that accessing health care and sources of education, knowledge and support varies within this cohort (Muller, Spencer, Meer & Daskilewicz, 2018). Morris and Rushwan (2015) argue that poor outcomes on adolescent males living with HIV are as a result of multifaceted barriers that institute an inhibitive environment for the discussion of adolescent sexual reproductive health since many communities have a deeply embedded sense of disapproval of adolescent sexual intercourse in such a way that is demonstrated through stigma around sexual health concerns, particularly HIV.

At an individual level Newton-Levinson, Leichliter and Chandra-Mouli (2018) assert that care-seeking behaviour amongst adolescent males may be restricted due to confidentiality issues and fear of other people finding out, embarrassment, insufficient knowledge about the infection, misinformation and myths, shame, and stigma. Publication by Nkomo and Kufankomwe (2020) reported that self-forgiveness plays an integral part in the lives of individuals living with HIV and AIDS. These authors concur that the ability to forgive oneself after diagnosis perpetuates acceptance of the HIV status and triggers health-seeking behaviour of attending to medical care and in due course find the confidence to disclose to friends and

families. It was paramount to include this publication in the review due to little understanding of the role of self-forgiveness on individuals living with such a chronic illness and taking into cognisant that adolescence is a phase of self-scrutiny. On that account, care-seeking behaviour of accessing information and services by adolescent males is influenced by a range of people including, peers, parents, caregivers, educators, and healthcare workers.

2.5 Clinical related matters to ART intake.

The latest recommendations by the International Aids Society -USA for antiretroviral therapy use for persons living with HIV emphasised a continuous assessment of adherence, with at least 95% adherence required for better therapeutic results. Larkan, Van Wyk, Stevens and Saris (2015) indicate that ART adherence that is almost up to par is extremely challenging for adolescent male patients given the complexities of prescribed ART regimens. Therefore, a fluctuating adherence results in the virus recommencing its replication up to 10 is to 10 viral particles produced daily (Meintjes et al, 2014). Nyamutsumba (2016) underlines that replication in viral particles triggers immune resistance towards ART and resistant to mutual strain may be non-responsive to the remaining regimens, which may pose a public health limitation. Kim et al (2017) argue that common clinical reasons related to non-adherence were issues with following particular instructions and changes in daily routines. In adolescents, variables correlating with ART were the number of prescribed drugs and low adherence. Lozupone et al (2014) found that consuming an increased volume of pills is the most common reported reason for ignoring and taking medication. This publication narrates that as an adolescent patient becomes increasingly experienced with various antiretroviral drugs, for instance, if they have taken more drugs previously, their regimens typically are then interrupted with more pills and more complex medication schedules. Shehnaz, Agarwal and Khan (2014) state that with physical and psychological adverse effects related to medication, thus, only 28.2% of adolescent males report having taken their medication as instructed by their clinician. The report by Unni, Sternbach and Goren (2019) revealed that frequent reasons for non-adherence concerns were reflected around treatment as a reminder of one's status and difficulty in asking health care workers follow-up questions about their treatment.

These authors further highlight that adolescent males who do not fit taking their medication to daily activities have challenges remaining to their treatment regimen. For Whiteside (2016) adherence should be viewed beyond just a problem of taking medication but rather as an occurrence that may entail certain changes in the lifestyle to accommodate the treatment regimen. According to Green and Lynn (2018) this observation concurs with prior studies on

health behaviour such as cessation of smoking, whereby changes in the environmental factors contribute towards breaking maladaptive chains of behaviour and has been reported to be a significant component in achieving desired behavioural outcomes. Piana, Danhof and Della Pasqua (2017) and Thurston et al (2014) contend that amending medical regimens at a clinical level may advance adherence amongst adolescents, nonetheless, the authors highlight the intake of medication happens in conjunction with a range of diverse issues beginning with adverse effects of medication, not wanting to be reminded of one's HIV status and being occupied with other life issues ultimately rendering their adherence below 95%.

2.6 Policy background on adolescent health

With a growing recognition of behavioural and structural causes towards health and disease, The National adolescent and youth health policy (2017) posits that the department of health strives for accelerated and preventative focus on the promotion of health and management. In addition, it is committed to the design of programmes that are responsive to both the social and structural determinants of health. The National Adolescent and Youth Health policy (2017) is set to assist the department of health in cartel with principal partners in government to modify the national conception of effective health advancement within adolescents. Adolescent health services are increasingly acknowledged as a priority in low- and middle-income countries. Thus, the adolescent and youth-friendly services approach has been urged by the National Department of Health and partners in South Africa as a technique of standardising health care services for adolescents in the country (Strauss, Rhodes & George, 2015). This is a method of service delivery that seeks to ascertain the provision of a comprehensive package of youth services that are accessible and admissible at all facilities of health.

According to the National Department of Health (2017) these services entail prevention, reduction of risk, advocacy and information sharing of miscellaneous health factors affecting adolescents, intended to be delivered in a manner that is client-centred and meets the need of the key population. The policy entails the Integrated Schools Health programme that focuses on remedying learner health issues including barriers to learning and implement interventions that allow the integration of health care services within the school schedule. The AYFS approach is of the view that facilities of health should entail ideal clinics, according to Ndlovu (2018) these are clinics with adequate infrastructure, enough staff, sufficient medicine and supplies and good administrative processes that rely on applicable clinical policies, standard operating procedures, and guidelines while harnessing stakeholder and partner support. As specified by the National Adolescent and Youth Health Policy (2017) the AYFS approach has

10 standards, wherein five (standard 1,3,6,9 and 10) speak relatively to the care and management of adolescents and youth. For Ndlovu (2018) the highlighted five standards above are perceived to be the minimum essential standards for AYFS to be recognised. Moreover, each of these standards includes a criterion that needs to be met in the interest of achieving the standard. Vukapi (2020) reports that AYFS standards are in alignment with particular national core standards and the ideal clinic criterion, which permits the feasibility to influence health systems strengthening methods and initiatives targeted at the overall improvement of quality in public health care settings. In South Africa, the loveLife non-government organisation was enacted to engage the public sector in implementing the National Adolescent Friendly Initiative which aimed at addressing barriers towards service uptake in primary health care and increasing the sufficiency and capacity of non-judgemental health care workers and providing services that are adequately equipped, easily accessible and appealing (National Department of Health, 2013). In Conjunction with Otwombe et al (2015) a quality improvement approach to AYFS adopted becomes measured against the predetermined standards and the criterion. The study by James et al (2018) in two subdistricts in Ekurhuleni reported that some of Gauteng's sub-districts performed poorly in the provision of adolescent and youth-friendly services compared to Northwest province. The authors argue that both provinces scored above 75% on standards 4 and 5 which are concerned with overall service delivery. However, services related to psychosocial assessments (standard 8) highlighted the difference in health care facilities and the management of adolescents, which presented concerns around their comprehensive management.

While evaluating the feasibility of the approach amongst these facilities, it was found that detriments towards the implementation were centred around lack of training and insufficiency of space to accommodate the services. Darteh, Kumi-Kyereme and Awusabo-Asare (2016) concur that this is evidenced in another study inquiring about the perceptions of young people concerning youth services in an urban environment. In this study, adolescents narrated their dissatisfaction with services as a result of lack of resources, long waiting period and poor quality of care demonstrated by shortages in staff, limited diagnostic equipment, stock-outs in medication. Summatively, findings revealed that adolescents perceived health care workers to be impolite and dismissive of the need for confidential and diplomatic service (Wilson et al, 2017). Ultimately, the report by James et al (2018) evidenced that none of the health care facilities in either district and subdistrict level met minimum criteria for the 5 significant standards required for the recognition of adolescent and youth-friendly services.

Against this backdrop, Schriver et al (2014) posit that rapid urbanisation in South African cities has led to the increase in the young urban population which is concentrated in large metropolitan settings and small-medium cities, necessitating the need to advance the quality of health services tailored to the needs of an urban and peri-urban adolescent. Chandra-Mouli, Lane and Wong (2015) maintain that all adolescents using public health services lack interventions that urgently address risky behaviours and sexual and reproductive health outcomes. To do this, these authors assert that there is a need for a detailed comprehension of factors that account for adolescent health outcomes, including the scrutiny of the physical surrounding, social context, approachability, and access to health services.

2.7 Impact of HIV and AIDS on individual health.

Dabus and Bekker (2017) identify that people living with HIV and AIDS encounter complications related to health conditions. Furthermore, UNAIDS (2016) reported that HIV weakens infection-fighting cells (CD4 cells) of the immune system in human beings. Thus, given that HIV infection deteriorates the immune system, these authors argue that HIV and AIDS exposes the infected to opportunistic infections and malignancies. Findings by Okkome-Nkoumou et al (2014) show that global evidence has proved that the most common infection associated with HIV infection is tuberculosis (TB), Pneumocystis jiroveci pneumonia (PCP), candida infection and cytomegalovirus infection. Limper, Adenis, Le and Harrison (2017) state that these predispositions result in fungal infections of the lungs and upon acquiring the immune deficiency syndrome, the body is left susceptible to a host of fatal illnesses. Other HIV and AIDS-related health complications include the development of cancer, ill-health in reproduction, noncommunicable diseases of cardiovascular, diabetes, renal dysfunction, and damage of the liver (Casper, Crane, Menon & Money, 2018). With regards to malignancies Reid et al (2019) indicate that Kaposi sarcoma is mostly correlated with HIV infection, accompanied by lymphoma, cancer of the anus and hepatocellular carcinoma. In addition, various sexually transmitted infections related to HIV entail human papillomavirus (HPV) and pelvic inflammatory disease. Casper, Crane, Menon, and Money (2018) posits that while ART may advance life span, its unintended consequences include the increasing risks of cardiovascular disease and dyslipidaemia. A report by Danforth et al (2017) and Pang et al (2018) indicate that persons on ART in North America and Europe are more vulnerable to diabetes. In addition, substantial morbidity in HIV-infected persons due to opportunistic infections leads to an increased social and economic burden.

2.8 Summary of the Chapter

Chapter two comprehensively explored the intricate challenges confronting black South African adolescent males in the context of the HIV epidemic. The literature review underscored the profound impact of HIV and AIDS on mental health, emphasising prevalent issues like depression and anxiety. Socioeconomic factors, including poverty and transportation barriers, were identified as significant hindrances to consistent adherence to antiretroviral therapy (ART). Clinical challenges, such as complex medication regimens and adverse effects, were acknowledged as pivotal considerations for improving therapeutic outcomes. Furthermore, the literature also delved into the interplay between HIV-related stigma and mental health struggles, highlighting the imperative for interventions addressing these psychosocial aspects. The policy landscape, particularly the National Adolescent and Youth Health Policy in South Africa, emerged as a framework for promoting comprehensive health services tailored to adolescents. Additionally, the literature elucidated the broader impact of HIV and AIDS on individual health, spanning vulnerabilities to opportunistic infections, various cancers, reproductive health issues, and noncommunicable diseases. The theoretical frame works: Psychosocial development theory and systems theory were explained as theoretical frameworks locating the study. It is against this background that the methodology grounding the study is clarified in the subsequent chapter.

CHAPTER THREE

RESEARCH METHOD

3.1 Introduction

In this chapter, a detailed explanation is presented regarding the methodology employed to achieve the study's aim and objectives. The discussion encompasses the research approach and design, the identified population, the sample chosen, and the procedures applied for sampling. Additionally, it outlines the research instrument, its pre-testing process, and the subsequent data collection and analysis methods. The chapter also delves into the criteria for ensuring the reliability and validity of the study, coupled with an exploration of the ethical considerations adhered to throughout the research process. Furthermore, it provides a supplementary discussion on the methods used for both data collection and analysis.

The study participants were selected from healthcare facilities supported by the Aurum Institute, situated in the Ekurhuleni metropolitan municipality. These facilities include primary healthcare centers (clinics), regional, and a tertiary hospital. Following approval of the study, the researcher was granted access to secure and quiet locations within these facilities to conduct six interviews and one focus group session.

3.2 Research Aim

The aim of the study was to investigate antiretroviral therapy (ART) adherence among HIV and AIDS male adolescent patients in Ekurhuleni.

3.3 Overall research question

What experiences do black males between the age of 16 and 21 years have on antiretroviral therapy?

3.4 Sub-questions

- What professional and programmatic patient management practices are attributable to adolescent ART adherence?

- What are the social and clinical factors leading to ART adherence amongst adolescent males?

- To what extent does sexual and reproductive health services reflect adolescent adherence to ART?

3.5 Research Objectives

- To explore the perceptions of living with HIV and AIDS and experiences of male adolescents living in Ekurhuleni.

- To explore clinical and social reasons related to adherence to antiretroviral therapy amongst male adolescents living with HIV and AIDS.

- To recommend best practices to find, link and manage adolescent males living with HIV and AIDS.

3.6 Research approach

Qualitative research approach is deemed suitable in understanding adherence amongst male adolescent patients living with HIV and AIDS. According to Aspers and Corte (2019) Qualitative research is concerned with interpretation, as it is a method that involves the collection and usage of a diverse experiential resources and approaches. Mohajan (2018) postulates that this design is focused not only on the objective stance of behaviour but additionally on the subjective meanings, own accounts of individual's attitudes, their motivations, circumstances and events in specific environment and institutions. Bansal, Smith and Vaara (2018) concur that qualitative research is an inquiry that utilises a range of methods such as interviews and in-depth analysis on natural occurrences and is absorbed in comprehensive narration of some events, as it focuses on motivations and meanings underpinning personal experiences, cultural symbols, phenomena, and rigorous understanding of processes in the social sphere (Alase, 2017). For Korstjens and Moser (2017) Qualitative research is a continual process, whereby an improved understanding of the scientific community is obtained through establishing new significant contrasts. For this reason, qualitative research is advantageous in facilitating teaching, identifying causality and to unearth fair descriptive distinctions (Gray, Wong-Wylie, Rempel & Cook, 2020). This method was ideal for this research report because the data was collected in hospitals, from male adolescents who are living with and are HIV and AIDS patients, with the aim of probing, exploring, and gathering rich description of experiences, motivations, and perceptions of adherence across this cohort.

A qualitative approach was considered to be feasible due to the following advantages: it is based on the notion that comprehends human and social interaction from the viewpoint and reference of participants themselves, allows the researcher to draw knowledge assertion based on subjective and objective perspectives (Rahman, 2020). This author further argues that this

approach of inquiry permits the researcher to collect data physically and enables the reading of non-verbal behaviour communication which yields to the depth of the data. The limitations of this approach, however, is that, due to a small number of the sample size, generalisability to the large population may be distorted or erroneous, furthermore, as a result of diversity amongst individuals, a small sample size may not sufficiently represent the population at large (Queirós, Faria, & Almeida, 2017).

3.7 Research design

The research design of this academic discourse is a single case study. Harrison, Birks, Franklin, and Mills (2017) states that a case study research is premised on a case. The authors postulates that it is an "individual representative of a group" where there is rich description and a brief allusion to the narrative compositions of case studies and the use of scholarly writing methods to validify the complexities of what is in question. This denotes that the researcher explored the phenomenon under scrutiny from its real-life setting. These authors further highlight that the series of events at a particular period is an important aspect, for that account, exploring the experiences of participants authorised the researcher to observe behaviour through the viewpoint of the participants themselves, therefore allowing the collection of verbatim data. According to Ridder (2017) using a case study design is an advantageous method to investigate a variety of social units wherein, several variables have potential importance in studying adherence amongst black male adolescents.

For Fenton and McFarland (2018) the advantages of this design are premised in; being rooted in real life occurrences, the case being studied resulting to a holistic and rich reports of a phenomenon; the potential to acquire high conceptual validity; the sufficiency of the case study to examine and review the hypothesised capability of causal systems, in conditions of individual and group cases as well as the solid procedures used, to advance new hypothesis. This demonstrated that an explorative qualitative design may allow for data that is ample to be transferred to an extensive particular group. The research study was conducted within seven health care facilities. A case study research is characterised by the use of a variety of data sources, consequently, case studies are rooted in deep and diverse sources of information (Zucker, 2016). Data collection was done at seven health care facilities, which are located in Ekurhuleni metropolitan city, and an inclusion criterion of requirements was applied towards the population.

3.8 Population, sample, and sampling procedures.

The targeted population of study that this inquiry focused on, was black adolescent males from seven health care facilities located in Ekurhuleni metropolitan city. This was due to the account that the sample that was obtained, will represent a broad study population and ascertain that small samples studied, may generate results that are accurate and to an extent, are able to be generalised on the larger population wherein the sample is drawn from (Martinez-Mesa et al, 2016). While in qualitative research the representativeness of the sample is of less focus, the central goal is to gather accounts that are specific, events or actions that can inform and strengthen understanding (Boddy, 2016). Nicholls (2017) postulates that the objective is to guarantee that the sample drawn from the population of research has the potential to yield rich results in data on the social phenomenon and the specific perception of a context. As the research approach is qualitative, participants were acquired using a non-probability or non-random purposive sampling. According to Vehovar, Toepoel and Steinmetz (2016) this is a selection of a specific group of people and has a set criterion for the inclusion in the study. Purposive sampling as a concurrence of non-probability sampling was used to ensure that the participants chosen, met the characteristics of the criteria.

