



**BODY IMAGE AND ANTIRETROVIRAL THERAPY ADHERENCE AMONG  
ADOLESCENTS AND YOUNG PEOPLE LIVING WITH HIV IN DURBAN, SOUTH  
AFRICA**

**Submitted in fulfilment of the requirement for the degree**

**Doctor of Philosophy (Psychology)**

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**April 2021**

## DECLARATION

I Patrick Nyamaruze certify that the work in this thesis entitled “Body image and antiretroviral therapy among adolescents and young people living with HIV in Durban, South Africa” has not previously been submitted for a degree nor has it been submitted as part of requirements for a degree to any other university or institution other than the University of KwaZulu-Natal.

I also certify that the thesis is an original piece of research and it has been written by me. Any help and assistance that I have received in my research work and the preparation of the thesis itself have been appropriately acknowledged.

In addition, I certify that all information sources and literature used in the thesis are cited according to the requirements of the American Psychological Association (APA), Seventh Edition (2019) reference style.

Patrick Nyamaruze (Student No: 210551048)

April 2021

## **DEDICATION**

This work is dedicated;

To my parents and siblings, this is our achievement; my fiancée, Tendai for your understanding and continued support throughout my academic career.

and;

To the adolescents and young people living with HIV and those individuals that continue to work hard in ensuring that these young people lead normal lives.

## ACKNOWLEDGEMENTS

The author wishes to express gratitude to the following people for their contributions toward the successful completion of my PhD study.

Thank you, Lord Almighty for how far you have brought me. It is in You I live and have my being.

I would like to express my profound gratitude to my supervisor, Prof. Kaymarlin Govender for his guidance and mentorship throughout my study period. Your endless capacity to provide me with mentorship over the past four years has provided me with the skills required to continue in the field of research. May the good Lord richly bless you!

A special thanks to the participants of this study and the gatekeepers (Tom Butterworth). Thank you for having shared your very personal experiences and am privileged to have met each one of you.

I owe a depth of gratitude to my fiancée, Tendai Mutamba, for the patience and sacrifices she made in order for me to complete this program. You were there from the beginning and stood by me throughout the hurdles of this PhD journey. I would also like to thank my family members who were emotionally present with me over the course of my studies despite the geographical barrier.

Dr. Richard Gregory Cowden for his invaluable insight, guidance and encouragement during my studies. Your unwavering support is invaluable and deeply appreciated.

I am grateful to my PhD colleagues (Dr. Kemist Shumba, Dr. Netsai Gwelo, Nosipho Makhakhe, Sphindile Machanyangwa) in the Discipline of Psychology for their support throughout these years. Thank you for the continued support and friendship.

Colleagues from the School of Applied Human Sciences and SAHS personnel: Ayanda Ntuli, Patricia Mthethwa, Cindy Naicker, Nelly Mtswele, Mhlengi Dlamini, Mlungisi Mbatha; Prof, Anna Meyer-Weitz, Luvuyo Makhaba, and Ntombi Mtwentula.

I cannot forget my dedicated research assistants who helped in the data collection, especially Lindokuhle Mkhaya who was with me throughout the entire data collection period.

My friends: Dr. Kemist Shumba, Dr. Thomas Gumbo, Takunda Mathathu, Danford Chibvongodze, Paidamoyo Nyambuya, and Zandile Mpofu,

## ABSTRACT

**Background:** The benefits of antiretroviral therapy (ART) for treating HIV among adolescents and young people living HIV (AYPLHIV) may be undermined by non-adherence to ART. Several reasons for non-adherence to ART have been reported among young people including internalised HIV-related stigma, body image concerns, and depression. Research into how AYPLHIV experience and make sense of feared or actual body changes is limited, yet these changes have emotional and psychological implications which may curtail adherence to ART. This doctoral thesis investigated the relationship between body image and various psychosocial factors; and explored the perceptions and feelings about body appearance among AYPLHIV in Durban, South Africa.

**Method:** A cross sectional, convergent parallel mixed method approach was adopted in which quantitative and qualitative data were concurrently collected in the same phase of the research process using non-probability sampling. For the quantitative part of the study, a total of 76 AYPLHIV (15-24 years) were conveniently sampled. Qualitative data were obtained through a series of semi-structured in-depth interviews with a sub-set of 18 AYPLHIV who were purposively and conveniently recruited from the quantitative sample. Descriptive statistics, Pearson Product Moment correlations, and mediational analyses were used to analyse the quantitative data whereas thematic analysis was used for the qualitative data analysis.

**Results:** The converging quantitative and qualitative results from this study provide evidence that body image is a significant issue among AYPLHIV and is differentially associated with various psychosocial factors. Self-esteem and adherence to ART were indirectly associated through a two-step path of internalised HIV-related stigma and then body appreciation. Findings from the qualitative analysis showed physical and psychosocial effects of living with HIV among young people including weight loss, body dissatisfaction and social withdrawal.

Coping mechanisms such as social support networks and physical exercises were highlighted as important in counteracting the physical and psychosocial effects of negative body image and living with HIV.

**Conclusion:** The findings from this study suggest that body image concerns are central to the health and well-being of AYPLHIV as they are related to several psychosocial challenges. The findings underscore the need for development of multi-pronged interventions to boost body image.

## ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral therapy
ARV(s)	Antiretroviral(s)
AYPLHIV	Adolescents and young people living with HIV
CYP	Children and Young People
CCMTS	Comprehensive Care Management, Treatment and Support
DoH	Department of Health
ESA(R)	Eastern and Southern Africa (Region)
HTC	HIV Testing and Counselling
MDG(s)	Millennium Development Goal(s)
PLHIV	People living with HIV
PMTCT	Prevention of mother-to-child transmission
PrEP	Pre-exposure prophylaxis
PEP	Post exposure prophylaxis
SDG(s)	Sustainable Development Goal(s)
SDT	Self-discrepancy theory
SRH	Sexual and Reproductive Health
STI(s)	Sexually Transmitted Infection(s)
UN	United Nations

UNAIDS	Joint United Nations Programme on HIV and AIDS
UNFPA	United Nations Population Fund
UNICEF	United Nations International Children's Fund
VLS	Viral Load Suppression
WHO	World Health Organization

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## LIST OF PUBLICATIONS

The following is a list of publications derived from this thesis.

### Journal Articles

Nyamaruze, P., & Govender, K. (2020) “I like the way I am, but I feel like I could get a little bit bigger”: Perceptions of body image among adolescents and youth living with HIV in Durban, South Africa. *PLoS ONE*, 15(1): e0227583.

<https://doi.org/10.1371/journal.pone.0227583>

## CHAPTER ONE

### INTRODUCTION

#### 1.1 Background

The HIV epidemic remains one of the world's most serious public health challenges. In 2019, approximately 38 million people were living with HIV up from 30.7 million in 2010 (The Joint United Nations Programme on HIV/AIDS, 2020). Most people living with HIV (PLHIV) are located in low- and middle- income countries, with 20.7 million living in the East and Southern African Region (ESAR) (UNAIDS, 2020). In the ESAR, adolescents and young people (10-24) are disproportionately affected by the disease; they accounted for 51% of all new HIV infections in 2019 and 16% of all PLHIV, globally (UNAIDS, 2020). Additionally, two-thirds of children living with HIV (67%) are found in this region. Profiles within the ESAR indicate that South Africa has the highest number of PLHIV in the region and globally (UNAIDS, 2020). Almost forty years into the epidemic, HIV remains a significant cause of death, globally. However, AIDS-related deaths have declined, driven mostly by antiretroviral treatment (ART) scale-up. In 2019, 690,000 people died of AIDS, a 37% decrease from 1.1 million in 2010 and a 59% decrease from the peak of 1.7 million in 2004 (UNAIDS, 2020).

In addition to the physical toll of the disease and mortality, the HIV epidemic has disrupted village and community life, resulted in loss of valuable human resource and eroded economic productivity and growth (Barnett, Whiteside, & Desmond, 2001; Dixon, McDonald, & Roberts, 2002). The long-term economic costs of addressing HIV and its effects, particularly in the health sector divert resources from other important needs and from economic investments. Thus, noting these potential impacts of HIV at the individual, community and country level, substantial concerted global action has emerged around the HIV epidemic. Initially, targets to combat HIV were set through the United Nations Millennium Declaration in 2000 (UN, 2005). Millennium Development Goal (MDG) 6 was specifically designed to

combat HIV/AIDS among other infectious diseases. It had two principal goals; firstly, to have halted and begun to reverse the spread of HIV by 2015; and, secondly, to achieve universal access to treatment for HIV among all those in need by 2010 (UN, 2015). MDG 6 evidenced relative success, for example, there was an approximate 40% reduction in new HIV infections between 2000 and 2013. Further, an increased number (800 000 in 2003 to 13.6 million 2014) of PLHIV were receiving ART, globally (UN, 2015). In 2015, the MDGs were replaced by Sustainable Development Goals (SDGs) in which commitment to end the HIV epidemic is reaffirmed in SDG3 (WHO, 2016).

Another global health effort to end the AIDS epidemic is the 90-90-90 strategy. This three-part target set to have 90% of all PLHIV to know their HIV status; 90% of all people with diagnosed HIV infection to receive sustained ART; and 90% of all people receiving ART to have viral suppression by 2020 (UNAIDS, 2014). This approach underscores HIV treatment as a panacea to the scourge of AIDS, and a key to preventing illness, death and averting new infections. South Africa has made significant strides towards the 90-90-90 targets. In 2019, 92% of PLHIV were aware of their status, of which 70% were on ART. Of those diagnosed and on ART, 64% were virally suppressed (UNAIDS, 2020). Findings from the South African National HIV Prevalence, Incidence, Behaviour and Communication Survey indicated that Viral Load Suppression (VLS) prevalence among PLHIV in South Africa was high among older adults (HSRC, 2019). An age group comparison indicated that adults aged 45-49 years had a VLS of 74.6% among HIV positive females and 71.8% among HIV positive males. In contrast, VLS prevalence was distinctly lower in younger people aged 15-24 years, females had the lowest VLS at 47% and males 49.1%.

Before the introduction of ART, very few people infected with HIV survived beyond ten years (Babiker et al., 2000). However, over the past two decades, HIV has become a manageable chronic illness for people who test and seek treatment. To achieve optimal results

from ART, high levels of patient adherence to ART (at least 95%) is essential to ensure optimal benefits (Turner, 2002). Specifically, ART increases viral suppression, improves physical and emotional well-being, and reduces mortality (Agwu & Fairlie, 2013; Onyango et al., 2017). Suppressed viral replication boosts immune functioning and reduces risk of onward transmission (Agwu & Fairlie, 2013). In hyper-endemic countries and regions such as ESA where it has been particularly challenging to stay on track with global treatment and prevention targets, ART uptake represents a key avenue for reducing the burden of HIV.

However, the potential benefits of ART for treating HIV may be subverted by non-adherence to treatment. Poor adherence to ART may lead to several adverse consequences on both individual and public HIV healthcare. At the individual level, non-adherence to ART can accelerate HIV resistance to treatment (Nachega et al., 2011). Further, a switch to second- and third-line ARV regimens for poorly adherent patients is associated with a higher pill burden, and the dosage often has intolerable side effects (Nachega et al., 2010). Treatment failure due to non-adherence is also a common cause of death among PLHIV (Ayalew, 2017). From a public health perspective, the interruption of adherence to ART is associated with an increased risk of onward HIV transmission to non-infected sexual partners (Stekler et al., 2018). Further, it may have downstream implications for healthcare costs such as hospital admissions due to HIV disease progression and opportunistic infections (Long et al., 2016; Meintjes et al., 2015).

Research from resource-poor settings highlights that adolescents and youth have lower medication adherence than adults (Adejumo et al., 2015). A plethora of reasons for non-adherence to ART have been reported among YPLHIV. These have usually been categorised under multiple levels including sociodemographic factors (e.g., poorer adherence among young people living in spaces with less privacy); structural and economic factors (e.g., limited access to food, high cost of transportation); psychosocial factors (e.g., stigma, lack of social support

networks); individual factors (e.g., forgetfulness, alcohol abuse); and treatment-related factors (e.g., high pill burden, negative side effects) (Adejumo et al., 2015).

Body image changes resulting from ART are among the reasons for non-adherence (Blashill & Vander Wal, 2010). Body image is a factor which appear amenable to change through targeted efforts that are directed towards harnessing and developing personal resources of AYPLHIV. Although psychological resources, including self-efficacy and resilience, have frequently been linked to better adherence to ART (Dale et al., 2014; Zhang et al., 2016), one underexplored avenue that also has the potential to promote adherence to ART among AYPLHIV is body image.

Body image relates to a person's perceptions, feelings and thoughts about his or her body (Martinez et al., 2005). Adolescents' sense of self-worth and perceptions of social relations are closely linked to their body image (Davison & McCabe, 2006). Thus, during the adolescence phase, young people tend to give much more importance to what others think about their appearance and seek validation from their peers on how they look (Cash & Smolak, 2011). It is not uncommon for adolescents to be dissatisfied with certain aspects of their body. A study on body image satisfaction among rural South African adolescents showed that 83.5% of the girls in the study demonstrated body dissatisfaction, with 58% expressing a desire for a thinner body size (Pedro et al., 2016). Individuals are likely to develop body image dissatisfaction when there is a discrepancy between ideal and actual body sizes (Wertheim et al., 2004). Body dissatisfaction is associated with numerous health related conditions. Previous studies suggest that adolescents who are dissatisfied with their bodies are more likely to perceive their health as fair or poor and more likely to show depression, low self-esteem and low social functioning (Field, 2004; Cruz-Saez et al., 2015). Living with HIV, which is a stigmatised health condition usually associated with body wasting may worsen body image concerns in young people.

People diagnosed with HIV are likely to experience alterations in bodily appearances resulting from the disease itself and treatment (Fingeret et al., 2007; Yang et al., 2015). These include significant, persistent changes in physical functioning and appearance such as fatigue, rash and lipodystrophy (Blanch et al., 2004; Dukers et al., 2001), which can negatively affect subjective perceptions of body image. Studies with both male and female participants have shown that alterations in body appearances have significant effects on the psychosocial well-being and quality of life for PLHIV (Huang et al., 2006; Sharma et al., 2007). A diagnosis of HIV is significantly related to poorer quality of body image and lowered life satisfaction (Mudgal & Tiwari, 2015) arising from internalised shame and fear of discrimination. Among PLHIV perceptions of body image may have important implications for ART adherence. Previous studies indicate that a poor body image is associated with patient's abandonment of ART and loss from care in young people (Ezekiel et al., 2009), and body image disturbance has been linked to poor ART adherence in gay men (Blashill & Vander Wal, 2010). Further research is required to assess the effect of body image on adherence to ART among young people, especially in the light of the centrality of body image in young adults.

Scholarly evidence indicates that research on body image has traditionally focused on understanding the negative aspects of body image such as body dissatisfaction (Smolak & Cash, 2011; Tylka, 2012). This has also been the case in the HIV literature (Blashill & Vander Wal, 2010). However, concentration on negative body image may have led to the neglect of research promoting positive body images. Recently, there has been a recognition of the importance of studying positive body image (Bailey et al., 2016). One component of positive body image is body appreciation. Body appreciation in individuals is highlighted by an attitude of acceptance and love toward all body features and functionality (Avalos et al., 2005). Body appreciation has been associated with favourable appearance evaluation, greater psychological

well-being, less body shame and body preoccupation, and fewer eating disorder symptoms (Avalos et al., 2005; Tylka & Wood-Barcalow, 2015a).

Body appreciation may act as a protective factor against psychological disturbances. Body image interventions that incorporate positive body image aspects, particularly body appreciation have the potential to equip individuals with self-protective cognitive skills to the extent that previously held body dissatisfaction may become negligible. Researching the relationship between body appreciation and adherence to ART is important as this may provide possible avenues for ART adherence interventions that address body image concerns in PLHIV.

People living with HIV may also fear stigma arising from physical changes that may be perceived as markers of HIV. Despite the interventions to eradicate HIV stigma, stigma continues to be a significant barrier to HIV prevention and treatment efforts. Studies in China, Zambia and South Africa have reported moderate levels of HIV-related stigma existing among their study samples (Hargreaves et al., 2018; Li et al., 2018). A survey of HIV-positive individuals in South Africa also reported that over one-third of the participants perceived themselves as having experienced HIV stigma. Further, people aged between 15-24 years were more likely to experience external, internalised and anticipated stigma (HSRC, 2015). Three different types of stigma have been identified in HIV literature; anticipated stigma, enacted stigma, and internalised HIV-related stigma (Earnshaw & Chaudoir, 2009). Internalised HIV-related stigma refers to the negative beliefs and feelings endorsed by those diagnosed with HIV infection (Audet et al., 2013). It is likely to make an individual more sensitive to both actual and anticipated rejection and stigmatisation by others (Chesney & Smith, 1999). Hence, addressing internalised HIV-related stigma can be the first step in alleviating other forms of stigma.

Internalised HIV-related stigma may have a negative impact on adherence to ART. Research from a cross-sectional study of PLHIV in the United States showed that internalised HIV-related stigma was associated with lower likelihood of adherence to ART after controlling for enacted and anticipated stigma (Earnshaw et al., 2013). Other studies in different locations, among different samples have reached the same conclusion that internalised HIV-related stigma results in suboptimal adherence to ART (Logie et al., 2018; Turan et al., 2019). Internalised HIV-related stigma also leads to lower adherence to HIV care visit (Rice et al., 2017), which leads to lower ART adherence as individuals who do not present for HIV care visits may not benefit from aspects of the HIV care experience such as the patient-physician relationship that may act as facilitators to ART adherence (Beach et al., 2006). Internalised HIV-related stigma is also negatively related to various psychosocial variables. Specifically, it is negatively related to levels of perceived social support and self-esteem, and positively related to higher levels of grief, passive problem solving and depression (Lee et al., 2002; Goudge & Ngoma, 2011; Murphy et al., 2018).

Self-esteem is related to one's beliefs about skills, abilities, and social relationships (Rosenberg, 1965). Thus, it is a key contributing factor in the perceptions that individuals place on themselves and their capabilities. People living with HIV may have their self-esteem damaged due to the physical and social impact the infection may cause in their lives, such as stigma, rejection, loss of social identity and bodily changes (Castrighini et al., 2013; Okwaraji et al., 2019). Low self-esteem may lead individuals living with HIV not to care for their health, and not to search for treatment whereas increased self-esteem makes individuals living with HIV to perceive themselves positively and actively practise health seeking behaviour (Castanha et al., 2006; Manhas, 2013).

Self-esteem may have a critical impact on adherence to ART for several reasons, yet few studies have investigated the relationship that exists between these two factors. For

example, lower self-esteem is associated with increased alcohol misuse and recreational substance use, which can impair judgment and may interfere with an individual's ability to adhere to treatment (Sileo et al., 2019). Conversely, self-esteem may buffer against the impact of negative life experiences and contribute to better health and well-being (Mann et al., 2004). Further studies that examine the relationship between self-esteem and adherence to ART are needed.

Social support is an interpersonal resource that can be particularly helpful for PLHIV. HIV infection and the related stigma can cause strain in an individual's social network structure, which may result in prejudice, discrimination and dissolution of social relations (Bastardo & Kimberlin, 2000; Varas-Díaz et al., 2005). Research indicates that among PLHIV, social support is one of the most important factors that may improve well-being and quality of life (Bekele et al., 2013). Social support buffers the negative impact of HIV stigma and HIV-related harmful beliefs (Colbert et al., 2010; Larios et al., 2009). Thus, family, peers, and the community can be major sources of support in sustaining care and treatment for HIV patients.

Social support positively influences adherence to ART by PLHIV. A study by Poudel et al. (2015) showed that low levels of perceived family support, particularly emotional support was associated with increased risk of non-adherence to ART by HIV-positive individuals. One review on ART adherence in middle-income and low-income countries highlighted that patient support was very important to treatment adherence (Nachege et al., 2010). Social support may also have a positive effect on issues pertaining to body image perceptions. Studies have shown that adolescents and young adults who perceive receiving adequate social support fare better than those who do not, in many areas of functioning including body image satisfaction (Barker & Galambos, 2003; Merianos et al., 2012). Living with a stigmatising condition like HIV represents a source of stress as patients often experience rejection and body dissatisfaction, and in these cases protective factors such as improved body appreciation, self-esteem and social

support can play an important role in decreasing negative affect and ultimately improve adherence to ART.

## **1.2 Rationale for the study/problem statement**

Although remarkable progress has been made in the global response towards ending the HIV epidemic by 2030, the burden of the global HIV epidemic remains highest among young people living in the countries within the ESAR (Govender et al., 2018). Alongside the social-structural issues (e.g., inadequate health infrastructure) that pose challenges to the HIV testing and treatment-related behaviour of young people living in the region (Cowden, Tucker, & Govender, 2020), the success of HIV treatment in promoting health in this population is highly contingent on the individual choices young people make about treatment-related behaviour. However, the benefits of ART for preventing and treating HIV may be undermined by non-adherence to ART. To advance health promotion initiatives designed to improve adherence to ART, further research is needed to identify and better understand salient mechanisms underlying non-adherence to ART in populations residing in HIV hyper-endemic contexts and for which unique social-structural vulnerabilities exist.

A wide range of reasons for non-adherence to ART have been reported among young people. The more frequently identified patient-related factors include perceived or internalised HIV-related stigma (Mutumba et al., 2015), body image concerns (Blashill et al., 2014) forgetting, alcohol use, and depression (Shubber et al., 2016). Patient-related factors are closest in proximity to the individual, many of which appear amenable to change through targeted efforts that are directed towards harnessing and developing personal resources of AYPLHIV. Although psychological resources, including self-efficacy and resilience, have frequently been linked to better adherence to ART (Dale et al., 2014; Zhang et al., 2016), some underexplored

avenues that also have the potential to promote AYPLHIV's adherence to ART are self-esteem and body appreciation.

The focus of this study is to examine relations between self-esteem, internalised HIV-related stigma, body appreciation, and adherence to ART by AYPLHIV who are residing in an HIV hyper-endemic country within the ESAR. Exploring these interrelationships could offer an improved understanding of mechanisms that may be involved to promote adherence to ART. Drawing on research that supports the efficacy of interventions designed to promote self-esteem (Bartelink et al., 2018), targeted efforts to enhance self-esteem could have downstream implications for reducing internalised HIV-related stigma, increasing body appreciation, and improving adherence to ART by young people.

Young people constitute the largest and fastest growing proportion of the general population in ESAR (UNPFA, 2019). The current youth bulge represents an enormous challenge for health services and health systems, as the sexual and reproductive health (SRH) and HIV service needs of the growing population remain unmet, particularly in low- and middle-income countries (Patton et al., 2016; Snow et al., 2015). Like their uninfected peers, AYPLHIV begin to explore their sexuality as they reach adolescence, some with the intention of getting married and bearing children (Bakeera-Kitaka et al., 2008). Young PLHIV are often confronted with a wide range of challenges as they struggle with normal adolescent developmental issues while carrying the burden of living with a highly stigmatised illness (Hosek et al., 2000).

Several studies on adolescents living with HIV in both low- and high-income countries have shown low and inconsistent condom use and low levels of disclosure among this population group (Okawa et al., 2018; Toska et al., 2017; Weintraub et al., 2017). Paucity of sexual health education and services tailored for AYPLHIV, continually contributes to

acquisition of other sexually transmitted infections (STIs), unintended pregnancy and high rates of onward HIV transmission to partners and offspring (Bauermeister et al., 2012). As HIV positive adolescents get older and engage in sexual and romantic relationships, additional research on their experiences of HIV disclosure, SRH needs, and other relationship-related factors is needed (Fairlie et al., 2014).

This study aims to understand the experiences of AYPLHIV, the unique SRH needs of this population group to support them in practising safer sexual practices and adopting healthy lifestyles. Furthermore, the findings of the present study could be used to develop policy guidelines for ensuring access to SRH services and to inform ART adherence interventions among AYPLHIV.

### **1.3 Aim and objectives of the study**

#### **1.3.1 Research aim**

The aim of the present study was to examine the relationship between body image and adherence to ART and understand perceptions of AYPLHIV pertaining to body image experiences. It also sought to explore the coping mechanisms that could be strengthened to promote adherence and well-being among AYPLHIV using a mixed methods approach.

#### **1.3.2 Study objectives**

The study seeks to:

1. Examine the relationship among each of the following factors on body image and adherence to ART in a sample of AYPLHIV in South Africa: social support, body appreciation, internalised HIV-related stigma, self-esteem, emotional well-being, and general health.
2. Investigate the association between self-esteem and adherence to ART as mediated by internalised HIV-related stigma and body appreciation among AYPLHIV.

3. Understand the thoughts and feelings of AYPLHIV on the appearance of their body and the strategies utilised to negotiate a positive body image.
4. Gain an in-depth understanding of the experiences of AYPLHIV and their SRH needs.

### **1.3.3 Research questions**

The research questions informing this study are as follows:

1. What is the relationship among each of the following factors: social support, body appreciation, internalised HIV-related stigma, self-esteem, emotional well-being and general health; and b) what is the relationship between these factors and body image and adherence to ART among a sample of South African AYPLHIV (15-24 years of age)?
2. What is the relationship between internalised HIV-related stigma, body appreciation, self-esteem, and adherence to ART among AYPLHIV?
3. How do AYPLHIV perceive and feel about their body appearance and what strategies do they use in negotiating a positive body image?
4. What are the SRH experiences and needs of AYPLHIV in Durban, South Africa?

### **1.4 Ethical considerations**

Initial access to the research participants was negotiated through the gatekeepers of the Blue Roof Life Space (BRLS), a state-of-the-art continuum of care centre for the treatment of HIV. Ethical approval for this study was obtained from the Humanities and Social Science Research Ethics Committee of the University of KwaZulu-Natal, South Africa (Protocol number: HSS/0522/018D). Participation in the study was voluntary as participants were informed of their right to withdraw from the study at any point without the fear of any negative consequences. A keen commitment to such ethical principles as informed consent, anonymity,

confidentiality, and voluntary participation was sustained throughout the study. Details of the ethical procedures are described in the data collection section (Chapter 3).

## **1.5 Outline of the thesis**

The outline of the thesis is presented below. This presentation includes the various aspects that are explored in each chapter.

### ***Chapter 1: Introduction***

Chapter One is an introductory chapter that provided a background to the study. In this chapter, an outline of the objectives, and need for the study is provided, including the typical research questions the study sought to answer.

### ***Chapter 2: Literature Review***

In this chapter, an overview of the literature review pertaining to the HIV epidemic and factors influencing AYPLHIV's adherence to ART. As this study has a strong focus on adherence to ART, literature pertaining to adherence and the factors that contribute to adherence are presented. Initially, a general overview of the global burden of HIV is provided and the chapter gradually progresses to portray South Africa as the epicentre of the epidemic. As part of the responses to the HIV epidemic, the chapter details South Africa's journey in adopting the wide use of ART and the success of optimum adherence in minimising mortality and improving well-being in individuals living with HIV. This section is followed by an examination of the concept of body image, which is central to young people's lives and one of the factors limiting optimum adherence. A fairly new concept, body appreciation is presented and its possible positive effects on adherence to ART. Other factors, such as self-esteem and internalised HIV-related stigma, which play an important role in the relationship between body image and adherence to ART are examined. Sexual risk behaviours that are prevalent among AYPLHIV

are also reviewed with an emphasis on positive prevention. This chapter is concluded by presenting the theoretical frameworks that informed the study.

### ***Chapter 3: Research Methodology***

In chapter three, a description of the research process utilised in conducting this study is provided. This includes the identification of, and justification for the use of a mixed-methods approach. The rest of the chapter describes the research setting, data collection instruments, the pilot phase of the study, data collection, and data analysis. The chapter ends by describing how ethical considerations were addressed.

### ***Chapter 4: Psychosocial factors associated with body image and adherence to ART among a sample of adolescents and young people living with HIV***

This chapter examined the relationship between body image, adherence to ART and the related psychosocial factors among AYPLHIV. The association between body image and the related psychosocial factors and adherence to and the related psychosocial factors are examined. The results are discussed in relation to the existing literature on body image and adherence to ART by people living with HIV.

### ***Chapter 5: Serial mediation model of internalised HIV-related stigma and body appreciation***

Chapter Four is a paper for publication. The paper is currently being reviewed by the *South African Journal of Science*:[sajs/submission/8354](https://sajs.org/submit/8354). The paper examines internalised HIV-related stigma and body appreciation as mediators of the relation between self-esteem and adherence to ART among AYPLHIV. This chapter is concluded by relating the findings to international literature and providing possible implications for policy and interventions.

### ***Chapter 6: Perceptions of body image and body image satisfaction among adolescents and young people living with HIV***

This is the first of three chapters that present the qualitative findings and discussion of the key themes identified in the study. The chapter begins with the demographic characteristics of the research participants. It focuses on AYPLHIV understanding of their body image and how it relates to various dimensions of their lives. Furthermore, it focuses on the various psychological sequel of a negative body image. A central concept the chapter examines is the perception of body satisfaction that is informed by different experiences including comparison with significant others.

***Chapter 7: Intimacy, sexual and reproductive health experiences of adolescents and young people living with HIV***

Chapter Six describes the in-depth qualitative research study that focuses on the lived experiences of AYPLHIV with regards to aspects of their intimate, and sexual and reproductive health experiences. The chapter also explores the pertinent issues regarding non-disclosure and reasons thereof.

***Chapter 8: Coping mechanisms adopted by adolescents and young people living with HIV***

In this chapter, protective factors identified by the participants are presented. In the preceding chapter the challenges and negative affect related to body dissatisfaction are presented. The coping mechanism identified by the participants to negotiate and maintain positive body image are presented and appropriate interventions are suggested.

***Chapter 9: Integrative discussion and conclusion***

This chapter provides an integrated discussion of the study's key findings, both the qualitative findings derived from in-depth interview with purposively selected AYPLHIV, and the quantitative results gathered through a cross-sectional survey with a relatively large group of participants. Overall, the chapter summarises the findings reported in this thesis in relation to the extant literature. The chapter is concluded by highlighting the doctoral study's contribution

to scholarship, proposals for interventions in both health and family settings to improve body image and adherence, as well as suggestions for future research. Limitations of the study are also highlighted in this section.

## **CHAPTER TWO**

### **LITERATURE REVIEW**

#### **2.1 Introduction**

This chapter provides an overview of extant literature pertaining to body image and adherence to ART among AYPLHIV. As this study was conducted among young people living with HIV, literature pertaining to adherence to ART, and the factors that influence it are presented. First, this chapter is introduced by providing a general overview of the HIV epidemic, prevalence of this phenomenon and programmes that have been initiated to mitigate the global epidemic. This section is followed by an examination of the concepts of adherence to ART and body image. Intrapersonal and interpersonal factors associated with body image and adherence to ART are also reviewed with specific focus on self-esteem, internalised HIV-related stigma, body appreciation and social support. This chapter concludes by presenting the Bronfenbrenner socio-ecological theory and Self-discrepancy theory, which guide the study. The socio-ecological theory indicates that individual behaviour is influenced by multiple interactive systems, suggesting that in understanding behaviour, it is fundamental to take cognisance of the individual and the broader external level influences with consideration of the interactions between these levels.

#### **2.2 The HIV epidemic in South Africa: A general overview**

After nearly two decades of government and civil society efforts to curb HIV in the ESAR, significant and laudable progress has been made in reducing both HIV incidence and prevalence. However, despite this encouraging progress the region is still home to the largest concentration of PLHIV, with 54.5% of the global number of PLHIV residing in the region in 2019 (UNAIDS, 2020). In the same year, there were 730 000 new HIV infections and 300 000 AIDS-related deaths (UNAIDS, 2020). Notwithstanding the progress made in the response to

alleviate HIV incidence and prevalence globally, adolescents and young people are still heavily affected by the disease. In 2019 alone, 260 000 young people between the ages of 15 to 24 were newly infected with HIV in ESA (UNAIDS, 2020). While the overall number of AIDS-related deaths fell by 48% between 2005 and 2016, AIDS-related deaths among adolescents and young people increased by 50% to approximately 55 000 deaths (UNAIDS, 2020). A generation of perinatally infected children who are growing into adolescence have been largely identified as the leading reason for these deaths (UNICEF, 2017).

Within the ESAR, certain countries are hardest hit by HIV. For example, South Africa has the biggest and most high-profile HIV epidemic in the region and the world, with an estimated 7.5 million people living with HIV in 2019. Further, the country accounted for more than a quarter (200 000) of the region's new infections in 2019 (UNAIDS, 2020). The HIV prevalence in the country equates to a proportion of approximately one in five people living with HIV. Women are disproportionately affected by HIV in South Africa. In 2017, 26% of women were estimated to be living with HIV, compared to around 15% of men (HSRC, 2019). Infection rates and prevalence among young people mirror the regional trends where adolescents and young people are heavily affected by the disease. In 2019, the estimated HIV prevalence among young people in South Africa aged between 15 and 24 years was 640 000, with the number of AIDS-related deaths in this age group approximately 6 900 (UNAIDS, 2020).

Certain high-risk areas and population groups particularly impacted by HIV can be identified. For example, in KwaZulu-Natal Province, estimates indicate that approximately 1.7 million people are living with HIV in the province (KZN Provincial AIDS Council, 2017). This equates to about 26% of the estimated number of PLHIV in the country marking the province as the epicentre of HIV. To reduce new HIV infections and AIDS-related deaths,

South Africa is committed to reaching the UNAIDS 90-90-90 Fast-Track targets (UNAIDS, 2018). One of the non-profit organisations, Médecins Sans Frontières working in Eshowe, South Africa, has achieved and surpassed UNAIDS' 90-90-90 HIV testing and treatment target, one year before the 2020 deadline indicating that the 90-90-90 targets are achievable (MSF, 2019). HIV treatment remains a key avenue to curb AIDS-related deaths.

### **2.3 HIV/AIDS treatment in South Africa**

Previously, HIV had been associated with immense human suffering; physically, socially and economically. During the first decade after the emergency of HIV, being infected with the virus was considered a death sentence and most children were orphaned, families were disintegrated and left without breadwinners as a result (May, 2003). However, the introduction of ART has offered hope to PLHIV as the treatment reduced mortality, increased life expectancy and improved quality of life significantly (Maartens et al., 2014). Prior to 2003, access to ART was limited mainly to a few affluent individuals and medical scheme beneficiaries (Adam & Johnson, 2009). In 2003, the South African government implemented an ART programme known as the Comprehensive Care Management, Treatment and Support (CCMTS) (DoH, 2010). As a result of this government initiative, ART became increasingly accessible, and significant progress has been made in enrolling patients onto the public ART programme. According to UNAIDS (2017) South Africa has the largest ART programme in the world, accounting for 20% of people on ART globally.

South Africa has made impressive progress in the roll out of ART since the start of the CCMTS programme. This progress has been made possible through the provision of cost-efficient treatment, decentralisation of service delivery to primary health care level and retaining patients on lifelong ART (DoH, 2010). Consequently, the unmet need for ART was reduced by 32% between 2007 and 2011 (Johnson, 2012). The ART programme in South

Africa was largely financed from the country's domestic resources. The country invests more than \$1.5 billion annually to run its HIV and AIDS programmes (UNAIDS, 2019). In 2013, the cost of buying ARVs in South Africa was reduced to the lowest price anywhere in the world through a more competitive bidding process (UNAIDS, 2013). In 2019, South Africa launched a new high-quality state-of-the-art HIV treatment. This single-pill HIV treatment, a first of its kind in the country is expected to improve treatment quality, retention of HIV patients and lower the cost of first-line HIV treatment regimens and at the same time minimising the need for more expensive second or third-line regimens (Gonzalez, 2019).

In 2016, the South African government incorporated the universal test and treat policy into the national ART guidelines (DoH, 2016). This strategy is aimed at eliminating HIV as it reduces the rate of onward transmission. The HSRC estimates on 90-90-90 strategy indicated that, 85% of people aged 15–64 years in South Africa who were living with HIV know their HIV status, 71% were receiving ART, and 62.3% were virally suppressed (HSRC, 2019). These estimates show that South Africa has made good progress towards the first UNAIDS 90% target. However, progress towards the second and third UNAIDS 90% targets has been less impressive. Despite its success in getting HIV-positive individuals diagnosed, South Africa has not achieved high levels of ART coverage and viral suppression (Johnson et al., 2017a). Optimal adherence to ART is one of the most important determinants of future HIV incidence trends, and it is therefore concerning that rates of adherence to ART are below the needed targets. Critical gaps still remain in achieving optimum adherence to ART. Several factors at the patient level, healthcare worker level and health system level were reported frequently as barriers to ART adherence, and these are discussed in detail in the following section.

## **2.4 Adherence to Antiretroviral Therapy (ART)**

Adherence is defined as the extent to which a person's behaviour in terms of taking medications, following a diet, and executing lifestyle changes follows agreed recommendations from a healthcare provider (WHO, 2013). Lack of adherence to ART is a major obstacle to the success of ART as suboptimal adherence is associated with inadequate viral suppression and the emergence of drug-resistant strains of HIV, which subsequently result in treatment failure and disease progression (Gupta et al., 2012). On the contrary, high levels of adherence have been consistently associated with improved immunologic and clinical outcomes (Focà et al., 2014), with a consequent increase in health-related quality of life (Vagiri et al., 2018). Promoting optimal adherence to ART is critical to ensuring the global success of treatment of HIV and consequently improved quality of life.

Effective ART treatment outcomes require adherence levels of greater than 95% (Nilsson Schönnesson et al., 2006). This degree of adherence is far greater as compared with other chronic diseases like hypertension and diabetes, where adherence rates of 70%-80% are adequate to attain treatment goals (Population Council, 2004) and is quite difficult for most HIV patients to maintain during the course of a lifelong illness (Mannheimer et al., 2002). Contrary to the high rates required for successful treatment, non-adherence to ART is widespread in all groups of treated individuals. Evidence indicates that 10% of patients report missing at least 1 ARV drug dose on any given day and 33% miss at least 1 drug dose within the past month (Ickovics & Meade, 2002). Most patients taking ARVs, regardless of their background or life situation, will encounter difficulties with adherence. Studies aimed at identifying factors that influence adherence assert that non-adherence rates range from 50%-80% in different contexts (Amico et al., 2005; Remien et al., 2007). Non-adherence has been found to diminish the immunological benefit of ART and increase AIDS-related morbidity, mortality, and hospitalisations (Knobel et al., 2001).

Nachega et al. (2009) argue that adherence to ART in young people is worse than in adults. This is particularly problematic given that a significant proportion of adolescents and young people are living with HIV and regularly engage in unprotected sex (Ssewanyana et al., 2018). Optimal adherence to ART is crucial, from both an individual and public health perspective. At the individual level, non-adherence to ART can lead to impairments in psychosocial functioning (e.g., weakening of social relationships and loss of self-esteem resulting from periods of illness), can accelerate HIV resistance to treatment (Nachega et al., 2011), and is a common cause of death among individuals with HIV (Biset Ayalew, 2017). From a public health perspective, interruption to ART adherence is associated with an increased risk of HIV transmission to non-infected sexual partners, can lead to drug-resistant strains of HIV (Stekler et al., 2018), and may have downstream implications for healthcare costs (Long et al., 2016).

Among adolescents ART success is influenced by multiple factors associated with their biological, social, and psychological development (Jobson, 2011). Adolescents may intentionally miss their dose to hide disclosure of HIV status. Disclosure of one's HIV status to family members and sexual partners is fundamental in the management of the HIV epidemic. However, disclosure of HIV serostatus among family members and sexual partners remains a significant challenge (Tshweneagae et al., 2015). Fear of stigma, discrimination and rejection have been frequently identified as reasons for non-disclosure of HIV positive status (Mburu et al., 2014).

Rwemisisi et al. (2008) report that lack of disclosure creates a context of confusion and mistrust and increases vulnerability to risky behaviour. From a public health standpoint, disclosure to sexual partners is perhaps the most important form of disclosure as it may encourage the partner of an HIV infected individual to seek HIV testing and to adopt safer sexual behaviour, such as condom use to prevent infection (Alemayehu et al., 2014). The low

levels of self-disclosure evidenced in adolescents is alarming considering that disclosure has been documented as essential for adherence to treatment regimes, mobilisation of social support, and prevention of further HIV transmission (Rwemisisi et al., 2008).

Other key factors contributing to non-adherence include alcohol and substance use, pill burden, doctor patient relationship and side effects (Rao et al., 2007; Remien et al., 2007). However, the introduction of once-daily and single-tablet ARV drug regimens has led to better adherence to ART as it is associated with fewer side effects and overcomes the challenge of pill burden (Pantuzza et al., 2017). Side effects, including bodily changes are likely to be a major factor for non-adherence to ART among adolescents as they fear that these physical changes would make them identifiable as HIV-positive (Loeliger et al., 2016). For example, recent findings have revealed potential links between dolutegravir and weight gain (Norwood et al., 2017), whereas raltegravir has been linked with development of skin rash (Nachman et al., 2018). These bodily changes arising from ART may contribute towards a negative view of the self and perceptions of loss of desirability (Guaraldi et al., 2008).

Body image disturbance has been associated with poor adherence to ART (Blashill, & Vander Wal, 2010). HIV and ART can cause lipodystrophy. The morphologic alterations arising from HIV and ART (severe fat loss and/or gain) may affect the behaviour and psychological well-being of HIV-infected individuals, including body image disturbance and adherence to ARV (Guaraldi et al., 2003; Plankey et al., 2009; Santos et al., 2005). A study conducted in Ghana, Kenya and Rwanda found that long term use of some types of ARV drugs can result in disfigurement (Ritzenthaler, 2005). Physical transformation contributes to a poor self-image and ultimately results in the patient's abandonment of ART and loss from care (Carr et al., 2000). A study by Kasper et al. (2000) revealed that 37% of their respondents either stopped or changed their medications because of lipodystrophy. Fifty seven percent of those who were adherent to ART stated that they had considered discontinuation of therapy, while

46% were considering changing medications if symptoms worsened. Hence, concerns about changes in body appearance may lead individuals to be less adherent to their ART regimen.

There is a deficiency of research specifically concerning adherence among adolescents in sub-Saharan Africa (Denison et al., 2018). As the paradigm of HIV prevention has shifted to treatment as prevention, it is necessary to investigate the relationship between perceptions of body-related concerns and adherence to ART among HIV-positive youth in order to promote a positive body image, increase adherence to ART and consequently quality of life among young people. Adherence interventions should also address body-related concerns as these are central to young people whose sense of identity is partially influenced by their physical appearance (Daniels & Gillen, 2015).

## **2.5 Body image**

Body image is a multidimensional construct representing cognitive, affective and behavioural responses to an individual's own physical and psychological attributes of one's body (Muth & Cash, 1997). Despite its complex make-up, body image has been defined as a combination of, "an individual's mental representation of the integrity and competence of their own physical self, as well as their awareness of how others perceive them" (Martinez et al., 2005, p. 150-151). Thus, body image relates to a person's perceptions, feelings and thoughts about his or her body. However, these feelings and thoughts are not entirely inherent but rather the image that an individual has of his or her body is largely determined by social experience (Grogan, 2008). Body image development is the result of a combination of internal and external factors. Studies on body image, have suggested various factors that impact the development of body image. Other researchers have classified these factors as an interaction between sociocultural, interpersonal and individual predictors (Rumsey & Harcourt, 2005). Some of the factors identified include, but are not limited to sex, gender, sexual orientation, race,

psychological and physical well-being, family dynamics, mass media, psychological factors and socio-economic status are, which are some of the important antecedents that shape an individual's perceptions of body image (Carlson & Kiemle, 2016).

Rucker and Cash (1992) proposed two distinct components that make up body image; perceptual body image and attitudinal body image. Perceptual body image refers to how a person subjectively assesses his or her physical appearance including the size of their body (Rucker and Cash, 1992). This assessment is influenced by a variety of factors including society's idealised standards of attractiveness. Attitudinal body image refers to a person's satisfaction or dissatisfaction with some other aspect of body appearance or with overall appearance (Ruuska et al., 2005). Both perceptual and attitudinal body image can create a positive or negative body image when a person compares and judges oneself to certain standards.

On the one hand, people with a positive body image hold favourable opinions of the body, engage in healthy behaviours, reject unrealistic ideal body images portrayed in the media and are more self-confident (Avalos et al., 2005). On the other hand, those with a negative body image are often not content with their body, feel less attractive and suffer from a variety of psychosocial problems such as anxiety, depression, poor self-esteem, and sexual inhibition (Lavin & Cash, 2000; Westerberg-Jacobson et al., 2010). Importantly, body image is not static; it can change in relation to mood, physical experience, and environment (Croll, 2005). The concept of body image is critical during adolescence.

### **2.5.1 Body image and adolescence**

Adolescence is a period in which the individual goes through many physical and cognitive changes resulting in increased evaluation and focus on body and appearance (Mitchell et al., 2012). The concept of body image is significant for most young people as it is

a fundamental aspect that has an enduring influence on emotional and interpersonal functioning. An Australian survey among 14 461 young people aged between 15–19 years found that 42.1 % of adolescent females were concerned about body image and identified body image as the third major issue of personal concern after coping with stress and school/study problems (Mission Australia, 2014). Young children may experience body image concerns (Smolak, 2011), however these concerns become increasingly pronounced in adolescence (Lunde et al., 2007). Adolescents' sense of self-worth and perceptions of social relations are closely linked to their body image (Davison & McCabe, 2006). Peer relationships play a more important role during adolescence than in childhood. Adolescents tend to give much more importance to what others think about their appearance and seek validation from their peers on how they look (Cash & Smolak, 2011). Bukowski (2003) asserts that being accepted by peers is one of the most central concerns during adolescence. Nevertheless, it is noteworthy that although every adolescent goes through biological, psychological, and social changes, the interpretation and impact of these changes depend on the context in which the adolescent develops (Steinberg, 2011).

Identity development is an important milestone during adolescence whereby young people explore and make significant life decisions regarding occupation, friendships, romantic partnerships, and gender roles (Erikson, 1968). Evidence suggests that these identity development processes are linked to body image (Voelker et al., 2015), thereby highlighting the pervasive nature of body image in adolescents' life. The body serves as an important source of reference for most adolescents' understanding of their identity and of their relations with the social world. A poor body image may hamper adolescents' development of interpersonal skills and positive relations with peers (Davison & McCabe, 2006). Research indicates that attractiveness and social acceptability of an individual's physical appearance has an impact on how he/she is perceived and treated by others (Cash & Smolak, 2011).

Peers are the most immediate and influential point of reference for appearance-based comparison. Through directly observing and comparing themselves to the physical attributes of their peers, adolescents learn what body images are associated with social privilege and popularity (Carey et al., 2014). Among adolescent girls mostly, appearance seems to be a pertinent way of expressing identity. During puberty, teenage girls are highly aware of their appearance and understand that the body becomes a pivotal instrument in social relations (Nanu et al., 2014). Hence, one can argue that the role played by body image in the social interactions of adolescents is gendered.

It is not uncommon for adolescents to be dissatisfied with certain aspects of their body. A national survey in Ireland examining adolescents' perceptions of and attitudes towards body image showed that 43% of participants aged 10 to 21 years were dissatisfied with their body image (O'Connell & Martin, 2012). Additionally, a study on body image satisfaction among rural South African adolescents showed that 83.5% of the girls in the study demonstrated body dissatisfaction, with 58% expressing a desire for a thinner body size (Pedro et al., 2016). Evidence indicates that dysfunctional evaluations of the body peak during adolescence (Littleton & Ollendick, 2003).

Body image dissatisfaction is the subjective feelings of dissatisfaction with one's physical appearance (Kimber et al., 2015). Individuals are likely to develop body image dissatisfaction when there is a discrepancy between ideal and perceived actual body sizes (Wertheim et al., 2004). Previous research has shown that more adolescent girls than boys are dissatisfied with their bodies and want to change the way they look (Meland et al., 2006). Furthermore, body dissatisfaction is associated with numerous health related conditions. Previous studies suggest that adolescents who are dissatisfied with their bodies are more likely to perceive their health as fair or poor and more likely to show symptoms of depression, low self-esteem, and low social functioning (Cruz-Saez et al., 2015; Field, 2004).

A systematic review conducted by Webb and Zimmer-Gembeck (2014) found that friends and peers influence adolescent body dissatisfaction through various mechanisms, including appearance-related teasing and criticism, judging the appearance of friends, and social exclusion. This is not surprising as peer pressure is greatest among adolescents. On the contrary, peers can positively impact adolescent body image by providing support to those who experience difficulties coping with changing physical appearance and/or those who are subjected to appearance-based teasing and criticism from other peers (Kenny et al., 2017). Body image in adolescents has been researched mostly in the context of eating disorders, physical exercises, and mental disorders (Grogan, 2008; Markey, 2010). Given the paucity of research linking body image to HIV treatment adherence among AYPLHIV, it is of utmost importance that the phenomenon be thoroughly investigated and understood.

### **2.5.2 Body image in HIV patients**

Chandler and Ngoksin (2013) emphasize that in sub-Saharan Africa, late diagnosis and poor treatment outcomes among adolescents living with HIV are frequently reported, especially among those who acquired HIV during adolescence. Both vertically and horizontally infected adolescents may experience bodily changes related to HIV infection and poor treatment outcomes. HIV infected adolescents are usually physically stunted and grow slowly as compared to their uninfected counterparts (Muhangi et al., 2013). Growth retardation has a negative psychological impact on adolescents for whom body image is an integral part of the adolescence phase (Naswa & Marfatia, 2010). Horizontally and vertically infected adolescents collectively represent a unique group in that they must manage the issues associated with adolescence (bodily changes, behavioural changes, the dawning of sexuality) while also coming to terms with the difficult reality of living with HIV (Fernet et al., 2007).

Effective management of HIV has become possible using ART. Because of more successful treatment options, HIV has transitioned from a terminal illness to a chronic condition with many perinatally infected children living to adolescence (Yang et al., 2015). As youth are living longer with HIV, they are likely to experience debilitating physical, mental and psychosocial factors that impact their well-being. People diagnosed with HIV are likely to experience alterations in bodily appearances resulting from the disease itself and treatment (Fingeret et al., 2007; Yang et al., 2015). Studies with both male and female participants have shown that alterations in body appearances have significant effects on the psychosocial well-being and quality of life for PLHIV (Huang et al., 2006; Sharma et al., 2007).

Generally, any chronic illness may transform the previous experience of the body (Chapman, 1998). The presence of illness is associated with a loss in confidence in the functioning of one's bodies (Williams, 1996). HIV and its treatment have various distinctive aspects of its own that impact on the body. These include significant persistent changes in physical functioning and appearance, such as fatigue, rash, lipodystrophy, and sexual dysfunction (Blanch et al., 2004; Dukers et al., 2001), which can negatively affect subjective perceptions of body image. A study conducted in two towns in the UK found that 70% of the participants in the HIV group expressed a desire for more physical contact as they felt that they were not receiving sufficient contact from others as a result of living with a stigmatised illness (Chapman, 1998). These findings suggest that a person with HIV may have negative feelings about their body, associated with a perception of not getting enough physical contact. These findings regarding negative feelings about the body were also substantiated by a study conducted by Martinez et al. (2005) with HIV-positive men and women, which found that patients' current perceptions of their body image were less favourable than their perceptions of themselves before they were infected. Thus, a diagnosis and knowledge of living with HIV is significantly related to a poorer body image.

More than 30 years after the discovery of HIV, the label of HIV seropositive is still highly stigmatizing (Koodibetse, 2015). Martinez et al. (2005) argued that the diagnosis of HIV is immutable and once given to an individual, it will remain irrespective of their current state of health. Furthermore, patients on ART reported negative feelings of being contaminated, and the act of taking ART medications as a daily reminder of the viral infection, which was related to lower life satisfaction (Yang et al., 2015). A diagnosis of HIV is significantly related to poorer quality of body image and lowered life satisfaction arising from internalised shame and fear of discrimination (Mudgal & Tiwari, 2015). Findings by da Silva and Alchieri (2013) suggests that in evaluating the body self-perception of PLHIV on ART even without specifying lengthy of treatment/or generation of drugs, there may be direct interference in the ability to interact, as patient often isolate themselves (social death) to avoid denouncing their status as HIV positive. Hence, it is difficult to disentangle HIV from body image, social relations and ultimately quality of life.

People living with HIV experience varied levels of body image satisfaction. Studies indicate that as compared to HIV negative individuals, PLHIV have low levels of body image satisfaction resulting from deterioration in their shape, size and functioning of their body (Jain & Tiwari, 2016; Yang et al., 2015). Body dissatisfaction among HIV-infected people has been associated with important health outcomes, such as poor adherence to ART (Blashill & Vander Wal, 2010), increased sexual behaviours that can transmit HIV (Blashill et al., 2014) and low self-esteem (Yang et al., 2015). A study by Jain and Tiwari (2016) among 40 HIV patients also showed lowered body image satisfaction and life satisfaction in general as compared to uninfected participants. Participants in that study explained the lowered body satisfaction as a result of stigma, lack of social support and being constantly reminded of their illness. In order to enhance the body image and quality of life of AYPLHIV, understanding the relationship between body image and psychosocial factors like shame and social support is pertinent.

Issues pertaining to body image are critical for adolescents who associate attractiveness with social desirability. An illness such as HIV potentially robs people of their health and in some cases, their desirable physical characteristics. The changes in body image which people with HIV undergo have been neglected by researchers and have often been researched in the Asian, European and American context among non-adolescent population groups (Jain & Tiwari, 2016; Martinez et al., 2005; Tate & George, 2001). Further research is required to assess the significance of body image for the emotional and psychological health of this group of people, especially in the light of findings that young people diagnosed with HIV during adolescence are confronted with dilemmas around the same normal issues of development that “healthy” adolescents face, like selecting a romantic partner and engaging in sexual activity (Ramjohn, 2012).

### **2.5.3 Body image and interpersonal relationships**

Peer relationships play a more important role during early adolescence than in childhood, with friendships becoming more intimate (Berndt, 1998). During this period, young people are concerned about their appearance and how this influences their acceptability by peers. Through socialisation and as they form relationships among each other, individuals create an appearance culture that is modelled and reinforced by peers (Cash & Smolak, 2011). Failure to conform to a certain set standard of physical appearance as described by the appearance culture is met by criticism in the form of teasing.

Appearance teasing is associated with lower body image satisfaction for both boys and girls (Cash & Smolak, 2011). For women and men alike, a negative body image is related to greater discomfort and concerns about approval and acceptance in social interactions (Cash et al., 2004). Importantly, acceptance by friends and perceived social support is associated with fewer body image concerns (Gerner & Wilson, 2005). For adolescents living with HIV, the

relationship between body image and peer interaction seems to be more complex as their interaction and acceptability with peers may be worsened by the stigma associated with HIV.

Physical attributes have noteworthy implications for sexual attraction. Different theories have been proposed to explain and describe the different mechanisms underlying sexual attraction in human beings. Social psychologists have generally argued that sexual preferences in physical attributes such as body shape and size are largely learned and are determined by the value that a particular culture attaches to a particular body shape (Grogan, 2006). Most evolutionary psychologists suggest that there are biological reasons for body shape and size preferences in potential sexual partners. A study by Davison and McCabe (2006) among adolescents showed that general attractiveness was the most important aspect of body image in predicting perceived relations with members of the opposite sex among both sexes. Additionally, the study reported that negative evaluations of the participant's bodies and concerns about others' negative evaluations of their bodies also predicted poor opposite-sex relations among boys and girls.

Physical appearance plays a crucial role in romantic and sexual relationships. Romantic relationships are complex and involve a variety of perceptions of self and partner (Swami et al., 2009). Research indicates that the opinions of others are equally important as individuals' own thoughts and feelings about their body. Meltzer and McNulty (2010) found that women who reported more positive feelings toward their bodies also reported being more confident that their partners find them sexually attractive and thus sexually desirable, whilst those who reported more negative feelings toward their bodies were anxious about romantic intimacy and had doubts that their partners desired them sexually. A study by Cash et al. (2004) indicates that body image can affect the quality and quantity of one's sexual experiences in romantic relationships, with a negative body image being associated with more self-conscious anxiety about and avoidance of sexual activity. Adolescence is a phase with significant physical

changes which are linked to the initiation of romantic relationships. This context facilitates an increased interest in the physical body, which is analysed, compared, and evaluated against peers and the societal standards. A qualitative study with AYPLHIV who are likely to experience unwanted physical changes, which seeks to explore the role of body image on peer and romantic relationships can potentially reveal new information on their needs as well as how to help them negotiate and maintain these relationships.

## **2.6 A shift towards body appreciation**

Research on body image has traditionally focused on understanding such negative aspects of body image as body dissatisfaction (Smolak & Cash, 2011; Tylka, 2012). This approach to body image allows the creation of therapeutic methods to alleviate symptoms of negative body image (Smolak & Cash, 2011). However, concentration on negative body image may have led to the neglect of research promoting positive body image. Tylka (2012) suggests that the conceptualisation of positive body image and negative body image as endpoints along a body image continuum contributed to the slow representation of positive body image in research. Further, a positive body image is distinct from a negative body image. It is a more complex concept than simply an absence of negative feelings towards one's body. Hence, an individual may report a positive body image but may also be dissatisfied with certain bodily appearances (Avalos et al., 2005). Recently, there has been recognition of the importance of studying positive body image (Bailey et al., 2016). Broadly defined, positive body image refers to the love, respect, acceptance, and appreciation held for one's body (Tylka, 2011). Having positive body image allows individuals to accept all aspects of their body, even those perceived as imperfect and which do not conform to media-portrayed societal ideals, and to appreciate the functions their body performs for them (Tiggemann & McCourt, 2013).

Research on positive image is increasingly becoming popular as the construct is associated with important outcomes such as increased acceptance of bodily imperfections and engagement in healthy self-care behaviours (Frisen & Holmqvist, 2010; Wood-Barcalow et al., 2010). One component of positive body image is body appreciation. Body appreciation in individuals is highlighted by an attitude of acceptance and love toward all body features, functionality, and health (Avalos et al., 2005). There are four fundamental aspects of body appreciation which are; the favourable perceptions of one's body, the acceptance of the body irrespective of its shape, the respect of the body's needs, through adopting healthy habits and lastly, the body's protection by rejecting non-realistic image standards promoted by mass media (Avalos et al., 2005). The concept of body appreciation impels engagement in self-care behaviour and rejection of societal prescribed ideals of beauty. Research into body appreciation can aid in understanding how to prevent body image disturbance and ways to promote health and well-being in AYPLHIV.

Body appreciation is connected with various positive characteristics such as women's self-esteem, positive affect, and proactive coping (Avalos et al., 2005; Swami et al., 2008). Among males, body image is associated with self-esteem, instrumentality, life satisfaction, and positive affect (Swami et al., 2008; Tylka & Kroon Van Diest, 2013). Body appreciation has been associated with favourable appearance evaluation, greater psychological well-being, less body shame and body preoccupation, and fewer eating disorder symptoms (Avalos et al., 2005; Tylka & Wood-Barcalow, 2015a). A study by Frisen and Holmqvist (2010) among adolescents found that individuals with high body appreciation viewed their bodies as functional objects, accepted their bodily flaws, and ignored appearance-related teasing from others. Given the association between body image and sexuality, a study by Satinsky et al. (2012) among women indicated that having higher body appreciation positively predicted sexual function.

Body appreciation may act as a protective factor against psychological disturbances. A grounded approach study among college women classified as having positive body image reported that the participants later appreciated features of their body that they previously disliked (Wood-Barcalow et al., 2010). Positive body image may lead individuals to change their attitude and behaviour towards body appearances promulgated by the media and society and adopt healthy behaviours. For example, a study among Swedish adolescents revealed that they viewed their bodies as important aspects of themselves that they need to appreciate and take well care of; for example, by exercising to maintain or even improve their functionality (Frisén & Holmqvist, 2010). Body image interventions that incorporate positive body image aspects, body appreciation in particular have the potential to equip individuals with self-protective cognitive skills to the extent that, previously held body dissatisfaction may become negligible. Researching body appreciation in PLHIV is pertinent, as patients are likely to experience undesirable bodily changes and shame associated with the illness that may hinder acceptance and love for one's body.

## **2.7 Psychosocial factors for body image and adherence to ART**

### ***2.7.1 Internalised HIV-related stigma***

Through the wide availability of ART and engagement with national and international organisations in the HIV dialogue, HIV has become increasingly normalised and socially acceptable as a chronic disease (Colvin, 2011). Despite the interventions to eradicate HIV stigma, it continues to be a significant barrier to HIV prevention and treatment efforts, more than three decades after the start of the global epidemic. Studies in China, Zambia and South Africa have reported moderate levels of HIV-related stigma existing among their study samples (Hargreaves et al., 2018; Li et al., 2018). In one study in the United States, 84% of patients in HIV care reported some level of internalised HIV-related stigma (Valverde et al., 2018). A

survey of HIV-positive individuals in South Africa also reported that over one-third of the participants perceived themselves as having experienced HIV stigma and people aged between 15-24 years were more likely to experience external, internalised, and anticipated stigma (HSRC, 2015). While major advances in prevention and treatment of HIV have been made in recent years, the epidemic persists in part due to challenges linked to HIV-related stigma (Walcott et al., 2016).

Generally, stigma refers to the recognition of a difference that is socially constructed based on a specific characteristic that is used to devalue a person who possesses it (Dovidio et al., 2000). Three different types of stigma have been identified in the HIV literature; anticipated stigma, enacted stigma and internalised stigma (Earnshaw & Chaudoir, 2009). Enacted stigma refers to the degree to which a person living with HIV believes he/she has actually experienced prejudice and discrimination from others in their community whilst anticipated stigma refers to the degree to which a person living with HIV expect that he/she will experience prejudice and discrimination from others in the future (Deacon, 2005). Internalised HIV-related stigma refers to the negative beliefs and feelings endorsed by those diagnosed with HIV infection (Audet et al., 2013). It is characterised by feelings of shame, guilt, and worthlessness (Tsai et al., 2013). Internalised HIV-related stigma is likely to make an individual more sensitive to both actual and anticipated rejection and stigmatization by others (Chesney & Smith, 1999). Hence, addressing internalised HIV-related stigma can be the first step in alleviating other forms of stigma. Existing stigma intervention studies have heavily focused on reducing enacted stigma (Stangl et al., 2013), despite evidence consistently suggesting that internalised HIV-related stigma is more prevalent than enacted stigma (Cuca et al., 2012; Pantelic et al., 2019).