Etikan, Musa and Alkassim (2016) indicate that purposive sampling is adequate in choosing accounts that are informative, specific and facilitates a deeper understanding of cases. These authors purport that the goal of purposive sampling is to provide focus to participants with characteristics that will aid in answering the research question. The sample of inquiry was of significance in providing the researcher with sufficient substantiation of both the theoretical and analytical generalisations from the population under study. In the focus group the sample was six male adolescents, followed by six individual interviews which were conducted separately from focus group. The sample was black adolescent males who are HIV and AIDS patients and reside in Ekurhuleni. The reason for choosing this sample is that it possesses the ability to inform the study, and has a great probability of participants to provide accounts of their adherence as HIV and AIDS patients.

Interviews were chosen to delve deeply into individual perspectives, while the focus group was selected to facilitate interactive discussions among participants, allowing for diverse viewpoints to emerge.

The sampling criteria in this regard was:

- Black adolescent male aged between 16 - 21 years.
- Participants should be patients of HIV and AIDS, on ART and a resident of Ekurhuleni metropolitan district.
- Participants to have a duration of 3 years and more on ART since diagnosis.

3.9 Research Instruments and Pre-testing of the research instruments

The research used a focus group schedule, and an interview schedule for individual interviews. Nyumba, Wilson, Derrick and Mukherjee (2018) assert that a focus group schedule is a preparation of a set of questions and sub-questions which indicate the number, the duration, and the scheduling of the session. in addition, an interview schedule is an instrument of research that utilises a set of predetermined questions with a series of response prompts. Barrett and Twycross (2018) concur that focus group and interview schedules are used frequently in qualitative approach research and denotes the use of open-ended questions and other questions that may be used together, to probe follow-ups and means of accessing more information. This method of instrumentation sufficed for the study as it guided interviews to be in alignment with the research questions, and the themes that instructed the research topic. Moreover, since the area of focus was on realities, opinions, views, and internal perceptions, using these schedules prepared the interviewer, while the instrument allowed the researcher an opportunity to explore further on the themes. This created a space where informative interactions took place and the elicitation of new concepts were probed further and had the potential to substantiate on the research theme. In this regard, the focus group session was held in a conference room at the selected health facility wherein, health protocols were observed. Alternatively, with the increasing utilisation of information and technology tools, interview sessions were additionally proposed to be conducted hybridlike, via WhatsApp joined calls while being mindful of issues of confidentiality.

The research utilised semi-structured interviews to deliberate on the aim and objective of the study. Into the bargain, the interviews were structured to probe information about the experiences of black adolescents' males living with HIV and AIDS, particularly adherence to ART and explore clinical, social, and various reasons towards adherence. Roulston and Choi (2018) state that semi structured interviews entail a set of questions and impartial topics to be

covered referred to as interview schedule and focus group schedule where the respondents have a high possibility of discretion to reply. Questions posed did not follow as set on the schedules, and questions that were not listed were asked as the researcher picked up on emerging themes while interviewees narrated. However, all the questions were asked, and wording of a similar nature was used from researcher to participant. This permitted the researcher to use skills of probing and making use of appropriate prompts for interesting points where information may have been a challenge to elicit. The researcher additionally used a focus group as an instrument, such being the case, Carey and Asbury (2016) indicates that a focus group interaction entails same features of an in-depth interview and in contrast, the area of inquiry occurs within a small group setting. This is to primarily investigate normative behavioural aspects, provide insight about how a collective think about a particular issue, about a set of ideas and opinions and the variability that exist in particular communities regarding experiences, practices, and beliefs. Reasons for using a focus group were based on the advantage that the researcher can observe non-verbal behaviour of participants as it allowed an opportunity that permitted the researcher to construct a rigorous assessment of feelings behind responses of participants to the issues under study.

The initial segment of both the interview and focus group schedule was centered on the demographics of participants. This was followed by the experiences of being a black adolescent male and living with HIV and AIDS, the professional and programmatic patient management practices that are attributable to adolescent ART adherence, the social and clinical factors leading to ART adherence amongst them, to what extent does sexual and reproductive health services reflect adolescent adherence to ART, and views in the society about adolescents who grow up living with HIV and AIDS. A predetermined set of questions was prepared, and additional inquiries were guided by the participants' responses. Table 3.1.1 below lays out the rationale for including all subjects in the Interview and focus group schedule.

Table 3.1.1 Various subjects in the interview and focus group schedule, and rationale for their inclusion.

Item	Rationale for inclusion
Biographical details	The introductory section of the interview and focus group schedule incorporated demographic information such as gender, race, age, and occupation to generate a socio-demographic profile of the participants.
The experiences of being a black adolescent male and living with HIV and AIDS.	The subject on the experience of being a black adolescent male living with HIV and AIDS was used to derive a context reinforced data, with an outlook to draw knowledge assertion based on constructive perspectives (Prior, & Talmy, 2021). Illustratively, there are various meanings of individual experiences on the influence of living with HIV and AIDS on young males in South Africa. This is due to the reason that knowledge is a construct grounded on personal experiences and hypothesis of the environment by those who inhabit the social world (Pulla & Carter, 2018). This inquiry was incorporated to present guidelines for the probe route.
The professional and programmatic patient management practices that are attributable to adolescent ART adherence.	It was assumed that, probing on the patient management practices would unearth the subjective experiences and perceptions of adolescents themselves regarding patient management practices, with the importance of understanding and uncovering not only the clinical factors but also the broader social, cultural, and contextual elements that impact

	the adherence behaviours of black adolescent males.
Relations with significant individuals offering you support. (Probe matters of status disclosure, possible influences of family, friends, external family members)	It was deemed significant to include a series of questions on the relationships that participants have, probing on disclosure and influences of social support. It was considered a possibility that this series of questions aligns with the emphasis on understanding the subjective experiences and perceptions of individuals within their social context. By delving into the dynamics of relationships with significant individuals, such as family, friends, and external family members, to uncover the nuanced ways in which these social connections impact the adolescents' experiences with HIV and adherence to ART.
Views in the society about adolescents who grow up living with HIV and how do they understand and make meaning to living with this condition.	The rationale behind this probe on the society's views and understanding of being an adolescent and living with HIV and AIDS was posed due to the existing mainstream research which pathologises adolescents living with this condition. It was under the premise that, sharing from their own experiences ideally positioned them to contribute to the narratives in the society, to affirm their validity or if they are preconceptions emanating from constructs that are societally conceived.

Pre-testing of the instrumentation involves the analysis of the research to determine whether the chosen methodology has the potential to yield results about the research question examined by the overall study (Taherdoost, 2016). For Mikuska (2017) pre-test speaks to the period of

time taken to direct the interviews, furthermore, to assess if there are any impediments that can emerge during the interviews such as participants not comprehending the research questions. According to this author research instruments such as interview and focus group schedules are pretested to demonstrate their feasibility purposes.

Thus, both the interview and focus group schedule were used with two research participants, however, the findings of the pre-test were not included in the data. Pernerger, Courvoisier, Hudson and Gayet-Ageron (2015) purport that a pre-test allows the researcher to identify uncertainties in the interview and focus group schedule, errors in the processes of the methodology, and the observation of non-verbal cues of participants as they respond to the interview questions. This became an enabler to the researcher, in utilising techniques and communication skills, that were applied to maintain and promote the reliability and quality of the study.

3.10 Methods of Data collection

According to Peters and Halcomb (2015) the selected methodology influences the method of data collection. Qualitative interviews were sufficient for this study. King, Horrocks and Brooks (2018) asserts that an interview is a face-to-face method of data collection from the participants through the use of questions that are open-ended. Against this background, qualitative interviews were leveraged, to collect data from the sampled pupils. This permitted the researcher to probe using explicit questions and utilise indirect strategies used in social work, in particular, empathy and mirroring of body language cues. This method is effective in obtaining rich and in-depth qualitative data (Oltmann, 2016). Therewith, data was collected using a focus group, thus, the grounds of additionally using this method is that it engendered a close proximity between participants, which facilitated the discovery of how different groups think and feel about the topic, which is useful when investigating a complex phenomenon. Newcomer, Hatry and Wholey (2015) argues that the usefulness of a focus group is centered around how it taps into interpersonal communication which can indicate sub-cultural values or group norms of a population and aids the researcher with an opportunity to solicit clarity as participants provide a diverse of information. The researcher was able to gain an in-depth perception and understanding of adherence on ART amongst black adolescent males. The effectiveness of this method is premised on how it allowed for note taking and audio recording. Contrarily, this required that note taking, and recordings are precise and accurate (largely verbatim), and it is similarly limited to the commitment of participants to the process in order to produce good results (Rosenthal, 2016). exhibited the potential to

These methods of data collection exhibited the potential to provide the researcher with access to private accounts with regards to participant's experiences, perceptions, and behaviours. This denotes that the meanings of central themes in the life world of participant's ought to be described and the main aim of interviewing subjects is based on the rationale to understand the contributary factors attached to the phenomenon being researched (Adhabi & Anozie, 2017). The researcher will was able to apply the skill of empathy as the interviews unfolded, following that, interviews were advantageous in acquiring the narratives behind the participant's subjective experiences. The degree to which the interviews were efficient, was influenced by the expertise of the researcher to conduct extensive interviews, since training of conducting interviews with participants has been obtained from the Social Work discipline and the researcher is able to apply interviewing skills such as: probing, active listening, and empathic listening.

3.11 Method of data analysis

Data analysis in research denotes giving sense of the empirical data gathered in the field work. Mayer (2015) states that it is a systematic process that aims to arrange and attach logic to data and to explain patterns and trends within the data that is collected. In accordance with this, the method of data analysis that the researcher harnessed, is thematic content analysis. According to Vaismoradi, Jones, Turunen and Snelgrove (2016) thematic content analysis is a method that is rooted in the identification, analysis and explanation of data based on the interconnection of basic themes. Thus, the interpretation of data considered the analysis of interconnectedness of themes that were emerging and the meanings they hold in relation to the study (Friese, Soratto & Pires, 2018). The study was reliant on understanding the meanings of participants and additionally used secondary sources such as journal articles in collusion with participants to give discourses of the convergences that occurred from the reviewed literature and the collected data. The process of analysing data involved various steps which are elaborated in sequential order subsequently:

Phase 1: *Familiarisation* with the data – As a means of collecting data, audio recordings were utilised. These recordings were subsequently reviewed and transcribed to identify distinct themes and patterns. To ensure consistency between spoken content and the researcher's written note Audio recordings were employed as a component of the data collection process. These recordings underwent transcription and were repeatedly listened to for the identification of various themes and patterns, the taken notes were thoroughly reviewed multiple times (Braun & Clarke, 2021).

Phase 2: *Generation of initial codes* – During this stage, themes were categorised into distinct codes. This process involved grouping similar themes, even if expressed differently, under the same code.

Phase 3: *Searching for themes* – Having organised the data into codes, these codes served as a foundation for identifying overarching themes. During this process, similarities in responses to specific questions were sought to construct cohesive themes.

Phase 4: *Reviewing themes* - According to Braun and Clarke (2021), While examining different themes, the researcher acknowledged that certain themes lacked substantial supporting information or needed to stand alone instead of being grouped with multiple sub-themes. The process of reviewing themes involved a repeated examination of the assigned codes to the information. This revisiting of themes provided an opportunity to ensure the appropriateness of certain data within a specific theme (Braun & Clarke, 2021)

Phase 5: *Defining and naming the themes* – This section involved categorising each finding of the analysis into distinct themes outlined in the final report. Each theme underwent a detailed analysis derived from the data provided by participants. Furthermore, each theme was connected to its relevance and association with the overall topic.

Phase 6: *Producing the report* – The ultimate report aimed to communicate to the reader the experiences of being a black adolescent male and living with HIV and AIDS. It sought to achieve this goal in a logical manner that instilled confidence in the analysis presented.

The selection of this method by the researcher was grounded in the belief that "a rigorous thematic approach yields an insightful analysis that addresses specific research questions" (Braun & Clarke, 2021). It proved valuable for exploring the perspectives of diverse participants, discerning similarities, and distinctions, and generating unexpected ideas.

3.12 Ensuring trustworthiness of the study.

Ethics in research include requirements on the work, protecting the dignity of participants and the publication of data in the research (Anney, 2014). The author Indicates that the research should attempt to highlight the presence of true nature of the phenomenon being studied and ensure that the study is credible. The researcher therefore abided by the Human Research Ethics Committee (Medical) proceeding criteria to assess the quality of the study: credibility; transferability; dependability and confirmability.

Credibility

Credibility denotes the extent to which the accounts of the research study are believable and appropriate with reference to the degrees of agreement between participants and the researcher and believable to critical readers (Noble & Smith, 2015). Therefore, techniques that were used, to sustain credibility in this research study included prolonged engagements, member checking and highlighting perspectives of participants. An approach of member checking was utilised to ensure credibility. Harvey (2015) states that member checking, similarly, known as: respondent validation is an important process wherein findings from the data and conclusions from the participants whom the data is originally attained from, is checked, and validated. The researcher was in constant check and validated observational and interview data with participants in the course of data collection. Into the bargain, the researcher employed the peer debriefing, alternatively known as analytical triangulation to advance the credibility and trustworthiness of the study. This is a process that allows the researcher to deliberate on the method of data collection, analysis, and interpretation with the peer debriefer who is not directly linked to the study on a continuum (Treharne & Riggs, 2014). In light of these considerations, the research supervisor was mandatory in advancing critical thinking during the process of the research, furthermore, the continuous guidance of the research supervisor contributed towards the provision of alternative viewpoints. The researcher attempted at great length, to produce adequate data that was analysed bearing in mind the implications for contextual influence of the data.

Transferability

In order for the study to be transferrable, the phenomenon under study should have the ability to be justifiably applied to another setting and feasibly produce results that are similar to some extent (Hadi & Closs, 2016). For Chowdhury (2015) transferability is focused on the generalisation of the study findings to a context and issue that the study is probing. Thus, in order to obtain transferability, the researcher yields detailed accounts of the research context, processes, and participants. Although there are challenges of meeting the criteria of dependability in qualitative research, it is of paramount that the research allows future researchers to repeat the study. Thick description is another method that is mandatory to use when seeking to obtain external validity or transferability. Amankwaa (2016) contends that this pertains to the provision of sufficient and rich details concerning the setting of the study, techniques used for sampling, the exclusion/inclusion criteria, the method of data collection and the method of data analysis, in order to allow the reader to be able to evaluate the degree

to which findings from the study are transferable to various surroundings or applicable to populations. This aids in directing the trustworthiness of the study and in certifying credibility.

Dependability

Despite the challenges of meeting the criteria of dependability in a qualitative research, it is therefore important for the researcher to permit researchers in the future to repeat the study. Equivalently, to attaining confirmability, there are significant steps that needs to be taken during the collection of data and analysis as an indication that the findings have emerged from the collected data and not the researcher's own biases (Chowdhury, 2015). Stratford and Bradshaw (2016) assert that dependability speaks to the research study being the same across time and allow repetitiveness. according to Connelly (2016) this should be checked through audits of the inquires. This denotes data and supporting documents being assessed by an external referee. The research supervisor was the external referee in this regard.

Conformability

Conformability pertains to the objectivity of the study during the collection of data and data analysis. The requirements therefore seek congruence between two or more independent individuals regarding accuracy, relevance or meaning of the data (Henry, 2015). Klanke (2016) concur that conformability refers to the quality of the results elicited by research with regards to how accurately they are supported by the participants and occurrences that are independent of the researcher. Techniques such data triangulation (researcher and context) can be effective tools of conformability, in addition, this was done through referencing literature and findings by various scholars to confirm and strengthen the researcher's descriptions of the findings (Hadi, Ansong & Solomon, 2019).

supplementary approaches that were deployed to ensure trustworthiness include, self-description/reflexivity, and thick description. Galdas (2017) suggest that the process of self-description and self-reflection play a significant role in assisting the researcher to admit and reduce biasness. With that said, self-reflection permitted the researcher to discuss his views within the study while highlighting how experiences, the level of knowledge and beliefs affected the discoveries from the study. Creating notes during field work and keeping and updated reflective journal aided the researcher to recognise any biases which may have been emerging while in data collection phase.

3.13 Ethical considerations

In order for the research to be lawful, ethics are important to be taken into consideration. In this regard, the research process should be of integrity and respect the dignity of participants. In addition, be rooted with honesty and transparency in relation to research participants and obtain an informed consent or assent if relevant (Iphofen & Tolich, 2018). Haines (2017) agrees that the research study should protect vulnerable people, uphold privacy, confidentiality and be inclusive. Reid et al (2018) state that ethical consideration in research are dilemmas and clashes that emerge over the better way to conduct research. To be considerate, this research study adhered to the standards of the research integrity avoiding fabrication, plagiarism, and falsification. Therefore, the following ethics were adhered to in conducting the research.

Informed consent

According to Roth and Van Unger (2018) informed consent refers to the knowledge that is given to participants about the research study, to allow them to make an informed decision. The decision results in obtaining permission from participants informed by the principle of no coercion and no deception of participants. For Nusbaum et al (2017) this process entails disclosing to participants about the study and informing them of their rights to withdraw from participation at any stage they may feel that they do not wish to continue further. An informed consent serves to provide participants with adequate information taking into consideration, the purpose of the study, procedures to be followed and potential risks and advantages of participation (Ryen, 2016). The consent additionally requires permission to voice-record interviews which is obtained from participants and will be stored and made available two years following publications or six years should if no publication results from the study.

Confidentiality and anonymity

Confidentiality is about protecting the identify of participants and not breaching their rights to privacy (Surmiat, 2018). The researcher may know the identities of participants, however, should exert relevant strategies to keep their identities disclosed. For Kamanzi and Romania (2019) confidentiality is a condition that permits the researcher to know demographic details about participants and employs steps to safeguard the details from being discovered. This author further asserts that the steps to realise confidentiality include the avoidance of mentioning names of people, religious or cultural backgrounds, places, family relationships, occupation, and various potential information of identification. For this purpose, confidentiality was ascertained through the use of pseudonyms to protect personal identity.

This was ensured during data analysis through the use of direct quotations of responses, which in any way, will not lead to the identification of the respondent. The data that was obtained from the study participants was handled and stored safely, after the completion of each interview, recordings and transcripts were protected from being copied, interception and theft. The data is therefore stored in a computerised database that is inaccessible to any user apart from the researcher. The collected data is anonymised through removing of participant identities to guarantee no link between participant and the data.

Avoidance of harm or non-maleficence

Jiggins and Asempapa (2016) emphasises the importance that no harm should come to participants due to their participation in the research. In addition, the author asserts that participants should not be exposed to pain or danger in the process of the research, either in a psychological, social, or medical research. There should be no adverse consequences to an individual as a result of their participation in the study. At best, the researcher is obligated to protect participants from any harm and under the principle of informed consent ensure that participants are assessed of all possible risks from participation (Smebye, Kirkevold & Engedal, 2015). Roberts (2015) highlights that participation in a social research may necessarily trigger participant to narrate on personal matters, bringing about emotional distress. If so, the author reiterates that the researcher's requirement is thus, act, make use of a contingency plan and ensure that the interaction in the research does not come to an end until there is a resolution of the emotional distress that has surfaced and an alternative to a follow-up assistance of counselling. Since the study may have induced emotional distress, counselling and debriefing sessions were optional ways that can were used to mitigate emotional distress.

Honesty

In the research process, maintaining honesty with participants is crucial (LaRossa & Bennett, 2018). The researcher ensured fairness in presenting the research report and accurately reported findings derived from the collected data (LaRossa & Bennett, 2018). To uphold this practice, feedback was documented, and the researcher maintained a reflective journal.

3.14 Summary of chapter

This chapter outlined the methodology employed to achieve the study's aim and objectives. It encompassed a detailed description of the research approach, design, population, sample, and sampling procedures. Additionally, it provided insights into the research instrument, its pre-testing, inclusion and exclusion criteria, and a rationale for selecting subjects for interviews and focus group schedules. The chapter further scrutinised the data collection method and analysis, addressing criteria for trustworthiness and ethical considerations adhered to during the study. The following chapter delves into the presentation and discussion of the study's findings.

CHAPTER FOUR

RESULTS AND DISCUSSIONS

4.1 Introduction

In this chapter, a very comprehensive analysis of the results in relation to the objectives of the study are introduced and discussed. In order to defend the identity of participants, pseudonyms have therefore been utilised. Different themes that emanated and determined on the basis of objectives are demonstrated with verbatim quotes and produce an understanding of every participant's lived experience of living with HIV and AIDS.

Tables 4.1 Demographic profile of participants (N=12)

Interviews

Demographic Factor	**Sub-category**	**No. of participants**
Gender	Male	6
Age	16 – 17 18 - 21	2 4
Occupation	Learner/student	6
Race	Black	6

Focus Group

Demographic Factor	**Sub-category**	**No. of participants**
Gender	Male	6
Age	16 – 17 18 - 21	3 3
Occupation	Learner/student	6
Race	Black	6

4.2 Demographic profile of participants

The table above depicts that all participants interviewed were black South African adolescents who are between the age of sixteen to twenty-one years of age. The research consisted of twelve participants who are all males. Out of the total, nine participants were born living with HIV and AIDS, while three participants acquired the infection through behavioural occurrences

(horizontal). Additionally, out of the total, three participants live in a household where there is a presence of a biological mother and father, while the remainder nine reside with their guardians, who are part of their extended family members.

All participants reside in Ekurhuleni and in various kathorus townships, five participants are in Grade 10, three in Grade 11, two participants in Grade 12 and two participants in vocational college. Participants utilise various health care facilities and attend different institutions of learning in Ekurhuleni and take various academic curriculums.

Most participants were between the ages of 18-21 years, the youngest participant was 16 years old and in Grade 10. The representation of various age groups, gender and various household structures was taken into consideration in light of the fact that, the publication by Amour et al (2022) emphasises that results derived from prevalent academic investigations have consistently indicated that male adolescents were an independent predictor of HIV and AIDS related mortality. These findings were aligned with reports by Jerene, Abebe, Taye, Ruff, & Hallstrom, (2019) and Mesic et al (2019) conducted in public health ART cohort and suggested that male patients were typically initiated on ART late, had more advanced illnesses, and exhibited worse clinical outcomes compared to their counterparts. It is argued that barriers to full participation in HIV care, elements influencing transition, and poor adherence may be responsible for the poor treatment outcomes in this unique cohort. Studies in HIV and AIDS proceeded to acknowledge paucity in research, particularly adherence amongst adolescent males, additionally, recommend that research endeavours aimed at identifying determinants of adherence to ART in adolescent males, and the development of interventions that will remedy low rates of virological suppression and increase the retention rate for this group, are solely required in this setting (Evans et al, 2013).

4.3 Description of participants and the setting of interviews.

The focus group was conducted in a conference room space that was arranged with chairs and a round table in the middle, all six participants of the focus group agreed to meet at Far East Rand Hospital in Springs since it was one of the closest and allowed adolescent clinic to take place on weekends. Six of the interviews conducted outside of the focus group were held in counselling rooms in various health care facilities, where participants were invited to quite venues with a rectangular table beside the wall and sat at diagonal opposite positions. During these interviews, some participants came wearing school uniform, while others wore casual clothing and bottled water was served during the discussions.

4.4 Objective one: To explore the perceptions of living with HIV and AIDS and experiences of male adolescents.

Theme 1: Navigating Identity Complexities: The Interplay of Stigma, Self-Worth, and Intersectionality Among Adolescent Males Living with HIV and AIDS.

Against this background, the experience of "Who am I" exhibited in manifold ways. Analysis of the responses brought two closely related themes to light, in particular, experiencing the pervasive notions surrounding HIV and AIDS and questioning one self-worth and place in society.

Each of the twelve participants reported that they had experienced a change in their lives after learning on their diagnosis, based on their observations around how people living with HIV and AIDS are treated either on films or hearing casual conversations around the community. In this view, there we disclosures by participants that the negative views and attitudes reflected by people in their social spaces, affected how they saw themselves. This perception about the self is narrated to be experienced because as patients, negative views about who they are reached deep within their emotions and thoughts, thus, created a deep sense of shame and a feeling of low self-worth.

"I often hear negative things about people that have HIV, so when I found that I have it too, I couldn't forget it because even though people are not talking negative things to me, its hard to ignore because I know they are talking about my situation" [Participant one: Focus group]

"When learners are making fun of each other at school, one learner said to the other learner that she is thin like someone who has aid, and the class laughed, that hurt me so much"[Participant four: Interview]

This believes as an aspect of culture and tradition, takes precedence in various African communities because some participants reported that, they had to rethink their choices if whether or not to disclose to others about their HIV status. Participants explained that they struggle with persistent feelings of worry and shame about how other people would perceive them based on their status. In their viewpoints, participants feel and timeously question if they will ever be accepted and valued by their peers and the community, particularly taking into consideration they are living with a condition that is still stigmatised. To reinforce this, participants revealed that, in instances where they struggle to gain weight or develop body sores due to ill-health, they become susceptible to public scrutiny amongst their peers. This speaks to social acceptance on how adolescent living with HIV and AIDS can be prone to bullying

based on their physical appearances. The responses given produce an idea that adolescent males manoeuvre around complex living circumstances, with late disclosure of their status adding to their sense of identity complexity, therefore, these adolescent males have to navigate their merging adolescence alongside managing a chronic health condition.

Participants in the study spoke about the need to grow and be strong men that can take care of their families, irrespective of being regular visitors to a health care facility, since they reside in economically challenged households. To highlight this, participants revealed that, in instances where there are no finances in the household, they miss their treatment days and find ways to assist their caregivers who are vendors in informal businesses. As a result of perceived social requirements, the intersection of multiple facets of identity, such as socioeconomic background, sexual orientation and race play a pivotal role in how these adolescents perceive themselves in relation to their health status.

Not only do these storylines demonstrate how participants formulate an identity template, but also introduce the intersection of traditional black masculinity ideals and HIV status. This is because male adolescents living with HIV and AIDS often encounter challenges to their perceived masculinity, as HIV and AIDS is sometimes associated with vulnerability. In essence, self-identity of male adolescents living with HIV and AIDS is deeply intertwined with their experiences of disclosure. participants narrated how, as they grow up, question, and formulate their identity in the subsequent quotes below:

"For me, I am always thinking about my condition, in my mind, I want to know and be a normal boy, but I am different because I am sick or I am not like other humans. As I have grown up in Tembisa, living with this condition makes me ask myself tough questions about who I am and who I will be maybe when I grow up. It's like having a person inside of you, a part of you that you can't ignore." [Participants : Focus Group]

"I think it is also the same for me, other kids don't have to think about their health condition when they play or have conversation with other people. When I was at the spaza shop, I heard two women talking about someone, I think it was their friend, but they were talking about her HIV status because they kept on saying that 'unamagama amathathu' (translated as; She has three alphabets), when they were speaking, they were laughing and making fun of her that she must drink her pills and stop having big mouth" [Participant 5: Interview]

The responses produce a substantiation of the notion that black adolescent males living with HIV and AIDS are inherently bound to question their identity from a younger age. Participants

correlated the value of their experiences being HIV and AIDS patients through a description of coexisting and social relations, which influences who they disclose their status to, and what kind or response they anticipate. In occurrences where the patient's status was disclosure to them earlier in their lives, participants were able to create ways in which they avoid disclosing their status indiscriminately as a way to protect themselves. In the study conducted In USA by Pantelic, Steinert, Park, Mellors and Murau (2019), found that when assessing adherence to antiretroviral therapy amongst patients living with HIV and AIDS, young males were significantly correlated with lower degree of adherence, into the bargain, major correlates of low adherence were identified in the relationship between the patient's negative self-image, and the number of days the patient did not take their medications, signifying that a more negative self-image predicted a greater non-adherence.

The responses from participants also warrant a citation of the psychosocial development theory. Stage 5 which is known as identity versus role confusion that takes place from the age of 12 to 18 years. According to this scholar, this takes place during the frequent turbulent teenage years and plays a paramount role in developing a sense of personal identity, which will continue to inform development for the rest of an individuals' life. In addition, an individual's identity provides them with an integrated and cohesive sense of self that endures amidst living. Thus, our sense of personal identity is moulded by our experiences and interactions with others, therefore, it is this identity that guide actions, belief, and behaviour as one moves along the adolescence spectrum. This scholar posits that adolescents need to establish a sense of self and personal identity, wherein, success results in the ability to remain true to oneself, while failure leads to role confusion and a weak sense of self.

Theme 2: Navigating the Shadows: Adolescents unravelling the mystery of their HIV and AIDS status and building resilience.

Participants referred to their observational learning of attending health care facilities regularly, however, without knowing reasons for the visitation as they were entering teenagerhood, informing their understanding of the world and the environment they live in, through being active participants of systems. In this theme, participants reported that they did not know about their HIV and AIDS status, however, were curious as to why they have their bloods drawn occasionally.

To elaborate further, eight participants asserted that a different illness was cited, such as cold & Flue, or eye-sight problems, whenever they asked their caregivers around the reasons of

regular intake of medication and not necessarily disclosure about their HIV and AIDS reactive status. It was reported that while attending regular visits to the health care facility, curiosity continued to mount, which was also informed by teachings from Life Orientation subject, that led to the realisation they might be living with HIV and AIDS. Participants expressed having deep thoughts around how they have acquired HIV and AIDS, since they did not partake in unprotected sex with an HIV and AIDS positive individual as per indications on the Life Orientation textbook.

"when I found out about it, I was told it was a virus, or kind of flue, I did not think at that moment that I will actually have to take medication forever, I was the only one who was taking medication in the house, so I used to ask myself why" [Participant five: Focus Group]

"I stay with my aunty and my uncle, so I did not know who to ask, my sister is the one who constantly takes me to the clinic, so I really did not know how come I got HIV" [Participant Two: Focus Group]

Thus, participants reported that dialogue engagements with their caregivers and health care workers around their HIV status began from the age 14 and 15 years, where they learned on how they acquired the virus. In addition, participants learned that they are orphaned and that their caregivers are not their biological parents.

"My grandmother told me that my mother died when I was six years old, she said that she was very sick, so in order for me not to be sick, I need to take medication. So I figured for myself that I may got HIV from my mom because my grandmother doesn't take medication" [Participant Four: Focus Group]

This speaks to household arrangements in South Africa, that a high proportion of male adolescents living with HIV and AIDS are either single or double orphaned, Moreso those growing up with vertically acquired HIV and AIDS and become increasingly receptive to manifold hardships negatively impacting their quality of life. While learning on their reactive status and the true realities of their lives, participants that were born living with HIV and AIDS explained that they experience continued emotional distress that stemmed from fear of death since one or two of their parents succumbed to the virus. six participants reported that as they grow up, they often assume that at a certain age, death would be eminent to them. To date, participants perceive themselves as capable of having a long life if they take their medication regularly and learn how to navigate a daily living from their health care workers.

In the following storylines, participants narrate their experiences of independently coming to the realisation that they are afflicted by HIV and AIDS.

"You know? I really didn't get it at first, I just thought that I was going to the clinic for check-ups and stuff, then as I kept going, I started noticing things that they were doing and the stuff that they were talking about. And I was like, let me put one and one together, and think why they take my blood, maybe I have this HIV/AIDSs thing. It was a bit scary, but also like something I was solving for myself" [Participant one: Interview]

"So, mina neh, bengi cabanga uguthi ugogo wu mama wami (translated as; I thought that my grandmother was my mother), so when I found out from the nurse that I have HIV, I thought that I got it from her, but I was told that no…my mother passed away when I was a baby and my grandmother started taking care of me, so be ngi no ku cabanga uguthi nami kusho ngi zo fa (translated as; I would often think that this meant that I will also die" [Participant 3]

"my aunt told me that when I play with other kids, if I start having a blood, then I must come home immediately. Also, she told me that I have flue every day that is why I must take medication even though I was not coughing…so I think I started noticing that I have something else" [Participant Five: Focus Group]

The storylines of participants are coherent with the view that the death of parents distorts adolescents and young people's quality of life and engenders instabilities resulting in mental and behavioural Challenges (Namisango et al, 2019). According to Ndlazi and Masango (2022) long term effects of orphanhood, particularly maternal death beyond the age of 16 years results in children suffering emotional distress from prolonged bereavement, which affects their capacity to develop positive coping strategies. Therefore, their customary coping strategy becomes silence and withdrawal which further exacerbates emotional distress. The experience of a participant below depicts how emotional distress emerge on an adolescent living with HIV and AIDS.

'You know? sometimes I am angry that why must I take the medication because it is not my fault that I have HIV, and sometime my heart is sore because why did I deserve to have this kind of sickness and other children don't? … No one can answer me that question," [Participant Four: Focus Group]

This account affirms the view that adolescents encounter different challenges when it comes to accepting and approaching diseases. Many adolescents are afraid, misinformed, in denial or lack familial or social support. Accordingly, providing care to adolescents is a multilateral

process in that no two adolescents are the same, however, they all need sensitive, flexible, cultural, and developmentally suitable care.

Participants in the aforementioned extracts echoed the idea that social constructions play a role on how an individual's identity develops. Adolescents' socialisation with their caregivers, educators, peers, and members of the wider community helps them define and reinvent who they are. Investigating similarities and differences between themselves and others in their social surroundings helps this particular group of adolescents develop their sense of self. Participants' behavior is somewhat impacted by their observational learning from their most knowledgeable other and peers, which in this case is primary exposure to their realities and how to negotiate daily life, as they learn the contrasts on how to manage living with HIV and AIDS.

This is consistent with Albert Bandura's (1977) theory of observational learning, which holds that learning occurs as a result of observing how others behave. It might also be a type of social learning, which can take many different forms and be based on many different processes. In people, this frame of learning appears to require a parent, kin, or instructor with an environment rather than support or reinforcement. A demonstrator assumes the role of someone in authority or with greater status in the surroundings, especially in childhood.

Theme 3: **Emerging from Adversity: Adolescent resilience in the face of HIV and AIDS challenges on mental health and support systems.**

Studies have highlighted that the transition from childhood through adolescence is characterised by major changes pertaining to physical, social, and psychological development which all have an increasing factor towards risks of mental health problems. Findings by Gaitho, Kumar, Wamalwa, Wambua, and Nduati (2018) demonstrate that this is more evident amongst adolescents living with HIV and AIDS, as a result of biological impact of this condition and its management, the required psychosocial responsibilities of living with HIV, and related social and environmental stressors. When probed on how their lives have changed after learning on the diagnosis. Participants reported on experiencing persistent pondering on their live outcomes since they felt like their livelihood survival is premised on the intake of a treatment. In their narrations, Five participants mentioned that living with HIV and AIDS meant that they are always expected to be mindful of when they experience a cut anywhere in their body, resulting in bleeding, they should seek help immediately, into the bargain, added that when conversations around sex are spoken about, they are reminded about their condition and worry that they will either need to disclose to their partners and friends or always remember

to use a condom, which brings fourth feelings and anxiety around disapproval from people and therefore, self-convince that they are not worthy of being loved and forming intimate relations.