Goffman (1963) identified three types of stigma; abominations of the body, blemishes of individual character, and tribal stigmas. Although all these different types of stigma can be observed in PLHIV, abominations of the body seem to have more impact in young people's

life who are more vested in physical attributes during this stage. The body of PLHIV plays two important roles in the stigmatisation process. The first one being that the body can provide physical or visual evidence of the condition (e.g., lipodystrophy) and secondly, even in the absence of clearly visible markers of the condition to others the body can work as a generator of self-stigmatising attitudes (Goffman, 1963). Given that the human body constitutes the vehicle for interaction with the world and others (Varas-Díaz & Toro-Alfonso, 2003); perceived negative body image may be a source for perceived stigma. This may result in disruptions in social interactions. When the marks that foster stigmatisation are evident and clearly visible, for example, wasting these marks entail an increase in stigmatisation. Findings from a study among 30 participants living with HIV showed that they perceived that their bodies evidenced their HIV status to others, and that this fostered stigmatisation and negatively influenced social interaction (Varas-Díaz et al., 2005). HIV-related stigma has been associated with psychosocial, economic, and public health costs.

Internalised HIV-related stigma may impact on the well-being of PLHIV and their participation in social activities. In a cross-sectional study of PLHIV in the United States of America, internalised HIV-related stigma was associated with lower likelihood of adherence to ART after controlling for enacted and anticipated stigma (Earnshaw et al., 2013). Other studies in different locations, among different samples have reached the same conclusion that internalised HIV-related stigma results in suboptimal adherence to ART (Turan et al., 2019; Logie et al., 2018). Internalised HIV-related stigma also leads to lower adherence to HIV care visit (Rice et al., 2017), which leads to lower adherence to ART as individuals who do not present for HIV care visits may not benefit from aspects of the HIV care experience such as the patient-physician relationship that may act as facilitators to ART adherence (Beach et al., 2006).

Internalised HIV-related stigma is negatively related to various psychosocial variables. Specifically, internalised HIV-related stigma is negatively related to the level of perceived social support and positive action coping, and positively related to the level of grief, passive problem solving, depression, anxiety, and hopelessness (Lee et al., 2002; Murphy et al., 2018). A study among adults living with HIV in the United States of America indicated that HIV-related stigma may increase patients' level of loneliness compared to the general population (Yoo-Jeong et al., 2012). HIV-related stigma may compromise the ability of infected people to adhere to ART by undermining social support and adaptive coping (Katz et al., 2013). A negative relationship exists between internalised HIV-related stigma and quality of life. In one recent study in Tanzania among an adult sample of PLHIV, high internalised HIV-related stigma was significantly associated with higher odds of poor life satisfaction and poor overall function (Parcesepe et al., 2020). A study by Holzemer et al. (2009) among PLHIV recruited participants from clinics in 14 sites in Africa, Puerto Rico, and the United States of America showed that stigma had a negative effect on quality of life independently of HIV-related symptoms and severity of illness.

The study's focus on internalised HIV-related stigma is influenced by the notion that internalised HIV-related stigma tends to have a stronger relationship with adherence to ART than other dimensions of HIV-related stigma, both theoretically and empirically (Earnshaw et al., 2013; Turan et al., 2017). Receiving an HIV diagnosis and possibility of a life on treatment may be experienced as stressful events (Nightingale et al., 2010) that may exceed one's psychological or social resources. Addressing internalised HIV-related stigma by investing in psychological resources such as self-esteem may be a way to help PLHIV to cope with challenges of stigma and achieve optimum adherence to ART adherence.

### ***2.7.2 Self-esteem***

The interest and importance of researching self-esteem has grown over the years partly because of its positive effect on well-being in general. Rosenberg (1965) defined self-esteem as an individual's overall positive evaluation of the self, including self-respect and self-worth. Self-esteem is related to one's beliefs about skills, abilities, and social relationships (Rosenberg, 1965). Thus, it is a key contributing factor to the perceptions that individuals place on themselves and their capabilities. An individual with high self-esteem evaluates him/herself positively and has self-confidence in their abilities to handle life challenges. In the same vein, Reasoner (2005) perceived self-esteem as comprising two distinct dimensions, which are competence and worth. Self-esteem is an integral aspect in the creation and maintenance of health and quality of life. People with high self-esteem experience more happiness, optimism, and motivation than those with low self-esteem, as well as less depression, anxiety, and negative mood (Pyszczynski et al., 2004). Although self-esteem is typically defined as a global and relatively stable trait (Harter, 1998; Rosenberg, 1965), chronic illness may impact negatively on self-esteem (Vitulano, 2003).

People living with chronic illness may suffer from ongoing physical symptoms as well as the accompanying psychological distress. In particular, PLHIV may have their self-esteem damaged due to the physical and social impact the infection may cause in their lives, such as stigma, rejection, loss of social identity and bodily changes (Castrighini et al., 2013; Okwaraji et al., 2019). Self-esteem is negatively correlated to HIV-stigma and positively correlated with social support (Dowshen et al., 2009). A study by Okwaraji et al. (2019) among outpatient HIV clinic attendees indicated that 40% of the respondents had low self-esteem. A comparison between perinatally HIV-infected adolescents and HIV negative adolescents indicated that the total mean self-esteem scores of HIV-infected adolescents (46.14) were significantly lower than those of HIV negative adolescents (50.35; Louthrenoo et al., 2018). Higher self-esteem may have a positive effect on adherence to ART.

Low self-esteem may lead individuals living with HIV not to care for their health, and not to search for treatment whereas increased self-esteem makes individuals living with HIV to perceive themselves in a positive way (Castanha et al., 2006; Manhas, 2013). Some of the subjective reasons for non-adherence to ART often cited by the patients are distress due to side effects, lack of insight and low self-esteem (Sahay et al., 2011). In a sample of adolescent cancer patients on antibiotic treatment, participants who had higher levels of self-esteem reported better adherence to the medication (Kennard et al., 2004). Self-esteem may have a critical impact on adherence to ART due to several reasons, yet few studies have investigated the relationship that exists between these two factors. For example, lower self-esteem is associated with increased alcohol misuse and recreational substance use, which can impair judgment and may interfere with an individual's ability to adhere to treatment (Sileo et al., 2019). Conversely, self-esteem may buffer against the impact of negative life experiences and contribute to better health and well-being (Mann et al., 2004). Further studies that examine the relationship between self-esteem, body image and adherence to ART are needed.

### ***2.7.3 Social support***

Social support plays a positive role in promoting people's physical and psychological health. Social support is a multi-dimensional construct. Generally, social support has been defined as beliefs that one is loved, respected, and esteemed by and involved with family, friends, and others (Heaney & Israel 2002; Yadav, 2010). House (1981) conceptualised four broad categories of social support: emotional support, instrumental support, informational support, and appraisal support. Social support can originate from different sources such as empathy, caring and love (emotional support), actual aid in time, money and energy (instrumental support), constructive feedback and affirmation (appraisal support), and information, advice and suggestions (informational support) (Heaney & Israel 2002; House,

1981). Social support can be particularly helpful for PLHIV as HIV infection is usually a stressful life event associated with a variety of negative reactions such as stigma.

HIV infection and the related stigma can cause strain in an individual's social network structure, which may result in prejudice, discrimination and dissolution of social relations (Bastardo & Kimberlin, 2000; Varas-Díaz et al., 2005). Research indicates that among PLHIV, social support is one of the most important factors that may improve well-being and quality of life (Bekele et al., 2013). Social support buffers the negative impact of HIV stigma and HIV-related harmful beliefs (Colbert et al., 2010; Larios et al., 2009). Family support and perceived support provides better psychological well-being, reduced stress, and better emotional well-being (Iwelunmor et al., 2008). Furthermore, social support is also crucial for HIV patients to develop positive coping and maintain a positive attitude (Nazik et al., 2013).

The positive influence of social support is not only limited to coping with stress related to stigma but contributes towards ART and dealing with aspects related to the fear of death (Calvetti et al., 2014). Social support positively influences adherence to ART by HIV-positive individuals. A study by Poudel et al. (2015) showed that low levels of perceived family support, particularly emotional support was associated with increased risk of non-adherence to ART by HIV-positive individuals. One review on adherence to ART in middle and low-income countries highlighted that patient support was very important to treatment adherence (Nachega et al., 2010). Social support may also have a positive effect on issues pertaining to perceptions on body image. Studies have shown that adolescents and young adults who perceive receiving adequate social support fare better than those who do not in many areas of functioning including body image satisfaction (Barker & Galambos, 2003; Merianos et al., 2012). Living with a stigmatising condition like HIV represents a source of stress as patients often feel rejected, and in these cases social support can play an important role in decreasing negative affect including negative body image.

## **2.8 Intimacy and sexual and reproductive health (SRH) in YPLHIV**

Adolescence is a phase characterised by significant physical changes, which are linked to the initiation of sexual relationships. As they reach adolescence, YPLHIV begin to explore their sexuality, some with the intention of getting married and bearing children (Bakeera-Kitaka et al., 2008). Several studies on sexual risk behaviour conducted in cohorts of PLHIV in ESA, who often were on ART have shown that PLHIV are highly sexually active (Bajunirwe et al., 2013; Eisele et al., 2008). A significant number of studies on adolescents living with HIV in both low- and high-income countries have shown low and inconsistent condom use and low levels of disclosure among this population group (Okawa et al., 2018; Toska et al., 2017; Weintraub et al., 2017). A systematic review among HIV positive adolescents and youth in sub-Saharan Africa indicated that HIV-positive adolescents and youth reported high levels of sexual risk-taking, even though most of the included HIV-positive adolescents and youth were already on ART and receiving HIV care (Toska et al., 2017).

Furthermore, a study in Togo among PLHIV on ART indicated that 74.6% were sexually active since initiation of ART, and 34.6% of these had risky sexual relations (Yaya et al., 2014). Nearly three-quarters of all pregnancies among HIV-positive adolescent women were reported to be unintended suggesting the unmet contraceptive need among this population (Toska et al., 2017). Young individuals are positioned as having higher chances to engage in risky sexual practice than old ones. Some of the plausible reasons for this include that young people are usually sexually hyperactive, sexual encounters are usually unplanned, alcohol consumption is common, and they usually have casual sex and multiple sexual partners (Molla & Gelagay, 2017).

There is a paucity of sexual health education and services tailor made for AYPLHIV, which continually contributes to acquisition of other STIs, unintended pregnancy and high rates of onward HIV transmission to partners and offspring (Bauermeister et al., 2012). Thus, for

young people, living with HIV intensifies the need for guidance in navigating the physiological, social, and behavioural changes and challenges during adolescence characterised by self-exploration and risk-taking (Okawa et al., 2018; Winskell et al., 2016). This study expands the current knowledge base on the understudied SRH needs of AYPLHIV. It aims to understand the experiences of AYPLHIV and the unique SRH needs of this population group to support them in adopting and sustaining safer sexual practices and leading a healthy lifestyle. The study is informed by the concept of “positive prevention” that stresses the right of HIV positive people to have a healthy sexual life, access strategies to protect their sexual health, prevent and treat STIs (Shapiro & Ray, 2007).

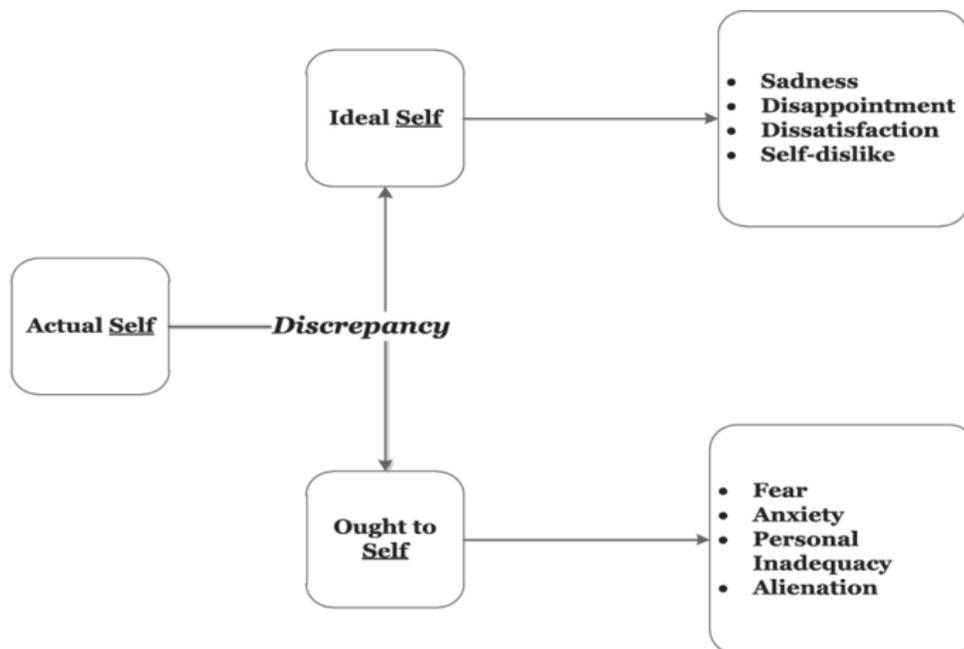
## **2.9 Theoretical framework**

This chapter discusses the Self-discrepancy Theory (SDT) (Higgins, 1987) and Ecological Systems Theory (Urie Bronfenbrenner, 1979; 2005). The two theories constitute the theoretical framework that informed this study. The chapter provides an overall discussion of the two theories, the main concepts, and the application of these theories to the current study.

### ***2.9.1 Self-discrepancy theory***

The concept of the self is multifaceted and complex. Individuals define themselves from different standpoints, such as social roles, as well as various temporal dimensions as marked by changes over time (Vartanian, 2012). According to the SDT, there are three domains of self. Higgins (1987) defines the first domain as the ‘actual’ self, which reflects an individual’s perceptions of his or her own attributes or characteristics. He also describes two other domains of self, the ‘ideal’ self and the ‘ought’ self that can direct individuals. The ‘ideal’ self refers to the attributes that an individual would like to possess or aspires to have whilst the ‘ought’ self reflects the qualities that an individual believes he/she should possess and is defined by feelings of obligation and responsibility. The SDT also suggests the distinction between two

perspectives on the self: one’s own standpoint and that of the significant others (Higgins, 1987). Six basic types of self-state representation are determined by combining each of the domains of the self with different standpoints of the self. These domains produce six self-states described by the SDT as actual/own, actual/other, ideal/own, ideal/other, ought/own, and ought/other (Higgins, 1987). When combined, these self-states can possibly lead to a number of different types of self-discrepancies.



**Figure 2.1: Representation of actual ‘Self’ in the self-discrepancy theory (Higgins,1987)**

When employing the SDT to body image research, most researchers have chosen to examine the discrepancy between the actual self and the ideal self as opposed to the actual self and the ought self as the majority of study findings have supported relationships involving actual/ideal discrepancies in a nonclinical sample, whereas relationships involving actual/ought discrepancies have produced mixed results (Halliwel & Dittmar, 2006). The self can be judged from two basic standpoints, which are one’s own personal standpoint and the standpoint of significant others (peers and family). On the one hand, actual own/ideal own discrepancy

explains an inconsistency in the current state of a person's actual attributes from his/her own standpoint and the ideal state that he or she personally desires to attain leading to dejection-related emotions (Higgins, 1987). On the other hand, actual own/ideal other discrepancy describes a state where a person's actual attributes, from his/her standpoint does not match the ideal state they believe significant others hope that they attain (Higgins, 1987). This discrepancy is also associated with dejection-related emotions such as shame arising from the perception that significant others are disappointed and dissatisfied with them. Individuals who experience greater self-discrepancy, either arising from actual own/ideal own discrepancy or actual own/ideal other discrepancy have intrinsic motivation for changing the self so as to reduce the discomfort and negative affect associated with self-discrepancy (Hall, 2014).

One of the primary objectives of the SDT is to outline the specific emotional consequences of perceiving a discrepancy between one's actual self and one's ideal/ought selves (Vartanian, 2012). There are consequences that arise when individuals compare one self-state to another self-state and find that a discrepancy exists between the two. In terms of body image, a discrepancy between how one sees one's self (actual/own) and how one would ideally like to be (ideal/own), is very common. Ultimately, the SDT proposes that inconsistencies in self-states lead to psychological discomfort and negative emotions (Moretti & Higgins, 1990). Discrepancies between how one actually is and how one would ideally like to be or feels he/she ought to be is associated with negative emotions such as depression, sadness, guilt, shame, embarrassment, self-contempt, and anxiety (Higgins, 1989; Strauman, 1992). The SDT poses that a difference between the actual self and the ideal self will occur if an individual perceives their actual self does not meet the standards of the self that is desired by them or a significant other (Higgins, 1987).

Cash and Green (1986) reported that body shape dissatisfaction involves the belief that one's physical appearance does not meet a certain ideal standard (Cash & Green, 1986).

Development of body image arises from socialisation patterns that are based mostly on peer and family relationships. Thus, when the perception of one's body matches cultural standards, that is essentially ideal standards, positive attitudes toward one's body are likely to occur. On the contrary, a discrepancy between actual and ideal appearance will likely result in low self-esteem and negative attitudes and feelings towards one's body (Bessenoff, 2006).

When applying the SDT to body image, this means that an individual is likely to be disappointed with himself or herself if their actual body is greatly different from the ideal body that they have in their mind or that they think some significant other has for them. The relevance of SDT to body image is largely based on the fact that there are cultural norms that espouse particular standards of attractiveness. In relation to HIV, there are certain bodily features that are recognised to be associated with the infection. Thus, when comparing one's actual self with the ideal own/ideal other, it is highly likely that the individual may not reach the ideal standard, resulting in a body-related self-discrepancy.

As mentioned earlier, discrepancy between actual and ideal self may lead to a variety of negative emotions and may pose as a risk factor for numerous aspects of psychopathology and psychosocial functioning including depression, anxiety, shame, poor interpersonal functioning, and poor self-esteem (Mason, et al., 2019). Previous studies found that self-discrepancy between actual and ideal appearance was positively related to body dissatisfaction (Heron & Smyth, 2013), negative mood and lowered self-evaluation (Bessenoff, 2006). Among PLHIV, self-discrepancy between actual and ideal appearance may lead to ART non-adherence in two ways. Firstly, living with HIV and taking ART may be associated with adverse unintended morphological changes like lipodystrophy (Blashill et al., 2014). Self-perceived body changes in PLHIV are associated with lower rates of adherence with time, with one study suggesting that non-adherence to ART may be a reaction aimed at stopping the progression of bodily changes (Santos et al., 2005). Thus, PLHIV may intentionally stop taking their ARVs

to avoid the resulting bodily changes associated with ART and consequently lessen the discrepancy between their ideal and actual states.

Secondly, psychosocial states such as depression and poor interpersonal functioning that results from an actual own/ideal own discrepancy are linked to ART non-adherence. Several studies have demonstrated an association between depression and non-adherence to ART, specifically cognitive symptoms of depression such as low mood, lack of interest and poor concentration which may result in loss of motivation for daily activities, including taking one's medication on schedule and forgetfulness (Nel & Kagee, 2013; Wagner et al., 2019). Furthermore, poor interpersonal functioning including lack of social support (Damulira et al., 2019), low self-esteem (Purwaningsih et al., 2019) and perceived HIV-related stigma (Madiba & Josiah, 2019) may increase non-adherence to ART among PLHIV.

Studies have suggested that the SDT plays a critical role in influencing motivation, self-esteem, and performance (Phillips & Silvia, 2005). Thus, the theory can be used in framing interventions for those individuals experiencing body image discrepancy. Interventions can be designed to focus on changing perceptions of the actual self and perceptions of the ideal or ought self (Vartanian, 2012). Changing perceptions of the actual self might require correcting individuals' biased perceptions of their own bodies. Youth living with HIV can be involved in cognitive behavioural programmes aimed at changing negative body images. Alternatively, changing perceptions of the actual self might involve making actual changes to the current self, such as by encouraging a healthy diet and exercise.

Neagu (2015) argues that body image does not simply reflect the biological endowment of the individual or the feedback received from the significant others but of significance is the way the body is experienced and evaluated by the subject himself. Hence, interventions to change body image discrepancy may also be targeted at changing the nature of the ideals that

people hold as self-guides. For most people, the ideals they hold are unrealistic and unattainable. It is commonly known and proven that ART has substantial side effects that include physiological changes. Thus, AYPLHIV should embrace the possibility of living a life with undesired characteristics and view those bodily changes caused by ART as part of the new ideal self. Another feature of body image-discrepancy that can be targeted in interventions is the importance that individuals place on appearance-related discrepancies. Learning to reduce the importance of body image to one's self-concept, and focusing instead on other aspects of the self, can go a long way towards improving an individual's self-perception. Thus, efforts directed at bolstering other skills and talents possessed by AYPLHIV can be a source of positive self-concept.

### ***2.9.2 Bronfenbrenner's socio-ecological theory***

Bronfenbrenner's (1979) socio-ecological theory focuses on the nature of the interaction of people with their environment. The theory has previously been used in understanding contextual and lifespan developmental influences on child developmental outcomes (Cummings et al., 2009; Nguyen & Huang, 2007). In this original model, Bronfenbrenner recognized there was not enough focus on individuals' own role in their development, and thus began further developing this model. In comparison to the original theory, bioecological systems theory adds more emphasis to the person in the context of development (Tudge et al., 2009). Bronfenbrenner suggested a process-person-context-time (PPCT) model comprising of four concepts namely process, person, context and time. In the PPCT model, proximal processes are progressively complex reciprocal interactions between a person and his or her environment, which "must occur on a fairly regular basis over extended periods of time" (Bronfenbrenner, 1995, p. 620). These interactions may involve persons, objects, or symbols. Although proximal processes are considered very important, the person's

own beliefs will reduce or enhance the power of those processes to influence behavior and development. Context generally refers to five interconnected systems, which are based on Bronfenbrenner's original model, ecological systems theory. These different levels will be discussed in detail in the following paragraphs. However, it is in the micro system that face-to-face interactions (i.e., proximal processes) occur. The addition of time to the model expands its explanatory potential. Considering time might help one to examine the nature of cross-generational human relationships (Bornstein et al., 2015).

The socio-ecological theory has also been applied in understanding the vast array of factors that influence health and well-being. In the context of health behaviour, the theory acknowledges that whereas individuals are responsible for bringing about and sustaining lifestyle changes required to reduce risk and improve health, individual behaviour is influenced by multiple factors (Gombachika et al., 2012). The theory emphasizes that individual sexual health behaviours are influenced by interrelated intrapersonal, interpersonal, community, and wider societal contexts (Linnan & Grummon, 2017). Thus, an individual's health behaviour does not occur in a vacuum, but within a context of multiple influences (Smith, 2011). These influences are conceptualised as a series of levels in nested arrangement, namely microsystem, mesosystem, exosystem, macrosystem, and chronosystem (Paquette & Ryan, 2001).

Individuals co-exist with their environments and are actively involved in these environments to such an extent that describing one without taking account of the other is unjustifiable. Harper et al. (2014) assert that there is a bi-directional and reciprocal relationship between the environment and the individual. They posit that situating an individual in his/her social context leads to a better understanding of the individual's behaviour. For the purpose of the study, three of the five levels (individual, interpersonal, organizational, community and societal level) identified by Sallis and Owen (2002) are used. Because optimum adherence to ART is a fundamental prerequisite for the treatment to be effective, the socio-ecological theory

provides an explanatory framework to understand factors that influence adherence to ART at the individual, interpersonal and community level. Enhanced understanding of these levels contributes to the recognition that interventions meant to promote adherence to ART must be delivered in the form of packages of services addressing multi-level barriers to ART adherence. Application of the socio-ecological framework will also be discussed in the sections to follow.

### ***2.9.2.1 Individual level***

This level represents the individual and includes psychological characteristics and behaviours such as knowledge, attitudes, and skills (Sallis & Owen, 2002). Several individual factors have been identified as barriers to ART adherence. Some of the most frequently reported individual barriers include forgetting, depression, internalised HIV-related stigma, and side effects (Mukumbang et al., 2017; Shubber et al., 2016). These individual barriers may affect patients' health service seeking behaviour and may lead to attrition from ART care. Previous research has found both interpersonal and individual mechanisms to be involved in determining adherence to ART. For example, self-efficacy (intrapersonal) has been shown to predict optimal adherence to ART (Turan et al., 2016), whilst concern about being seen (interpersonal) taking antiretroviral drugs (ARVs) was also associated with non-adherence to ART (Ahmed et al., 2018).

Among PLHIV, internalised HIV-related stigma has been widely proven to be a risk factor for non-adherence to ART as these individuals usually have a diminished view of self, which is associated with maladaptive health behaviours such as avoiding taking ARVs (Helms et al., 2017). Internalised HIV-related stigma leads to lower clinic visit adherence, which is associated with lower adherence to ART (Rice et al., 2017). Along with pervasive internalised HIV-related stigma, PLHIV are particularly vulnerable to developing a negative body image (Mudgal & Tiwari, 2015). A combination of internalised HIV-related stigma and negative body

image may further erode an individual's self-esteem. Evidence indicates that ruminating and dissatisfaction with one's body can lead to low mood and self-esteem (Verplanken & Tangelder, 2011).

Most of the individual factors that may hinder adherence to ART are potentially modifiable (Dilorio et al., 2009). Hence, the socio-ecological theory can guide the development of interventions designed to improve adherence to ART. For example, prior studies have identified therapeutic exercise intervention and cognitive behavioural therapy for body image (CBT-BISCCBT) as stand-alone interventions that have been successfully applied among PLHIV to improve adherence to ART (Daniels & Van Niekerk, 2018; Lamb et al., 2018). Most studies focusing on internalised HIV-related stigma interventions have used psycho-educational strategies and counselling to alleviate stigma (Stangl et al., 2013). Recently, Tsai et al. (2017) used a livelihood intervention to reduce internalised HIV-related stigma among persons living with HIV. Participants in that particular study reported reduced internalised HIV-related stigma, positive changes in confidence and self-esteem.

### ***2.9.2.2 Interpersonal level***

The second level includes interpersonal processes, which provide social identity and role definition such as partner, friends, and family. People exist in a social environment where they are constantly influenced by significant others. The closest social circle in a young person's life can positively or negatively influence individual behaviour. Family and peers can provide social support, which is associated with an array of behavioural, psychological, and physical health benefits or alternatively increase the chances of problem behaviour and create barriers to adopting a healthy lifestyle (Hagell et al., 2018). Evidence suggests that perceived family support, family cohesiveness and positive peer relations help to prevent adolescents from engaging in many risky sexual behaviours (Majumdar, 2006).

It is critical to understand the influence of interpersonal influences on adherence to ART. Support from friends and family has been implicated in promoting patient adherence to ART by encouraging optimism and self-esteem, buffering illness-related stress, and reducing patient depression (Shumaker & Hill, 1991). The absence of social support is associated independently with a worse quality of life in both the physical and mental dimensions (Perez et al., 2009). Non-adherence to ART is a complex challenge involving multi-level system factors. For example, individual level barriers manifest and interact with other systems as in the case of patients with negative body image, low self-esteem and internalised HIV-related stigma (individual level) encountering lack of social support (interpersonal level), are likely to experience more non-adherent behaviour. Evidence from some studies indicate that internalised HIV-related stigma is associated with certain interpersonal factors such as loneliness and lower social support (Berger et al., 2001; Takada et al., 2014), which may mediate the relationship between internalised HIV-related stigma and poor adherence to ART (Turan et al., 2016).

Peer support is essential in improving adherence to ART as evidenced by the introduction and support for peer-based interventions. A study by Mburu et al. (2014), found that youth-friendly centres created an environment where adolescents could speak privately with their peers who were facing similar circumstances, thereby serving as a coping resource by reducing isolation and creating a sense of acceptance (Marino et al., 2007). Other studies from Zambia show that peer and other forms of social support are important in helping adolescents to take up services and remain positively engaged in care (Menon et al., 2007). Social support from peers may also act as a potential buffer against body dissatisfaction (Webb & Zimmer-Gembeck, 2014). High social support from family and friends fosters psychological well-being, enhances self-esteem, and promotes adaptive coping with stressors (Cohen, 2004; Umberson et al., 2010). These psychosocial benefits translate to improved adherence through

decreased negative affect and engagement in health-promoting behaviours (Purwaningsih et al., 2019; Weaver et al., 2005).

### ***2.9.2.3 Community level***

The community level include contexts in which social relationships are embedded such as schools, community-based organizations, and the socio-economic status of neighbourhood (Sallis & Owen, 2002). This level also constitutes norms, values, standards, and social networks which are equally important in influencing ART adherence. HIV remains a highly stigmatized condition in South Africa which is largely driven by stereotypes and prejudices prevailing in communities (Wadley et al., 2019). In some instances, HIV stigma may lead to rejection and isolation from family and friends which can lead to low self-esteem, depression, and suicidal thoughts (Zeng et al., 2018). Numerous studies have shown that stigma is associated with poor adherence to ART (Pantelic et al., 2020; Turan et al., 2019; Logie et al., 2018), highlighting the need for HIV stigma reduction interventions in the community.

Stressful life events, unemployment and lack of nutritious food may all lead to ART non-adherence. As part of their treatment, PLHIV are advised to eat healthy and nutritious food which may be challenging to secure for unemployed people living in contexts of poverty. Unemployment and low-income hinder access to healthy foods, may affect intentions to seek health care, increase worries about health and the future which ultimately may lead to ART non-adherence (Yakob & Ncama, 2016). In resource constrained and fragile settings, such as those found in South Africa where food insecurity is common and unemployment rates are high it is important to address these community factors that may hinder ART adherence. Interventions that aim to improve ART adherence may need to create job opportunities to ensure self-reliance among PLHIV and introduce sustainable food support programs for PLHIV and their families.

Non-governmental organisations (NGOs) are located within communities and are critical in providing ART services including counselling, ART adherence support, peer support groups, advocacy, and community mobilisation (Hushie et al., 2016). Since NGOs are situated in communities, they are the first line of defence in addressing HIV and poverty. More importantly most of these NGOs provide youth friendly services that appeal to young people and are likely to lead to increased use of health services. While each adolescent living with HIV has unique life circumstances, understanding the basic individual, interpersonal and community factors that influence adherence to ART is a vital step towards surrounding them with ‘protective factors’ at the different levels of the ecological model. Multi-level interventions should be most effective in improving ART adherence.

## **CHAPTER THREE**

### **METHODOLOGY**

#### **3.1 Introduction**

This chapter describes the methodology that was used in undertaking the study. A detailed description of the research setting will be presented and discussed first. This is followed by a description of the research design and rationale for the choice. The different stages including the sample description, sampling strategy, data collection method, research instruments, data collection procedure, data analysis and lastly ethical considerations will be presented. These stages will be presented separately for the quantitative and qualitative components of the study. The chapter conclusion comprises a section on how the data will be stored, in line with the University of KwaZulu-Natal's requirements.