One of the common shared sentiments by participants was that family dynamics, particularly in communal households characterised by arranged care, disclosure of HIV and AIDS status is only limited to a number of household members, which makes it challenging to build resilience around regular intake of their medication, and fears of being socially isolated by their own family members. Three participants noted that discussions on acquiring HIV and AIDS during Life Orientation lessons only address it as a behaviourally acquired condition, neglecting to mention the possibility of being born with it. Consequently, they feel overlooked and are treated as if they are at fault. These findings indicate that despite the presence of established social support systems within the households of adolescent males, there is a lack of perceived emotional and practical support from these networks. Thus, this suffices to share light into the nature and dynamics of social support systems which may and may not contribute to resilience and wellbeing of this collective. In addition, these revelations by participants demonstrate that although social support systems can be satisfied by social caregivers emerging as educators at school, friends, pastors in faith-based organisations and other exemplary figures in the community, adolescent males still experience a dilemma of forming emotional and supportive relationships where they will feel empowered to disclose their HIV status without fear of rejection.

Participants in the study spoke about the challenges they encounter when seeking and receiving psychosocial support. In conjunction with stigma and discrimination, participants shared around limited access to mental health services. Three participants noted that their healthcare providers frequently advise them against engaging in sexual activity, expressing a culturally ingrained perspective in healthcare delivery. This perspective may overlook the reality that adolescence is a phase marked by exploring sexuality. Thus, laments the need to adopting a more youth-centric approach to healthcare, rather than an authoritative "I know better because I am an adult" stance, which could foster open and courageous dialogues addressing mental health determinants and dismantling barriers to support. Ultimately, study participants asserted that they frequently experience a sense of isolation from others, leading them to seek continuous alternative social groups where they won't attract attention or raise alarms. In doing so, they aim to maintain the confidentiality of their status.

Three participants share their insights on how they experience mental unwellness as they manage living with HIV and AIDS.

"I always feel different you know, usually when I am sick, I sometimes think that my friends or learners at school can see what I am sick with, and I become scared and spend time alone" [*Participant Six: Interview*]

"u *mamcane uthe ngi nga tsheli muntu ukuthi ngiya gula, manje mangi vakashile a ngi khoni uku phuza ama philisi ngoba ngi ya saba ukuthi ba zo bona (translated as: my aunt said that I should not tell anyone that I am sick, so when I am visiting other family members, I find it challenging to take my medication because I am scared that they will see or find out that I am sick)" [Participant Two: Interview]*

"We were seating in a group during break, we were speaking about sex, and we also spoke about HIV, Sabelo said that if he found that he had HIV, he was going to kill himself…from that day I stopped chilling with them, and I stopped having friends and eat alone now" [Participant Four: Focus Group]

The findings can be interpreted from the standpoint of systems theory, elucidating how various elements in the environment influence human behaviour. This perspective helps us grasp the significance of family involvement in shaping an individual's functioning. When viewed through the lens of systems theory, one can understand how family, school, and the broader community can have both positive and negative effects on the life of an adolescent as they grow. Drawing on the analysis above, it is asserted that the progress of a black adolescent male living with HIV and AIDS is shaped not solely by individual family circumstances but also by a blend of living arrangements within the community. According to Carter (2017) this reconceptualisation is effortlessly unnoticed. Recognising the various system factors influencing an individual's well-being, it is evident that adolescent males may shape their goals based on the quality of individuals in their communities, making them susceptible to negative social conditions. This demographic composition has been deemed by the society to expose children to quality relations deficiency. Raphael-Leff (2018) asserts that many ordeals encountered by households raising adolescent males living with HIV and AIDS, fundamentally, are as a result of large social and societal problems.

According to the World Health Organisation report (2019) adequate mental health is characterised by an individual's capability to effectively handle the typical stresses of daily living, allowing them to work and contribute productively and fruitfully. The South African Depression and Anxiety Group (SADAG) states that there is an existing mental health crisis amongst adolescents. Approximately a third (31.5%) of adolescent's suicide ideation and

attempts need medical attention, 17.6% of adolescents have considered taking their lives, while one in four university students are diagnosed with depression, and more than one in five 18-year-olds have one or more suicide pivots (SADAG, 2018). It is against this background that researchers have noted this transition from childhood to adulthood as comprising of major psychosocial changes heightening the risk of developing mental unwellness. Into the bargain, these observations are more pronounced among adolescents living with HIV and AIDS, due to the biological impact of the disease, proceeding treatment and the psychosocial burdens and HIV related social and environmental stressors. Increased occurrence of depression (41%), anxiety (16%) and post-traumatic stress disorder (PTSD) (21%) have been found among school-attendees aged 14 – 15 years in Cape Town (Das-Munshi et al, 2016). Subsequently, the report by Kamndaya et al (2017) found that adolescent males living with HIV and AIDS and orphaned by AIDS are more likely to report symptoms of depression, and post-traumatic stress when compared to HIV-negative adolescents or non-orphaned children.

4.5 Objective Two: To explore clinical and social reasons related to adherence to antiretroviral therapy amongst male adolescents living with HIV and AIDS.

Theme 1: Thriving Amidst Economic Challenges: Navigating livelihoods of adolescents living with HIV and AIDS.

Adolescents living with HIV and AIDS and were exposed to HIV perinatally, may have lost one or both parents and potentially siblings to Aids. Not only does this create an atmosphere of loss and grief in different households, but also necessitates the need for alternative care arrangements in black families, which may not be adequately fulfilled. At times, this may result in this cohort being susceptible to stigma, as they transition to new households. When probed on how they navigate their livelihoods with focus on socioeconomic background, participants shared that they reside in households where either one of their caregivers is employed or reside in a household where none of the caregivers / parents are formally employed. In their narrations, four participants shared that their caregivers run small informal businesses, thus, they often need to provide a helping hand. Additionally, one participant added that till date, he still wakes up at 4am to help his uncle make fat cakes to sell in the local garage since it puts food on the table and sometimes creates an allowance budget for him. Five participants shared that in instances where there is no food in the household, they rely on their external family members for assistance or receive food parcels from the local NGO's or Faith Based Organisations. Two participants shared that they are raised by their grandmothers and reported that they survive on their senior citizen grants. Participants in this study describe how they

reside in households that are economically challenged and additionally mentioned that they reside in informal housing that are often crowded due to living arrangements that includes living with external family members in a single house; however, their caregivers make attempts for economic provision. While narrating about their households' backgrounds, participants explained that they infrequently miss taking their medication in instances where there is no food in the household. Two participants shared that they take their medication at 20:00 at night, thus, in instances where the household did not have supper, they would inadvertently miss their daily intake. Individuals who live in close proximity to their healthcare centers do not face any financial burden when attending their clinical appointments. In contrast, those who visit multiple healthcare facilities or must be redirected to a different facility for more advanced medical treatments report incurring transportation expenses and the necessity of purchasing meals or snacks during their visit, leading to additional financial outlays. All participants shared that they are beneficiaries of the National School Nutrition Programme in their respectful schools, thus, two participants who regularly take their medication in the morning before school have mentioned that they align this routine with the meals provided at school, particularly when breakfast is not available at home. Three participants share how they navigate adherence to ART while residing in economically challenged households.

"*My uncle sells amagwinya (fat cakes) at the garage, we have to wake up early so that we can sell to the people that are going to work, so I eat at the stall first before going to school, but usually in winter because in summer people don't buy them a lot, so sometimes we are able to buy enough grocery*" [*Participant One: Focus Group*]

"*There is no one working, my grandmother does not work, I accompany her to Shoprite or Post Office when she fetches her grant, and then we buy few things and some bathing stuff for me, sometimes we get meat from my aunty, I only ask money for important things only and can get some if my grandmother has*" [*Participant Three: Focus Group*]

"*We get food from the church and vouchers, and sometimes clothes. My mother and aunt sometimes works at the church, and they give us stationery or books. she gives me money to buy something at school when she has it, and also she saves money for me. I have only missed one day, when my mom did not have money because I have to take two taxis to Far East*" [*Participant Two:Interview*]

Based on the above narratives, it is evident that the employment status of caregivers or parents is a pivotal determinant for adolescent males living with HIV and AIDS and on ART,

particularly with regards to dietary requirements for managing the condition, as well as variable costs needed when needing to attend a clinical visit. Although their caregivers are not formally employed, they make means to provide economically, through running informal businesses, or managing old age grants well. In their study, Zungu et al (2021) found that due to an unbalanced distribution of income and widespread poverty in South Africa, the impact of poverty is felt through limited access to resources, inadequate food (especially healthy food), and food insecurity impacting negatively on ART adherence. In addition, these authors highlight that food assistance has been relatively found to improve ART adherence and reduce other preceding psychosocial demands. Moreover, housing remains a challenge in South Africa, with 7.9% of adolescents living with HIV and AIDS recorded to be residing in information housing, which limits privacy to ART intake. The HIV Report (2021), revelated that when there is lack of privacy related to ART, and when young people do not have enough space to be themselves, they might end up spending time on the streets where they can be influenced by peer behaviours from other adolescents. Into the bargain, the report further laments that social vulnerabilities translates into adolescents experiencing significant challenges accessing health care, resulting in poorer management of treatment, and weakened developmental outcomes.

Theme 2: Navigating the Unwelcoming Terrain: Adolescents' Struggle for Accessible and Adolescent-Centric Healthcare

When asked to describe the last day they went to a health care facility, participants indicated that they dreaded their visits and often contemplated attending. In this theme, participants shared at great length that the reception in health care facilities is not welcoming for them. The narrations depart from health engagement and access perspective of what an ideal clinic would look like for them. Participants in the study abandoned the view that health care facilities are adolescent and youth friendly. In understanding access to health care in their context, to them, having access to healthcare means being able to go to a clinic where healthcare workers provide their services, without feeling like they are doing you a favour. In their responses, four participants described instances in which they were yelled at by healthcare workers, while six participants expressed discomfort in sharing clinic days with adults. Participants in the study did not have many insights to report on positive experiences of utilising a healthcare facility, on the contrary, they often expressed a desire to complete their clinic visits quickly and return home. Moreover, participants frequently expressed a preference for assistance from student healthcare workers, noting their often more approachable and accommodating approach when providing services. One of the common shared sentiments by participants was that clinic hours

are not convenient for school learners, for this reason, restricted their engagement with clinical visits and instilled a fear of returning to the clinic if they missed their scheduled days, primarily due to concerns about potential mistreatment.

These findings indicate that a there are underlying issues that warrant cautious consideration around the quality of care or the overall adolescent patient experience in health care facilities, and how they meet the expectations or needs of the persons concerned. In addition, they underscore the significance of not only providing health care treatment, but also ascertaining that patients feel comfortable and well-cared for during their clinical visits. Moreover, the findings calls into question the effectiveness of healthcare delivery, the standard of human interactions, and the setting of the clinics. Furthermore, participants preference for assistance from students may be indicative of a more client-centered approach often adopted by students, or it could signify a perceived lack of approachability or empathy among more experienced healthcare workers. However, it is also paramount to acknowledge that student healthcare workers may not have the same level of expertise as their more experienced counterparts, which could impact the quality of care given. The difficulty of clinic hours for learners indicates yet another level of healthcare accessible complication. When clinic hours do not coincide with students' schedules, who frequently have set timetables, they may find it difficult to get healthcare services because it not only restricts access but also but also contributes to a sense of fear and anxiety among adolescents who worry about the consequences of missing scheduled appointments. The fear of mistreatment upon returning to the clinic after missing appointments highlights the significant impact of negative experiences on patient behavior, as this potentially deters individuals from seeking necessary care, leading to delays in treatment, which can have serious health consequences and overall retention in care.

These accounts by participants corroborate the publication by Zanoni, Sibaya, Cairns and Haberer (2019) on their research about adolescents living with HIV and AIDS In South Africa. The authors posit that a significant structural obstacle to care, adherence and retention for adolescents living with HIV and AIDS is their attendance at clinics during school hours. The learner's discord, which limits retention in care, is created by the conflict between attending school and going to the clinic. Adolescents frequently worry about the health care worker’s reaction following brief failures in compliance or missing appointments which results in long-term disengagement from treatment.

The following insights were shared by three participants as they narrated their experiences when engaging with health care facilities.

"*There was this day where I missed my appointment, it wasn't my fault because I am in Grade 11 and we have afternoon studies, and I can't go in the morning because the line is long and I finish late, so I end up no longer going to school when that happens. So, sometimes I don't go to the clinic and wait for another day if I am not busy at school" [Participant Six: Interview]*

"I always pray that when is my turn to come to the clinic, I find a student here because they are nice people, and they speak to me nice. The nurse who usually takes my temperature and gives me my file is not nice. She speaks loudly and when I miss my appointments, she speaks out loud that even people who are waiting at the waiting area can hear her, I don't like coming here, but because I must come, I don't have a choice" [Participant Four: Focus Group]

'*'sometimes I am scared to come here because you see older people who are sick and think that you will end up like that. It is better when there are other children or a learner like me wearing a school uniform'' [Participant Two: Focus Group]*

These narratives capture the sense that through adverse engagement with the health care facilities, participants had a different experience and expectations of the health care facility and the healthcare workers. The study by Cluver et al (2018) reveals that the provision of sufficient information and confidentiality considerations around adolescent health data is not associated with retention in care, and nor is treatment support groups, since there is limited data indicating the participation of adolescents, more so attending of an adolescent-specific support group. Thus, this may indicate the challenges that adolescents encounter when relating to adult-centered health care services. Into the bargain, the publication indicates that staff related factors that were significantly related with increase adolescent retention, was the adolescents' perceptions around health care workers who were kind and allocated time to their needs, additionally, it was ambiguous whether hurried appointments were as a result of health care worker's attitudes and administrative demands, which corroborates with adult literature on the importance of the relationship and engagement of service users with the healthcare facility and the health care workers.

Having said that, it is a human feature that an individual within a system is able to create and continue relationships. Shem, Kim and Hashimoto (2015) assert that positive relationships are mandatory for a person's physical and emotional wellbeing, however, it is evident that participants have their ideal expectations of how adolescent-centered services should be implemented as quoted in the response of two of the participants.

"Before coming to this clinic, I was at Charlotte Maxeke Hospital, they were so quick there and the staff was very nice. All the time, they were happy to see me and tell me that I am doing well when they write down my weight on the scale." [Participant Four: Interview]

"I have been coming to this clinic since I was a child, it always the same, sometimes I become sad if the nurse that I like leaves. I always wait longer on the line until I see the nurse that I prefer so that I can ask questions when we are talking about my file" [Participant Four: Focus Group]

Sentiments shared by participants affirms the view that adolescent males least utilise healthcare facilities. Thus, indicating the correlation between their engagement in healthcare and their adherence to antiretroviral therapy.

In sharing their experiences, participants locate their willingness to utilise the healthcare facility to its maximum, only when there is a relative workforce that is able to relate to them from a psychosocial level, therefore, in the absence of this, retention in care becomes impossible. On that premise, this is in agreement with what Saberi, Ming and Dawson-Rose (2018) postulate, that in order to improve engagement in care amongst adolescent, particularly the male cascade, healthcare workers serving this population could scrutinise their health care facility environment, notably the location, how welcoming the clinic is and separated from adult services. Lastly, utilising digital enablers to communicate with patients as a way to provided blended services in addition to medical care. The study further demonstrates that technology is a noted paramount methodology for enhancing adolescent-friendliness of healthcare services, preserving communication with adolescents, and improving overall engagement with care. Into the bargain, since these methods of communications such as applications and multimedia streaming chats are nearly ubiquitous amongst youth, can be leveraged to improve engagement in health care and deliver multimodal interventions. These discoveries corroborate with the findings of Medich et al (2019) who argues that a weekly text message intervention to a control condition of increasing adherence to ART, was correlated with lower risk of ART nonadherence at twelve months and lower risk of virological failure compared to the control group. Supplementarily, Erguera et al (2019) ascertain that utilising digital enablers to improve retention in care has the potential for early identification of problems, timeous problem solving, increasing health access and reduce the number of lost to follow up adolescents.

Theme 3: Navigating Adherence Challenges: The complex relationship between adolescents, antiretroviral therapy, and healthcare facilities.

The relationship and incumbent factors that an adolescent male has with antiretroviral therapy and their healthcare facility constitutes to an observed viral load. This theme reflects the participants experiences on antiretroviral medication. The management of HIV and AIDS requires a continued health engagement to yield positive outcomes. For this reason, following the prescribed methods of ART medication, attending regular clinical visits, and accessing psychosocial support and education are key elements to viral load suppression. Participants narrated about their regimens and how they have moved in between 1st line and 2nd line treatment. Nine participants who have been on ART since birth reported that they often get tired to take their medication. They went on to describe situations in which they forgot to take their prescribed medication and, even when they remembered later, chose not to take the pill because of a lack of motivation. Five participants in the focus group reported a pattern in which they occasionally skipped a day of medication intake, for instance, taking their medication on Monday, skipping Tuesday, and resuming on Wednesday. Several participants disclosed that when they episodically take their medication, they encounter a heightened occurrence of side effects, consequently leading to an increased likelihood of taking the medication intermittently, occasionally even twice a week.

“mina ngiyakhohlwa sometimes, kotwa ma ngi khumbula ngiya phuza, (Translated as; I tend to forget, but when I remember to take my dose, I take it), if a ngi wa phuzi for iskhathi eside, yi la ngi gula khona (translated as; Should I not take my medication for a long period, when resuming, that is where I feel sick/ experience side effects” [Participant Four: Interview]

Participants in this study described how they frequently feel too tired to take their medication or intentionally skip it due to fatigue. This exhaustion stems from the lifelong commitment to medication, and they believe they deserve a break. For those who contracted HIV and AIDS through horizontal transmission often struggle to accept the fact that they must take medication for the rest of their lives. They often have a strained relationship with their medication because it necessitates carrying it with them, which is a novel concept that adds to their stress and discomfort. Two participants, who received their diagnosis four years ago, shared that during the first and second years following their diagnosis, taking medication daily felt like a constant reminder of living with HIV and AIDS. This made it challenging for them to adhere to their medication regimen and even muster the motivation to face the medication containers. All participants expressed their inability to remember a time when they consistently took their

medication for a continuous three-month period. Nevertheless, they made an effort to ensure that as their clinical visit day approached, they diligently adhered to their medication regimen to prevent their viral load from spiking excessively during the check-up. Three participants share how they take their medication.

"Sometimes I feel like this medication is a lot to take, I remember when I was given many pills and the nurse said that they will help prevent TB, because when you have HIV and AIDS, you can also have TB. I didn't finish them because they were so many and when I take them every day, I feel like they don't not finish" [Participant Six: Interview]

"Mina kuba inkinga ma ku mele ngi hambe nama philisi lawa or ngi ya wa khohlwa, ngeke ngikhone uku wa phuza pham' kwa majita, nakhona a ya ngi khumbuza uguthi ngi ya gula… eish (translated as: For me, the problem is when I have to travel with this medication or forgetting them, I cannot even drink them next to the boys, they remind me that I am sick)" [Participant Six: Focus Group]

"Before, I was getting tired of how many pills I was taking, but it became better when I started taking one pill each day, I am able to take one pill even though I feel lazy or tired because it is quick. [Participant Three: Interview]

Based on the above articulations, it is evident that the relationship that an adolescent has with HIV and AIDS medication influences their adherence and retainment in care. While not all of them have a history of adverse viral load suppression, they still engage in the practice of skipping their medication by granting themselves self-approved treatment breaks. Similarly, to the study by Claborn et al (2015) and Mohd Salleh et al (2018) found that ART adherence literature repeatedly references treatment fatigue as a potential barrier, together with side effects. These scholars contend that treatment regimen fatigue factors in, the psychological fatigue dimension associated with long-term HIV and AIDS management. In addition, they maintain that pill fatigue is a diverse characteristic of treatment fatigue that may coincide with but is different from pill burden. Therefore, it is a feeling of being "worn out" by having to take ART medication daily, along with the resulting behaviours such as avoidant coping (Taking "pill holidays'), medication forgetfulness and other employed strategies to manage or triumph this psychological and physical fatigue. These narratives also demonstrate that adherence education on ART is a critical requirement to prevent drug resistance, while a continued medical care may assist with monitoring of the health status. Comprehensively, the paucity in literature on ART-related pill fatigue suggest that this is an under studied phenomenon which

is needed, considering its's salience in the lives of people living with HIV and AIDS and those that are navigating the stage of adolescence as well. According to Jaiswal et al (2020) this suggests that pill fatigue may be a factor connected to challenges that include side effects, internalised stigma, and forgetfulness. Pill fatigue additionally seems to overlap with participants' other adherence-related barriers.

4.6 Objective Three: To recommend best practices to find, link and manage adolescent males living with HIV and AIDS.

Theme One: Empowering Health Literacy: Navigating the complex landscape of adolescent HIV and AIDS management.

Adherence education and awareness of HIV and AIDS management is crucial for adolescent males. Since this chronic condition is complex, it requires ongoing medical care and various multidisciplinary interventions. In this context, participants were probed on how they use health information regarding ART in their day-to-day life. Adherence to treatment and health education therefore plays an integral role in improving health outcomes and the quality of life for these individuals. Participants conveyed a recurring lack of comprehensive information pertaining to the content of their medical files. Consequently, this simplified approach often leads to an omission of vital nuances contained within their medical records, which might otherwise provide critical insights into the overall health and medical history of the participants. Participants described a limited interaction with healthcare providers. Their discussions with healthcare workers were mainly triggered when they missed appointments and were reminded not to do so. Interestingly, five participants admitted to not understanding the information in their medical records or the purpose of regular blood tests. Nevertheless, they complied with these requirements because they were instructed to do so. Consequently, four participants mentioned that their medications changed, and they had to take more pills without a clear understanding of why. This often occurs when they transitioned from their initial treatment to a different one (1st line to 2nd line regimen) which typically involves the probability to an increase in pill consumption to manage virological failure. Insights in this theme are similar to the findings by Byansi et al (2021) who states that there is a significant positive relationship between knowledge and medication adherence practices as a strong predictor of adherence to ART. Thus, the author states that an increase in knowledge around medication use, is linked with higher adherence level. Into the bargain, since it is notable that distorted intake of ART amongst various individuals living with HIV and AIDS may impact cognitive development. The study by Asaolu and Agbede (2022) found that there is a

significant association between education attainment and medication adherence practices. Further studies by Bongfen, Torpey, Ganle & Ankomah (2020) employing an objective assessment of adherence education in public health interventions confirm this socio-demographic factor. Having said that, individuals concluded from their personal experiences and the fact that at least the trip to the health care facility was done. Two participants share their insights about their limited knowledge regarding their files and clinical history:

‘*’I think they write the dates to come to the clinic, I don’t know what they write on the file, but I always see the nurse checking if the medication I took the last time is finished, and also, they write your weight from the scale” [Participant one: Interview]*

“The nurse always takes my blood, but I don’t know when, I just come to the clinic regularly and I hear that maybe on this day they are going to take blood, and then next time I come to the clinic I just fetch the medication” [Participant Four: Focus Group]

Post-diagnosis, adherence education is critical for adolescent males living with HIV and AIDS to increase the likelihood of their retention in care. This is grounded in the notion that acquiring appropriate methods of adhering to antiretroviral therapy (ART) is essential for the success of the medication. Given that adherence can be challenging for adolescent males as they navigate matters of school, relationships, and their own sense of identity, adherence education can serve as an entry point for addressing specific concerns around ART. For instance, adolescents may have questions about side effects of medication, the reasons for drawing blood every three to six months, and the significance of the results. By educating adolescents about the meaning of regular blood draws as a vital indicator of viral load volumetrics, healthcare providers can engage in discussions about the social and clinical factors that can impact viral load numbers. This knowledge sharing, which is psychosocially cognisant, facilitates a deep understanding of the importance of adherence, the creation of strategies for taking medication continuously, the learning of how to manage side effects, and ultimately, the coping with emotional challenges related to living with HIV and AIDS. Through this scrutiny, the notion that medical file orientation for adolescent males living with HIV and AIDS serves as a gateway to adherence education and transparency is substantiated. By granting adolescents access to their medical records, healthcare providers can foster a sense of ownership and engagement in their care. This can lead to a deeper comprehension of the significance of adherence to antiretroviral therapy (ART), as well as a greater willingness to discuss concerns or challenges related to taking medication. Furthermore, transparency surrounding medical information can help to build trust between adolescents and their healthcare providers, which can further enhance

adherence and retention in care. Ultimately, medical file orientation can contribute to improved viral suppression rates among adolescent males living with HIV and AIDS. These findings lend support to the ecological study's contention that individuals who have access to multidisciplinary adolescent clinics with individualised support are far less likely to have gaps in care compared to adolescents treated when these services are not available (MacPherson et al, 2015). In addition, the authors contend that despite considerable variation in participant groups, settings, and content of interventions, there is evidence of effectiveness among adolescents attending public health facilities who receive adherence education and counselling aimed at improving empowerment.

Theme Two: Unlocking Holistic Healthcare: Navigating Awareness and Barriers in Accessing Allied Services for Adolescent HIV and AIDS Management.

From a systems theoretical approach, with a focus on the operational structure of healthcare facilities, a range of allied services plays a pivotal role. These encompass specialised domains such as dietetics, speech-hearing and audiology, physiotherapy, clinical services, social work, and psychology. Service users are encouraged to avail themselves of these allied services, as doing so not only optimises the facility's capabilities but also contributes significantly to the individual's overall well-being and holistic health. Adolescent males engaged in HIV and AIDS management have communicated a tendency to exclusively access a singular service line, namely the chronic illness clinic. Despite presenting diverse health needs as service users, there appears to be a lack of awareness among participants regarding the comprehensive range of services available at the clinic and how these services could significantly contribute to their adherence to antiretroviral therapy. Thus, it is argued that enhanced understanding and communication regarding the available services are essential for ensuring the holistic well-being of these individuals.

Certain participants have conveyed that, despite acquiring knowledge about allied services, the prospect of utilising them poses a challenge due to an absence of a positive and progressive relationship with the healthcare facility. There is a prevailing concern that seeking additional assistance may subject them to scrutiny, discrimination, and stigma. Consequently, these individuals express a preference for fulfilling their primary purpose at the facility and promptly returning home, reflecting a hesitancy to engage further with available services. This underscores the importance of fostering an environment that promotes trust and minimises potential barriers to accessing necessary healthcare resources. However, Two participants, who had encountered virological failure and subsequently underwent hospital admission, reported

that upon their discharge, they were directed to seek assistance from dieticians for the management of their body mass index and the Social Work office for counselling. Notably, one participant shared that the dietician recommended Ensure dietary supplements, significantly aiding in the improvement of his viral load and facilitating the recovery of his body. Additionally, the participant highlighted that these referrals played a crucial role in his enrolment on the food parcel list, which persisted for a duration of one year. This illustrates the tangible positive impact of coordinated healthcare services in addressing multifaceted aspects of an individual's health and well-being, thus, the collaborative efforts of multidisciplinary teams facilitate knowledge sharing, resulting in enhanced health outcomes, signifying the successful implementation of a standard operating procedure, leading to progressive outcomes for the service user. Two participants expressed a lack of awareness regarding allied services, highlighting that their sole purpose for visiting the clinic is to obtain medication:

Researcher: "Are you aware of any other types of services/ programmes that are offered in the hospital or should be implemented to build on what the health facility already has?"

Participant: "I don't know, I just come to my usual clinic for my appointment, I try to come early so that I can get my medication and finish early before the queue is long and go home. So, I don't ask about other things that are done in the hospital" [Participant Four: Interview]

"I prefer seeing sister Dikeledi only when I am here, and when she is not around, I just fetch my medication and go home because I don't want anyone else to know my personal staff. I am scared that I will be judged and that person wouldn't even know my story…so I just avoid going to other departments, I am okay" [Participant six: Interview]

The accounts by participants highlight a potential gap in knowledge regarding the comprehensive range of services available at the clinic beyond medication provision. Challenges include a hesitancy to engage due to perceived scrutiny and discrimination, emphasising the need for fostering trust. The report by Woollett, Pahad, and Black (2021) suggests that within adolescent clinics, there appears to be a degree of anonymisation concerning their HIV status. However, in blended clinics comprising of both adults and adolescents, characterised by a reduced adolescent presence, they might be more noticeable, making their HIV status more evident. However, instances of successful collaboration among multidisciplinary teams showcase positive outcomes, demonstrating the importance of comprehensive healthcare approaches. Moreover, specific cases illustrate the tangible benefits of referrals, such as improved viral loads and sustained support through initiatives like food

parcel programs and counselling sessions. Overall, these narratives underscore the significance of informed and integrated healthcare practices in addressing the diverse needs of adolescent service users. Findings by Smith et al (2018) indicate that the preferences of young HIV-infected patients in engaging with Sexual Reproductive Health issues mirror their approach to HIV management. They desire services that are adolescent-friendly, convenient, and characterised by enhanced service quality from clinic staff. Inadequate awareness of comprehensive service provision at facility level and societal bias against adolescents living with HIV, particularly from adults, contributes to a sense of mistrust among young individuals towards adults, especially healthcare professionals (Case, Patelic & Cluver, 2020). According to Grimsrud, Pike and Bekker (2020), Healthcare models that leverage collaborative efforts between service users and providers may play a role in retaining adolescents in treatment and positively influencing stigma associated with HIV and AIDS. Therefore, interventions for services catering to adolescents with HIV and AIDS may gain advantages from implementing peer interventions at the clinic level, incorporating peer treatment navigators, and ensuring the inclusion and representation of adolescents in multidisciplinary teams. In tandem, these young individuals may learn readiness skills as they transition to adult clinic and be retained in care.

Theme Three: Bridging the Gap: Leveraging innovative technologies for seamless adolescent HIV and AIDS transition and healthcare enhancement.

This theme involves exploring how innovative technologies, such as digital technologies and mobile applications, can be strategically employed to facilitate the transition of adolescent males with HIV and AIDS from paediatric to adult care. It delves into programmatic and policy considerations that impact the implementation of these interventions, with an attempt to ensure a seamless transition and improved overall healthcare outcomes for this cohort.

Participants in the study conveyed their reliance exclusively on traditional methods for accessing healthcare facilities, primarily through physical visits. Despite possessing mobile phones and being included in the contact lists of healthcare workers, some participants clarified that these devices were primarily used for contact tracing rather than seeking check-ups or addressing health-related queries or medication complications. Four participants highlighted challenges in responding to calls during school hours or having left their phones at home due to school policies, resulting in missed communication with healthcare workers. Additionally, three participants shared difficulties in adhering to medication collection schedules during extended school holidays, expressing uncertainty about whether they could contact the clinic to inform them of such situations.

"I get calls from the tracers calling from the hospital, at least that helps with reminding me that the date is coming closer, but sometimes they use different numbers, or they call while still I am at school" [Participant one: Interviews]

When questioned about recommending adolescent sexual and reproductive health services to their peers and providing relevant insights, participants expressed a desire for healthcare facilities to cultivate a more inviting atmosphere. They envisioned being treated with the kindness and understanding comparable to how teachers engage with them at school, even if they do not encounter healthcare workers daily. Participants emphasised the importance of improved communication with counsellors, suggesting platforms such as WhatsApp for more frequent and convenient interactions, as the current monthly or quarterly sessions may be insufficient during clinical visits where time constraints limit their ability to engage with counsellors about their health concerns.

"We have youth hours in my clinic, and I can go there afterschool, but sometimes, I just want to ask a question or maybe tell the nurse that its school holidays and I cant come to the clinic to come fetch my medication, so if I can call or send a message" [Participant Three: Focus Group]

"I only see the nurse when I collect my medication, I don't see the case manager or counsellor, I see her sometimes only when they say that my viral load is high, and they refer me to her. I will then see her after 3 months or six months" [Participant Five: Interview]

Insights in this theme are similar to the study by Woollett, Pahad, and Black (2021) indicating a notable occurrence that children who are living with HIV and AIDS are now entering their adolescent years in large numbers. This is observed in health systems that are struggling and lack sufficient resources, especially in South Africa, where a significant part of the population consists of adolescents, Moreso technologically savvy, yet this remains an untapped entrance to health care provision. Johannesburg's healthcare system grapples with a high volume of patients, frequently outnumbering available healthcare service providers. Consequently, there has been a swift increase in employing various paraprofessionals to fill service delivery gaps. Recognising the enduring challenge of managing adolescent HIV in South Africa, there is a pressing need for various and agile investments to mitigate viral resistance, enhance retention in care and improve viral suppression for this vulnerable demographic (Maskew, Bor, MacLeod, Carmona, Sherman, & Fox, 2019).

The implementation of health systems and programmatic interventions plays a crucial role in shaping the overall health outcomes for service users. Therefore, the way standard operating procedures are established should reflect the realities on the ground, ensuring they are both feasible and adaptable to the continually evolving health determinants of adolescents living with HIV and AIDS. The National Department of Health defines an Ideal Clinic as a well-equipped clinic that possesses excellent facilities, a proper staff complement, ample medication and resources, efficient administrative procedures, and an ample supply of essential items. It adheres to relevant clinical policies, protocols, and guidelines, while leveraging support from partners and stakeholders. An Ideal Clinic engages in collaborative efforts with government departments, the private sector, and non-governmental organisations to tackle the social determinants of health. Within the framework of an Ideal Clinic, Integrated Clinical Services Management becomes a central focus. This management approach aims to address the increasing prevalence of chronic diseases in South Africa efficiently and cost-effectively, with a section that focusses on adolescent and youth services. Having said that, Participants base their conclusions on personal experiences and observations during clinical visits, describing their experiences as service users as less than satisfactory. Two participants provide perspectives regarding their utilisation of healthcare facilities and offer insightful recommendations based on their experiences.

"Usually when I come to the clinic, I only listen to the nurse of the doctor, I don't ask questions, even though I have them, because I would sometimes be scared to ask or don't want to be judged, so I think that if I was able to write down my questions and send them, it would be better" [Participant Six: Interview]

''if my aunt does not remind me or ask me about my appointment, I sometimes forget because I don't check my clinic card regularly. The nurse or counsellor will only call you when you have missed your appointment. Sometimes I forget and maybe if they could remind us as the date comes closer" [Participant one: Interview]

Convenient healthcare features for adolescents are frequently outlined in policies. Yet, in resource-limited settings with high HIV and AIDS prevalence and busy healthcare settings, an efficient strategy to establish an adolescent clinic would involve scheduling all adolescent patients on a designated day, which is still a challenge to implement for various health care facilities in South Africa. This analysis highlights the impact of resource planning and availability in healthcare facilities, and the implementation of adolescent services on improving

adherence to antiretroviral therapy (ART) and achieving viral suppression. Given expanding mobile phone and Internet usage among adolescents, and a need for strategies to increase ART adherence, the review by Griffee, Martin, Chory, and Vreeman (2022) systematically assessed whether digital interventions could be used to improve adolescent ART adherence. While the use of mobile phones and the Internet in low and middle-income countries is not yet universal, it is anticipated to increase in the future. This growth could lead to a more widespread acceptance and effectiveness of digital interventions aimed at enhancing antiretroviral therapy adherence amongst adolescents living with HIV and AIDS. Therefore, these scholars posit that there is a critical need for thorough implementation research studies to assess the most efficient and sustainable ways to utilise digital interventions for promoting adolescent adherence in these settings.