#### **3.2 The research setting**

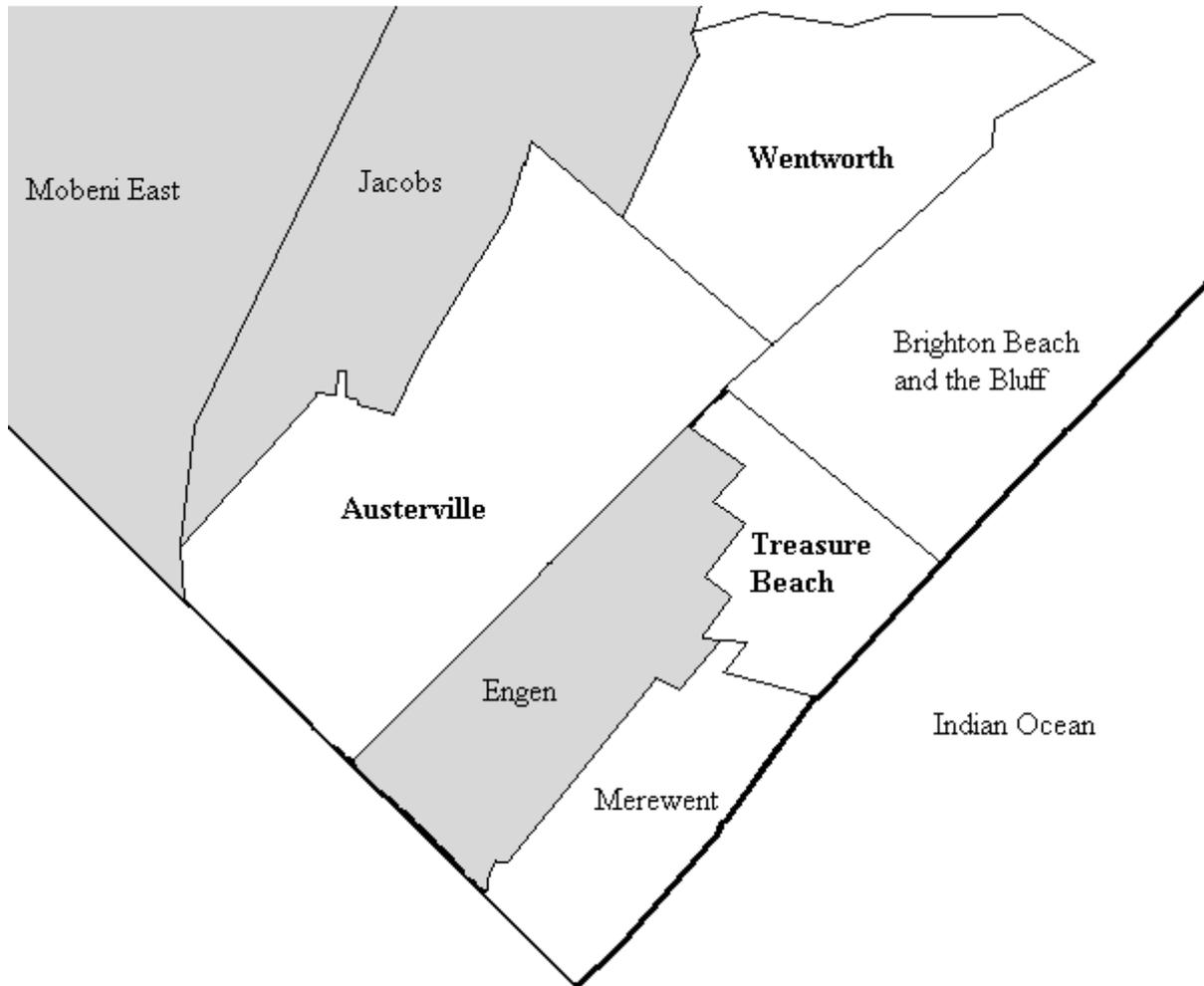
The study was conducted at the BRLS, located in the Wentworth area, Durban, South Africa. Wentworth is a township in Durban, located on the east coast of KwaZulu-Natal. It is home to approximately 30 000 residents. It is located completely inside an area known as the South Durban Basin. The name Wentworth refers to three areas, Wentworth, Austerville and Treasure Beach. All the three are located next to heavy industry (Austerville and Wentworth border Jacobs) or the Engen oil refinery (Austerville and Treasure Beach). The Wentworth area is located near major freeways M4 and M7 and is approximately 11 km south of Durban City Centre. The township is a predominantly coloured community. The area comprises a mixture of dwellings, including flats, single-family homes and the Rainbow Gardens, which is made up of sub-economic flat roofed, two-roomed houses (Naidu, 2014). The primarily spoken languages in Wentworth are English, Zulu and Afrikaans. The area is ridden with crime, gang

violence and has an equally high incidence of associated drug and alcohol abuse (Anderson, 2009).

In 2009, many people in the Wentworth area were living below poverty datum line and HIV/AIDS prevalence was estimated to be as high as 40 % (Stephen Lewis Foundation, 2009). This is not surprising since KwaZulu-Natal has the highest HIV prevalence in the country, approximately 12.2% (KZN Provincial AIDS Council, 2017) as compared with 6.8 and 5.6% in Northern Cape and Western Cape, respectively (NC Provincial AIDS Council, 2017; WC Provincial AIDS Council, 2017). The province has an HIV incidence of 2.3% compared to the national incidence of 1.8% and has 1 622 870 PLHIV which is (15.8%) of the total population between the ages of 15yrs and 49yrs (KZN DoH, 2016). These inter-provincial differences in HIV prevalence in South Africa have been explained to be a result of the low prevalence of male circumcision and high prevalence of multiple/concurrent partnerships in KZN Province as compared to other provinces (Johnson et al., 2017b).

The BRLS was founded in 2005. Through the support of Keep a Child Alive co-founder Alicia Keys and the Stephen Lewis Foundation, the BRLS is an established state-of-the-art continuum of care centre for the treatment of HIV. The BRLS provides comprehensive HIV services to AYPLHIV. Among its services, BRLS provides HIV counselling and testing (HCT), free HIV care, psychosocial and adherence support (including specialized psychosocial support for children and their caregivers, as well as a youth support group), nutritional assessment, education and support, tuberculosis screening, crisis pregnancy counselling and career support. However, it is important to note that these services are not limited to the people living in the Wentworth area as people from as far as Umlazi community (located approximately 16 km away) also access these services. The researcher noted that some patients preferred to access their treatment from the BRLS since it was far away from their communities and this guaranteed some form of confidentiality especially for those patients who preferred to

keep their HIV status a secret. Through provision of the aforementioned services, the BRLS has become an integral part of the South African government's efforts to provide HIV treatment and support for all.



*Figure 3.1: Map of Wentworth showing location of the study area*

Areas that are part of the greater community of Wentworth are written in bold. The grey shading indicates industrial areas.

### **3.3 Research paradigm and design**

More often than not, scientific research is carried out within the confines of a particular paradigm (De Vos, 2005). Therefore, it is crucial that researchers clearly indicate the specific

paradigm within which their study is located, and the reasons thereof for choosing that paradigm. The main paradigms or worldviews that traditionally are presented and used in research are those of positivism/postpositivism and constructivism/interpretivism (Creswell & Clark, 2017). The current study uses a mixed method research (MMR). Proponents of MMR strive for an integration of quantitative and qualitative research strategies and thus, this approach does not fall comfortably within either positivism/postpositivism or constructivism/interpretivism (Yvonne Feilzer, 2010). As such a relatively new paradigm, pragmatism has been frequently linked with MMR (Morgan, 2014).

Pragmatism, when regarded as an alternative paradigm, sidesteps the contentious issues of truth and reality and orients itself toward solving practical problems in the real world (Creswell & Plano Clark, 2017). Thus, pragmatism allows the researcher to be free of practical constraints imposed by choosing between postpositivism and constructivism (Morgan, 2014). Most of the focus in MMR is on practical, procedural issues about how to combine the strengths of qualitative and quantitative methods rather than philosophical claims. Pragmatism does not expect to find unvarying causal links or truths but aims to interrogate a particular question or phenomenon with the most appropriate research method (Yvonne Feilzer, 2010). Thus, for the current study, the appeal of pragmatism was more about its practicality than in its broader philosophical basis.

A research design is the overall plan that guides the researcher on how to select participants, and the techniques for data collection (Welman et al., 2005). Selecting a good research design should be guided by an overarching consideration that specifies whether the chosen design does the best possible job of providing trustworthy answers to the research question (Polit & Beck, 2004). The nature of the present research problem, aims, research objectives and questions could only be fully covered by combining both quantitative and qualitative methods. As noted earlier, a MMR was adopted as the research design for the

current cross-sectional study. The MMR design was the most appropriate design for the study as it was expected to maximise the validity of the eventual results (Mouton, 1996).

Johnson and Onwuegbuzie (2004) state that in a MMR, the researcher combines quantitative and qualitative research techniques, methods, approaches and language into a single study. Furthermore, data is either collected concurrently or sequentially and later integrated at one or more stages of the research process (Teddlie & Tashakkori, 2003). Thus, the goal of MMR is not to substitute either the quantitative or qualitative approaches to research, but rather to draw from the strengths of these approaches and to minimise possible weaknesses. In line with this argument, Creswell (2014) asserts that the use of MMR is based on the premise that a combination of quantitative and qualitative methods presents a more enhanced insight into the research problem and questions than using one of the methods independently. Because of its potential for broader understanding of research interests and social issues, MMR potential provides opportunities for devising policy frameworks and programmes aimed at social change.

There are three main types of MMR which are convergent parallel mixed methods design, sequential explanatory mixed methods design and sequential exploratory mixed methods design (Creswell, 2014). In undertaking this study, the convergent parallel mixed method research design (Fig. 2) was deemed most appropriate as it allows for the concurrent collection of both quantitative and qualitative data (Onwuegbuzie & Leech, 2005). Furthermore, it entails that the researcher concurrently conducts the quantitative and qualitative aspects in the same phase of the research process and allows the two sets of data in the analytical phase to be analysed separately with the option of merging data during the interpretive phase of the study (Creswell & Clark, 2017). Thus, the results of either the quantitative or qualitative research process do not necessarily depend on the results of the other. It is worth noting that sometimes data is incorporated during the analysis phase, but only in

circumstances where it is envisioned to add value and understanding to the data set. In the convergent parallel design, the qualitative and quantitative design have equal importance for addressing the study's research questions (Johnson & Onwuegbuzie, 2004).

### **3.3.1 Rationale for using the mixed method design**

The present study had several research questions that could not be sufficiently answered using either a quantitative or qualitative approach alone. Thus, to fully understand the current topic, related research questions, and to generate deeper and broader insights, it was relevant to use MMR. Saunders et al. (2009) state that the two main advantages of employing multi methods in the same study are that different methods can be used for different purposes within a study and hence different aspects of the research questions are addressed. The first research objective aimed to assess the relationship between body image and adherence to ART, and various psychosocial factors such as social support and self-esteem. This objective was quantitative in nature and hence could be adequately addressed by employing a quantitative design. The other objectives, for example the third objective exploring perceptions and feelings held by AYPLHIV about their body appearance was of a phenomenological nature and hence it was necessary to adopt a qualitative research design. The social phenomena under study was complex, hence integrating different kinds of research approaches was essential to understanding these complexities.

Secondly using multi-methods approach enables triangulation to take place. MMR serves seven purposes which are complementarity, completeness, developmental, expansion, corroboration/confirmation, compensation, and diversity (Venkatesh et al., 2013). For the present study, MMR was considered appropriate in terms of complementarity, completeness and compensation. It was envisaged that the MMR would be crucial in ensuring total representation of the topic of interest (completeness), gathering mutual perspectives about



for this study. Lastly, data analysis and issues of validity and reliability of the data are explained.

### ***3.4.2 Research design***

Quantitative methods are research techniques used to gather information dealing with numbers and other aspects of research that are measurable. They are used to test a hypothesis or determine an association between independent and dependent variables (Neuman, 2014), as well as establishing the strength of the relationship between variables, usually by statistical tests (Couchman & Dawson, 1995). For the purposes of this study, the researcher used a cross-sectional quantitative survey, whereby data were gathered at one point in time (Neuman, 2014). Huysamen (1994) consents that a cross-sectional design typically comprises different individuals who are examined in terms of one or more variables at approximately the same time. Cross-sectional studies are used both descriptively and analytically (Brownson & Petitti, 1998). A cross-sectional design was appropriate for this study because it is descriptive, aimed to examine the relationship between body image, body-appreciation, adherence to ART, self-esteem, social support, and internalised HIV-related stigma among AYPLHIV.

### ***3.4.3 Sampling strategy and research participants***

Polit and Beck (2004) define a population as the entire aggregation of cases that meet a designated set of criteria whilst target population refers to the group of individuals which the researcher would like to make generalisations. The target population for this present study are AYPLHIV and receiving ART. Sampling is a process of carefully selecting units to participate in a research study (Neuman, 2006). Youth living with HIV have often been described as a hard-to-reach population, thereby making their recruitment to participate in research difficult (Magnania et al., 2005). The most appropriate sampling technique to recruit participants was convenience sampling. Convenience sampling is a non-probability sampling technique that

involves selecting respondents primarily based on their availability and willingness to respond (Shaughnessy et al., 2009). The participants were affiliated with the BRLS where they received their medication. The researcher approached the clinic and was allowed to invite the clients to participate in the study when they came for their regular check-ups. This research sampling was used because it was convenient and cost effective as it offered the researcher the opportunity to spend time at the centre and collect the data when the participants availed themselves.

Eligibility criteria specify the characteristics that must be possessed by people in a population to be included in a study (Polit & Beck, 2004). In this study, the eligibility criteria were: participants aged 15-24 years; knowledge of HIV diagnosis and undergoing treatment at the time of the study; and willingness to participate in the study. Out of 104 participants approached, 76 agreed to participate in the study. This represents a response rate of approximately 73%.

#### ***3.4.4 Research instruments***

Data collection was in the form of self-administered questionnaires. Respondents have been shown to give more positive and socially desirable responses in face-to-face surveys than in self-administration surveys (Tourangeau & Smith, 1996). Furthermore, sensitive health problems can also be under-reported in face-to-face interviews as compared to self-administered questionnaires. Thus, sensitive questions as is the case with some of the questionnaires in this study are best asked by more impersonal, self-administration methods as they lead to higher levels of reporting and increase respondents' willingness to disclose sensitive information (Bradburn, 1983). The questionnaire consisted of a section to capture socio-demographic information of the participants such as gender and age. The quantitative measures used in the study have been used in previous studies including the Body Appreciation

Scale (BAS-2), the Morisky Medication Adherence Questionnaire (MMAS-8), the Rosenberg Self-Esteem Scale (RSES), the Body Self-Image Questionnaire (BSIQ) (used to measure negative evaluation), the RAND 36-Item Health Survey (SF-36) (used to measure emotional well-being and general health), and the Internalised AIDS-Related Stigma Scale (IA-RSS). The complete research questionnaire used in this study is attached as Appendix 4.

*Bio-demographic Data:* Bio-demographic data were collected and used to gain an understanding of the characteristics of the sample and to aid statistical investigation. These included questions related to gender, age, race, and mode of transmission.

*Rosenberg Self-Esteem Scale (RSES; Rosenberg, 1965)*

The RSES, a widely used self-report instrument for evaluating individual self-esteem was used to measure self-esteem. The RSES is a 10-item measure of self-respect and self-acceptance. Items (e.g., ‘I feel that I am a person of worth, at least on an equal plane with others’) are rated using a four-point response format (1 = *Strongly disagree*; 4 = *Strongly agree*), half of which are reverse scored. Responses to all items are aggregated for a total score. The scale ranges from 10-40. Scores between 15 and 25 are within normal range; scores below 15 suggest low self-esteem. Findings of various studies support the validity of the RSES (McMullen & Resnick, 2013; Park & Park, 2019). Internal consistency estimates reported for the RSES in prior research have been  $\geq .76$  (Supple et al., 2013). The RSES had good internal consistency at  $\alpha = 0.73$  in a South African sample (Makhubela & Mashegoane, 2017). The calculated Cronbach alpha in this study was 0.82.

*Internalised AIDS-Related Stigma Scale (IA-RSS; Kalichman et al., 2009)*

The IA-RSS consists of six items that were adapted from the AIDS-Related Stigma Scale (Kalichman et al., 2005) to measure negative self-perceptions and self-abasement about being a person living with HIV. Items (e.g., ‘I hide my HIV status from others’) are rated on a dichotomous scale (0 = *Disagree*; 1 = *Agree*) and are summed for a total score. Considering

that the degree of stigma is measured along a continuum, there is no clear cut-off for determining individuals with internalised stigma. However, higher scores indicate greater internalised stigma. Evidence in support of the scale's construct validity has been shown through analyses showing statistically significant correlations of moderately-sized magnitude between internalised HIV-related stigma and depression symptom severity and between internalised HIV-related stigma and mental health-related quality of life (Tsai et al., 2013). Prior research involving samples of South Africans have revealed internal consistency values of  $\geq .73$  for the IA-RSS (Kalichman et al., 2009). The overall Cronbach's alpha coefficient for this study was 0.74.

*Body Appreciation Scale-2 (BAS-2; Tylka & Wood-Barcalow, 2015b)*

The BAS-2 contains 10 items that measure a person's acceptance, appreciation, self-care, positivity about their body (Tylka & Wood-Barcalow, 2015b). Participants rate the items (e.g., "I feel good about my body") using a five-point response format (1 = *Never*; 5 = *Always*). The mean score of the scale was calculated by averaging all items, so the scoring range that could be obtained ranged from 1 to 5. A higher score indicates higher levels of body appreciation. The BAS-2 has been validated in numerous samples of different countries and languages (e.g., Malaysia, Sweden, & Brazil) and showed a one-dimensional factor structure in all samples of different cultures (Baceviciene & Jankauskiene, 2020). The scale has been used with children and young people aged between 12-19 years old and demonstrated good test-retest stability (Lemoine et al., 2020) and reported internal consistency values of  $\geq .80$  for women and men in the majority of studies (Halliwell et al., 2017), and evidence supports the construct validity (e.g., convergent, discriminant) of the BAS-2 (Tylka & Wood-Barcalow, 2015b). In the absence of any available reliable local scales to measure body appreciation, the BAS-2 was the only viable scale to use.

*Morisky Medication Adherence Questionnaire (MMAS-8; Morisky et al., 2008)*

The MMAS-8 comprises eight items that assess patient adherence to medication for chronic conditions. The first seven items (e.g., ‘When you feel like your symptoms are under control, do you sometimes stop taking your medicine’) are rated using a dichotomous response format (1 = *Yes*; 0 = *No*). A five-point response format (A = 0; B-E = 1) is used to rate the final item (e.g., ‘How often do you have difficulty remembering to take all your medicine’), which is transformed to a dichotomous score prior to aggregation of item responses. In this study, responses to each of the MMAS-8 items were aggregated such that higher scores reflected worse adherence to ART. Evidence supports the psychometric utility of the MMAS-8 as a valid and reliable measure of medication adherence (e.g., Morisky et al., 2008; Okello et al., 2016), including adherence to ART (Saal & Kagee, 2012). The calculated Cronbach alpha in this study was 0.77.

*Multidimensional Scale of Perceived Social Support (MSPSS, Zimet et al., 1988)*

The MSPSS measures perceived social support along three dimensions, which are family (items 3, 4, 8, and 11), friends (items 6, 7, 9, and 12) and significant others (items 1, 2, 5, and 10) in the form of a 12-item, self-administered questionnaire. Each item is rated on a 7-point scale, ranging from 1 (very strongly disagree) to 7 (very strongly agree). A higher score indicates greater social support perceived by an individual; the total possible score ranges 12-84, or it can be scored according to its subscales by adding the items in each subscale and then dividing by 4 (Zimet et al., 1988). The MSPSS has been found reliable in various different samples internationally. Examples include its use among HIV-positive men and women in Nepal (Shrestha et al., 2019;  $\alpha = 0.93$ ), among children affected by HIV/AIDS in Ghana (Doku et al., 2015;  $\alpha = 0.88$ ), and among caregivers of AIDS-orphaned children in South Africa (Kuo et al., 2012;  $\alpha = 0.86$ ). In this study, the Cronbach’s alpha coefficients of the family support

(items 3, 4, 8, 11), friend support (items 6, 7, 9, 12), and significant-other support (items 1, 2, 5, and 10) subscales were 0.93, 0.96, and 0.88, respectively.

*The RAND 36-Item Health Survey (SF-36, Ware & Sherbourne, 1992)*

Ware and Sherbourne (1992) developed a 36-item short-form (SF-36) questionnaire to measure quality of life. The questionnaire addresses eight domains that make up a multidimensional scale: physical functioning (10 items), social functioning (2 items), role limitations due to physical problems (4 items), role limitations due to emotional problems (3 items), mental health (5 items), energy/fatigue (4 items), bodily pain (2 items), and general health perception (5 items) of an individual or a group. A single item evaluates the patient's perception of change in health over the past year but is not included in the scoring. Each of the eight health concepts is measured on a scale of 0 (worse health) to 100 (best health). Domain scores are totalled and averaged to give the overall RAND 36 total score, also scaled from 0 to 100. Higher scores indicate good quality of life. The International QOL Assessment (IQOLA) Project supported the feasibility of cross-cultural use of the SF-36 (Ware et al., 1995). An evaluation of the SF-36 conducted in Ghana showed that the standardised alpha coefficient was 0.86 (Frempong-Ainguah & Hill, 2014). In this study, the Cronbach's alpha coefficients of the emotional well-being (items 24, 25, 26, 28, 30) and general health sub-scale (items 1, 33, 34, 35, 36) were .73 and .76, respectively.

*The Body Self-Image Questionnaire Short-Form (BSIQ-SF, Rowe et al., 1999)*

The BSIQ-SF measures body image in young adults. The original form of the questionnaire consisted of 9 subscales with 3-7 items per subscale, or 51 items total. In this study, the researcher used the BSIQ-SF. This scale consists of 27 items to be scored on a 5-point Likert scale (Not at all true of myself = 1, Slightly true of myself = 2, About halfway true of myself = 3, Mostly true of myself = 4, and Completely true of myself = 5). It is subdivided

into nine subscales (overall appearance evaluation, fatness evaluation, health/fitness evaluation, negative affect, health/fitness influence, social dependence, investment in ideals, attention to grooming, and height dissatisfaction). Each subscale had three questions and each subscale score ranges from a minimum of 3 to a maximum of 15. The subscale of negative affect was assessed in this study. The BSIQ-SF offers a theoretically and empirically supported questionnaire to efficiently measure nine dimensions of body image (Rowe, 2005) as well as reduce response burden, which has been proposed to lead to poorer response rate, lower completion and consequently reduced data quality (Rolstad et al., 2011). Internal consistency reliabilities range from .68 to .92 (Daniels & Van Niekerk, 2011; Rowe et al., 1999). The Cronbach's alpha coefficient for the negative evaluation sub-scale (items 8, 17, 26) was .78.

#### ***3.4.5 Pilot study***

A pilot study is a trial run study done in preparation of the complete study (Polit et al., 2001). In some cases, just like in the current study, a pilot study is conducted for the sole purpose of pre-testing research instruments, including questionnaires or interview schedules (Van Teijlingen & Hundley, 2001). A pilot study assists the researcher in ascertaining whether the proposed methods or instruments are appropriate and easily understood by the respondents. When piloting a research instrument, researchers are cautioned to look out for difficulties by respondents in responding to questions, check for ambiguities and respondents giving several answers to the same question as this indicates that the instrument is not reliable (De Vaus, 1993; Fink & Kosekoff, 1985). In this study, a pilot study was conducted with 12 youths conveniently selected from the target sample to test the appropriateness of the questions, comprehension, and data collection procedures. Generally, the participants found the research instrument suitable and captured the relevant information related to body image among

AYPLHIV. Approximately 58% of the participants were females, and over 40% of them had been living with HIV for more than 4 years.

The young people who participated in the pilot study were excluded from the main study and pilot results were not included in the findings presented in the thesis. After the respondents finished completing the pre-testing questionnaires, they were asked to give their comments on the wording of questionnaires, confusing questions, and unclear instructions. Despite that the sample was small, feedback from the participants was essential to improving and refining the research instrument before the main investigation commenced. Following feedback from participants and findings of the pilot study the practical considerations which needed attention included:

- The time limit for completion of questionnaires. It took longer for the respondents to complete the questionnaire; hence the time was increased from 30 minutes to 40 minutes.
- Word choices on some of the psychological instruments were changed to improve understanding of the concepts. However, this was done without compromising the meaning of the items and content of the questionnaire.

Generally, the participants did not suggest any major changes to the instrument. The descriptive statistics and psychometric properties of the scales used in the main study are presented in Table 1 below.

**Table 3.1: Summary of Psychological measures used to measure constructs in the quantitative study**

<b>Variable</b>	<b>Measure</b>	<b>Items</b>	<b>Scale range</b>	<b>Mean</b>	<b>SD</b>	<b>Cronbach alpha (<math>\alpha</math>)</b>
Body image	The Body Self-Image Questionnaire Short-Form (BSIQ-SF)	3	3-15	7.53	3.22	0.78
Body appreciation	Body Appreciation Scale-2 (BAS-2)	10	10-50	40.49	5.20	0.84
Self-esteem	Rosenberg Self-Esteem Scale (RSES)	10	10-40	15.61	1.63	0.82
Social support	Multidimensional Scale of Perceived Social Support (MSPSS)	12	12-60	5.23	0.94	0.93
Internalised HIV-related stigma	Internalised AIDS-Related Stigma Scale (IA-RSS)	6	0-6	2.93	1.37	0.74
ART adherence	Morisky Medication Adherence Questionnaire (MMAS-8)	8	0-8	2.83	1.59	0.77
Emotional well-being	The RAND 36-Item Health Survey (SF-36)	5	0-500	341.05	68.27	0.73
General health	The RAND 36-Item Health Survey (SF-36)	5	0-500	333.88	86.48	0.76

### ***3.4.6 Data collection and procedure***

Conducting research with young people is regarded a tedious process as one needs to negotiate challenges arising from accessing the sample, power relations and ethical issues of consent. It is even difficult when one is conducting research with AYPLHIV as they are regarded as a 'hard to reach' or 'hidden population' (Bell et al., 2003). Youth living with HIV are often difficult to reach as they are often socially and economically disenfranchised and their membership is not readily distinguished or enumerated based on existing populations (Lambert, 1990). Consequently, the researcher had to spend a lot of time approaching clinics, government organisations as well as non-governmental organisations that work with AYPLHIV. The researcher was turned down by most of these organisations mainly because of capacity reasons as they argued that they did not have the capacity within their organisations to accommodate a research study. Eventually, the researcher managed to get in touch with one NGO (BRLS) that expressed interest in the study.

A meeting was set, where the researcher met with the Director of the centre, submitted a full proposal as per his request and explained the aims and objectives of the study. He expressed interest in the study but however had to meet with the other stakeholders before responding. A few weeks after the meeting, the researcher was granted permission to conduct the study with the adolescents and young people who were patients at the centre and to adhere to all the protocols as stated in the proposal. The researcher and the organisation entered into a collaborative partnership whereby BRLS offered their resources to the researcher to accomplish the research goals in return the researcher had to share the findings with the organisation. A gatekeeper letter was issued (see Appendix 6). The gatekeeper letter and the study proposal were submitted to the University of KwaZulu-Natal's Humanities and Social

Sciences Research Ethics Committee. Ethical clearance was granted (HSS/0522/018D) (see Appendix 1).

After ethical clearance was granted by the Humanities and Social Sciences Research Ethics Committee, the researcher entered the field on an introduction and familiarisation tour. The researcher was introduced to the nurses, social worker and monitoring and evaluation officer at BRLS. These staff members were key to the study as they were directly involved with the youth and played an important role in introducing the researcher and making him a credible person. Through this initial contact with the clinic staff, the researcher was advised to look for research assistants to assist with data collection as some of the youth at the clinic were not fluent in English. Two master's students in the social sciences (male and female) were chosen to serve as research assistants.

The quality of data obtained in a research study depends on the quality of work done in the field. Researchers prefer to collect data on their own to ensure that all procedures are performed correctly and with the requisite professionalism. However, in some instances, it is necessary to employ research assistants to assist in data collection. When research assistants are used, it is necessary to select competent individuals and train them thoroughly and effectively (Korb, 2012). The researcher unpacked the study aims and objectives. Although both research assistants had some knowledge in data collection procedures as they were also collecting data for their master's degrees, they met with the researcher three times a week over a two-week period before the study commenced where they were trained in interviewing skills and the administration of questionnaires. This was done to enhance their data collection skills and ensure that they could completely uphold acceptable ethical standards during data collection such as privacy, anonymity, and confidentiality. The researcher demonstrated how the research procedures should be carried out and the research assistants were given an opportunity to practice the procedures through role play and simulation; one as the researcher

and the other as a participant. Feedback was given to each research assistant on skills that needed improvement.

The researcher visited the BRLS centre daily to meet with the patients as they came in to collect their medication and when they visited the youth centre for other reasons such as counselling. The participants were approached with the help of facility nurses and clinician and requested to participate in the study. Researchers have noted that the recruiter's professional role and established therapeutic relationship with the participants is influential in determining (non) participation (Donovan, 2003; Jenkins & Fallowfield, 2000). The centre staff facilitated the initial recruitment process and introduced willing participants to the research team. The aims and objectives of the study were explained to the participants in the language that they understood; they were informed of the voluntary participation nature of the study, and the right to withdraw from the study at any time. Participants were also guaranteed of anonymity and confidentiality. Thereafter, the informed consent form was read to participants by the researcher to provide verbal informed consent for their participation in the interview. Participants were also requested to sign the informed consent form. Written parental consent was obtained on behalf of all legal minors who indicated their interest in participating. Written assent was also obtained from legal minors.

After informed consent was given to participate in the study, questionnaires were administered in a quiet office that was provided by the clinic. The questionnaires were self-administered after instructions were read out and explained. The researcher and the research assistants were present to interpret and answer all the questions that were raised and to clarify any ambiguities. Administering the questionnaires lasted for about 40 minutes. An average of 11 respondents completed the questionnaires weekly. Data collection lasted for a period of eight (8) weeks. The respondents were provided with some refreshments at the end of the interview as a token of appreciation for their willingness to participate in the study.

### **3.4.7 Statistical analysis**

Data collected for the quantitative component of this study were captured on statistical programme IBM Statistical Package for the Social Sciences (SPSS), version 21.0 and Package nlme, version 3.1-148 following the appropriate scoring and coding of each measure. Analyses were two-tailed and a  $p$ -value of 0.05 or less was considered statistically significant. The specific statistical analyses strategies employed to answer each quantitative research question are presented in detail in chapters four and five.

## **3.5 Qualitative component of the study**

### ***3.5.1 Introduction***

A qualitative research study was done to explore the lived experiences of AYPLHIV on the appearance of their body and to understand the coping mechanisms used to overcome various life stressors. The next section explains the qualitative research design, sample selection and outlines the procedure used in data collection for this study. Lastly, the researcher describes how the data were analysed and further reflect on issues of trustworthiness.

### ***3.5.2 Research paradigm and design***

An interpretive paradigm stresses the importance of subjective experiences in the creation of reality as opposed to an attempt to generate an objective truth (Myers, 2009). This approach to research seeks to explore the meanings of actions and experiences of research participants (Neuman, 2014). The interpretative approach places an emphasis on the subjective experiences of individuals as the basis for obtaining detailed descriptions of events. Although participants might be viewed as a homogenous group since they are all living with HIV, they come from diverse contexts and have differing subjective experiences. As such, it is not

uncommon to have multiple lived experiences (Willis, 2007). The interpretative approach to qualitative inquiry was viewed as relevant because it informs the researcher of the varying experiences that AYPLHIV encounter in their day-to-day experiences. The interpretive paradigm views reality as complex and socially constructed (Willis, 2007), thereby making this paradigm suitable to understand the perspectives of participants in relation to body image construction.

The interpretive paradigm has several varieties such as hermeneutics, constructionism and phenomenology (Neuman, 2014). The present study is phenomenological, whereby the researcher attempted to understand the subjective experiences of the research participants as they made sense of their own experiences (Smith & Osborn, 2008). Subsequently, the researcher became an active interpreter in the process of making sense of the participant's social world through a process of active interpretations (Fade, 2004). In making interpretations, the researcher is directly involved in the process of creating knowledge and his/her personal experiences and point of view impacts the manner in which interpretations are made. The interpretive approach acknowledges that research is not value-free and therefore it is vital to explore and address the researchers' biases (Creswell, 1998). This approach cautions the researcher to guard against his/her own preconceived knowledge, beliefs, and judgment, and in so doing the participant's subjective reality is presented (Fade, 2004; Reid et al., 2005). Thus, the interpretative approach attempts to gain an insider perspective of the phenomenon under study, while recognising the researcher's role as the primary analytical instrument (Fade, 2004). Accordingly, the interpretive paradigm emphasizes on a qualitative design.