The key point is that when adolescent males facing challenging conditions in their homes have access to more resources and support at the healthcare level, it enhances their likelihood of achieving positive outcomes in terms of medication adherence. These findings confirm the veracity that adolescent males diagnosed with HIV and AIDS face challenges in seamlessly transitioning into the treatment system. Many of them belong to social and economic strata marked by poverty, orphanhood, family difficulties, and other factors that hinder their effective integration into the treatment process. Additionally, it is important to emphasise that these adolescents find it difficult to independently initiate and adhere to treatment, and their motivations for seeking healthcare are inconsistent over time. This is also highlighted in the Mzanzi Wakho findings as reported by Van Staden (2022), since support for ART adherence and other care is not adequately addressed by healthcare service providers alone. Consequently, the author argues that in order for adolescents to achieve positive sexual health outcomes, there is a pressing demand to expand the provision of sexual and reproductive health services tailored for adolescents, along with the necessary support. The findings by Waid and Uhrich (2020) corroborate the above assertation by stating that a positive youth development approach to service delivery for adolescents living with HIV and AIDS is paramount to enable adolescents' progressing autonomy. Programmes for positive youth development involve actively encouraging personal agency and responsibility. They employ respectful methods to engage young pupil and concentrate on their strengths and abilities, aiding them in overcoming adversities and risks. Rather than regarding adolescents as patients with problems to be managed, the perspective is that adolescents possess potential to be developed and are capable of actively participating in resolving their own challenges (Catalano et al, 2019). In this regard

adolescents themselves influence the methods used in service provision, often incorporating other creative non-verbal approaches like arts, culture, and sports.

4.7 Summary of the chapter in terms of objectives and themes

The chapter delved into the multifaceted experiences and challenges faced by adolescent males living with HIV and AIDS. Objective One focuses on understanding the perceptions and experiences of these adolescents, revealing the complex interplay of stigma, self-worth, and resilience. Theme One, "Navigating Identity Complexities," sheds light on the challenges associated with stigma and self-identity, while Theme Two, "Navigating the Shadows," explores how adolescents grapple with understanding their HIV and AIDS status and building resilience. Theme Three, "Emerging from Adversity," underscores the resilience demonstrated by adolescents in overcoming challenges related to mental health and support systems.

Objective Two examined the clinical and social reasons impacting adherence to antiretroviral therapy (ART). Theme one, "Thriving Amidst Economic Challenges," highlights the economic obstacles faced by adolescents living with HIV and AIDS. Meanwhile, Theme Two, "Navigating the Unwelcoming Terrain," delves into the difficulties adolescents encounter in accessing adolescent-centric healthcare. Lastly, Theme Three, "Navigating Adherence Challenges," explores the complexities surrounding adherence to ART and interactions with healthcare facilities.

Objective Three explores recommendations to enhance the management of adolescent males living with HIV and AIDS. Theme One, "Empowering Health Literacy," emphasises the importance of educating adolescents on managing HIV and AIDS. Theme Two, "Unlocking Holistic Healthcare," advocates for improved access to allied services tailored to adolescent needs. Finally, Theme Three, "Bridging the Gap," suggests leveraging innovative technologies to streamline healthcare transitions and enhance overall healthcare experiences for adolescents living with HIV and AIDS.

Table **4.2.1** below illustrates the structure of the study and various themes derived from the research findings. Each theme is discussed in conjunction with subsequent findings.

Table 4.2.1 Summary of themes

OBJECTIVE ONE: To explore the perceptions of living with HIV and AIDS and experiences of male adolescents.

Theme 1: Navigating Identity Complexities: The Interplay of Stigma, Self-Worth, and Intersectionality Among Adolescent Males Living with HIV and AIDS.

Theme 2: Navigating the Shadows: Adolescents unravelling the mystery of their HIV and AIDS status and building resilience.

Theme 3: Emerging from Adversity: Adolescent resilience in the face of HIV and AIDS challenges on mental health and support systems.

OBJECTIVE TWO: **To explore clinical and social reasons related to adherence to antiretroviral therapy amongst male adolescents living with HIV and AIDS.**

Theme 1: Thriving Amidst Economic Challenges: Navigating livelihoods of adolescents living with HIV and AIDS.

Theme 2: Navigating the Unwelcoming Terrain: Adolescents' Struggle for Accessible and Adolescent-Centric Healthcare

Theme 3: Navigating Adherence Challenges: The complex relationship between adolescents, antiretroviral therapy, and healthcare facilities.

OBJECTIVE THREE: To recommend best practices to find, link and manage adolescent males living with HIV and AIDS.

Theme One: Empowering Health Literacy: Navigating the complex landscape of adolescent HIV and AIDS management.

Theme Two: Unlocking Holistic Healthcare: Navigating Awareness and Barriers in Accessing Allied Services for Adolescent HIV and AIDS Management.

Theme Three: Bridging the Gap: Leveraging innovative technologies for seamless adolescent HIV and AIDS transition and healthcare enhancement.

CHAPTER FIVE

SUMMARY OF FINDINGS, CONCLUSIONS AND RECOMMENDATIONS

5.1 Introduction

Chapter Five highlights the primary outcomes derived from the research study. In tandem with these findings, conclusions are expounded upon, and recommendations are put forth for the fields of social work practice, social work education, and potential avenues for further research.

5.2 Main Findings

Objective 1: To explore the perceptions of living with HIV and AIDS and experiences of male adolescents.

The study delved deep into the nuanced world of male adolescents living with HIV and AIDS, aiming to understand their perceptions and experiences. It unearthed a complex arrangements of emotions and challenges these individuals face daily. Among the most prominent findings were the internalised stigma and shame associated with the diagnosis, which often led to a questioning of self-worth and a sense of isolation. Participants revealed how societal attitudes, encountered through various mediums like films or community conversations, influenced their self-perception, contributing to feelings of inadequacy and fear of judgment. Moreover, the diagnosis triggered significant life changes, forcing participants to grapple with their identity and place in society. This exploration highlighted the profound impact of HIV and AIDS on the psychological well-being of male adolescents, underscoring the need for targeted interventions to address these complex emotional issues.

Objective 2: To explore clinical and social reasons related to adherence to antiretroviral therapy amongst male adolescents living with HIV and AIDS.

The study uncovered a multitude of clinical and social factors that influence adherence to antiretroviral therapy (ART) among male adolescents living with HIV and AIDS. Economic constraints emerged as a significant barrier, with participants often facing food insecurity, which compromised their ability to adhere to medication schedules. Additionally, discomfort and perceived mistreatment within healthcare facilities deterred participants from attending clinic appointments regularly. Adherence to ART posed further challenges, with many participants expressing feelings of fatigue, forgetfulness, and intentional non-compliance. This section of the study shed light on the intricate web of barriers that hinder consistent engagement

with treatment, emphasising the need for holistic interventions that address both clinical and social determinants of health.

Objective 3: To recommend best practices to find, link, and manage adolescent males living with HIV and AIDS.

Building on the insights gleaned from the research, the study proposed a set of recommendations to improve the identification, linkage, and management of adolescent males living with HIV and AIDS. These recommendations included enhancing communication channels within healthcare facilities to foster trust and openness between patients and providers. Adopting multidisciplinary approaches to care, integrating psychosocial support, and educational interventions were also highlighted as crucial strategies to address the diverse needs of this population. Furthermore, the study emphasised the importance of community engagement and empowerment, advocating for the creation of supportive environments that promote resilience and well-being. Overall, the recommendations aimed to create a comprehensive support system that addresses the complex challenges faced by adolescent males living with HIV and AIDS, ultimately improving health outcomes and quality of life.

5.3 Conclusions

Conclusions drawn from the study suggest that the experiences of black South African males aged 16-21 living with HIV and AIDS are complex and multifaceted. The pervasive influence of HIV and AIDS-related stigma significantly impacts participants' self-worth and societal positioning. Intersectionality highlights the intricate interplay of socioeconomic factors, sexual orientation, and race with health status, creating challenges in navigating adolescence while managing a chronic health condition. Economic constraints contribute to missed treatments, revealing the intricate relationship between financial struggles and health management. The study underscores the tension between traditional masculinity ideals and the realities of living with HIV and AIDS, as participants strive to reconcile societal perceptions with their roles as family figures. Healthcare system challenges, including discomfort, perceived mistreatment, and barriers to seeking care, are evident, emphasising the need for improved patient-centered approaches. Medication adherence emerges as a critical concern, with fatigue, intentional non-compliance, and challenges in daily medication routines prevalent. The analysis of delivering comprehensive adolescent services that consistently adjust based on current best practices recommends for ongoing support, education, and tailored interventions to address the unique needs of adolescents living with HIV and AIDS, emphasising the importance of empowering support systems. Additionally, economic strain and healthcare attendance complexities highlighting the necessity for agile investments and improved communication within health systems to enhance the overall well-being of this vulnerable demographic.

In parallel, the utilisation of the Psychosocial Development theory and the Systems Theory proved to be adequate theoretical locations for interpreting the findings of the study. Employing the Psychosocial Development Theory, the findings illuminated the profound impact of HIV and AIDS-related stigma on participants' self-identity and emotional well-being. Through the lens of Erikson's stages of identity development, the study discerns how the disclosure of HIV status and the revelation of orphan status act as critical junctures, shaping the participants' coping mechanisms and influencing their perceptions of self and the world. Moreover, the study demonstrates the relevance of the Systems Theory of Social Work in understanding the multifaceted challenges within family, healthcare, economic, and educational systems. It reveals the intricate interplay of these systems, underscoring the importance of a holistic approach to address the socioeconomic factors affecting health management, limited disclosure within families hindering support systems, and systemic issues within healthcare structures demanding patient-centered interventions.

5.4 Recommendations

Based on the findings and conclusions, the subsequent recommendations are provided:

5.4.1 Recommendations for Social Work practice

Social work as a profession is encouraged to advocate for the decentralisation of youth services by entrusting implementation to collaborative partners, including Non-Governmental Organisations (NGOs) and other significant stakeholders within the health sector. In this context, the establishment and utilisation of youth clubs can serve as instrumental case finding and management centers steered by social workers. Alternatively, there is a proposal for the creation of strategically positioned health hubs, discreetly integrated into communities so as not to overtly reveal the primary focus on HIV and AIDS intervention, with the primary aim of mitigating associated stigma and bringing health interventions on the doorstep of adolescent service users. In addition, Social worker can lobby management centers and youth clubs as scouting grounds for identifying adherence champions who can subsequently be employed by healthcare facilities to actively contribute to the implementation of youth health policies. This strategic initiative not only facilitates the integration of policies but also serves as a means to address unemployment concerns among the youth, with a specific focus on those living with HIV and AIDS. Social workers in Social Development are urged to leverage their advocacy skills to champion the advancement of improved policies, emphasising active participation in policy development processes. It is essential that these policies are informed by comprehensive needs assessments and inclusive stakeholder participation, ensuring a holistic and well-informed approach to policy formulation, which can translate to implementable Standard Operating Procedures.

5.4.2 Recommendations for Social Work Education

Social work education should thoroughly investigate how social development interventions in health can align with global best practices to optimise the contributions of Centers of Excellence (CoEs) within health departments. By scrutinising international standards and benchmarks, social work education can identify effective strategies that enhance the effectiveness and impact of CoEs, ensuring that it remains informed by and contributes to advancements in the field, ultimately reinforcing their role within health departments. Leverage digital disruptors, including health management apps, for streamlined health services. This encompasses functions such as appointment reminders and the dissemination of critical information, including dates for blood draws, all of which contribute to an efficient database for potential research purposes. Furthermore, encourage the employment of digital tools, to gain insights into patient behaviour. Utilise Enterprise Resource Planning (ERP) systems to reduce turnaround times for file retrieval, thereby minimising waiting periods. This digital transformation will aim to alleviate the administrative burden on clinicians, allowing more time for patient interactions, fostering discussions on adherence education. Additionally, explore opportunities within the Fourth Industrial Revolution (4IR) and Virtual Clinics for enhanced mental health assessment tools and improved patient care modalities. Lastly, for Social Work education, it is recommended to explore the effectiveness of introducing periodic within-discipline training or eLearning courses in social work practice. This education can delve into the impact of such training initiatives on enhancing healthcare worker competencies, specifically in addressing health variables relevant to the complexities faced by black adolescent males living with HIV. Evaluating the ability of these training methods to keep healthcare workers updated with global standards and professional advancements is crucial for informing best practices in continuous professional development within the social work discipline.

5.4.3 Recommendations for further research

For further research, it is recommended to delve deeper into the aspects of adherence to antiretroviral therapy among black adolescent males living with HIV. Exploring the specific factors influencing medication adherence, such as the intersectionality of socioeconomic background, sexual orientation, and race, would provide a more robust discourse. Additionally, investigating the impact of disclosure dynamics within families and its correlation with support systems for medication routines could shed light on effective interventions. Further studies could also explore the effectiveness of decentralised healthcare services, like youth clubs or

health hubs, in mitigating stigma and improving adherence. Moreover, understanding the role of digital health tools, including apps, in promoting adherence and mental health among this demographic is an avenue worth exploring. Into the bargain, research on the integration of Fourth Industrial Revolution (4IR) technologies, like Virtual Clinics, and their impact on healthcare accessibility and adherence would contribute to innovative strategies for better health outcomes. Lastly, further research should focus on developing methodologies to monitor the transition of adolescents who have transitioned from adolescent clinics to adult clinics. Investigating effective strategies for knowledge transference during this critical phase of healthcare transition is essential. This includes understanding how information and support systems can be seamlessly transferred, and identifying and mitigating any gaps that may arise during the transition process. A comprehensive exploration of best practices in facilitating the continuity of care for adolescents moving into adult healthcare settings would contribute valuable insights to enhance healthcare outcomes during this transitional period.

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APPENDICES

SOCIAL WORK
THE SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT (SHCD)

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Appendix A

Parent/Guardian Participant Information sheet

Title of the study: *Adherence to Antiretroviral Therapy (ART) Amongst black adolescents. A case study on the perceptions of HIV and AIDS adolescent male patients in Ekurhuleni, South Africa*

Good day,

Introduction

My name is Bradley Monyai, and I am a postgraduate student registered for the degree MA in Social Work at the University of the Witwatersrand. As part of the requirements for the degree, I am conducting research to explore the perceptions and experiences of living with HIV and AIDS amongst Black adolescent male patients. It is hoped that the information gathered could assist in identifying clinical and social reasons related to adherence to antiretroviral therapy. I hope the results will enable me to recommend best practices to find, link and manage adolescent males living with HIV and AIDS, resulting in holistic service delivery to the patients concerned. The outcome of this study could inform both knowledge base and practice of Social Work and Social Development in health care settings.

Invitation

As a parent/guardian to a black adolescent male patient living with HIV and AIDS in Ekurhuleni, you are ideally positioned to contribute to my research. I therefore wish to invite your child to participate in my study. If you accept my invitation, their participation would be entirely voluntary, and they are free to withdraw at any time without penalty. Both the child and the parent/guardian must agree to the inclusion of the child in the study.

What does participation involve?

Refusal to participate will have no consequences for the child's medical treatment or access to antiretroviral drugs. If you and your child do agree to his participation, I will arrange to interview them at a time and place that is suitable for them. To observe Covid 19 protocols the

meeting will be held at an open space environment wherein physical distancing of 2 meters (6 feet) needs to be guaranteed, preventing face to face positioning. Face masks and/or eye protection (face shields, goggles, or glasses) must be worn and will be made available to participants. In preparation and during the interview, recommendations for hand sanitizing will be followed. The interview will last approximately one hour. If you choose to allow your child to participate, they may withdraw from the study at any time and they may also refuse to answer any questions that they feel uncomfortable with answering. If you decide to give consent for participation, I will ask your and their permission to tape-record the interview. No-one other than the researcher and the supervisor will have access to the tapes. The tapes will be kept in a locked cabinet for two years following any publications or for six years if no publications emanate from the study. A copy of their interview transcript without any identifying information will be stored permanently in a locked cupboard and may be used for future research.

Risks and benefits

There are no personal benefits to participating in this study. There is the possibility that some of the questions may cause a participant distress. If this happens, it may be necessary to suspend the interview and I will refer them to free distress counselling by one of the counsellors listed below. A list of the proposed questions is available on request to parents/guardians and the children in advance.

The following sites have been selected for data collection and registered case facilitators and social workers as personnel capacitated in HIV and AIDS case management and counselling have agreed to be part of the distress protocol. At **Bertha Gxowa Hospital**, Ms Nhlanhla Baleka: Case Facilitator (072 526 2475) will be handling referred participants.

Pholosong Hospital, Ms Kopano Mapheleba: Social Worker (067 085 3195)

Tembisa Health Care Centre Ms Mokgethi Maleka: Case Facilitator (078 579 8326).

Tembisa Hospital, Kgaodi Letsoalo Social Worker (067 677 1448)

Tambo Memorial Hospital, Ms Nosipho Mgijima: Social Worker (079 786 5488)

Thelle Mogoerane Hospital, Ms Lesedi Tsheola: Social Worker (073 344 7382)

Far East Rand Hospital, Ms Kedigetse Hlalethoa: Social Worker (072 602 9268)

Debriefing will be done onsite, and participants have a choice of either group counselling or individual counselling. The principal investigator is a registered Social Worker and will also be available to offer debrief counselling.

Cost and payment

There is neither cost nor payment involved in participation.

Confidentiality

Please be assured that your name and that of your child and all personal details will be kept confidential and no identifying information will be included in the final research report. The results of the research may also be used for academic purposes (including books, journals and conference proceedings) and a summary of findings will be made available to participants upon request.

Any questions?

Please contact me on 081 094 1433 or email 1137961@students.wits.ac.za, or my supervisor Professor Thobeka Nkomo on 011 7174583 or email Thobeka.Nkomo @wits.ac.za if you have any questions regarding my study. We shall answer them to the best of our ability.

This study has been approved by the Human Research Ethics Committee (Medical) of the University of the Witwatersrand, Johannesburg ("Committee"). A principal function of this Committee is to safeguard the rights and dignity of all human subjects who agree to participate in a research project and the integrity of the research.

If you have any concern over the way the study is being conducted, please contact the Chairperson of this Committee who is Dr Clement Penny, who may be contacted on telephone number 011 717 2301, or by e-mail on Clement.Penny@wits.ac.za. The telephone numbers for the Committee secretariat are 011 717 2700/1234 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za and Rhulani.Mukansi@wits.ac.za

Thank you for reading this Study Information Sheet.

SOCIAL WORK
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Appendix B

Participant Information Sheet (18 – 21 years)

Title of the study: *Adherence to Antiretroviral Therapy (ART) Amongst black adolescents. A case study on the perceptions of HIV and AIDS adolescent male patients in Ekurhuleni, South Africa*

Good day,

Introduction

My name is Bradley Monyai, and I am a postgraduate student registered for the degree MA in Social Work at the University of the Witwatersrand. As part of the requirements for the degree, I am conducting research to explore the perceptions and experiences of living with HIV and AIDS amongst Black adolescent male patients. It is hoped that the information gathered could assist in identifying clinical and social reasons related to adherence to antiretroviral therapy. I hope the results will enable me to recommend best practices to find, link and manage adolescent males living with HIV and AIDS, resulting in holistic service delivery to the patients concerned. The outcome of this study could inform both knowledge base and practice of Social Work and Social Development in health care settings.

Invitation

As a black adolescent male patient living with HIV and AIDS in Ekurhuleni, you are ideally positioned to contribute to my research. I therefore wish to invite you to participate in my study. If you accept my invitation, your participation would be entirely voluntary, and you are free to withdraw at any time without penalty.

What does participation involve?

Refusal to participate will have no consequences for your medical treatment or access to antiretroviral drugs, if you agree to participation, I will arrange to interview you at a time and place that is suitable for you. To observe Covid 19 protocols, the meeting will be held at an open space environment wherein physical distancing of 2 meters (6 feet) needs to be

guaranteed, preventing face to face positioning. Face masks and/or eye protection (face shields, goggles, or glasses) must be worn and will be made available to participants. In preparation and during the interview, recommendations for hand sanitizing will be followed. The interview will last approximately one hour. If you choose to participate, you may withdraw from the study at any time and may also refuse to answer any questions that make you feel uncomfortable with answering. If you decide to give consent for participation, I will ask your permission to tape-record the interview. No-one other than the researcher and the supervisor will have access to the tapes. The tapes will be kept in a locked cabinet for two years following any publications or for six years if no publications emanate from the study. A copy of the interview transcript without any identifying information will be stored permanently in a locked cupboard and may be used for future research.

Risks and benefits

There are no personal benefits to participating in this study. There is the possibility that some of the questions may cause a participant distress. If this happens, it may be necessary to suspend the interview and I will refer you to free distress counselling by one of the counsellors listed below. A list of the proposed questions is available on request to participants in advance.

The following sites have been selected for data collection and registered case facilitators and social workers as personnel capacitated in HIV and AIDS case management and counselling have agreed to be part of the distress protocol. At **Bertha Gxowa Hospital**, Ms Nhlanhla Baleka: Case Facilitator (072 526 2475) will be handling referred participants.

Pholosong Hospital, Ms Kopano Mapheleba: Social Worker (067 085 3195)

Tembisa Health Care Centre Ms Mokgethi Maleka: Case Facilitator (078 579 8326).

Tembisa Hospital, Kgaodi Letsoalo Social Worker (067 677 1448)

Tambo Memorial Hospital, Ms Nosipho Mgijima: Social Worker (079 786 5488)

Thelle Mogoerane Hospital, Ms Lesedi Tsheola: Social Worker (073 344 7382)

Far East Rand Hospital, Ms Kedigetse Hlalethoa: Social Worker (072 602 9268)

Debriefing will be done onsite, and participants have a choice of either group counselling or individual counselling. The principal investigator is a registered Social Worker and will also be available to offer debrief counselling.

Cost and payment

There is neither cost nor payment involved in participation.

Confidentiality

Please be assured that your name and all personal details will be kept confidential and no identifying information will be included in the final research report. The results of the research may also be used for academic purposes (including books, journals, and conference proceedings) and a summary of findings will be made available to participants upon request.

Any questions?

Please contact me on 081 094 1433 or email 1137961@students.wits.ac.za, or my supervisor Professor Thobeka Nkomo on 011 7174583 or email Thobeka.Nkomo @wits.ac.za if you have any questions regarding my study. We shall answer them to the best of our ability.

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Appendix C

Participant Information Sheet (16 – 17 years)

Title of the study: *Adherence to Antiretroviral Therapy (ART) Amongst black adolescents. A case study on the perceptions of HIV and AIDS adolescent male patients in Ekurhuleni, South Africa*

Good day,

Introduction

My name is Bradley Monyai, and I am a postgraduate student registered for the degree MA in Social Work at the University of the Witwatersrand. As part of the requirements for the degree, I am conducting research to explore the perceptions and experiences of living with HIV and AIDS amongst Black adolescent male patients. It is hoped that the information gathered could assist in identifying clinical and social reasons related to adherence to antiretroviral therapy. I hope the results will enable me to recommend best practices to find, link and manage adolescent males living with HIV and AIDS, resulting in holistic service delivery to the patients concerned. The outcome of this study could inform both knowledge base and practice of Social Work and Social Development in health care settings.

Invitation

As a black adolescent male patient living with HIV and AIDS in Ekurhuleni, you are ideally positioned to contribute to my research. I therefore wish to invite you to participate in my study. If you accept my invitation, your participation would be entirely voluntary, and you are free to withdraw at any time without penalty. Both the child and the parent/guardian must agree to the inclusion of the child in the study.

What does participation involve?

Refusal to participate will have no consequences for your medical treatment or access to antiretroviral drugs, if you agree to participation, I will arrange to interview you at a time and place that is suitable for you and your parent/guardian. To observe Covid 19 protocols, the meeting will be held at an open space environment wherein physical distancing of 2 meters (6

feet) needs to be guaranteed, preventing face to face positioning. Face masks and/or eye protection (face shields, goggles, or glasses) must be worn and will be made available to participants. In preparation and during the interview, recommendations for hand sanitizing will be followed. The interview will last approximately one hour. If you choose to participate, you may withdraw from the study at any time and may also refuse to answer any questions that make you feel uncomfortable with answering. If you decide to give consent for participation, I will ask your and parent/guardian's permission to tape-record the interview. No-one other than the researcher and the supervisor will have access to the tapes. The tapes will be kept in a locked cabinet for two years following any publications or for six years if no publications emanate from the study. A copy of the interview transcript without any identifying information will be stored permanently in a locked cupboard and may be used for future research.

Risks and benefits

There are no personal benefits to participating in this study. There is the possibility that some of the questions may cause a participant distress. If this happens, it may be necessary to suspend the interview and I will refer them to free distress counselling by one of the counsellors listed below. A list of the proposed questions is available on request to participants in advance.

The following sites have been selected for data collection and registered case facilitators and social workers as personnel capacitated in HIV and AIDS case management and counselling have agreed to be part of the distress protocol. At **Bertha Gxowa Hospital**, Ms Nhlanhla Baleka: Case Facilitator (072 526 2475) will be handling referred participants.

Pholosong Hospital, Ms Kopano Mapheleba: Social Worker (067 085 3195)

Tembisa Health Care Centre Ms Mokgethi Maleka: Case Facilitator (078 579 8326).

Tembisa Hospital, Kgaodi Letsoalo Social Worker (067 677 1448)

Tambo Memorial Hospital, Ms Nosipho Mgijima: Social Worker (079 786 5488)

Thelle Mogoerane Hospital, Ms Lesedi Tsheola: Social Worker (073 344 7382)

Far East Rand Hospital, Ms Kedigetse Hlalethoa: Social Worker (072 602 9268)

Debriefing will be done onsite, and participants have a choice of either group counselling or individual counselling. The principal investigator is a registered Social Worker and will also be available to offer debrief counselling.

Cost and payment

There is neither cost nor payment involved in participation.

Confidentiality

Please be assured that your name and all personal details will be kept confidential and no identifying information will be included in the final research report. The results of the research may also be used for academic purposes (including books, journals, and conference proceedings) and a summary of findings will be made available to participants upon request.

Any questions?

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SOCIAL WORK
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Appendix D

Participant Information sheet

Focus Group (18 – 21 years)

Title of the study: *Adherence to Antiretroviral Therapy (ART) Amongst black adolescents. A case study on the perceptions of HIV and AIDS adolescent male patients in Ekurhuleni, South Africa*

Good day,

Introduction

My name is Bradley Monyai, and I am a postgraduate student registered for the degree MA in Social Work at the University of the Witwatersrand. As part of the requirements for the degree, I am conducting research to explore the perceptions and experiences of living with HIV and AIDS amongst Black adolescent male patients. It is hoped that the information gathered could assist in identifying clinical and social reasons related to adherence to antiretroviral therapy. I hope the results will enable me to recommend best practices to find, link and manage adolescent males living with HIV and AIDS, resulting in holistic service delivery to the patients concerned. The outcome of this study could inform both knowledge base and practice of Social Work and Social Development in health care settings.

Invitation

As a black adolescent male patient living with HIV and AIDS in Ekurhuleni, you are ideally positioned to contribute to my research. I therefore wish to invite you to participate in my study. If you accept my invitation, your participation would be entirely voluntary, and you are free to withdraw at any time without penalty.

What does participation involve?

You are invited to join a Focus Group, which will comprise six people your own age who will be gathered together for the purpose of a discussion about issues around adherence to antiretroviral therapy. The discussion is expected to last about 60 minutes (1 hour) and will take place at the following health care facilities; Bertha Gxowa Hospital, Pholosong Hospital, Tembisa Health Care Centre, Tembisa Hospital, Tambo Memorial Hospital, Thelle Mogoerane Hospital and Far East Rand Hospital during clinical visits. I will be the moderator in the discussion. Anonymity cannot be guaranteed in a Focus Group as some participants may recognize one another, but I will ask all present to observe confidentiality and not repeat the discussions to anyone else. However, I have no means of enforcing this. Refusal to participate will have no consequences for your medical treatment or access to antiretroviral drugs. To observe Covid 19 protocols, the meeting will be held at an open space environment wherein physical distancing of 2 meters (6 feet) needs to be guaranteed, preventing face to face positioning. Face masks and/or eye protection (face shields, goggles, or glasses) must be worn and will be made available to participants. In preparation and during the interview, recommendations for hand sanitizing will be followed. The interview will last approximately one hour. If you choose to participate, you may withdraw from the study at any time and may also refuse to answer any questions that you feel uncomfortable with answering. If you decide to give consent for participation, I will ask your permission to tape-record the interview. No-one other than the researcher and the supervisor will have access to the tapes. The tapes will be kept in a locked cabinet for two years following any publications or for six years if no publications emanate from the study. A copy of your interview transcript without any identifying information will be stored permanently in a locked cupboard and may be used for future research.

Risks and benefits

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The following sites have been selected for data collection and registered case facilitators and social workers as personnel capacitated in HIV and AIDS case management and counselling

have agreed to be part of the distress protocol. At **Bertha Gxowa Hospital**, Ms Nhlanhla Baleka: Case Facilitator (072 526 2475) will be handling referred participants.
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Thelle Mogoerane Hospital, Ms Lesedi Tsheola: Social Worker (073 344 7382)
Far East Rand Hospital, Ms Kedigetse Hlalethoa: Social Worker (072 602 9268)
Debriefing will be done onsite, and participants have a choice of either group counselling or individual counselling. The principal investigator is a registered Social Worker and will also be available to offer debrief counselling.

Cost and payment

There is neither cost nor payment involved in participation.

Confidentiality

Please be assured that your name and all personal details will be kept confidential and no identifying information will be included in the final research report. The results of the research may also be used for academic purposes (including books, journals, and conference proceedings) and a summary of findings will be made available to participants upon request.

Any questions?

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the Committee secretariat are 011 717 2700/1234 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za and Rhulani.Mukansi@wits.ac.za

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Appendix E

Participant Information sheet

Focus Group (16 – 17 years)

Title of the study: *Adherence to Antiretroviral Therapy (ART) Amongst black adolescents. A case study on the perceptions of HIV and AIDS adolescent male patients in Ekurhuleni, South Africa*

Good day,

Introduction

My name is Bradley Monyai, and I am a postgraduate student registered for the degree MA in Social Work at the University of the Witwatersrand. As part of the requirements for the degree, I am conducting research to explore the perceptions and experiences of living with HIV and AIDS amongst Black adolescent male patients. It is hoped that the information gathered could assist in identifying clinical and social reasons related to adherence to antiretroviral therapy. I hope the results will enable me to recommend best practices to find, link and manage adolescent males living with HIV and AIDS, resulting in holistic service delivery to the patients concerned. The outcome of this study could inform both knowledge base and practice of Social Work and Social Development in health care settings.

Invitation

As a black adolescent male patient living with HIV and AIDS in Ekurhuleni, you are ideally positioned to contribute to my research. I therefore wish to invite you to participate in my study. If you accept my invitation, your participation would be entirely voluntary, and you are free to withdraw at any time without penalty.

What does participation involve?

You are invited to join a Focus Group, which will comprise six people your own age who will be gathered together for the purpose of a discussion about issues around adherence to antiretroviral therapy. The discussion is expected to last about 60 minutes (1 hour) and will take place at the following health care facilities; Bertha Gxowa Hospital, Pholosong Hospital, Tembisa Health Care Centre, Tembisa Hospital, Tambo Memorial Hospital, Thelle Mogoerane Hospital and Far East Rand Hospital during clinical visits. I will be the moderator in the discussion. Anonymity cannot be guaranteed in a Focus Group as some participants may recognize one another, but I will ask all present to observe confidentiality and not repeat the discussions to anyone else. However, I have no means of enforcing this. Refusal to participate will have no consequences for your medical treatment or access to antiretroviral drugs. To observe Covid 19 protocols, the meeting will be held at an open space environment wherein physical distancing of 2 meters (6 feet) needs to be guaranteed, preventing face to face positioning. Face masks and/or eye protection (face shields, goggles, or glasses) must be worn and will be made available to participants. In preparation and during the interview, recommendations for hand sanitizing will be followed. The interview will last approximately one hour. If you choose to participate, you may withdraw from the study at any time and may also refuse to answer any questions that you feel uncomfortable with answering. If you decide to give consent for participation, I will ask your permission to tape-record the interview. No-one other than the researcher and the supervisor will have access to the tapes. The tapes will be kept in a locked cabinet for two years following any publications or for six years if no publications emanate from the study. A copy of your interview transcript without any identifying information will be stored permanently in a locked cupboard and may be used for future research.

Risks and benefits

There are no personal benefits to participating in this study. There is the possibility that some of the questions may cause a participant distress. If this happens, it may be necessary to suspend the discussion and I will refer you to free distress counselling by one of the counsellors listed below. A list of the proposed questions is available on request to participants in advance.

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have agreed to be part of the distress protocol. At **Bertha Gxowa Hospital**, Ms Nhlanhla Baleka: Case Facilitator (072 526 2475) will be handling referred participants.
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Debriefing will be done onsite, and participants have a choice of either group counselling or individual counselling. The principal investigator is a registered Social Worker and will also be available to offer debrief counselling.

Cost and payment

There is neither cost nor payment involved in participation.

Confidentiality

Please be assured that your name and all personal details will be kept confidential and no identifying information will be included in the final research report. The results of the research may also be used for academic purposes (including books, journals, and conference proceedings) and a summary of findings will be made available to participants upon request.

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Appendix F

Parent/Guardian Participant Information sheet

Focus Group (16 – 17 years)

Title of the study: *Adherence to Antiretroviral Therapy (ART) Amongst black adolescents. A case study on the perceptions of HIV and AIDS adolescent male patients in Ekurhuleni, South Africa*

Good day,

Introduction

My name is Bradley Monyai, and I am a postgraduate student registered for the degree MA in Social Work at the University of the Witwatersrand. As part of the requirements for the degree, I am conducting research to explore the perceptions and experiences of living with HIV and AIDS amongst Black adolescent male patients. It is hoped that the information gathered could assist in identifying clinical and social reasons related to adherence to antiretroviral therapy. I hope the results will enable me to recommend best practices to find, link and manage adolescent males living with HIV and AIDS, resulting in holistic service delivery to the patients concerned. The outcome of this study could inform both knowledge base and practice of Social Work and Social Development in health care settings.

Invitation

As a parent/guardian to a black adolescent male patient living with HIV and AIDS in Ekurhuleni, you are ideally positioned to contribute to my research. I therefore wish to invite you and your son to participate in my study. If you accept my invitation, your participation would be entirely voluntary, and you are free to withdraw at any time without penalty.