Objectives of this research study included an understanding of the lived experiences of AYPLHIV in relation to their body image. As such, a qualitative research design was adopted as it helps in exploring, explaining and interpreting social experiences in their natural context (Creswell, 2003). Furthermore, this design allows the researcher to obtain 'thick descriptions'

of participants' perceptions and their experiences (Neuman, 2014). Further, use of a qualitative design allows the researcher an opportunity to capture the subjective feelings of the participants (Neuman, 2014; Ulin et al., 2002). The thoughts and perceptions of participants were viewed as unique. Qualitative research recognises that multiple realities exist. Thus, it is crucial to understand the behaviour of participants in their own contexts as well as the influence of political, historical, socio-economic and cultural factors (Streubert & Carpenter 1995; Terre-Blanche & Kelly, 1999).

The current study employed a qualitative research design using in-depth interviews. Ulin et al. (2002) emphasize that depth takes precedence over breadth in qualitative research. This research design was chosen because some of the research objectives required more than quantification and generalisation of data. Generalisation is normative in, and synonymous with quantitative inquiry (Neuman, 2014). In this second phase, the researcher wanted the opportunity to pose questions that would offer participants the opportunity to bring forth diverse and relevant dimensions the researcher might never have envisaged. Morse (1992) asserts that qualitative research approaches the phenomena of interest from a holistic perspective by including the underlying values and the context as part of the phenomena. This approach is significant as it provides a considerable amount of rich data from a relatively small number of people.

Qualitative research is typically exploratory in nature and generates rich and detailed data that contribute to an in-depth understanding of phenomenon understudy. Donalek (2004) suggests that qualitative designs are ideally used in areas of limited knowledge. These designs are suitable in the early stages of knowledge development and provide researchers with a new way of approaching old problems (Wright & Schmelzer, 1997). The study aimed to provide new insights to the experiences of body image in AYPLHIV. Creswell (1994, p. 23) states that, "certain types of social research problems call for specific approaches". The qualitative design

is located within the interpretative paradigm, which assumes that social reality is neither singular nor objective but is rather shaped by human experiences and social contexts (ontology) and is therefore best studied within its socio-historic context (epistemology) (Neuman, 2014).

### ***3.5.3 Sample and sampling procedure***

To select information-rich cases (Patton, 1990), purposive sampling was used to select study participants. Neuman (2014) posit that qualitative research samples purposively, with a specific purpose in mind. He further describes purposive sampling as sampling where individuals or groups with special knowledge of the topic are chosen. Hence, study participants were not only selected because they were conveniently available at the time the research was conducted, but rather they were chosen because they met certain criteria. Purposive sampling is also referred to as judgemental sampling (Neuman, 2014), suggesting that researchers use their judgement to decide who is best representative of the population regarding the attributes or characteristics under investigation.

The researcher should establish in advance the attributes that the participants for study should possess. In this study, a total of 20 young PLHIV, aged between 15 and 24 years were initially selected and included in the study as this size is ideal for interpretative phenomenological study. Among the young people approached, two could not participate because of time constraints as they had to attend classes and the researcher could not schedule an appointment with them since they were not staying close to the centre. The final sample comprised 18 participants. Thus, the sample of young people for the qualitative component is a sub-set of the 76 AYPLHIV sampled for the quantitative component of this study. Of the 18 interviews conducted, 12 were single session interviews. Two repeat interviews were conducted with five participants. Only one participant was interviewed three times. The follow-up interviews provided the opportunity not just to verify understandings formed in the

first interview but to also seek clarification on things that the researcher had not fully understood. Subsequent interviews were tailored for individuals, based on what was said in the previous interviews (Jenkins & Fallowfield, 2000). The participants were selected based on consent and availability to participate in the in-depth interviews. Participants who had successfully completed the questionnaire and showed a keen interest in sharing their experiences were selected. The following inclusion criteria was used: being a person aged 15 to 24 and living with HIV; being treated with anti-retroviral drugs; and reported knowledge of mode of HIV transmission.

#### ***3.5.4 Semi-structured interview schedule***

Consistent with the interpretative approach, an interview schedule was used to collect the data during individual in-depth interviews. An interview schedule ensures that relevant issues are “covered systematically and with some uniformity, while still allowing flexibility to pursue the detail that is salient to each individual participant” (Ritchie et al., 2013, p. 115). Flexibility of the interview schedule is of importance as it enables the interviewer and the interviewee to interact, whereby the researcher can fully probe and explore relevant issues raised spontaneously by the interviewee. Probes are key to the interview process as initial responses from participants are usually at a fairly surface level. Hence, follow-up questions are essential to obtain a deeper and fuller understanding of the participant's meaning including their reasons, feelings, opinions and beliefs (Ritchie et al., 2013).

The interview schedule was fairly structured whereby easier and general questions were asked first and then specific questions later (Townsend & de la Rey, 2016). However, the researcher was cognisant of the fact that the interview schedule was not concrete but rather fluid and as such in accordance with the interview process, some questions were asked earlier than they appeared on the schedule. This highlights the significance of the researcher as the

key instrument in data collection who must actively engage with the participants to ensure depth and breadth of data collected (Patton, 1990). The interview schedule (Appendix 5) consisted of questions which were arranged in three layers, firstly; the thoughts and feelings of AYPLHIV on the appearance of their body, secondly; the perceptions of how body image influence relationship with significant others, lastly; the strategies utilised by AYPLHIV to negotiate a positive body.

### ***3.5.5 Piloting the interview schedule***

A pilot study was conducted on the interview schedule to ensure that it would elicit rich and relevant data to the study. A pilot study ensures the vigour and reliability of a study by exploring if questions were; constructed appropriately, easy to understand, logically arranged and if research questions could be answered using data generated through the interview schedule (Janghorban et al., 2014). A pilot study was conducted with two young PLHIV who were not included as respondents in the main study. Piloting the interview schedule helped the researcher to remove some of the questions that seemed not to contribute any relevant data and it also ensured that there was coherence in the way questions were asked. More so, this process provided the researcher with an opportunity to improve his skills in conducting semi-structured interviews and provided a ground for self-assessment and researchers' preparedness to conduct the interviews (Nunes et al., 2010; Padgett, 2016).

### ***3.5.6 Child friendly methods of conducting research***

Children and Young People (CYP) are perceived as strong, and knowledgeable experts on their own lives, capable of forming their own views (Shaw et al., 2011). When doing research with CYP caution should be taken to ensure that their needs and rights are not violated. Power inequalities between children and adult researchers are inevitable and it can be difficult to reduce the unequal power relations between an adult researcher and a child. Consequently,

several methods have been used to ensure that research with young people is cognisant of their rights (Eder & Fingerson, 2003). Mandell's (1988) least-adult role is an interesting effort that suggests that researchers must distance themselves from an adult status and adopt a peer status. The researcher refrained from taking a position of authority, created a relaxed atmosphere prior to embarking on the data collection process and made an effort not to impose his subject perspectives on the participants (Shaw et al., 2011).

The current research is of a sensitive nature as it deals with adolescents who need special care when conducting research and additionally these adolescents were living with an often-stigmatised disease. Caution was taken to ensure that the needs and rights of the young people were not violated. The study location was a friendly youth centre. Participants were familiar with the youth centre as they were collecting their ART at the centre. Further, they were getting social support from the same youth centre. The questionnaires and interview schedules were pilot tested with young people of the same age as the study's participants to ensure that the language was appropriate and the length acceptable. For some of the participants in the study, English was an additional language, thus the researcher used research assistants to ensure that participants understood their role in the study by explaining the study objectives and procedure in their vernacular language (IsiZulu).

### ***3.5.7 Qualitative data collection procedure***

Ethical clearance for the study was granted by the Humanities and Social Science Research Ethics Committee of the University of KwaZulu-Natal (Protocol number: HSS/0522/018D). Gatekeeper permission was obtained from the BRLS. Two research assistants who were fluent in isiZulu were recruited and trained. Although the study was of a sensitive nature, no negative effects were anticipated. However, if there were any negative consequences resulting from the research study, the researcher had arranged with the

psychologist and counsellors at the youth centre to assist the participants. Despite awareness of the availability of psychological services at their disposal, none of the participants requested for these services.

Two master's students (male and female) were chosen to be research assistants. The rationale for choosing both sexes was influenced by fact that some of the participants might be ashamed to express themselves when being interviewed by the opposite sex. The interviewer's sex can substantially affect the response rate in data collection. Johnson and DeLamater (1976) suggest that if participants are embarrassed about the topic being discussed they are less likely to opt to participate, especially with someone from the opposite sex. Alhojailan (2020) support the above assertion and argue that both men and women act differently in the company of the other sex, acting more formally and expressing less. The female research assistant was assigned to interview female participants whilst the male research participant was assigned to male participants.

The researcher had initially met the participants during the first phase of quantitative data collection and had asked them to participate in the interviews at a convenient time. The researcher invited a total of 20 participants who had participated in the questionnaires for interviews. Again, the researcher explained the purpose of the interviews and requested the participants to sign an informed consent indicating their consent to participate in the study. Written parental consent was obtained on behalf of all legal minors who indicated their interest in participating. Written assent was also obtained from legal minors. After the informed consent form was given to participate in the study and permission to record the interview was granted, data collection was conducted in a quiet office that was provided by the youth centre. The interviews were audio-recorded, and each interview session lasted between 30 - 50 minutes. The interviews were conducted by the researcher and the two research assistants. The research assistants interviewed participants who preferred to be interviewed in isiZulu whilst the

researcher interviewed seven participants who consented to being interviewed in English. The participants were provided with some refreshments at the end of the interview as a token of appreciation for their willingness to participate in the study.

### ***3.5.8 Data analysis***

Audio-recorded interviews were translated and transcribed verbatim by the research assistants since most of them were conducted in the local language (isiZulu). The principal researcher transcribed the interviews conducted in English verbatim. Verbatim transcription ensure that the researcher does not miss relevant data and also demonstrates rigour (Seale & Silverman, 1997; Silverman, 1993). During this phase, the researcher made every effort to minimise the effects of distortions and bias.

As evidenced by this study, qualitative research usually produces large amounts of textual data in the form of transcripts, which make analysis time consuming and labour intensive. To lessen this burden, Computer Assisted Qualitative Data Analysis Software (CAQDAS) such as NVivo can be utilised. CAQDAS ensure easy, effective and efficient coding (Zamawe, 2015). NVivo 10 software program (QSR International, Melbourne, Australia) was used to aid in the sorting and organising the large data set. This software enabled the researcher to work efficiently with large amounts of text, facilitating both depth and sophistication of analysis (King, 2004). However, it has been argued that researchers using CAQDAS should be cognisant that these software packages simply aid the analysis process, and ultimately the researcher must always remain in control of the data analysis process (Zamawe, 2015). As such, the researcher used thematic analysis to further analyse the data and reach conclusions.

The goal of a thematic analysis is to identify patterns of interest emanating from the data that can be used to address the research questions. Braun and Clarke (2006) distinguish between a theoretical thematic analysis that is driven by the specific research questions and an inductive one that is more driven by the data itself. The present analysis was more theoretically driven by the research questions as the researcher was concerned with addressing specific research questions and analysed the data with this in mind. However, Braun and Clarke (2012) argue that in reality, coding and analysis often use a combination of both inductive and theoretical thematic analysis. They claim that in conducting analysis one cannot be completely inductive, as researchers always have some preconceived ideas that guide what is worth coding. At the same time as researchers, we rarely overlook the “semantic content of the data when we code for a particular theoretical construct” (Braun & Clarke, 2012, p. 58-59).

Braun and Clarke (2006) provide a set of flexible guidelines, which can be adapted by researchers in conducting data analysis. However, they caution that these guidelines should not be treated as a ‘recipe’ but rather the researcher should be flexible and creative during this process. Scholars emphasize that data analysis is not an orderly and stepwise process as presented below, but rather it is a dynamic process which requires moving back and forth between data collection and analysis (Creswell, 2003; Nowell et al., 2017). Ultimately, Braun and Clarke (2006) argue that a rigorous thematic analysis can produce trustworthy and insightful findings. The following stages outlined by Braun and Clarke (2006) were followed:

1. Familiarising yourself with your data
2. Generating initial codes
3. Searching for themes
4. Reviewing themes
5. Defining and naming themes

## 6. Producing the report

The process of data collection gave the researcher a partial idea of what the data looked like and by the time data analysis began, the researcher had a general idea of the data. The researcher read and re-read all the transcripts independently, including those that were translated and transcribed verbatim by the research assistants to familiarise with the content (Braun & Clarke, 2006). Through this process of immersing with the data, the primary researcher became accustomed to the written accounts of all the participants. Starks and Trinidad (2007) argue that researchers should provide a faithful witness to the accounts in the data and be mindful of their own pre-existing thoughts and perspectives to ensure an honest presentation of participants' experiences. As the researcher immersed himself with the transcripts, short notes relating to key ideas and his thoughts and reflections on the issues that were emerging from the transcripts were made on the margins of the transcripts. It is worthwhile to note that at this stage, note-making was casual rather than systematic as the notes consisted of disorderly ideas rather than organised ideas.

The systematic analysis of data through coding began in this second phase. After re-reading the transcripts, the researcher had a more vivid idea of the data and started to identify the key concepts found in the transcripts. Important and interesting ideas in the data were labelled, marking initial codes (King, 2004). As the analysis was more driven by the research questions, all the data that were potentially relevant to the research questions were coded. In this stage, coding was guided by the principle of 'inclusivity' whereby all the ideas that seemed relevant were coded as it is easier to discard the irrelevant ideas than recoding the entire data set (Braun & Clarke, 2012). The coding stage marked the initial phase of interpretation as some of the codes captured the semantic meaning whereas others only captured the latent meaning. The researcher coded ideas that were believed to capture the qualitative richness of the data set (Boyatzis, 1998).

Following identification of initial codes, the researcher collated these, and a list of different codes was developed. Once all the data was coded and collated, emerging themes were extracted (Braun & Clarke, 2006). The codes that shared some similar features were clustered together to form themes that described a meaningful pattern of data (Braun & Clarke, 2012). However, some of the themes seemed to be broad and these were developed into main themes and sub-themes. At the fourth stage, the generated themes were reviewed and refined to ensure quality (Braun & Clarke, 2012). The researcher essentially assessed the themes to check whether they meaningfully captured the data, and it was evident that some of themes did not adequately capture the data and had to be collapsed into one theme. As such, the researcher had to recode the ideas that best captured the new theme highlighting the iterative process of analysis (Nowell et al., 2017).

After reviewing the themes, the researcher had to clearly determine the different aspects of data that each theme captured. The identified themes were clearly named to give the reader a sense of their meaning and these were accompanied by a detailed analysis and presentation of extracts that supported them (Braun & Clarke, 2006). During the final stage, the researcher produced a report, which presented the themes in a logical and meaningful manner responding to the research and literature (Braun & Clarke, 2006). The researcher provided an interpretation of the findings based on the themes discovered during the analysis.

### ***3.5.9 Trustworthiness of the study***

After conducting a research study, it is essential that the research process and findings be subjected to quality analysis to ensure the integrity of the research process and credibility of the findings (Long & Johnson, 2000). In quantitative studies, the quality of the study is achieved through measurement of validity and reliability (Neuman, 2006). However, in qualitative research, emphasis is placed on achieving trustworthiness, which is the amount of

trust and authenticity that can be attributed to the research process and results (Bless et al., 2013). There is no consensus on the terminology used for reliability and validity in qualitative studies. Neuman (2006) uses the terms dependability or consistency to refer to reliability while truthfulness denotes validity. Lincoln and Guba (1985) suggested four key dimensions for assessing rigour in qualitative research: credibility; transferability; dependability; and confirmability. The study adopted these aspects to ensure the trustworthiness of the outcome of this study.

### ***3.5.9.1 Credibility***

To ensure the credibility of the findings, Lincoln and Guba (1989) argue that researchers should provide an accurate and truthful depiction of the participant's subjective experience. Hence, a credible study reports a fitting representation of the participants' experiences. The researcher provided verbatim extracts from the participants to ensure that the study findings represent the participant's views and not those of the researcher. Furthermore, the participants were given a copy of the transcripts and final study to confirm whether the interpretation accurately described their experiences (Shenton, 2004). During the phase of data collection, the researcher spent approximately two months engaging and working with the youth centre and participants. They were several support groups and social activities that the researcher attended during data collection. Through this participation and prolonged time in the field and working closely with the participants, the researcher obtained a deeper understanding of the participants' context and core issues with the potential to affect the quality of the data thereby minimising distortions of information (Onwuegbuzie & Leech, 2007). Extended time in the field also improved trust between the researcher and participants as they were more open to talk freely during interviews. The researcher constantly sought support from the study supervisor during the different phases of data analysis, presenting findings and discussion. Frequent debriefing sessions help widen the researcher's vision and may

mitigate researcher bias (Shenton, 2004). Feedback from the supervisor helped to improve the quality of the findings.

### ***3.5.9.2 Transferability***

In most qualitative studies, generalizability is not a characteristic; hence the emphasis is on transferability. According to Bitsch (2005, p. 11), the “researcher facilitates the transferability judgement by a potential user through ‘thick description’ and purposeful sampling”. The study used purposive sampling in line with the research focus. The participants were selected from an information rich sampling frame that satisfied the study’s requirements. Recruitment of participants was done until new information was redundant. Transparency involves clearly describing the procedure involved in conducting the interviews as well as painting a clear picture of the stages involved in the data analysis. The procedures involved in conducting the interviews were clearly elaborated from the initial contact with the gatekeeper to the invitation to participate and finally exiting the field. To ensure the depth of data required by this approach, data were collected using in-depth interviews and data analysis was conducted using thematic analysis. In strengthening transferability, a clear and detailed description of the context and characteristics of participants was also clearly articulated (Graneheim & Lundman, 2004).

### ***3.5.9.3 Dependability***

Dependability refers to the extent to which research procedures are clearly documented to allow other researchers to audit (Polit et al., 2001). In the current study, dependability was ensured by providing a detailed layout and explanation of the methodology and methods used in the study. Throughout the research, the researcher was aware of his subjective experiences and recorded these in reflexive journal. These experiences informed decisions on some of the

choices made in research design and data generation. Guba (1981) asserts that subjective self-assessment can reduce researcher bias and increase dependability.

#### ***3.5.9.4 Confirmability***

When researchers do not make their agenda and philosophical orientation clear, it becomes impossible to assess and confirm the credibility, dependability, and transferability of the research (Horton et al., 2016). The current study was grounded in the interpretive paradigm and sought to understand the lived experiences of adolescents and young people on how they perceived their body image. Throughout the study, the researcher explained and justified the reasons for theoretical, methodological, and analytical choices that were employed to inform the readers about the decisions made. The reflective journal also assisted the researcher in documenting all the events that happened in the field and his personal reflections in relation to the study (Lincoln & Guba, 1985). Lastly, the study's participants were given the final research study and they mostly agreed with the inferences drawn by the researcher about their experiences.

### **3.6 The role of the researcher**

In qualitative research, the researcher is the key instrument as he/she is actively involved in both data collection and analysis (Patton, 1990). Although the principal researcher was not involved in conducting some of the interviews, he ensured that the research assistants were thoroughly trained to improve their interview skills, for example probing and iterative questioning. The duty of analysing the interviews was the researcher's sole mandate. The researcher was aware of the importance of reflexivity and being unbiased as he engaged in the process of co-constructing of meaning and interpretation of participants' experiences (Reid et al., 2005; Smith & Osborn, 2008). Subsequently, to ensure that scientific credibility was adhered to in this study, the researcher maintained his self-reflexive position and was always

wary of his own beliefs and assumptions when engaging with the data. Moreover, epistemological reflexivity helped the investigator to examine how the study could be improved for example the reflection on research design showed that including the clinic staff in recruiting participants would significantly increase chances of participation in the study.

### **3.7 Data management and storage**

All the interviews conducted for the qualitative component of this study were audio-recorded and transcribed verbatim with participants' permission. Audio-recorded files were transferred from the digital audio recorder onto a CD that was safely stored away in the supervisor's office in the Discipline of Psychology, School of Applied Human Sciences, Howard College campus, University of KwaZulu-Natal. Data will be kept for at least five years. The questionnaires were also sealed and locked in appropriate office storage boxes, where they will be kept safe and secure in the supervisor's office for five years. Thereafter, both the quantitative and qualitative files will be either deleted or destroyed. Both electronic copies of the quantitative and qualitative data are kept safely in a password protected computer to ensure confidentiality and avoid possible access to the data by any third party

### **3.8 Conclusion**

In this chapter a detailed description and justification of the methodology used during both the quantitative and the qualitative components of this doctoral study was provided. The mixed method design that was used and the reasons for preferring such an approach was described in this chapter. The research context, sampling techniques, research instruments, and data collection procedures were also outlined. The chapter is concluded through a discussion of how trustworthiness was achieved and explanations on storage of the data. The results and discussions of the qualitative study are presented in the next chapters.

## CHAPTER FOUR

### **Psychosocial factors associated with body image and adherence to ART among a sample of adolescents and youth living with HIV**

#### **4.1 Introduction**

The needs of adolescents and youth living with HIV (AYPLHIV) are much more sensitive and varied than those of adults. On the one hand, they must simultaneously deal with 'adult' issues like practicing safe sex and adhering to treatment. On the other hand, they must address issues traditionally associated with adolescence, such as body image, peer pressure and forming individual identities (Davison & McCabe, 2006). It is not uncommon for PLHIV to experience a negative body image partly from notions of living with a stigmatised disease and from perceived wasting of the body (Fingeret et al., 2007; Yang et al., 2015). Perceived and experienced alterations in body appearances can have significant effects on psychosocial well-being and quality of life (Huang et al., 2006; Sharma et al., 2007). Among PLHIV, a negative body image is associated with poor adherence to medication (Blashill et al., 2014).

Despite AYPLHIV being seemingly at high risk for developing a negative body image, most of the studies have investigated the effect of a negative body image, but attention to the protective factors in the context of HIV has been rare. Identification of these factors could assist with planning interventions to promote positive body image. There is currently limited data regarding body image and protective factors among PLHIV in sub-Saharan Africa. Prior studies in HIV uninfected populations indicate that individuals with high self-esteem tend to evaluate their bodies positively and feel good about themselves (Swami et al., 2009). Moreover, social support was an important factor in coming to terms with changes in appearance, specifically when support helps to minimise feelings of difference (Hodder et al., 2014).

Given that psychosocial factors influence body image significantly, it is therefore important to examine this relationship among a sample of AYPLHIV who are more likely to be at risk of developing a negative body image. It is expected that a negative significant relationship would exist between negative body image and each of the psychosocial factors included in the study (social support, self-esteem, body appreciation, emotional well-being, and general health), excluding internalised HIV-related stigma. The researcher further hypothesized that a significant positive relationship between ART adherence and each of the psychosocial factors (social support, self-esteem, body appreciation, emotional well-being, and general health) except for internalised HIV-related stigma would be found. Lastly, the study hypothesized that a significant negative relationship between body image and ART adherence would be found. It was hoped that the study would contribute to fill gaps in information about how psychosocial factors act to ameliorate the effects of negative body image among AYPLHIV.

Using the Statistical Package for the Social Sciences version 21.0 for Window (IBM SPSS), standard descriptive statistics were used to describe the sample characteristics. The Pearson product-moment correlation coefficients were conducted to examine the relationship between the variables. The correlation coefficients of  $-1.00$ ,  $0$ , and  $+1.00$  represent perfect negative correlation, no relationship, and perfect positive correlation, respectively. It should be noted that for the variable of body image, social support, and health related quality of life, the researcher presents the subscales (negative evaluation, social support from significant others, social support from family, social support from friends, emotional well-being, general health). All statistical tests were performed using two-tailed tests, and a p value of 0.05 or less was considered statistically significant.

## 4.2 Results

### 4.2.1 Characteristics and background of respondents

The demographic characteristics of the sample are presented in *Table 4.1*. The final sample comprised  $N = 76$  (male, 56.6%) seropositive young people residing in Durban, South Africa. Participants ranged between 15 and 24 years of age ( $M = 19.36$ ,  $SD = 2.56$ ) and identified racially as African (82.9%) or Coloured (17.1%). Most participants self-identified themselves as Christians (71.1%), Muslim (3.9%), and the remaining 25% did not indicate their religious affiliation. A majority of the sample had fulfilled high school equivalency requirements (67.1%) or completed post-secondary education (29.0%). The remainder had not completed any formal education (3.9%). A higher proportion reported being horizontally infected with HIV (52.6%) relative to those who indicated being vertically infected (47.4%).

**Table 4.1: Respondents' socio-demographics (N=76)**

Characteristics	N	%
<b>Sex</b>		
Male	43	56.6
Female	33	43.4
<b>Religious Affiliation</b>		
Christian	54	71.1
Muslim	3	3.9
Unaffiliated	19	25.0
<b>Age</b> (Range:15-24, $M = 19.36$ , $SD = 2.56$ )		
<b>Race</b>		
African	63	82.9

Coloured	<b>13</b>	<b>17.1</b>
<b>Education</b>		
No formal education	<b>3</b>	<b>3.9</b>
Matric	<b>51</b>	<b>67.1</b>
Tertiary education	<b>22</b>	<b>29.0</b>
<b>Mode of transmission</b>		
Horizontal	<b>40</b>	<b>52.6</b>
Vertical	<b>36</b>	<b>47.4</b>

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#### ***4.2.2 Relationship between body image, adherence to ART and psychosocial factors in a sample of AYPLHIV***

The Pearson-moment correlation coefficient ( $r$ ) was used to examine the relationship between body image, adherence to ART and the six psychosocial factors (self-esteem, internalised HIV-related stigma, body appreciation, emotional well-being, social support and general health). Significant correlations between body image, adherence to medication and the various psychosocial factors were observed (see Table 4.2). The sub-scale of negative evaluation had a significant negative correlation with social support from family ( $r = -.28, p < .05$ ), body appreciation ( $r = -.38, p < .01$ ), emotional well-being ( $r = -.30, p < .01$ ), general health ( $r = -.39, p < .01$ ) and a significant positive correlation with internalised HIV-related stigma ( $r = .33, p < .01$ ). Adherence to medication had a significant positive correlation with support from family ( $r = .28, p < .05$ ), support from significant others ( $r = .39, p < .01$ ), body appreciation ( $r = .44, p < .01$ ), general health ( $r = .26, p < .05$ ) and a significant negative correlation with internalised HIV-related stigma ( $r = -.36, p < .01$ ). Interestingly, while no significant relationship was established between the sub-scale of negative evaluation and adherence to medication, the results still suggest that the negative perceptions held by

individuals regarding their body image, may influence medication taking behaviour as indicated in their negative association ( $r = - 0.14, p < 0.05$ ).

**Table 4.2: Correlation matrix between body image, adherence to medication and related psychosocial factors**

Variable	<i>M</i>	<i>SD</i>	NE	MA	SSSO	SSF1	SSF2	SE	IS	BA	EW	GE
Negative evaluation (NE)	7.53	3.22	1									
Medication adherence (MA)	2.83	1.59	-.14	1								
			[-.09, .36]									
Social support significant others (SSSO)	5.95	1.27	-.00	.39**	1							
			[-.23, .22]	[-.57, -.18]								
Social support family (SSF1)	5.39	1.75	-.28*	.28*	.29**	1						
			[-.47, -.06]	[-.47, -.05]	[.07, .49]							
Social support friends (SSF2)	4.35	1.88	-.17	.15	.03	-.25*	1					
			[-.38, .06]	[-.36, .08]	[-.19, .26]	[-.45, -.03]						
Self-esteem (SE)	15.61	1.63	-.04	.06	-.01	.08	.02	1				
			[-.26, .19]	[-.28, .17]	[-.24, .21]	[-.15, .30]	[-.21, .24]					
Internalised stigma (IS)	2.93	1.37	.33**	-.36**	-.20	-.20	-.17	-.23*	1			
			[.11, .52]	[-.15, .54]	[-.40, .03]	[-.40, .03]	[-.38, .06]	[-.43, -.01]				
Body appreciation (BA)	40.49	5.20	-.38**	.44**	.29*	.43**	-.04	.20	-.40**	1		
			[-.56, -.17]	[-.61, .24]	[.07, .48]	[.23, .60]	[-.26, .19]	[-.02, .41]	[-.57, -.19]			
Emotional well-being (EW)	341.05	68.27	-.30**	.17	-.13	.18	.08	.33**	-.40**	.27*	1	
			[-.49, -.08]	[-.38, .06]	[-.35, .10]	[-.04, .39]	[-.15, .30]	[.11, .52]	[-.57, -.19]	[.05, .47]		

General health (GH)	333.88	86.48	-.39**	.26*	-.02	.31**	.16	.22	-.14	.30**	.39**	1
			[-.57, -.18]	[-.46, -.03]	[-.25, .20]	[.09, .50]	[-.07, .37]	[-.01, .42]	[-.36, .09]	[.08, .49]	[.18, .56]	

*Note.* *M* and *SD* are used to represent mean and standard deviation, respectively. Values in square brackets indicate the 95% confidence interval for each correlation. The confidence interval is a plausible range of population correlations that could have caused the sample correlation (Cumming, 2014). \* indicates  $p < .05$ . \*\* indicates  $p < .01$ .

### 4.3 Discussion

The purpose of the study was to examine the relationship between body image, adherence to ART and the related psychosocial factors among AYPLHIV. The findings of this study showed that the sub-scale of negative evaluation was significant and negatively correlated with social support from family, body appreciation, emotional well-being, general health, and a significant positive correlation with internalised HIV-related stigma was observed. Adherence to medication was significant and positively correlated with support from family, support from significant others, body appreciation, general health and a significant negative correlation with internalised HIV-related stigma was observed.

A negative subjective evaluation of an individual's body as it relates to body size, shape, muscularity, and weight is common among AYPLHIV. Stronger perceived negative evaluation was associated with higher internalised HIV-related stigma. People living with HIV are likely to accept and internalise the widespread stereotypes associated with their illness (Kim et al., 2015). The internalisation of negative messages and stereotypes contribute to an unfavourable perception of the self. When an individual has discernible physical features that may be attributed to living with HIV and distinguishes them as different from others, it may lead to the development of a negative body image. These individuals are also at risk of experiencing internalised HIV-related stigma as they fear that their physique serves as a marker of the presence of HIV, making it difficult to conceal the illness (Varas-Díaz & Toro-Alfonso, 2003). The findings support previous research suggesting that high HIV stigma is associated with negative body image (Palmer et al., 2011).

The results of this study provide an understanding of the importance of social support, especially from family and significant others, for AYPLHIV who have a negative body image. When support from family and significant others is readily available and positive in terms of

tangible support, belongingness, and social intimacy, it is likely to lead to significantly higher levels of body image satisfaction (Merianos et al., 2012). On the contrary, sociocultural pressures to attain a socially desirable physique, particularly comments by family, partners, and friends may contribute to a negative evaluation of one's body (Rajagopalan & Shejwal, 2014). Negative body evaluation was negatively related with body appreciation. This is not surprising as previous studies found that body appreciation protects against body dissatisfaction (Andrew et al., 2015). Promoting a positive appraisal of one's body through accepting and holding a favourable opinion of the body including the seemingly unattractive diverse appearances and shape may mitigate negative body evaluation.

The results of this study revealed a significant negative relationship between negative evaluation and emotional well-being and general health in AYPLHIV. This finding implies that the less satisfied individuals are with their body image, the more likely they are to experience worse emotional well-being and general health. People with a negative body image frequently suffer from negative emotions such as depression and poor quality of life (Begovic-Juhant et al., 2012). This finding was consistent with findings from another study that indicated absence of an overall relationship between body image and depression, however, subscales of the scale used to measure perceptions of body image such as appearance evaluation were significantly correlated with depression (Hamilton, 2008). This supports the rationale for choosing a sub-scale of negative evaluation in this study as it better captures the essence of negative body image. The negative relationship between negative evaluation and emotional well-being and general health in the present study, underscore how central feelings about one's appearance tend to be among young people and how impairing these concerns can be, particularly when coupled with the awareness of living with a stigmatised disease.

According to the findings of the present study, a significant positive relationship was found between adherence to ART and body appreciation. This study is one of the first to establish this relationship. Body appreciation is a facet of positive body image. Evidence indicates that positive body image is likely to be protective of psychological well-being and it is not linked to disengagement in healthy activity and self-care (Tylka & Wood-Barcalow, 2015a). Body appreciation has previously been found to be negatively associated with behaviours that impact negatively on adherence to medication such as depression, anxiety, and alcohol use (Andrew et al., 2015; Ramseyer Winter et al., 2019). Body appreciation can be a protective factor for ART adherence through buffering the effects of a negative body image on adherence to medication. This initial finding on the association between adherence to ART and body appreciation presents empirical support for the development of intervention programs that promote body appreciation and aim to improve adherence to ART among AYPLHIV.

The study findings suggest that internalised HIV-related stigma is a concern among AYPLHIV, which is likely to lead to non-adherence to ART. The issue of HIV-related stigma in South Africa remains a concern, despite the efforts of public health professionals to destigmatise HIV. For AYPLHIV, the perception and internalisation of HIV-related stigma, coupled with the lack of supportive social relationships, can lead to decreased engagement in healthcare and non-adherence to ART (Pantelic et al., 2020). Given the aforementioned negative health outcomes that AYPLHIV may experience due to the deleterious effects of internalised HIV-related stigma, it is vital to equip young people with the necessary skills and surround them with resources needed to combat the negative effects of internalised HIV-related stigma.

The present study confirmed the positive association between perceived social support and adherence to ART (Poudel et al., 2015). Social support is important to PLHIV for multiple reasons, including its potential to decrease negative affect (Colbert et al., 2010). It encourages

adaptive coping (Nazik et al., 2013), bolsters knowledge of ART (Wagner et al., 2002) and increases an individual's self-efficacy to adhere to ART (Li et al., 2017). The present findings suggest that social support is essential in achieving positive health outcomes among AYPLHIV. With an increase in social support from family and significant others, the patient's tendency to ART use will increase. In the context of body image concerns, social acceptance and support from family and friends is critical for AYPLHIV in buffering the effects of negative affect such as body dissatisfaction and consequently improving adherence to ART.

Non-adherence to ART is a limiting factor in the successful treatment of HIV and can lead to the development of viral resistance, ultimately compromising the health of the person living with HIV (Robbins et al., 2014). Adherence to ART was significantly associated with general health. This finding was consistent with a part of the results of a longitudinal study indicating that consistent adherers have better physical function and general health, compared with non-adherers (Wang et al., 2009). Improving and facilitating patients' consistent adherence to ART has individual and public health benefits. On the individual level, it is associated with better health outcomes including improved general health and higher CD4 counts whilst on the public health level it will lead to viral suppression, lower chances of onward transmission and lower healthcare costs (Long et al., 2016; Nachega et al., 2011; Stekler et al., 2018).

Finally, the researcher found a negative but not statistically significant relationship between negative evaluation and adherence to medication. However, in previous studies a negative and significant correlation has been found between adherence to ART and various dimensions of body image (Lamb et al., 2018; Blashill et al., 2014). The difference in the results of these prior studies with the present study could be explained by difference in the methods used for data collection and the small sample size used in this study. Longitudinal studies with a bigger sample that capture changes in body image and adherence to ART over time may

improve confidence in the validity of the conclusions drawn about the association of body image with adherence to ART.

#### **4.4 Conclusion**

This study examined the relationship between body image, adherence to ART and six psychosocial factors (self-esteem, internalised HIV-related stigma, body appreciation, emotional well-being, social support, and general health) among AYPLHIV. The findings add to the literature that demonstrates the association between adherence to ART and various psychosocial factors such as social support. Among AYPLHIV, body appreciation is a relatively new concept that can be cultivated to enhance a positive body image and improved adherence to ART. Future longitudinal studies using a bigger sample should explore in more detail the nature and association between body appreciation and adherence to ART.

## CHAPTER FIVE

### **Serial mediation model of internalised HIV-related stigma and body appreciation**

#### **5.1 Introduction**

Increases in availability and uptake of ART have played an important role in the decline of new vertical and horizontal HIV infections, and HIV-related mortality. ART increases viral suppression and improves physical and emotional well-being (Agwu & Fairlie, 2013; Onyango et al., 2017). In hyper-endemic countries and regions where it has been particularly challenging to stay on track with global treatment and prevention targets, ART uptake represents a key avenue for reducing the burden of HIV. However, the benefits of ART for preventing and treating HIV may be undermined by non-adherence to treatment. Thus, a crucial part of maintaining and being able to capitalise further on the benefits of ART for individual treatment and the ultimate goal of ending HIV is optimal adherence to ART by PLHIV. To advance health promotion initiatives designed to improve adherence to ART, further research is needed to identify and better understand salient mechanisms underlying non-adherence to ART in populations residing in HIV hyper-endemic contexts and for which unique social-structural vulnerabilities exist.

The purpose of this part of the study was to examine relations between self-esteem, internalised HIV-related stigma, body appreciation, and adherence to ART by AYPLHIV who are residing in an HIV hyper-endemic country within East and Southern Africa (ESA). The present study tests for evidence of internalised HIV-related stigma and body appreciation as serial mechanisms linking self-esteem and adherence to ART among a sample of South African AYPLHIV. The researcher hypothesized that self-esteem and adherence to ART would be linked indirectly via a sequential path of internalised HIV-related stigma followed by body appreciation. It was hoped that the study would contribute to research on adherence to ART by

offering an improved understanding of mechanisms that may be involved in promoting adherence ART.

Statistical processing was performed using R (R Core Team, 2019). Study variables were initially screened for gross univariate and multivariate outliers. Standardised values for all variables were within acceptable limits (i.e.,  $z \leq |3.29|$ ), indicating there were no univariate outlier concerns. Mahalanobis distance ( $\chi^2(4) = 18.47, p < .001$ ) did not reveal any multivariate outliers (all  $D^2$  values  $\leq 11.92$ ). Univariate skewness (max. =  $|.86|$ ) and kurtosis (max. =  $|.76|$ ) values indicated that all variables were approximately normal in distribution. Descriptive statistics, internal consistency estimates, and zero-order correlations among the study variables are reported in Table 5.1. Omega total ( $\omega$ ) estimates of internal consistency for all measures were  $\geq .74$ .

Path modelling procedures were performed using maximum likelihood estimation with robust standard errors. Evidence of mediation was tested using a global approach, which involves determining mediation effects after first establishing adequacy of model fit. Following existing recommendations (see Mueller & Hancock, 2008; Worthington & Whittaker, 2006), model fit was evaluated using a combination of absolute, incremental, and residual-based fit indices. Specifically, the researcher reports the Chi-square goodness-of-fit statistic (and its associated p-value), the comparative fit index (CFI), the Tucker Lewis index (TLI), the standardized root mean square residual (SRMR), and the root mean square error of approximation (RMSEA). Along with the statistical significance of the Chi-square test statistic ( $p > .05$ ), values of  $\geq .90$  for CFI and TLI and values  $\leq .10$  for RMSEA and SRMR were used as benchmarks to guide the evaluation of model fit (Hopwood & Donnellan, 2010; Weston & Gore, 2006). The study also reports the Akaike information criterion (AIC) to allow comparisons between estimated models, with lower AIC values indicative of a more favorable level of fit (Burnham et al., 2011).

## 5.2 Results

Self-esteem evidenced a negative association with internalised HIV-related stigma and a positive association with body appreciation, but was unrelated to ART adherence. Body appreciation associated negatively with internalised HIV-related stigma and positively with adherence to ART. There was a negative association between internalised HIV-related stigma and adherence to ART (see Table 5.1).

Based on the researcher's theorising that internalised HIV-related stigma and body appreciation would be serial mediators linking self-esteem with adherence to medication, the researcher began with the most parsimonious baseline full mediation model in which the relation between self-esteem (X) and adherence to ART (Y) was specified to occur via internalised HIV-related stigma (M1) and then body appreciation (M2). Additional paths were sequentially integrated into subsequent models to determine whether less restrictive models were favoured over those that were more parsimonious. Because model estimation was based on cross-sectional data, a series of conceptually viable alternative models were also estimated.

**Table 5.1: Descriptive statistics, internal consistency estimates, and zero-order correlations among study variables (N=76)**

Variable	$M \pm SD$ (range)	(1)	(2)	(3)	(4)
(1) Self-esteem	15.61 $\pm$ 1.63 (11, 19)	(.82)			
(2) Internalised stigma	2.93 $\pm$ 1.37 (1, 6)	-.23** [-.43, -.01]	(.74)		
(3) Body appreciation	40.49 $\pm$ 5.20 (29, 50)	.20* [-.02, .41]	-.40*** [-.57, -.19]	(.84)	
(4) Antiretroviral therapy adherence	5.17 $\pm$ 1.59 (1, 8)	.06 [-.17, .28]	-.36** [-.54, -.15]	.44*** [.24, .61]	(.77)

*Note.* \*  $p < .10$ , \*\*  $p < .05$ , \*\*\*  $p < .001$ . 95% confidence intervals presented in brackets. Omega total ( $\omega_t$ ) internal consistency estimates presented in parentheses along diagonal.

Fit indices for all mediation path models are reported in Table 5.2. The baseline full mediation model (Model 1) in which internalised HIV-related stigma and body appreciation were specified as serial mediators linking self-esteem with adherence to ART evidenced an unsatisfactory level of fit. Inclusion of a direct effect between self-esteem and adherence to ART (Model 2) worsened model fit. Although model fit improved when a path was added to Model 1 linking self-esteem with body appreciation (Model 3), there remained an unsatisfactory level of fit to the data. A substantial improvement in model fit was found by adding a path to Model 1 linking internalising symptoms with adherence to ART (Model 4). All model fit indices indicated that Model 4 had a satisfactory level of fit to the data and was identified as the best fitting model. The researcher proceeded with comparing all alternative models to Model 4.

The researcher compared Model 4 to variations of Models 1 and 4 where the order of self-esteem and adherence to ART were inverted (Models 5 and 6), as well as an alternative to Model 4 where the order of internalised HIV-related stigma and body appreciation was interchanged (Model 7). Fit indices revealed that each of these alternative models had an unsatisfactory level of fit to the data. AIC values also supported a superior level of fit for Model 4, which the researcher retained as the best fitting model.

The standardised path coefficients for Model 4 are reported in Figure 5. Self-esteem was negatively associated with internalised HIV-related stigma, and, in turn, internalised HIV-related stigma was negatively associated with body appreciation and adherence to ART. Body appreciation associated positively with adherence to ART. Taken together, the results are consistent with indirect-only mediation and suggest that self-esteem is indirectly associated with adherence to ART via internalised HIV-related stigma and body appreciation.

**Table 5.2: Fit indices for serial mediation models (N=76)**

	Model fit indices					Comparative fit index
	$\chi^2$ (df)	CFI	TLI	RMSEA [90% CI]	SRMR	AIC
Model 1 <sup>#</sup>	7.30 (3)	.889	.777	.137 [.000, .287]	.058	996.73
Model 2 <sup>##</sup>	6.72* (2)	.878	.634	.176 [.024, .348]	.060	998.65
Model 3 <sup>###</sup>	5.38 (2)	.913	.738	.149 [.000, .325]	.050	997.58
<b>Model 4<sup>†</sup></b>	<b>2.48 (2)</b>	<b>.988</b>	<b>.963</b>	<b>.056 [.000, .290]</b>	<b>.030</b>	<b>994.71</b>
Model 5 <sup>††</sup>	16.13* (3)	.660	.320	.240 [.121, .378]	.090	1008.15
Model 6 <sup>†††</sup>	13.21* (2)	.710	.130	.272 [.132, .439]	.080	1007.94
Model 7 <sup>‡</sup>	13.21* (2)	.710	.130	.272 [.132, .439]	.080	1003.49

Note. <sup>#</sup>Self-esteem → Internalised stigma → Body appreciation → Antiretroviral therapy adherence.

<sup>##</sup>Model 1 with direct path added: Self-esteem → Antiretroviral therapy adherence.

<sup>###</sup>Model 1 with direct path added: Self-esteem → Body appreciation.

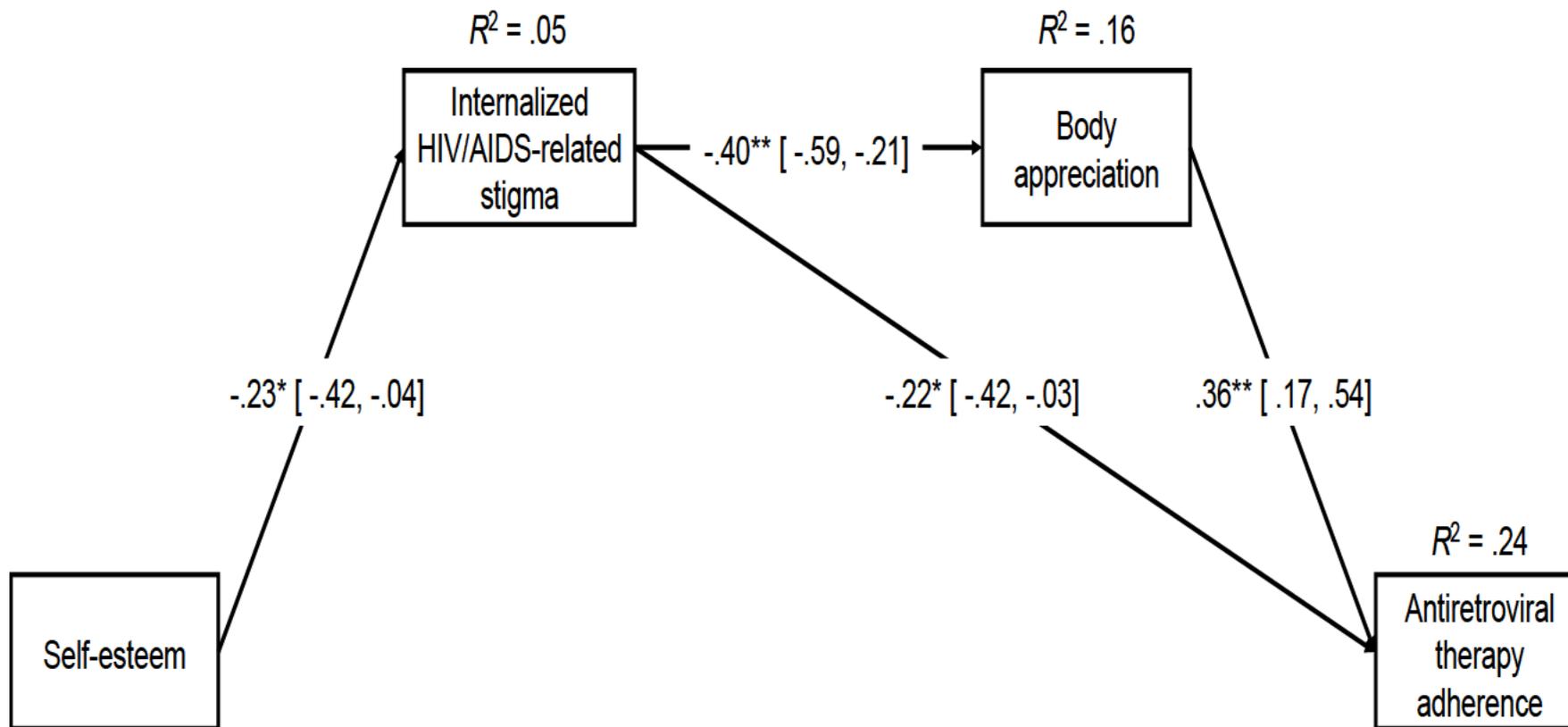
<sup>†</sup>Model 1 with direct path added: Internalised stigma → Antiretroviral therapy adherence.

<sup>††</sup>Alternative to Model 1 in which the ordering of self-esteem and antiretroviral therapy adherence is reversed.

<sup>†††</sup>Alternative to Model 4 in which the ordering of self-esteem and antiretroviral therapy adherence is reversed.

<sup>‡</sup>Alternative to Model 4 in which the ordering of internalised stigma and body appreciation is reversed.

\* $p < .05$ . Entries in boldface reflect best fitting model.



**Figure 5.1: Final serial mediation model**

Figure 5: Final serial mediation model of relations between self-esteem, internalised HIV/AIDS-related stigma, body appreciation, and adherence to antiretroviral therapy. Note. Standardised coefficients and 95% confidence intervals reported. \* $p < .05$ , \*\* $p < .001$ .

### **5.3 Discussion**

The purpose of this study was to examine relations between self-esteem, internalised HIV-related stigma, body appreciation, and adherence to ART among a sample of AYPLHIV in order to acquire further insight into potential pathways for promoting adherence to ART among young people. As hypothesized, the results revealed that self-esteem and adherence to ART were linked indirectly via a sequential path of internalised HIV-related stigma followed by body appreciation. There was also evidence of a one-step indirect effect linking self-esteem with adherence to ART adherence via internalised HIV-related stigma, although such an effect did not emerge for body appreciation. Collectively, the results offer support for internalised HIV-related stigma and body appreciation as mechanisms underlying the relation between self-esteem and adherence to ART.

The finding that self-esteem is not directly associated with adherence to ART is consistent with a broader body of research on the mechanisms (e.g., counselling, social support) underlying the relation between self-esteem and adherence to medication (Hussain et al., 2016). Evidence of a two-step indirect effect suggests that the sequential path of internalised HIV-related stigma and then body appreciation represents one mechanism that accounts for the relation between self-esteem and adherence to ART. This sequential pathway can be interpreted in the context of existing conceptual models that highlight the role of low self-esteem in precipitating health risk behaviour. Conceptualising self-esteem within the framework of identity theory (see Cast & Burke, 2002), both the initial distress of receiving an HIV seropositive diagnosis and the ongoing experience of living with HIV have the potential to disrupt the process of self-verification. Disturbances to self-verification can lead to a depletion of self-esteem, thereby reducing the capacity of self-esteem to operate as a buffer against stressors that emerge (Crocker & Quinn, 2000).

Among AYPLHIV, low self-esteem may increase vulnerability to internalised HIV-related stigma that arises out of the self-deprecating consequences of evaluating the self against stigmatising social norms (e.g., promiscuity) about HIV (Brown et al., 2001). Internalisation of HIV-related stigma is associated with fear of developing identifiable markers of the disease (e.g., lipodystrophy), which can heighten a person's sensitivity to bodily changes, and increase bodily shame (Palmer et al., 2011). Previous research has found that the psychological sequelae of body image disturbance (e.g., depression) can have negative implications for adherence to ART (Blashill et al., 2014), suggesting that similar mechanisms may be involved in the relation between body appreciation and adherence to ART. Taken together, the two-step indirect effect found in this study suggests that AYPLHIV who receive support to reduce or protect against internalised HIV-related stigma may benefit by experiencing higher levels of body appreciation, which in turn could lead to better adherence to ART.

A unique contribution of this study to the evidence on adherence to ART among AYPLHIV is the inclusion of body appreciation as a sequential mechanism through which self-esteem and adherence to ART are linked. Previous studies have highlighted the importance of identifying mechanisms by which internalised HIV-related stigma is associated with adherence to ART to enhance the efficacy of treatment approaches for improving adherence to treatment (Helms et al., 2017). Based on the results of this study, other intrapersonal (e.g., depression) and interpersonal (e.g., social support) factors that could affect ART adherence among AYPLHIV should be targeted alongside body appreciation issues to promote ART adherence.

The finding of a two-step indirect effect via internalised HIV-related stigma and then body appreciation was supplemented by a one-step indirect effect via internalised HIV-related stigma, which aligns with prior research involving self-esteem, internalised stigma, and adherence to

medication (Frias et al., 2019). Considering the findings of this study did not support a one-step mediating effect for body appreciation, internalised HIV-related stigma appears to play a key role in linking self-esteem and adherence to ART. Should the availability of resources for promoting adherence to ART be limited by infrastructure or economic constraints, treatment approaches targeting adherence to ART might consider prioritising internalised HIV-related stigma over body appreciation.

#### **5.4 Practical implications**

The current findings suggest that intervention initiatives targeting internalised HIV-related stigma and body appreciation may offer viable pathways for improving adherence to ART. Several standalone interventions have successfully addressed internalised HIV-related stigma and body appreciation in isolation. Cognitive behavioural therapy approaches have been effective at reducing internalised HIV-related stigma by challenging maladaptive patterns of thinking and building internal self-regulatory resources (e.g., coping skills) to manage stigma (Tshabalala & Visser, 2011). Writing-based functionality interventions (Alleva et al., 2018) and fitness training interventions (Ginis & Bassett, 2011) have been successful at improving body image perceptions (including body appreciation and satisfaction with body functionality) and generalised self-efficacy by encouraging people to focus more on the functionality of their body and less on their appearance. Many of these standalone approaches could be integrated into interventions that incorporate other key components (e.g., social support) to provide a multi-pronged and more comprehensive approach to targeting decisions to adherence to ART and behaviours among AYPLHIV.

Higher body appreciation is positively associated with higher levels of self-esteem (Khalaf et al., 2021). People who have a positive body image accept and acknowledge the individuality

and functionality of their own bodies (Tylka & Wood-Barcalow, 2015a), which lead them to accept and appreciate their bodies unconditionally as they focus more on what their body can do than on how their body looks. The positive thoughts about the body that individuals develop may lead them to be more satisfied with their lives and have a high level of self-esteem (Grogan, 2008). Therefore, organisations involved with AYPLHIV should pay attention and show initiation to develop strategies to enhance their positive body image and subsequently their self-esteem such as conducting guided imagery exercises and teaching strategies for resisting the effect of the media.

### **5.5 Limitations and future research directions**

The findings of this study offer additional insight into the mechanisms underlying the relation between self-esteem and adherence to ART, but there are several limitations to acknowledge. First, the cross-sectional nature of the data limits the ability to establish causal inferences and draw definitive conclusions about directionality. Although several models were compared to identify the best fitting model from the alternatives, longitudinal studies are needed to establish the directionality and causal pathways linking the variables included in this study. Second, the sample comprised a relatively homogenous group of Black and Coloured African AYPLHIV who were recruited from a single source located in a populous urban setting. Coupled with the convenience sampling approach that was used to recruit participants, caution should be applied when generalising the findings to other populations of APLHIV. Additional research is needed to determine the replicability of the findings in specific populations, particularly among vulnerable young key populations (e.g., young men who have sex with men) who may be at increased risk of sub-optimal adherence ART (Lall et al., 2015). Third, it is possible that the findings of this study are confounded by the omission of relevant variables (e.g., self-efficacy, autonomous motivation) that might exert a stronger mediating effect on the relation between self-

esteem and adherence to ART adherence. Future studies might consider integrating additional variables into modeling procedures to explore the relative strength of alternative indirect mechanisms that link self-esteem with adherence to ART. Inferences about the causal effects of internalised HIV-related stigma and body appreciation on adherence to ART are likely to be improved by using experimental designs (e.g., manipulation-of-mediator designs) that offer a more robust approach to mediation (Pirlott & MacKinnon, 2016). Fourth, the findings should also be considered alongside the small sample of participants in this study.

## **5.6 Conclusion**

In summary, the results of the current cross-sectional study provide preliminary evidence of both one-step (through internalised HIV-related stigma) and two-step (through internalised HIV-related stigma and then body appreciation) indirect effects linking self-esteem and adherence to ART by AYPLHIV. Notwithstanding the need to determine whether the results reported herein replicate in other key populations by employing more sophisticated methodological approaches, the findings raise the intriguing possibility of promoting adherence to ART in young people through targeted intervention initiatives that seek to resolve internalised HIV-related stigma and improve body appreciation. In the next chapter, attention will be paid to the qualitative findings and discussion.

## **CHAPTER SIX**

### **Perceptions of body image and body image satisfaction among adolescents and young people living with HIV**

#### **6.1 Introduction**

Adherence to ART plays a very important role in the survival and quality of life of AYPLHIV. Issues related to body image and its impact on adherence to ART is becoming increasingly important as the roll out of ART continues. Additionally, with the routine provision of ART becoming a reality for PLHIV in South Africa, it is expected that their life span will be considerably extended, and the most important questions will be ‘how to maximize quality of life?’. Young people diagnosed with HIV during adolescence are confronted with dilemmas around the same normal issues of development that “healthy” adolescents face: issues like selecting a romantic partner and engaging in sexual activity (Ramjohn, 2012). Making a decision about whether to disclose one’s status is a difficult experience for young people who are seeking intimacy as they fear rejection. For AYPLHIV, stigma continues to stand between them and the ability to lead a long, full, and healthy life (Mellins & Malee, 2013).

A review by Jain and Tiwari (2016) suggests that there is a dearth of studies showing the impact of HIV on body image satisfaction and life satisfaction in general among infected individuals. This qualitative study was therefore conducted to address the following objectives: i) to understand the thoughts and feelings of AYPLHIV on the appearance of their body, ii) to understand the experiences of AYPLHIV as they pursue intimate and sexual relationships, and iii) to explore the strategies utilised by AYPLHIV to cope in challenging environments and maintain a positive body image. To respond to these issues, a semi-structured interview schedule was used

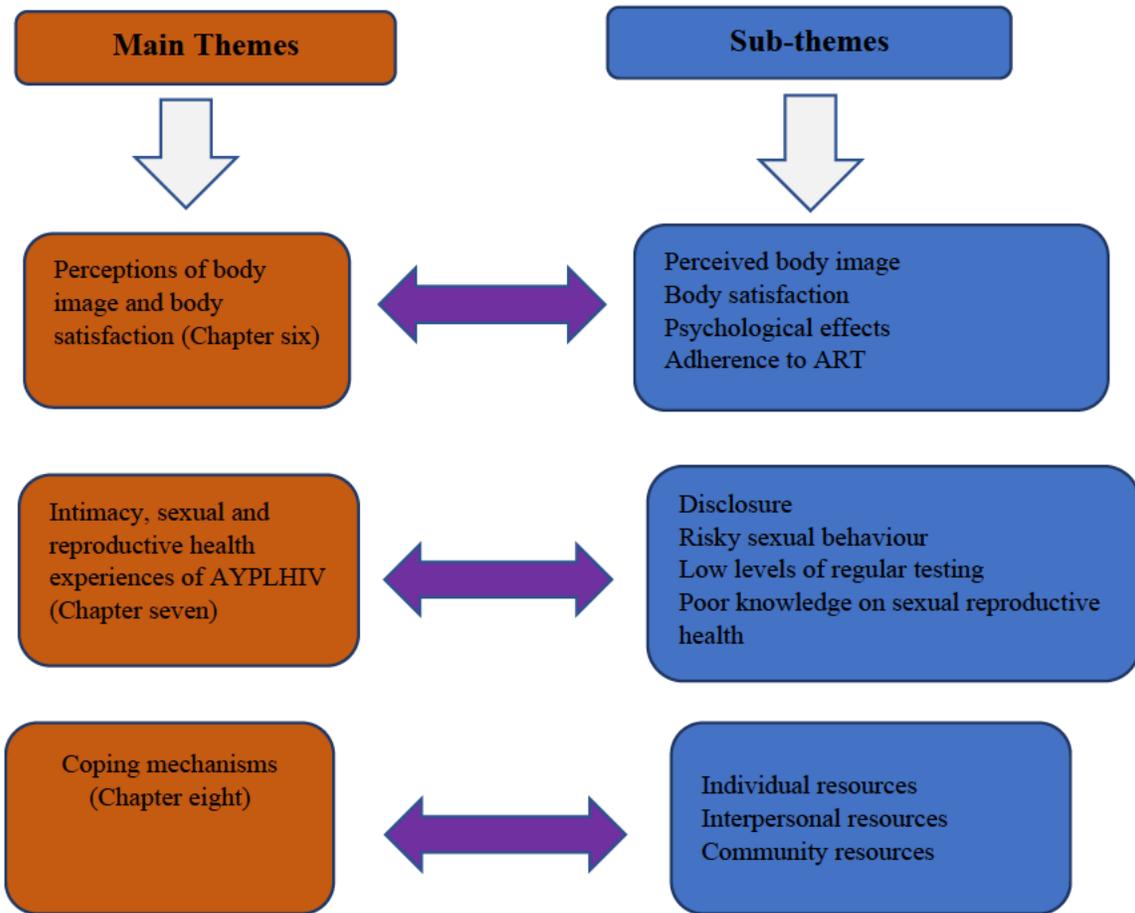
to conduct 18 in-depth interviews. Transcripts of the recorded interviews were translated verbatim to English language. Data were analysed using NVIVO and the six steps of thematic analysis described by Braun and Clarke (2006) as outlined earlier.

Several themes were derived from the data set generated through the semi-structured interviews, and the findings are presented below.

## **6.2 Emergent themes from the findings**

The following themes which present the most salient issues in this study, are not mutually exclusive. The researcher does not seek to suggest that the themes discussed represent an exhaustive list of the most salient topics regarding body image, adherence to ART and access to sexual and reproductive health (SRH) among AYPLHIV. In the results chapter, the findings and discussion sections are presented separately.

Using thematic analysis, three main focus areas were identified with various sub-themes. While presenting these findings thematically, the researcher acknowledges that these themes are inter-related. These broad themes were: perceptions of body image and body image satisfaction; intimate, sexual, and reproductive health dynamics; and coping mechanisms adopted by AYPLHIV. Within these broad themes, different sub-themes were identified as outlined in Fig 6. Each of these themes and the corresponding sub-themes are presented and discussed in detail in individual chapters.



*Figure 6.1: Summary of emergent themes and sub-themes of the qualitative findings*

## 6.3 Findings

### 6.3.1 Socio-demographic characteristics of the sample

In total, eighteen AYPLHIV participated in the study (Table 6.1). Study participants were within the ages of 15-24 years, with a mean age of twenty years. Of the total sample (n = 18), ten were females and eight were males.

**Table 6.1: Socio-demographic information of the Participants (n=18)**

<b>Participants</b>	<b>Age</b>	<b>Gender</b>	<b>Education</b>	<b>Religion</b>	<b>Race</b>	<b>Mode of transmission</b>
Participant 1	18	Male	Matric	Christianity	African	Horizontal
Participant 2	20	Male	Tertiary education	Christianity	African	Horizontal
Participant 3	19	Male	Matric	Christianity	African	Perinatal
Participant 4	22	Male	Tertiary education	Christianity	African	Horizontal
Participant 5	23	Female	Tertiary education	Christianity	Coloured	Horizontal
Participant 6	23	Male	Tertiary education	Christianity	African	Perinatal
Participant 7	19	Male	Matric	Christianity	African	Perinatal
Participant 8	21	Female	Tertiary education	Christianity	Coloured	Perinatal
Participant 9	24	Female	Tertiary education	Christianity	African	Horizontal
Participant 10	18	Female	Matric	Christianity	Coloured	Perinatal
Participant 11	19	Female	Matric	Muslim	African	Horizontal
Participant 12	21	Female	Tertiary education	Christianity	African	Perinatal
Participant 13	19	Female	Matric	Muslim	African	Horizontal
Participant 14	22	Male	Tertiary education	Christianity	African	Horizontal
Participant 15	24	Female	Tertiary education	Muslim	African	Perinatal
Participant 16	19	Female	Matric	Christianity	African	Horizontal
Participant 17	22	Female	Tertiary education	Christianity	Coloured	Horizontal
Participant 18	20	Male	Tertiary education	Christianity	African	Perinatal

Most participants (n = 61) had tertiary level education. Most participants (n = 14) were Christians with only three participants identified as Muslims. One participant did not indicate any religious affiliation. More than half of the participants (n=10) highlighted that they were horizontally infected while the remaining eight (n=8) indicated that they were vertically infected. A summary of the participants' socio-demographic characteristics are tabulated below (Table 6.2).