What does participation involve?

Your son is invited to join a Focus Group, which will comprise six people their own age who will be gathered together for the purpose of a discussion about issues around adherence to antiretroviral therapy. The discussion is expected to last about 60 minutes (1 hour) and will take place at the following health care facilities; Bertha Gxowa Hospital, Pholosong Hospital, Tembisa Health Care Centre, Tembisa Hospital, Tambo Memorial Hospital, Thelle Mogoerane Hospital and Far East Rand Hospital during clinical visits. I will be the moderator in the discussion. Anonymity cannot be guaranteed in a Focus Group as some participants may recognize one another, but I will ask all present to observe confidentiality and not repeat the discussions to anyone else. However, I have no means of enforcing this. Refusal to participate will have no consequences for their medical treatment or access to antiretroviral drugs. To observe Covid 19 protocols, the meeting will be held at an open space environment wherein physical distancing of 2 meters (6 feet) needs to be guaranteed, preventing face to face positioning. Face masks and/or eye protection (face shields, goggles, or glasses) must be worn and will be made available to participants. In preparation and during the interview, recommendations for hand sanitizing will be followed. If you choose to participate, your son may withdraw from the study at any time and may also refuse to answer any questions that they feel uncomfortable with answering. If you decide to give consent for participation, I will ask your and his permission to tape-record the interview. No-one other than the researcher and the supervisor will have access to the tapes. The tapes will be kept in a locked cabinet for two years following any publications or for six years if no publications emanate from the study. A copy of your interview transcript without any identifying information will be stored permanently in a locked cupboard and may be used for future research.

Risks and benefits

There are no personal benefits to participating in this study. There is the possibility that some of the questions may cause a participant distress. If this happens, it may be necessary to suspend the discussion and I will refer you to free distress counselling by one of the counsellors listed below. A list of the proposed questions is available on request to participants in advance.

The following sites have been selected for data collection and registered case facilitators and social workers as personnel capacitated in HIV and AIDS case management and counselling have agreed to be part of the distress protocol. At **Bertha Gxowa Hospital**, Ms Nhlanhla Baleka: Case Facilitator (072 526 2475) will be handling referred participants.

Pholosong Hospital, Ms Kopano Mapheleba: Social Worker (067 085 3195)
Tembisa Health Care Centre Ms Mokgethi Maleka: Case Facilitator (078 579 8326).
Tembisa Hospital, Kgaodi Letsoalo Social Worker (067 677 1448)
Tambo Memorial Hospital, Ms Nosipho Mgijima: Social Worker (079 786 5488)
Thelle Mogoerane Hospital, Ms Lesedi Tsheola: Social Worker (073 344 7382)
Far East Rand Hospital, Ms Kedigetse Hlalethoa: Social Worker (072 602 9268)
Debriefing will be done onsite, and participants have a choice of either group counselling or individual counselling. The principal investigator is a registered Social Worker and will also be available to offer debrief counselling.

Cost and payment

There is neither cost nor payment involved in participation.

Confidentiality

Please be assured that your name and all personal details will be kept confidential and no identifying information will be included in the final research report. The results of the research may also be used for academic purposes (including books, journals, and conference proceedings) and a summary of findings will be made available to participants upon request.

Any questions?

Please contact me on 081 094 1433 or email 1137961@students.wits.ac.za, or my supervisor Professor Thobeka Nkomo on 011 7174583 or email Thobeka.Nkomo @wits.ac.za if you have any questions regarding my study. We shall answer them to the best of our ability.

This study has been approved by the Human Research Ethics Committee (Medical) of the University of the Witwatersrand, Johannesburg ("Committee"). A principal function of this Committee is to safeguard the rights and dignity of all human subjects who agree to participate in a research project and the integrity of the research.
If you have any concern over the way the study is being conducted, please contact the Chairperson of this Committee who is Dr Clement Penny, who may be contacted on telephone number 011 717 2301, or by e-mail on Clement.Penny@wits.ac.za. The telephone numbers for the Committee secretariat are 011 717 2700/1234 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za and Rhulani.Mukansi@wits.ac.za

Thank you for reading this Study Information Sheet.

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Appendix G

Consent sheet for participation

Title of the study: *Adherence to Antiretroviral Therapy (ART) Amongst black adolescents. A case study on the perceptions of HIV and AIDS adolescent male patients in Ekurhuleni, South Africa*

Type of questions to be asked in the interview: Semi-structured

This denotes that questions posed may not follow as set on the schedule and questions that are not listed, may be asked as the researcher picks up on emerging themes while the interviewee narrates.

I hereby consent to participate in the research study. The purpose and procedures of the study have been explained to me. I understand that:

- My participation in this study is voluntary and I may withdraw from the study without being disadvantaged in any way.
- I may choose not to answer any specific questions asked if I do not wish to do so.
- There are no foreseeable benefits, however, the possibility that some of the questions may cause distress associated with participation in this study.
- My identity will be kept strictly confidential, and any information that may identify me, will be removed from the interview transcript.
- A copy of my interview transcript without any identifying information will be stored permanently in a locked cupboard and may be used for future research.
- I understand that my responses will be used in the write up of a master's research report and may also be presented in conferences, published in book chapters, journal articles or books.

Name of Participant: _____

Date: _____

Signature: _____

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Appendix H

Parent/Guardian Consent sheet (16 – 17 years)

Title of the study: *Adherence to Antiretroviral Therapy (ART) Amongst black adolescents. A case study on the perceptions of HIV and AIDS adolescent male patients in Ekurhuleni, South Africa*

Type of questions to be asked in the interview: Semi-structured

This denotes that questions posed may not follow as set on the schedule and questions that are not listed, may be asked as the researcher picks up on emerging themes while the interviewee narrates.

I/We hereby grant consent for my/our child to participate in the research study. The purpose and procedures of the study have been explained to Me/Us.

I/We understand that:

- My/our child's participation in this study is voluntary and they may withdraw from the study without being disadvantaged in any way.
- My/our child may choose not to answer any specific questions asked if they do not wish to do so.
- There are no foreseeable benefits, however, the possibility that some of the questions may cause distress associated with participation in this study.
- My/our child's identity will be kept strictly confidential, and any information that may identify them, will be removed from the interview transcript.
- A copy of their interview transcript without any identifying information will be stored permanently in a locked cupboard and may be used for future research. No-one other than the researcher and the supervisor will have access to the tapes. The tapes will be

kept in a locked cabinet for two years following any publications or for six years if no publications emanate from the study.

- I/We understand that my/our child's responses will be used in the write up of a master's research report and may also be presented in conferences, book chapters, Journal articles or books.

Name of Participant: _____

Name of Parent/Guardian_____

Date: _____

Signature: _____

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Appendix I

Consent sheet for participation in a Focus Group (18 - 21 years)

Title of the study: *Adherence to Antiretroviral Therapy (ART) Amongst black adolescents. A case study on the perceptions of HIV and AIDS adolescent male patients in Ekurhuleni, South Africa*

Type of questions to be asked in the interview: Semi-structured

This denotes that questions posed may not follow as set on the schedule and questions that are not listed, may be asked as the researcher picks up on emerging themes while the interviewee narrates.

I hereby consent to participate in the research study. The purpose and procedures of the study have been explained to me. I understand that:

- My participation in this study is voluntary and I may withdraw from the study without being disadvantaged in any way.
- I may choose not to answer any specific questions asked if I do not wish to do so.
- There are no foreseeable benefits, however, the possibility that some of the questions may cause distress associated with participation in this study.
- My identity will be kept strictly confidential, and any information that may identify me, will be removed from the interview transcript.
- Confidentiality cannot be guaranteed with a focus group discussion; thus, the researcher encourages the importance of internal confidentiality amongst focus group discussion participants, which relies on adherence to ground rules and observance of aspects of the consent process. As a potential participant, I am compelled to respect others confidentiality by not repeating what is said in the focus group discussion to others.

- A copy of my interview transcript without any identifying information will be stored permanently in a locked cupboard and may be used for future research.
- I understand that my responses will be used in the write up of a master's research report and may also be presented in conferences, published in book chapters, journal articles or books.

Name of Participant: _____

Date: _____

Signature: _____

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Appendix J

Parent/Guardian Consent sheet for Focus Group participation

(Participant aged 16 – 17 years)

Title of the study: *Adherence to Antiretroviral Therapy (ART) Amongst black adolescents. A case study on the perceptions of HIV and AIDS adolescent male patients in Ekurhuleni, South Africa*

Type of questions to be asked in the interview: Semi-structured

This denotes that questions posed may not follow as set on the schedule and questions that are not listed, may be asked as the researcher picks up on emerging themes while the interviewee narrates.

I/We hereby grant consent for my/our child to participate in the research study. The purpose and procedures of the study have been explained to Me/Us.

I/We understand that:

- My/our child's participation in this study is voluntary and they may withdraw from the study without being disadvantaged in any way.
- My/our child may choose not to answer any specific questions asked if they do not wish to do so.
- There are no foreseeable benefits, however, the possibility that some of the questions may cause distress associated with my/our child's participation in this study.
- My/our child's identity will be kept strictly confidential, and any information that may identify them, will be removed from the interview transcript.
- Confidentiality cannot be guaranteed with a focus group discussion; thus, the researcher encourages the importance of internal confidentiality amongst focus group discussion participants, which relies on adherence to ground rules and observance of aspects of the

consent process. As a potential participant, My/our child is compelled to respect others confidentiality by not repeating what is said in the focus group discussion to others.

- A copy of their interview transcript without any identifying information will be stored permanently in a locked cupboard and may be used for future research. No-one other than the researcher and the supervisor will have access to the tapes. The tapes will be kept in a locked cabinet for two years following any publications or for six years if no publications emanate from the study.

- I/We understand that my/our child's responses will be used in the write up of a master's research report and may also be presented in conferences, book chapters, Journal articles or books.

Name of Participant: _____

Name of Parent/Guardian_____

Date: _____

Signature: _____

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Appendix K

Assent sheet for participation

Participant aged (16 – 17 years)

Title of the study: *Adherence to Antiretroviral Therapy (ART) Amongst black adolescents. A case study on the perceptions of HIV and AIDS adolescent male patients in Ekurhuleni, South Africa*

I hereby consent to participate in the research study. The purpose and procedures of the study have been explained to me. I understand that:

- My participation in this study is voluntary and I may withdraw from the study without being disadvantaged in any way.
- I may choose not to answer any specific questions asked if I do not wish to do so.
- There are no foreseeable benefits, however, the possibility that some of the questions may cause distress associated with participation in this study.
- My identity will be kept strictly confidential, and any information that may identify me, will be removed from the interview transcript.
- A copy of my interview transcript without any identifying information will be stored permanently in a locked cupboard and may be used for future research.
- I understand that my responses will be used in the write up of a master's research report and may also be presented in conferences, published in book chapters, journal articles or books.

Name of Participant: _____

Date: _____

Signature: _____

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Appendix L

Assent sheet for participation in a Focus Group

Participant aged (16 – 17 years)

Title of the study: *Adherence to Antiretroviral Therapy (ART) Amongst black adolescents. A case study on the perceptions of HIV and AIDS adolescent male patients in Ekurhuleni, South Africa*

I hereby consent to participate in the research study. The purpose and procedures of the study have been explained to me. I understand that:

- My participation in this study is voluntary and I may withdraw from the study without being disadvantaged in any way.
- I may choose not to answer any specific questions asked if I do not wish to do so.
- There are no foreseeable benefits, however, the possibility that some of the questions may cause distress associated with participation in this study.
- My identity will be kept strictly confidential, and any information that may identify me, will be removed from the interview transcript.
- Confidentiality cannot be guaranteed with a focus group discussion; thus, the researcher encourages the importance of internal confidentiality amongst focus group discussion participants, which relies on adherence to ground rules and observance of aspects of the consent process. As a potential participant, My/our child is compelled to respect others confidentiality by not repeating what is said in the focus group discussion to others.
- A copy of my interview transcript without any identifying information will be stored permanently in a locked cupboard and may be used for future research.
- I understand that my responses will be used in the write up of a master's research report and may also be presented in conferences, published in book chapters, journal articles or books.

Name of Participant: _____

Date: _____

Signature: _____

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Appendix M

Consent form for audio-taping of the interview

Title of the study: *Adherence to Antiretroviral Therapy (ART) Amongst black adolescents. A case study on the perceptions of HIV and AIDS adolescent male patients in Ekurhuleni, South Africa*

I hereby consent to the tape-recording of the interview.

I understand that:

- The recording will be stored in a secure location (a locked cupboard or password protected computer) with restricted access to the researcher and the research supervisor.
- The recording will be transcribed and any information that could identify me will be removed.
- When the data analysis and write up of the research report is complete, the audio-recording of the interview will be kept for two years following any publications or for six years if no publications emanate from the study.
- The transcript with all the identifying information directly linked to me, will be stored permanently, and may be used for future research.
- Direct quotes from my interview, without any information that could identify me may be cited in the research report or other write-ups of the research.

Name of Participant: _____

Signature: _____

Date: _____

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Appendix N

Parent/Guardian consent form for audio-taping of the interview

Title of the study: *Adherence to Antiretroviral Therapy (ART) Amongst black adolescents. A case study on the perceptions of HIV and AIDS adolescent male patients in Ekurhuleni, South Africa*

I/we hereby consent to the tape-recording of the interview.

I/we understand that:

- The recording will be stored in a secure location (a locked cupboard or password protected computer) with restricted access to the researcher and the research supervisor.
- The recording will be transcribed and any information that could identify my/our child will be removed.
- When the data analysis and write up of the research report is complete, the audio-recording of the interview will be kept for two years following any publications or for six years if no publications emanate from the study.
- The transcript with all the identifying information directly linked to my/our child will be stored permanently and may be used for future research.
- Direct quotes from my/our child's interview, without any information that could identify them may be cited in the research report or other write-ups of the research.

Name of Participant: _____

Parent/Guardian_____

Signature: _____

Date: _____

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Appendix O

Consent form for audio-taping of the focus group discussion

Title of the study: *Adherence to Antiretroviral Therapy (ART) Amongst black adolescents. A case study on the perceptions of HIV and AIDS adolescent male patients in Ekurhuleni, South Africa*

I hereby consent to the tape-recording of the interview.

I understand that:

- The recording will be stored in a secure location (a locked cupboard or password protected computer) with restricted access to the researcher and the research supervisor.
- The recording will be transcribed and any information that could identify me will be removed.
- When the data analysis and write up of the research report is complete, the audio-recording of the interview will be kept for two years following any publications or for six years if no publications emanate from the study.
- The transcript with all the identifying information directly linked to me, will be stored permanently, and may be used for future research.
- Direct quotes from my interview, without any information that could identify me may be cited in the research report or other write-ups of the research.

Name of Participant: _____

Signature: _____

Date: _____

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Appendix P

Parent/Guardian consent form for audio-taping of the focus group discussion

Title of the study: *Adherence to Antiretroviral Therapy (ART) Amongst black adolescents. A case study on the perceptions of HIV and AIDS adolescent male patients in Ekurhuleni, South Africa*

I/we hereby consent to the tape-recording of the interview.

I/we understand that:

- The recording will be stored in a secure location (a locked cupboard or password protected computer) with restricted access to the researcher and the research supervisor.
- The recording will be transcribed and any information that could identify my/our child will be removed.
- When the data analysis and write up of the research report is complete, the audio-recording of the interview will be kept for two years following any publications or for six years if no publications emanate from the study.
- The transcript with all the identifying information directly linked to my/our child will be stored permanently and may be used for future research.
- Direct quotes from my/our child's interview, without any information that could identify them may be cited in the research report or other write-ups of the research.

Name of Participant: _____

Parent/Guardian_____

Signature: _____

Date: _____

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Appendix Q

Assent form for audiotaping of the interview

Title of the study: *Adherence to Antiretroviral Therapy (ART) Amongst black adolescents. A case study on the perceptions of HIV and AIDS adolescent male patients in Ekurhuleni, South Africa*

I hereby consent to the tape-recording of the interview.

I understand that:

- The recording will be stored in a secure location (a locked cupboard or password protected computer) with restricted access to the researcher and the research supervisor.
- The recording will be transcribed and any information that could identify me will be removed.
- When the data analysis and write up of the research report is complete, the audio-recording of the interview will be kept for two years following any publications or for six years if no publications emanate from the study.
- The transcript with all the identifying information directly linked to me, will be stored permanently, and may be used for future research.
- Direct quotes from my interview, without any information that could identify me may be cited in the research report or other write-ups of the research.

Name of Participant: _____

Signature: _____

Date: _____

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Appendix R

Assent form for audio-taping of the focus group discussion

Title of the study: *Adherence to Antiretroviral Therapy (ART) Amongst black adolescents. A case study on the perceptions of HIV and AIDS adolescent male patients in Ekurhuleni, South Africa*

I hereby consent to the tape-recording of the interview.

I understand that:

- The recording will be stored in a secure location (a locked cupboard or password protected computer) with restricted access to the researcher and the research supervisor.
- The recording will be transcribed and any information that could identify me will be removed.
- When the data analysis and write up of the research report is complete, the audio-recording of the interview will be kept for two years following any publications or for six years if no publications emanate from the study.
- The transcript with all the identifying information directly linked to me, will be stored permanently, and may be used for future research.
- Direct quotes from my interview, without any information that could identify me may be cited in the research report or other write-ups of the research.

Name of Participant: _____

Signature: _____

Date: _____