**Table 6.2: Summary of the socio-demographic information of participants**

<b>Characteristics</b>	<b>Number</b>	<b>%</b>
<b><i>Sex</i></b>		
Male	8	44
Female	10	56
<b><i>Age group</i></b> (Mean age =20)		
15-19	7	39
20-24	11	61
<b><i>Level of education</i></b>		
Matric	7	39
Tertiary education	11	61
<b><i>Religion</i></b>		
Muslim	3	17
Christianity	14	78
Not indicated	1	5
<b><i>Race</i></b>		
African	14	78
Coloured	4	22
<b><i>Mode of transmission</i></b>		
Horizontal	10	56
Perinatal	8	44

### **6.3.2 Perceptions of body image and body image satisfaction**

The concept of body image is significant for most young people as it is a fundamental aspect that has an enduring influence on emotional and interpersonal functioning. Body image concerns are common among PLHIV. Despite its complex make-up, body image has been defined as a combination of, “an individual’s mental representation of the integrity and competence of their own physical self, as well as their awareness of how others perceive them” (Martinez et al., 2005, p. 150-151). Thus, body image relates to a person’s perceptions, feelings, and thoughts about his or her body. However, these feelings and thoughts are not entirely inherent but rather the image that an individual has of his or her body is largely determined by social experience (Grogan, 2008). Under this overarching theme, several sub-themes were identified namely: perceived body image; body satisfaction; psychological effects; and ART adherence.

#### **6.3.2.1 Perceived body image**

Participants in the study explained about various ways in which they perceived their body. The common description was physical, whereby they described their physique. Commonly identified issues included weight loss and skin sores.

##### ***Weight loss***

Even in the current era of ART, weight loss and muscle wasting remain significant clinical problems. Responses from the participants indicated great concern over weight loss. Most of the participants mentioned that their body size was small as a result of significant weight loss. There was a desire to gain some weight and have a much bigger body size. Some of the responses indicating weight are indicated below:

*I like the way I am, but I feel like I could get a little bit bigger instead of getting too small you see, just to gain a little bit in my body, so I used to get sick, lose weight and gain it again, so that how it is (Participant 6).*

*You see when I have been sick and lost weight that is where I started lacking self-love, then if I have picked up and gained some weight, let me say maybe I have lost weight and end up wearing size 28, since I am size 30 now that is where I lack self-love. If a person says I am thin, I always remember that indeed I have lost weight (Participant 9).*

*Yah, it does bother me sometimes with my weight, you know I'm not picking up weight, sometimes I look like-my age is 23 but I look smaller than my age, you know and a person will tell me that I look smaller than my age; sometimes a person will tell me you know "what's wrong with you? You look smaller than your age, you are not right?" (Participant 14)*

*I have a small body, I am light in complexion umm I do not care what people can say about my body, like saying I am thin and all those things (Participant 5).*

*After that because at first I didn't take them on time and instead of getting better it was getting worse and my body was not gaining and then she [nurse] told me I must always take them [ARVs] because she gave me like a timetable when I should take them and I started get used to it and I got back to normal (Participant 2).*

From the above quotes, it is clear that these participants were not happy with their body weight and desired to gain some weight. In the case of Participant 14, weight loss was significant to an extent that his age did not correspond with his body size. Participants struggled to maintain constant body weight as it was constantly changing because of periods of sickness likely to be

worsened by non-adherence to ART. However, Participant 2 indicated that adhering to and taking treatment timeously was vital to maintaining weight. In addition to taking treatment on time, eating healthy and maintaining regular eating habits was also key to avoid weight loss. However, eating was not enough in some instances as it did not lead to any significant weight gain. These differing perspectives are indicated below:

*Well, what I would do like I said to you, before it used to be hard like the eating and stuff like that, but now I can say I've started to gain an appetite where I'm constantly eating on a regular basis things that are right, so physically I can see there is improvement as compared to where I was before, maybe it's not where I want to be, but there is improvement (Participant 11).*

*I won't say that I am satisfied with the way I look, I wish that I could be fitter, I could you know but I can't, I can't change somethings, sometimes I can eat as much as I want but I can't pick up weight you see (Participant 8).*

Failure to gain weight in the case of Participant 8 can be a result of the dietary nutrients being taken or other challenges such as stress. For some of the participants, weight loss was attributed to change in treatment regimens and being in stressful and challenging situations. They pointed out that challenges within the family contributed to weight loss. Stress may lead to missed meals, poor food choices and/or completely loss of appetite ultimately leading to weight loss. Additionally, some HIV drugs have been known to reduce appetite, make food taste bad, and prevent the body from absorbing food in the right way. These factors contributed to weight loss in some of the participants as stated below:

*Maybe if I am facing some challenges, for example at home, if I have some issues with someone at home because it is common that families have some disagreements, so I have that issue that if I am going through hard times, I lose weight, if there is something that is bothering me, I lose weight and pick up again when things are okay (Participant 3).*

*I will tell her you know what maybe I can stress upon this, this is the problem, I have not been eating well because of a, b and c and stuff like that. Well, like as I said before it used to be hard like the eating, but now I can say I have started to regain my appetite (Participant 7).*

For some of the participants, weight loss was evidenced through clothes not fitting any more. When clothes became loose, this signalled weight loss. This also point out to the challenge of constantly changing one's wardrobe in order to keep up with the constant weight changes. Considering that most of the participants were from low-income areas, weight loss may be associated with the economic burden of constantly looking for clothing that fitted the current weight of participants. Responding to the question of their perception on how their body looks, one of the participants stated that:

*It does not look good. Sometimes you will think, you know like when you try and fit in something and it's not fitting and you know it was fitting maybe two months or maybe a month and you will feel like eish, no something is wrong (Participant 12).*

The overall loss of weight was associated with a desire to gain weight in certain body areas. For the female participants, having bigger buttocks was deemed important to enhance their looks and physical attractiveness. When such desirable physical traits were absent in the presence of weight loss it led to feelings of self-hate and discontent with one's body. Concerns about loss of weight

and physical attractiveness were more common among females as noted by the following contentions from some of the female participants:

*There are certain areas that I would like to gain...maybe two sizes bigger or a size bigger at least (Participant 12).*

*I can say it does have a shape, but I do not have bums; that is the thing I do not like. I need to look sexy and feel nice and have that confidence unlike when you are having a flat bum and people are talking about you (Participant 5).*

*Because I also end up undermining myself, and when I look at myself I feel like I have lost too much weight, especially if I have been sick and lost weight that is where I undermine myself and feel like I do not like myself, except when...you see right now, I can feel myself (Participant 13).*

Issues of weight loss were of particular concern among young people, both males and females living with HIV. Most of the participants mentioned challenges related to maintaining body weight. Weight loss was further worsened by stressful living conditions such as family arguments. Female participants were more concerned with the loss of weight in certain body parts especially the buttocks as this affected their physical attractiveness. Furthermore, feelings of self-loathe were mentioned resulting from the weight loss.

### ***Skin sores***

Skin conditions are common in HIV infected people, particularly in resource-limited settings. Perceptions of body image were not limited to the physical build of the body only but were also influenced by the skin condition. In the description of how they perceived their body, some of the

participants indicated the presence of sores on their skin. Even when the sores had healed, they left spots on the skin which were a reminder of the sores that were there before.

*When I found out that I was HIV positive there were some symptoms on my body, I started developing some sores. It wasn't clear at first, in terms of what was happening with me. The first time I was told that I had TB I was treated for TB, then after some months, it was discovered that I was HIV positive. Eh...it is okay now, I like it it's just the spots of the sores, but I am trying to remove them. Like if a person can look at me for a very long time and does not tell me what they are looking at, I end up thinking that maybe they are looking at the way my skin is. It makes me feel uncomfortable (Participant 9).*

For some of the participants skin sores had implications for clothing style and intimate relationships as noted below:

*I used to have some little scratches as if something has scratched me so when I wear these tops that are fashionable these days people can see. So, when I am with him [boyfriend], he will just ask all of a sudden, why do I have scratch marks in my body (Participant 13).*

*The negative feedback that I get from people makes me feel bad and undermine myself. Because I cannot wear outfits that I like, I am always wearing long jeans; if not pants its leggings. I will be trying not to show off my spots, you see. I am now able to accept it because people do not know most things about my body; I always cover it (Participant 3).*

It is clear from the above that participants were not comfortable showing off their skin and were making attempts to cover those parts of their bodies that revealed the spots. Loss of confidence in one's body was also highlighted, mostly emanating from how others perceived the participants' bodies either explicitly by asking or implicitly by staring. The presence of sores and spots on the

body impacted the choice of clothing, with participants opting to wear clothes that covered their whole body, which in most cases was not their preferred clothing style. Skin sores could also potentially affect the intimate relationships of young people as they may lack confidence to reveal their bodies and also when these sores may suggest the possibility of HIV infection (unintentional disclosure) leading to discrimination.

### ***Distorted perceptions of weight***

It seemed that some of the participants held inaccurate perceptions of their weight. There were discrepancies in how they felt and thought about their body as compared to their actual body weight. They thought that they had lost a significant amount of weight, but however feedback from others suggested otherwise.

*Other than that, they will just see you every day (the same person) or every week or every second month and today you are still the same. In some cases, some people will be saying, you are actually looking fatter, but you think no it can never be, there is no way (Participant 2).*

*But the funny thing is like when you ask somebody else, they always say you look the same, and then you can feel obviously that you're not the same but if you ask somebody they will say to me you are the same man unless maybe something is a drastic change and then they will tell me you know what, what's going on what's eating you to me you were right, something wrong? (Participant 7).*

*It is like something within my mind that maybe I feel like I have lost a bit of weight or maybe I am changing, but the other person cannot actually see, they probably notice it once it is very big (Participant 3).*

The above assertion may also show that the participants are conscious that they are living with a disease, which is associated with weight loss and pre-occupation with these thoughts may lead to a distorted body image. It might also be that people giving feedback may provide positive feedback that participants have not lost weight to boost their confidence and well-being.

### **6.3.2.2 Body satisfaction**

Despite reported weight loss and skin sores, some of the participants reported that they were satisfied with their body images. One of the participants explained that he could perform any duties and was not physically constrained in any way. He stated that:

*I am satisfied because I can do things that I want to do and my body is flexible and allows me to do those things (Participant 15).*

In one instance, body satisfaction was explained in terms of normalcy as the perceived body image was not different from significant others and hence it was embraced without any fear of shame. This is highlighted below:

*What I can say is that I feel normal. There is nothing I am ashamed of about my body. I am just like the rest (Participant 18).*

It was noted that body satisfaction was also derived from weight gain. Eating food with nutritional value regularly and also taking treatment according to professional advice led to better health outcomes and participants had confidence in their body images. The following are some of the descriptions by participants on how they felt about her bodies:

*My body is okay, I do not have any problem, I have a rich body and I am okay. So, they ask me what is that I am eating that makes me gain so much weight that is why I am saying*

*even the pills do not affect me and I also think I am eating what is right and I must continue with that (Participant 17).*

*I feel my body is okay; it is healthy and has strong immune system. So, you can't tell by looking at my body that I have a problem, or I am living with this virus, because I am following health guidelines and healthy eating. Maybe if my body didn't have a strong immune system and it was weak, maybe that would affect me (Participant 10).*

*No, it does not; it is just the same because I'm just like any other person as fit as any other person and a lot of people don't know that I'm on tablets (Participant 4).*

It is evident from the above explanations that a healthy body was important to the participants as it did not mark the presence of a disease. Having a healthy and fit body is important for PLHIV and on ART as this does not differentiate them from the rest of the population. This also suggests that stigma and discrimination against PLHIV is still an issue in society as noted that participants did not want others to know that they were on ART. However, in responding to the question of body satisfaction, one of the participants explained that:

*I would say it looks normal, but at some point, knowing your status you always feel that you are different. I do feel satisfied with my body (Participant 18).*

Hence, even though the body may not show any physical signs of an illness, the diagnosis of HIV on its own potentially impacted on how the participant felt about the self. On a personal level knowledge of one's status led to feelings of being different from others who are not HIV infected.

Some participants expressed that they were following proper eating habits and they were already identifying improvements in their body physique. However, they had an ideal body weight that they wished to attain for them to be satisfied with their bodies. The following was said:

*Well, what I would do like I said to you is, before, it used to be hard like the eating and stuff like that, but now I can say I've started to gain my appetite where I'm constantly eating on a regular basis things that are right, so physically I can see there is improvement as compared to where I was before, maybe it's not where I want to be, but there is an improvement (Participant 11).*

Body dissatisfaction was also reported by some of the participants. One of the participants explained how she struggled to gain weight irrespective of the amount of food she consumed. She also wished to be fitter, and she explained that:

*I won't say that I am satisfied with the way I look, I wish that I could be fitter, I could you know but I can't, I can't change some things, sometimes I can eat as much as I want but I can't pick up weight you see (Participant 12)*

### **6.3.2.3 Psychological effects**

#### **Loss of self-confidence/self-esteem**

Positive body image and healthy self-esteem are important to young people's health and well-being. Dacey and Kenny (1994) have described physical characteristics as central to adolescents' sense of self, in contrast to the greater importance placed on internal characteristics in later years. Adolescents' sense of self-worth and perceptions of social relations may therefore be closely linked to their body image. Responses from the participants indicated that negative feedback on body appearance from significant others impacted on their self-esteem and confidence. A negative body image which arose from feedback from others and perceptions (or experiences) of a wasting

body and sores was associated with various negative feelings such as self-doubt and lack of self-love as narrated below:

*I end up doubting myself and lack self-love (Participant 14).*

*You see when I have been sick and lost weight that is where I start lacking self-love, then if I have picked up and gained some weight, let me say maybe I have lost weight and end up wearing size 28, since I am size 30 now that is where I lack self-love. If a person says I am thin, I always remember that indeed I have lost weight (Participant 9).*

One of the participants explained that losing weight affected her sense of worth. However, when she regained her weight, she felt good about herself. She explained referring to her current state that:

*Because I also end up undermining myself, and when I look at myself, I feel like I have lost too much weight, especially if I have been sick and lost weight that is where I undermine myself and feel like I do not like myself, except when...you see right now, I can feel myself (Participant 13).*

There was also an attempt to resist succumbing to negative feedback in a bid to protect oneself, but in this case, it was met with limited success. This is indicated by one of the participants who claimed that:

*Before, I used to pretend like it doesn't make me feel... you know like it doesn't eat me, but I would go home and then think on myself that something is wrong (Participant 7).*

A negative body image is largely associated with loss of self-confidence and self-esteem. The society, particularly interactions and feedback from others affect how young people perceive and

construct their body image. A poor body image may hamper young peoples' development of interpersonal skills and positive relations with others.

#### **6.3.2.4 Adherence to ART**

In this study, only two participants mentioned that they had stopped taking their ART medication at some point because of side effects related to body changes. One of the participants indicated that after switching to a different treatment regimen he had difficulties eating and as a result started to lose weight. He explained that:

*Like in the beginning when the medication was switched, it became a little of a process that every time I took it, it would come out same time. So, it was making it hard for me to eat and I started losing some weight. That is when my mother started to notice like the patterns and see that I was not taking all the medication (Participant 1).*

For one on the participants, the body changes she was experiencing were not only self-perceived but significant others including friends could also see the changes she was experiencing. She narrated that,

*My body was not the same anymore. I just could feel that the pills were changing how I look. The body I used to have when I was in high school was very different. Some of the girls were asking what I was taking to lose weight and I don't know because I was not taking anything. All I wanted was my original body back, but I didn't get it back because it became worse when I skipped taking the pills. But now I know I should take them [ARVs] everyday if I want to live for many years (Participant 12)*

Even though most of the participants narrated the different body changes they were experiencing as well as the accompanying psychological effects, most of them adhered to their ART regiments.

As will be discussed in the following chapter (eight), the different coping mechanisms employed by the young people seemed to be critical in maintaining ART adherence among the participants.

#### **6.4 Discussion**

During the phase of adolescence and youth, young people progress through key developmental tasks towards physiological and psychological maturation (Linders, 2017). The transition through this challenging period of development centres on discovering, choosing, and shaping the self within the broader social environment (Harter, 2006) as well as navigating related challenges including establishing independence and autonomy, exploring and forming intimate friendships and sexual relationships (Christie & Viner, 2005). Central to this phase is conforming to group norms and belonging to peer groups. Peers play a crucial role in promoting or hindering normal psychological and social development in adolescence (Stanton-Salazar & Spina, 2005). They serve as role models; provide standards for acceptable behaviour, whilst sanctioning one another for nonconforming behaviour through ridicule or ostracism (Smetana, 2010). Body image is one aspect that is central to adolescence and youth as they are in the process of understanding themselves and creating an identity for themselves.

The concept of body image is complex and encompasses an individual's attitude and perception of their physical self as well as awareness of social interpretation of their body by others (Martinez et al., 2005). Body image is an important psychosocial variable among individuals living with HIV due to the variety of actual and perceived changes in physical appearance and bodily function resulting from illness and treatment. Cabrero et al. (2010) found that 55% of 965 patients on ART perceived that they had suffered changes in body shape since they started treatment. Poor body image is strongly associated with low self-esteem and low self-worth (Croll, 2005), both of

which can severely limit the potential for young people to succeed in different aspects of life. The body is inextricably tied to HIV since it is through the body that people are exposed to the infection and experience the illness. In this sense, the participants mentioned physical changes that they experienced from living with HIV as well as the psychosocial factors arising from these bodily changes.

Weight loss remains one of the complications in HIV persons on ART (Wanke et al., 2000). Although HIV infection in the current era of ART has become a survivable and chronic condition, treatment regimens pose significant potential metabolic side effects. People living with HIV often experience changes in body shape and weight, which can result in a negative body image and body image dissatisfaction to which adolescents and young people are particularly vulnerable. When individuals are dissatisfied with their appearance, it may lead to poor health and well-being. Most participants in the study, both males and females indicated concern with unintentional weight loss. A study among adults aged between 25 and 64 years by Pienaar et al. (2017) found that significantly more HIV infected participants reported experiencing diarrhoea, as well as involuntary weight loss, compared to HIV uninfected participants. One study has shown that the prevalence of thinness among HIV infected people in the era of ART is about 8.8% (Mariz et al., 2011). Weight loss continues to be a common problem among HIV infected patients, even in the era of ART (Koethe & Heimbürger, 2010). This prevalence of weight loss and wasting has not changed over time, occurring in those treated successfully with ART, those for whom ART failed, and those who are ART naive (Tang et al., 2005). Furthermore, the Nutrition for Healthy Living data also suggested that the use of ART has not eliminated weight loss as an issue of concern in HIV infected individuals (Mangili et al., 2006).

The participants had appetite problems and struggled to eat on a regular basis, leading to weight loss. This is not surprising as HIV is associated with biological factors such as loss of appetite, gastrointestinal complications and oral and oesophageal sores that affect an individual's desire for food and ability to eat, leading to inadequate dietary intakes (Colecraft, 2008; Suttajit, 2007). The most common physical sign of nutrition inadequacy in HIV is weight loss. If not addressed, weight loss will likely lead to growth failure in HIV-positive children (Arpadi et al., 2000), accelerate disease progression, increase morbidity and reduce survival of HIV patients (Hsu et al., 2005). Problems with appetite and eating were worsened by different life stressors such as, family problems, physical isolation and anxiety about the future. Hormones released in response to stress such as corticotropin-releasing hormone have been reported to suppress appetite during stress (Takeda et al., 2004).

Weight loss was associated with concern about a small body size that did not correspond to the age of the participants. Diminished growth is highly prevalent in HIV infected individuals. Poor growth is often attributable to recognisable secondary conditions that accompany HIV infection; however, poor growth is also encountered in HIV infected children with no discernible secondary illnesses (Arpadi, 2005). Adolescents living with HIV are likely to experience delays both in the age of onset of puberty and their progression through the pubertal stages (Szubert et al., 2015). Thus, AYPLHIV may have reduced weight and height growth compared to their uninfected peers. Adolescents and young people may be self-conscious or embarrassed about not being as developed as their peers. Later maturation is associated with risk for psychosocial problems, including lower self-esteem and depression, and may have implications for reproductive health (Brogly et al., 2007; Majaliwa et al., 2009). Hence, AYPLHIV may be more distressed

about their actual or perceived maturational delay than about their underlying chronic illness. Those with abnormal pubertal maturation may need psychological and nutritional support.

Physical appearance is influential in the development of young people as individuals become more aware of their appearance during this phase and often become preoccupied with their looks. Lack of a “bum” was a concern particularly for females as it impacted on their feelings and perceptions of being “sexy”. This ideal body type in African cultures was also reported in a study by Kelch-Oliver and Ancis (2011) where most participants reported that a Black ideal body was larger than that encouraged by the dominant culture, and that this ideal standard includes being shapely and curvy. Perceptions of physical attractiveness are important to young people as they are a stronger predictor of positive friendships and peer acceptance (Hanna, 1998). Physical attractiveness is also important in romantic attraction, as it is one of the first things individuals notice about a prospective partner. Males value physical attractiveness in a partner more than females (Buunk et al., 2002), with Black adolescent boys preferring specific body parts such as hips, buttocks, and thighs to be larger than the dominant norm (Thompson & Sargent, 1996). Furthermore, there is a cultural acceptance of curvier body types among African cultures, whereby Black women report greater comfort with and even idealisation of fuller figures (Franko & Striegel-Moore, 2002). Hence, a body type that does not closely resemble this is associated with low self-esteem and confidence among females.

Whilst feedback from significant others highlighted that some of the participants had normal healthy weight, the participants perceived themselves as underweight. The perceptions of body size expressed differed from the actual body size. These findings confirm those of Matoti-Mvalo and Puoane (2011) where a larger percentage of women perceived themselves as underweight than the actual numbers who were underweight. Distorted perceptions of body weight

were common, which could be a result of knowledge of living with HIV. Prior to the widespread availability of ART, HIV was labelled “slim disease” and was characterised by weight loss and wasting (Yuh et al., 2015). Hence, it is possible that participants had internalised this picture of the body and associated characteristics of PLHIV. Even in the present day where ART has proved to be effective in treating HIV, the association between HIV and weight loss has not completely disappeared. A study by Matoti-Mvalo and Puoane (2011) indicated that a large percentage of participants in their study identified a thin figure as being representative of someone who is HIV positive whilst none of them associated a large figure (overweight and obese) with a person infected with HIV.

Although mortality from HIV related skin conditions is not rife, the condition is associated with negative psychosocial reactions. In general, people with skin dermatosis may experience fearful anticipation of social interactions and develop avoidance-coping mechanisms thereby preventing them from partaking fully in social and recreational activities (Tuckman, 2017). The knowledge of HIV status can further compound the negative reaction towards the presence of skin sores. Feelings of being uncomfortable in social situations, unsolicited questions about one’s skin from partner and attempts at concealing sores by wearing clothes that cover the whole body were some of the concerns raised by participants. A study by Shittu et al. (2016) found that 80% of the patients stated that mucocutaneous lesions were a source of embarrassment, affected not only their social activities (60%) but their sexual activities (48%) as well as relationship with partners, close friends, and relatives (65%). Similarly, patients cited considerable quality of life impairment resulting from skin lesions (Raju et al., 2005). Skin problems can result in psychosocial effects such as anxiety that seriously affect the lives of PLHIV.

Furthermore, the presence of skin sores can be a source of shame especially when individuals compare themselves to their peers. In this case, when individuals engage in upward social comparison whereby, they compare themselves to peers with normal skin or in some cases with popular media models they may find themselves lacking in terms of beauty trends that emphasize smooth and spotless skin. Successful treatment of skin conditions, which improves the patient's symptoms and changes their physical appearance, can lead to positive psychological effects and a better quality of life (Langley et al., 2010). However, in some instances some spots will remain irrespective of dermatological interventions subsequently leading to a discrepancy between the actual and ideal self. In such cases, greater body image satisfaction is achieved by accepting and acknowledging the existence of spots as part of one's being. Thus, this underscores the need to equip patients with tools to accept their skin condition and to reduce the impact the remaining spots may have on everyday life. Cognitive behavioural interventions can focus on teaching AYPLHIV to reduce the importance that appearance has on one's self-concept, and focus instead on other aspects of the self, such as skills and talents possessed by individuals.

Young people are particularly susceptible to social pressure associated with physical appearance, as this period is critical to the formation of one's identity and self-worth. Some of the participants expressed dissatisfaction with their bodies. Body dissatisfaction refers to the discrepancy between an individual's perceived current body size and perceived ideal body size (Wertheim et al., 2004). It was the participants' wish to gain overall body weight, with some wanting to gain in specific body parts whilst others wanted to get rid of skin spots, which were a reminiscence of skin condition. Dissatisfaction with physical appearance is a common experience for many adolescents (Biolcati et al., 2017). The stigma associated with HIV may compound body

dissatisfaction. Feelings of shame or “being dirty” associated with a sexually transmissible disease like HIV may impact on how a young person views their body (DeLaMora et al., 2006).

There was discrepancy between a desired body size versus the present body size and desired skin versus current skin condition. This discrepancy can be understood using the self-discrepancy theory (SDT). The SDT explains discrepancy whereby there is inconsistency in a person’s actual attributes from his/her standpoint and the ideal state he/she personally desires to attain leading to dejection-related emotions such as disappointment and low self-esteem (Higgins, 1987). In the study, several negative emotions including disappointment and dissatisfaction were mentioned by the participants, indicating the presence of a discrepancy between the actual and ideal body image.

Lacking self-love, self-doubt, undermining the self and concealing certain aspects of the body was reported in the study. Discrepancy between the ideal and actual self will likely lead to concealment as a way to cope with distressing body image thoughts (Cash & Smolak, 2011). However, concealment is a short-term fix for the anxiety caused by body concerns as in the longer term it reinforces the belief that an individual’s body is unacceptable. Field (2004) suggests that adolescents who are dissatisfied with their bodies are more likely to perceive their health as poor and more likely to show low self-esteem and low social functioning. The adverse outcomes of body dissatisfaction in adolescents suggest an urgent need for these issues to be addressed in both health and family settings (O’Dea, 2012). Cultivating positive body-image and a strong sense of self-worth are likely to help young people become more content with their bodies.

Among this sample most of the participants highlighted that perceptions of body image did not have any effect on ART adherence. There are three possible reasons for this. Firstly, the sample was drawn from a centre that offer ART adherence counselling and support programmes to

PLHIV. Individual and group counselling interventions improve adherence, viral suppression, and retention in care among AYPLHIV (Casale et al., 2019). Secondly, as it will be further elaborated in chapter eight, the coping mechanisms employed by the young people in the study (e.g., spirituality and social support) may also have contributed to better ART adherence. Lastly, the responses were gathered from face-to-face interviews with the participants. Participants may have provided socially desirable responses in the form of adherence over-reporting as they were cognisant that adherence will be perceived favourably by the researchers (Do et al., 2013).

Fears of rejection by families, peers and partners are common. This condition can be amplified by the presence of symptoms indicating the presence of HIV such as deteriorating body weight, skin sores and loss of control over one's body. A combination of nutritional counselling and exercise targeting youth living with HIV can counter the issue of weight loss and its accompanying effects. The narratives suggest that weight loss was also a result of inadequate food intake, due to altered metabolism resulting mostly from treatment. Nutritional counselling can improve an individual's immune function, limit disease complications, and improve quality of life and survival (Enwereji et al., 2019; Segal-Isaacson et al., 2006). Research with PLHIV indicates significant improvements following moderate levels of routine exercise in as little as 6 weeks (Jagers & Hand, 2016). Physical exercise plays a vital role not only in improving physical appearance and well-being, but also has psychosocial importance in avoiding being stigmatised.

## **6.5 Conclusion**

The connection between physical appearance and body image is fundamental, because how an individual perceives his/her body affects how one ultimately feels and treats one's body. Living with HIV often undermines subjective feelings of body satisfaction. Weight loss and skin sores

are some of the physically visible attributes that may contribute to a negative body image. These visible characteristics are often accompanied by a range of psychological sequel including loss of self-esteem and feelings of self-loathe. Youth living with HIV desire to look physically fit and healthy like their HIV uninfected peers. Optimum ART adherence to the correct treatment regimen accompanied with a nutritional plan, physical exercise and cognitive behavioural therapy can combat the negative perceptions on physical appearance and offset the body changes that may arise from living with HIV and taking ART.

## CHAPTER SEVEN

### **Intimacy, sexual and reproductive health experiences of adolescents and youth living with HIV**

#### **7.1 Introduction**

Young people constitute the largest and fastest growing proportion of the general population in Eastern and Southern Africa (ESA) (UNFPA, 2019). The current youth bulge represents an enormous challenge for health services and health systems, as the sexual and reproductive health (SRH) and HIV service needs of the growing population remain unmet particularly in low-and middle-income countries (Patton et al., 2016; Snow et al, 2015). The wide availability of antiretroviral therapy (ART) has resulted in many vertically infected children to survive to adolescence. These, coupled with the large numbers of young people who are behaviourally infected, have contributed to a huge burden of AYPLHIV in Southern Africa (UNAIDS, 2019). Youth living with HIV are often confronted with a wide range of challenges as they struggle with normal adolescent developmental issues while carrying the burden of living with a highly stigmatised illness (Hosek et al., 2000).

A significant number of studies on adolescents living with HIV in both low- and high-income countries have shown low and inconsistent condom use and low levels of disclosure among this population group (Okawa et al., 2018; Toska et al., 2017). A paucity of sexual health education and services tailor made for AYPLHIV continually contribute to acquisition of other STIs, unintended pregnancy and high rates of onward HIV transmission to partners and offspring (Bauermeister et al., 2012). High levels of sexual risk-taking among HIV-positive adolescents and youth have been reported with most pregnancies among HIV-positive adolescent women being

unintended, suggesting the unmet contraceptive need among this population (Toska et al., 2017). As HIV positive adolescents get older and engage in sexual and romantic relationships, additional research on their experiences of HIV disclosure, sexual and reproductive health needs, and other relationship-related factors is needed (Fairlie et al., 2014).

This chapter focuses on the SRH needs of AYPLHIV in Durban, South Africa. This study expands the current knowledge base on the understudied SRH needs of AYPLHIV and aims to understand from their own experiences, the unique SRH needs of this population group to support them in practising safer sexual practices and adopting healthy lifestyles. A qualitative approach was chosen because of its ability to enrich the understanding of health and illness in small and understudied populations (Fiese & Bickham, 1998). This paper describes the SRH related experiences of being an adolescent infected with HIV such as reasons for (non) disclosure; partner preference; low perceived risk; and access to and use of contraceptives.

## **7.2 Findings**

Data elicited through in-depth interviews revealed several themes. The emergent themes revolved around intimate and sexual and reproductive health experiences of AYPLHIV. These are presented in the subsequent sections.

### **7.2.1 Disclosure**

#### ***7.2.1.1 Experiences of (non)-disclosure***

HIV disclosure is associated with potential individual and public health benefits such as initiation of ART, greater condom use and partner HIV testing. In this study, disclosure of HIV status seemed to be a very difficult process for most of the participants suggesting that their potential for individual and public health benefits was limited. Non-disclosure was very common among the

participants and there was a preference to keep their status private. Some participants explained that:

*You see like people don't really tell you their status so you will never know whether the girl is negative or positive unless maybe you go to the same clinic or you meet at the same clinic, you know this person maybe you know from the time she was small that this person is positive (Participant 2).*

*I think the funniest thing at some point is that you know when you are dating you do not know each other's status right? So, you might feel depressed and stressed too much, but only to find that she also has one too, but you have been overthinking about it and she is relaxed (Participant 7).*

*I don't like people to know my status. (What about when it comes to having sex?). I will suggest that we use a condom and maybe I will tell her after dating for some time (Participant 18).*

Family and friends were not disclosed to for different reasons such as fear of being judged. One of the participants explained that she had not disclosed to any of her friends but only one “*because we have the same problem*” (Participant, 6). Non-disclosure of HIV status was associated with challenges in taking treatment whereby one would take treatment in secrecy to avoid accidental disclosure. Responding to the questions of experiences of (non)-disclosure, one of the participants explained that:

*Because even my brothers and sisters they do not know. I only take them [ARVs] when they are not around. I think it's probably one of the best solutions I ever came across. Because you know families are not the same (Participant 14).*

Participants narrated the different ordeals that they had gone through in an attempt to disclose their HIV status, especially to romantic partners. However, most of them were not keen to disclose their status to romantic partners. They resorted to making excuses or delaying having sex. This technique is highlighted by some of the participants who explained that:

*Yes, I do reach that point of having sex, but as I said earlier you know I always like to create something like an excuse that we do not have sex. The fact is I cannot say it right now because we are still young, so if you like open and disclose about my status to this person at this age you know. It is too early; you wouldn't know what that person will do. Yes, so I think maybe in later stages (Participant 14).*

*Um...usually I would say that I am not ready, and at some point, we should get married, and I make it at a point that she understands it that I am having this situation that I need to deal with it right now, so like coming up with excuses or something (Participant 7).*

Although most of the participants highlighted that it was difficult for them to disclose their status and resorted to delaying tactics, some noted that it was neither proper nor sustainable. Hence, they suggested that it was appropriate to disclose their status so that their partners could decide whether to continue with the relationship. This is explained below:

*It won't be a good thing if he finds out by himself, because he has to take an informed decision whether he continues dating you since you are HIV positive, instead of you forcing him, because he doesn't know, if you haven't told him he doesn't know that you are sick, so that he can also get some treatment if he has been already infected (Participant 5).*

The different narrations from the participants highlighted that for those that had disclosed, disclosure was not intentional. For some, being caught with unknown tablets led them to disclose

their status whilst for others the pressure from partners to engage in sexual activity forced them to eventually disclose their status. These different experiences are presented below:

*No, they were in my bag, when I was visiting home in Pinetown, I used to pass through him first, then he would open my bag and see my tablets. And, then there were these scratch marks, so he would ask what is really wrong with me, you see. Okay fine, but I always wanted to tell him, but I was scared, but I had no choice but to tell him, because he ended up shutting off from me, because you could see the way he was asking that he knew that there was something wrong (Participant 11).*

*No, that was the reason that pushed me to tell him, because he was busy insisting that we engage in sexual activity and then I kept on saying, no we must wait, and because we have been dating for years, he would ask “what are we really waiting for?” You see, and then I kept on saying there is something I have to tell you, and he would get more irritated when I said that hence I would finally say nothing. So, he used to send me a text on WhatsApp and it is not easy to respond on WhatsApp. So, I said to him, no I will tell you, he asked to call me, and I said no, and he asked what it was exactly, so it then got to an extent that I had to tell him. I wanted to tell him face to face because you would not know how a person is going to react when you are telling him over the phone. So, I was expecting that he would want nothing to do with me. Ooh the time he asked me, he was holding my hand, and he begged me to talk, so I said...I wanted to talk but I failed, and finally, I told him. I just told him that I am sick, I did not mention what exactly the sickness is, I just said I am sick and then I let his hand go off mine. I did not care whether he liked to continue holding my hand or not. So, before that, he kept quiet for some time, and I was like, eish I have done a terrible mistake. I felt like he hated me (Participant 8).*

Disclosure is an emotional process as it entails feelings of either acceptance or rejection. The above narratives point to the fear that most participants highlighted as justification for non-disclosure of one's HIV positive status. This is not surprising since most young people are in that stage where acceptance, intimacy and love are critical for their well-being.

Although most participants expressed the desire to keep their status private, there was one who clearly stated that he had told all his relatives about his status and he was not afraid of people talking about his status. He explained that:

*I have told completely all my relatives about my status, I'm not afraid of them I'm not afraid of even who comes in at home, even if they ask me questions you know maybe I'm talking about my status if they walk in, I will carry on talking about what I'm talking about because it is my status, if you want to go out and talk to your friends and neighbours, it's your own story (Participant 2).*

The general understanding among the participants was that disclosure was associated with negative reactions from significant others. However, experiences from those who had disclosed their status to significant others suggested that the disclosure process was not always associated with negative experiences. For example, one of the participants narrated his experiences of disclosing to his partner that:

*It was, it was- well the day when I told her the action was normal, she said it doesn't change the person that I am because my parents also have it, they've had it so. When I explained to her and gave her all the details, she said it does not make a difference as an individual (Participant 18).*

The above experiences of non-(disclosure) highlight that participants preferred to keep their status private. It was also evident that they utilised different tactics to avoid or delay disclosing their status to others. Some disclosure experiences were associated with positive reactions such as acceptance and non-judgemental reactions. However, it is important to understand the reasons for non-disclosure among AYPLHIV.

### ***7.2.1.2 Reasons for non-disclosure***

Participants mentioned several reasons for non-disclosure of HIV positive status. These included trust issues, fear of abandonment/rejection, stigma and discrimination, and fear of being accused of infidelity. These reasons are presented below.

#### ***Trust issues***

Some HIV-positive people may be reluctant to disclose their status as they do not trust the people they are disclosing to, that they can keep their status a secret. Participants explained that it is difficult to disclose especially in new relationships since trust is still developing. Hence, period of dating also determines the level of trust that one can put in a partner and be willing to disclose. Participant 6 shared her reasons for taking longer to disclose to her partner and explained that:

*It was hard though because you will not find it easier to trust a person, so we were in love for a very long time before I disclosed to him. It was not easy because I am that person who finds it difficult to talk so if there is something that is bothering me, I feel like writing it down. So, I asked him to give me his phone, and he gave me the phone and I wrote it down... Then we continued dating, I got pregnant and gave birth in 2017. We had started dating in 2016 (Participant 6).*

Another participant also explained that she was scared to disclose her status to her partner since they had only been dating for 5 months. She indicated that she would only be ready at least after a year of dating. This also highlights that trust was built over time; hence, the participant needed more time. Responding to the question of how long they had dated and when she would be comfortable to disclose her status she said:

*I think it is five months now. We have never talked about our statuses. He does not know, I am scared to tell him. I am planning to disclose it to him at least after dating for one year (Participant 12).*

Most participants were not eager to disclose their statuses to their partners since they felt that they were still young and hence chances of breaking up were very high. Thus, the fear was that partners would go on to disclose their status to others after breaking up without their approval. One participant said:

*It's just that, we as teenagers can love each other for a very short time you see, so maybe when we break up, he will tell his friends you see. I do not trust him to share this with him (Participant 9).*

Trust to disclose one's HIV status could also be earned through the manner participants felt they were being treated by significant others and their attitude towards HIV. Thus, participants expressed that they were likely to disclose to people who cared about them and who had a positive attitude towards HIV. This position is illustrated by the following responses from some participants:

*It depends on how you feel about the person and how they are treating you. So, you see a person who cares about you and a person who does not and vice versa (Participant 2).*

*It depends on the person because if you see that someone is talking about HIV as a problem then we have a problem. Let's say for instance you are my girlfriend and when we are talking you say I don't want to have HIV because my friend has it and that doesn't give me the confidence to tell that I'm also HIV positive you see so it will be better to break up with her without telling her (Participant 7).*

Participants were comfortable to disclose their statuses to people who they trusted to keep their statuses private. Lengthy periods of dating and attitude towards HIV determined the trust that was given to significant others. One participant claimed that she would not disclose her HIV positive status to her friends since “a lot of them are still childish” (Participant, 13) suggesting that they could not keep the disclosure secret and could discriminate her.

### ***Fear of abandonment/rejection***

Fear of abandonment/rejection was widely identified by most participants as a reason for non-disclosure of an HIV positive status. Most young people are at a stage where they are looking to establish intimate relationships and possibly start families. Disclosure of an HIV positive status may impact negatively on attempts to find a partner. Participants shared almost similar experiences regarding actual experiences and expected fears of rejection which are presented below:

*Yes, I had a girlfriend, actually girlfriends, but none of the relationships worked, because of their parents you know, if their parents know something, they will tell her to stay away from me. So, I can see changes and people's attitude change after knowing your status you know (Participant 2).*

*I feel that telling my partner about my status will scare him away and he will not talk with me again (Participant 12).*

The above sentiments of fear of rejection were also expressed by another participant who feared being embarrassed in front of his friends. He stated that:

*For me now I'm thinking; if I start this relationship, now what if this girl is negative, I'm thinking all of that it's just in my head and what if she rejects me and embarrasses me you know in front of other people that know me, other friends that know me, the crowd that I hang around with and let me feel down, bring down my personality in front of them (Participant 14).*

It seemed that disclosure was very difficult, particularly to a negative partner. In an attempt to avoid the experience of rejection and abandonment, one of the participants suggested that disclosing to a partner who was also positive was easier as they would understand their circumstances. He explained that:

*I don't know how the negative person will react but a positive one will understand. I guess I will prefer someone who is positive because we both have this [HIV], and she won't leave me or be ashamed of being with me (Participant 18).*

Although the fear of abandonment and rejection was commonly reported in intimate relationships, one of the participants mentioned that he did not anticipate any support from his family after disclosing his status. Hence, this lack of support could be equated to being abandoned in a time of need. Explaining his family, the respondent stated that:

*They are not the same, like my family they are judging too much. Yes, so like in my whole family I do not see a person who would support me (Participant 7).*

### *Stigma and discrimination*

Socially shared norms and beliefs about HIV may discourage people from status disclosure. PLHIV have been stigmatised because the disease is generally perceived as fatal, contagious, and associated with behaviours outside of social norms. There were concerns among the participants on how others will react after disclosing to them. One of the participants stated that since most people were not educated on the disease, they were likely to react negatively to an HIV positive status disclosure. Responding to why he had not disclosed to his partner he explained that:

*Obviously, I was anxious and worried, like if I tell her, the reaction because that's the main thing. I was scared and concerned because you don't know how the person will respond, because most people are uneducated as for what is it about, and people can talk the minute you tell them, the first thing that comes to somebody's head, they will think, hey this person is dying (Participant 2).*

HIV unlike other chronic illnesses such as cancer is widely stigmatised since it is associated with behaviours that some people disapprove of such as sex work or infidelity and it is believed that HIV is only transmitted through sex, hence the disease is a result of personal irresponsibility or moral fault that deserves to be punished. As a result of these norms, participants were afraid to disclose for fear of being stigmatised and discriminated. One of the participants highlighted this stigma that is directed towards PLHIV and explained that:

*You can still live; people out there are dying from other things apart from this. Right now people are dying from cancer, but people do not stereotype cancer like that and somebody who has cancer they say ah shame, shame, shame, shame, shame, but the minute somebody says you know what, I'm HIV positive, he becomes a suspect, people are*

*disgusted, so why aren't we disgusted with cancer the way we are with HIV where cancer is taking more people than HIV (Participant 13).*

Lack of accurate knowledge about HIV contributed to stigma and discrimination. It was suggested by one of the participants that one needed to be mentally strong to disregard the negative comments that followed disclosing one's HIV positive status. Fear of being looked at differently was also identified as a reason for not disclosing an HIV positive status. These views are explained below:

*If you have maybe like a crowd of friends and you mention something about it, something that you are HIV positive the comments that come out of there are very bad so if you are not mentally strong to tell yourself you know what, what these people are saying isn't really true because people only speak about what they hear (Participant 2).*

*It will be too difficult for me to tell my friends because they will look at me differently (Participant 8).*

### ***Accusations of infidelity***

Disclosure of one's HIV positive status can often be a difficult issue, particularly in the context of relationships. HIV status disclosure to sexual partners has several potential risks for the individual, including blame and accusations of infidelity. The experiences of participants suggested that sexual partners believed that HIV was predominantly transmitted through sexual means, and hence an HIV positive status would be equated to infidelity. This issue was commonly reported by female participants, suggesting that among males, infidelity was condoned. Some of the female participants explained their experiences relating to disclosure and infidelity:

*That's the thing that people don't understand like there are various ways that you can get infected and at the end of the day you know that it's not your fault, but someone that does not know you will accuse you of sleeping around (Participant 6).*

*I cannot, he would blame me and wonder how I got infected when I am still young. Some people do not know that this disease is gotten in different ways (Participant 13).*

*I am scared, she will judge me (Participant 1).*

Non-disclosure was common among the participants. The commonly mentioned reasons for not disclosing were trust-related issues, fear of abandonment/rejection, stigma and discrimination, and the fear of being accused of infidelity.

### **7.2.2 Risky sexual behaviours**

Experiences shared by the participants regarding intimate and sexual experiences indicated that engaging in risky sexual behaviours was frequent. There was lack of condom use, low levels of HIV testing and poor knowledge about sexual and reproductive health (SRH).

#### **7.2.2.1 Lack of condom use**

Condom use does not offer total protection against HIV and other known sexually transmitted infections (STIs). However, it significantly reduces the risk of HIV infection. In this study, condom use among the participants was relatively low. One of the participants explained that initially they used condoms but deferred on one occasion and have since been having unprotected sex. She explained that:

*We have been using protection. He tried unprotected sex before, and I refused, I told him it is not a good idea because we had just met each other by then and we didn't know about*

*our statuses and then he said “okay”. It was just a single night that we slept without using protection. After that we have never used protection again, we have never used it again (Participant 9).*

The above quotation indicates that the participant and her partner had engaged in unprotected sex without knowledge of each other’s status. Unprotected sex was also common among couples who knew each other’s statuses. Some of the participants indicated that they preferred sex without condoms especially when they were aware that both partners were living with HIV. The following are some of the responses from the participants:

*We are comfortable without...with the unprotected sex (Participant 6).*

*It is obvious! And if you know each other, and you have been dating for a long time, what are you hiding then? You must do it without the condom and enjoy it (Participant 5).*

*No, no, no! I do not want that life! If we are both sick? Hell no! we will not use it (Participant, 13).*

It seemed that one of the reasons for not using protection was to ensure that sex is enjoyable. For others who had not disclosed their status, introducing condoms during sex was associated with unfaithfulness and begged questions for the reason to use condoms. Thus, participants would likely not use condoms to avoid disclosing their status. In relation to condom use, Participant 4 explained that:

*Yes, it seems like a hassle for me because if they see you taking out a condom, they will be suspicious (Participant 4).*

Low perceived HIV risk was also highlighted through the narration of one of the participants. She had disclosed her status to her partner, yet the partner had to enquire if she would be comfortable using a condom. Hence, knowledge of a positive status was not associated with condom use. The participant narrated her experience with her partner that:

*Okay, he asked me that if we do sex, do I want to do unprotected sex, and I was like me, he is asking me, what is that? Do I want protection or not? Oh no he did not say it like that, he said, if we have sex, will I not feel comfortable if...bear in mind he is asking me if we use a condom. I do not know whether he wanted me to say something else, but my answer was "it's your life". If you don't use a condom what are you expecting to happen I asked him that and he said no, the reason I asked you this question is that I didn't want to make you feel like I hate you when I'm using it, so I want to hear it from you. There is no way a person can just accept so easily, I was suspecting him but why would he hide when I have told him already that was my other question because he wasn't supposed to relax that much (Participant 8).*

The experience of the participant may also suggest that not all people disclose their status even when the other partner has disclosed. The narrations indicate that the participants frequently engaged in risky sexual behaviour, particularly unprotected sex. A few of the participants indicated that they used condoms consistently during sexual encounters. Condom use negotiation by female partner and communication on adopting safe sexual health practices is highlighted in the following explanations:

*There was a day where we wanted to try and I said no, because we had no condom, so I asked him to stop. Then he agreed, he had no problem. We agreed that we must use a*

*condom when having sex. But I have never tried talking to him about taking an HIV test together (Participant 11).*

*We always use protection but when she said she wanted a baby we had unprotected sex, but our child is HIV negative (Participant 4).*

*It has gone to that point of us having sex and we are making sure that we are using protection and she also goes on regular checks at the clinic, just to make sure we know she is safe. And we have spoken about like maybe if something goes wrong in future, we need to tell her how we need to go about like we do try to get a lot of information and stuff like that (Participant 18).*

#### **7.2.2.2 Low levels of regular HIV testing**

Late diagnosis of HIV is associated with complicated treatment regimens and worse overall prognosis. From the participants' narration it was evident that there was a lack of regular HIV testing. Some of the participants only sought testing after developing advanced symptoms of HIV like weight loss, coughing and headaches. The participants explained the different circumstance that eventually led them to seek an HIV test and these are presented below:

*Eventually when I had to go and do a test, in that year I was already sick. Yes, I had lost weight and I coughed a lot, even coughed blood and I thought I had TB at that time, I could not do anything (Participant 7).*

*I started getting headaches and then I just lost interest in everything and right there I started feeling this is not right. Things are not right I've started to fit into clothes like 26 and 24 so, I'm thinking now things are not right here and then I was later advised I think it's like few days before my birthday I was advised you know to take an*

*HIV test and then from there basically it was only two options from this, it's either you are going to give up that very moment, give up and perish or accept it like well how other people have accepted and say you know what this is faith so I need to make sure I move forward (Participant 18).*

One of the participants also explained that her partner was reluctant to go and test after she had disclosed her HIV positive status to him. It is not clear whether the partner was reluctant because he was already aware of his status or it was low perceived risk of being infected with HIV. The female participant described her partner's behaviour after disclosing to him that:

*He is quiet, but my friends whom I have told are advising me to go with him to the clinic. It is going to be like I do not trust him. But he did not force me to tell him, I did that voluntarily. So, it will not be easier for me to say boom! You too must go for a test (Participant 10).*

Schools have the potential to make valuable contributions to HIV prevention because they harbour large numbers of youths, hence, there is increased accessibility. One of the participants explained that she was diagnosed with HIV during a school-based HIV testing programme and was immediately linked to care and treatment. She stated that:

*It's this thing that they do in schools, whereby they will come to do testing, then I tested, and I discovered that I was HIV positive, then they said I must go to a clinic and they recommended the Blue Roof clinic (Participant 17).*

### **7.2.2.3 Reproductive intentions and poor knowledge of sexual reproductive health**

Some of the participants expressed a desire to marry and have children. However, they lacked knowledge on the availability of effective measures to prevent mother-to-child transmission of

HIV. The participants were anxious about the future and leaving their children as orphans when they die. For this reason, they preferred an HIV negative partner who would outlive them. However, with the use of ART many young people with optimum adherence are living well into late adulthood. These misconceptions and concerns held by the participants are presented below:

*I want to have a family one day but sometimes when I research about it, it seems so difficult. You know having kids living with it [HIV], it's difficult. It's possible, but at some point, I think that it's a miracle (Participant 15).*

*I think it would be fine, because I would have known that I have someone with the same situation, but at some point, I will think about the future you know, that maybe if we carry on doing this sex thing, the chances of us living much longer are small. If it were up to me, I would want a partner who is HIV negative because having someone who is not sick gives me the sense of closure that my kids can live and have someone to look after them. But if both of us are positive, we can die anytime and leave our kids and I do not want them to have the same life that I led (Participant 2).*

Some of the participants resorted to books to gather knowledge whilst others indicated the need to seek professional help from nurses. It seemed that there was lack of comprehensive knowledge on critical SRH issues like use of pre-exposure prophylaxis (PrEP). Some of the sources of information and knowledge gaps are explained below:

*I can't remember the title of the book, but in the book like it explains like the window periods and stuff like that and how the whole procedure works and then I think there is some medication for females that can be taken before even contracting HIV (Participant 15).*

*We will also need to speak to a professional, because the two of us are not experts so at least if we can speak to somebody within the medical fraternity, maybe a nurse or somebody that deals with this in depth and then obviously that person will explain thoroughly and will put the information that we have gathered with the information we got from the person and can ask and kind of compare and see the way forward, the steps that must be taken on how we need to keep ourselves safe and also have children (Participant 18).*

The experiences from the participants show that there is a knowledge gap on key SRH issues. Youth living with HIV require accurate and comprehensive information about HIV transmission, prevention, use of PrEP and post-exposure prophylaxis (PEP), and methods of having safe births and living with serodiscordant partners.

## **7.3 Discussion**

### ***7.3.1 Experiences of (non)-disclosure***

Sharing an HIV status can help HIV positive individuals to cope with the stress of living with HIV. Disclosure of an HIV positive status has been defined as an autonomous process of communicating or revealing one's HIV status to a sexual partner, family, or units of society (Obermeyer et al., 2011). The decision to disclose can be complicated and may be associated with positive or negative responses. Self-disclosure may be associated with positive outcomes such as increased emotional, financial, and material support from family and friends, intimacy with partners, and reduced risky sexual behaviour (Atuyambe et al., 2014; Dessalegn et al., 2019). While one may receive love and support from family and friends, others may not be as accepting and this may lead to loss of economic support, stigma, blame, rejection by sexual

partners, physical and emotional abuse, discrimination, disruption of family relationships and threats to personal well-being (Maeri et al., 2016).

The participants had differing views about onward self-disclosure to family, friends, and romantic partners. Most of the participants in the current study were not comfortable to disclose their status particularly to non-family members and preferred to keep it a secret. This is similar to other studies which found that disclosure is low among young people (Nöstlinger et al., 2015; Grainger, 2016), and when it happens it is usually to a selected few (Elopre et al., 2016). For some of the participants disclosure was involuntary as in some cases they were found with pills and had to explain the reason for carrying pills. A previous study has documented concealment of medication by PLHIV to keep their status a secret (Arrey et al., 2015).

Self-disclosure is a complex and difficult decision which results in adolescents putting a lot of effort to maintain the secrecy of their status as this is perceived to be self-protective behaviour (Daniel, 2015). In line with previous studies, barriers to disclosures include fear of rejection, stigma and discrimination, and fear of being accused of infidelity (Hogwood et al., 2013; Mburu et al., 2014). The fear of rejection was expressed more in relation to romantic partners. The participants reasoned that disclosing to potential romantic partners could lead to rejection, hence secrecy was the only strategy to maintain relationships. Disclosure to romantic partners is the most challenging form of disclosure, especially for the youth (Wiener & Battles, 2006).

It was the participants' perspective that disclosure was more difficult when one did not know the status of the person being disclosed to, and some preferred dating other HIV positive individuals to avoid rejection and feelings of shame from prospective partners. Serosorting has been reported in several studies as a strategy employed by PLHIV to choosing same HIV status partners (Eaton et al., 2009). Dempsey et al. (2012) also found that the lowest disclosure rates were

to partners of unknown status. In this study, participants implemented different strategies to delay disclosure and/or avoid disclosure to significant others. For example, they delayed having sex with their partners with some citing that they wanted to wait until they were married, whilst others suggested that they were using condoms. This finding is consistent with prior literature demonstrating strategies to avoid disclosure while protecting partners through the use of condoms under the pretext of family planning (Maeri et al., 2016).

However, some of the participants mentioned that it was important to disclose to their current partners so that they could make an informed decision to continue dating them. Disclosure, particularly to romantic partners has the potential to play significant roles in both HIV prevention and management. Self-disclosure among adolescents living with HIV increases condom negotiation and use, improves adherence to ART, and reduces levels of unprotected sex (Evangeli & Foster, 2014). Disclosure to sexual partners is arguably the most important form of disclosure from a public health standpoint (Thoth et al., 2014). This is particularly relevant in sub-Saharan Africa where there is an increase in HIV incidence and prevalence among young people largely resulting from horizontal transmission (Kharsany & Karim, 2016).

Stigma and discrimination are significant barriers to adolescent onward disclosure. During adolescence, young people attempt to formulate and establish a sense of identity and belonging, especially through establishing peer relationships (Brown & Larson, 2009). Disclosure of an HIV positive status might increase the chances of being socially ostracised by peers. For many young people, the cost of disclosing outweighs the benefits (Midtbø et al., 2012). Youth living with HIV desire to be 'normal' and recognised as young people first and foremost (Hogwood et al., 2013). Disclosing one's status may lead to being labelled as 'HIV-positive' first, making them different and susceptible to stigma and rejection. Lack of knowledge of HIV and myths equating HIV to

death continue to fuel stigma. The participants noted that the prevailing norms and misconceptions regarding HIV were for the most part negative and this contributed to non-disclosure. Discriminatory norms and beliefs are constructed and perpetuated within communities and society-at-large and these are subsequently perceived and internalised by individuals (Ojikutu et al., 2016). Internalised HIV-related stigma may further militate against health seeking behaviour and adherence (Turan et al., 2019). Persistent community stigma accentuates the need to demystify myths about HIV and popularise HIV as a chronic and treatable condition.

Onward disclosure is often a difficult issue, particularly in the context of relationships. In the early stages of a relationship, individuals are still building trust and figuring the best time to disclose. It was noted that length of the relationship was important in building trust before disclosure. Similar results have been found in the region (Mbichila et al., 2018). Adolescent relationships might be flirtatious and not enduring, further complicating disclosure for fear of partners disclosing their status when they break up. Previous studies have found that the concern over an individual's status being shared with others in the community militated against disclosure (Krüsi et al., 2018). Furthermore, studies have revealed that disclosure rates were low among casual and short-term sex partners (Bairan et al., 2007). The flirtatious and non-enduring nature of adolescent relationships suggest facilitating a combination of interventions that include self-disclosure strategies and promoting condom negotiation and use.

Some of the young people in the study believed that disclosing their HIV positive status to their sexual and romantic partners was the right thing to do. Disclosing to partners was often cited to be difficult because of fear of being accused of infidelity (Mulrenan et al., 2015). The young people, particularly females were worried that partners would not understand that there are different ways that people become infected as some of them mentioned that they were infected

perinatally. The high rate of infection amongst women particularly in ESA contributes to the blame of women as being promiscuous, and serving as vehicles of HIV infection, and through this process of othering, men are absolved of blame for their role in high incidence of HIV infection (Petros et al., 2006). Evidence shows that most young people infected perinatally are living longer (Lowenthal et al., 2014), suggesting that they may not necessarily have been infected through sexual activity but rather were infected at birth. Furthermore, in monogamous relationships, evidence indicate that males in most cases are the source of infection (Kambarami & Sumbulu, 2017). This finding points the need to challenge ‘scapegoating’ or ‘othering’ of HIV infection and create a safe environment for all genders to disclose their status without fear of blame.

### ***7.3.2 Sexual risky behaviour***

Sexual risk behaviour is a major concern in the prevention and management of HIV in the general population. In AYPLHIV, this may be aggravated by their compromised health condition. Results from the present study showed that some of the participants insisted on partners to use condoms during sexual encounters. In most cases, this was motivated by the desire not to infect the partner in serodiscordant relationship. Similarly, Farrington et al. (2016) mentioned partner protection as a potential motivation for condom use among PLHIV. However, in instances where the couple wanted to have a child, condoms were not used. Similarly, a study among heterosexual PLHIV in India reported the desire to have a child led some partners in serodiscordant marriages to have unprotected sex (Chakrapani et al., 2010).

Being HIV positive and childlessness causes double stigma (Kawale et al., 2014). Hence, the desire to meet societal standards of having children and overcoming social stigma, were significantly more important compared to the risk of infecting others or being re-infected.

Responses also show that condom use was very low among the participants despite knowing their HIV positive status. Similar to results from this study, studies have documented high prevalence of unprotected sex among AYPLHIV (Ssewanyana et al., 2018). The reported prevalence of inconsistent condom use was attributed to: lack of sexual satisfaction with condoms; the desire to have children; and fear of involuntary HIV disclosure.

Beliefs that condoms reduced sexual satisfaction also emerged. Prior studies highlight that individuals who believe condoms reduce pleasure than unprotected sex may be less likely to use condoms in practice (Randolph et al., 2007). Subsequently, inconsistent condom use in HIV positive youth poses dangers for onward transmission and HIV superinfection. To promote the sexual health of PLHIV, it is key to promote consistent condom use through overcoming difficulties and beliefs that interfere with maintaining safe sex. One of the ways is explained by the Pleasure Project which states that, “Safer sex and good sex are not mutually exclusive” (Knerr, & Philpott, 2006, p. 108). Health programmes should adopt a pleasure-focused approach to safer sex that aims to promote condom use as part of sexual intimacy. Condom use and negotiation of safer sex practices in sexual practices implore the issue of whether or not to disclose one’s serostatus to sex partners. Some of the participants, avoided introducing condoms to their partner as this would reflect that they were sick. Moreover, condom use within serious relationships may suggest mistrust and infidelity (Coma, 2014). To sustain sexual and romantic intimacy and avoid potential risk of abandonment and rejection adolescents were less willing to insist on condom use with sexual partners (Toska et al., 2015).

Lack of condom use was associated with low perceived risk. Surprisingly, some of the participants explained that sexual partners particularly males insisted on unprotected sex even after learning of the positive status of partners. Previous studies have reported partner’s condom refusal

as the main reason of condom non-use among women living with HIV (Ayiga, 2012; Moazen et al., 2017). However, this reluctance to initiate condom use may also suggest that the partners were already aware of their positive status but were reluctant to disclose most likely to avoid rejection and blame.

There was also reluctance to get tested particularly among males despite the knowledge that partners had tested positive. This can possibly be a result of personal barriers to HIV testing such as low perceived risk of infection (Deblonde et al., 2010), fear of testing HIV positive, rejection, stigma and discrimination (Mohlabane et al., 2016; Musheke et al., 2013). Furthermore, partners of couples who test first are often blamed for the infection hence the delay to seek testing services among males (Maeri et al., 2016). It is imperative to encourage young people especially males to access HIV testing and counselling (HTC) to improve early diagnosis for HIV and prevent further transmission of HIV through improved access to care and treatment (Sanga et al., 2017). One way of mitigating personal and societal barriers to HIV testing is the use of HIV self-tests. This strategy will promote regular HIV testing, allay fears about stigma and confidentiality when testing in public facilities, and will likely lead to earlier diagnosis and treatment of HIV (Richter et al., 2010).

Among adolescents and young adults living with HIV infection, HIV testing rates are low, and they are more likely to be unaware of their HIV infection than any other age group (Van Handel et al., 2016). In line with these previous findings, this study suggests lower levels of HIV testing among the participants. Some of the participants only learnt about their HIV status after being severely ill for some time suggesting increased chances of young people unknowingly exposing partners to HIV infection. Other participants also learnt about their positive status after being tested during school visits by the BRLS team. Despite legal and ethical concerns from child

rights and human rights organisations that the school setting is not conducive to providing HCT without violating the rights of youth, findings suggest that school-based HCT is more accessible and convenient than a health facility-based HCT service (Lawrence et al., 2015). These findings point to the need to roll-out and promote HIV testing programs especially in schools where most adolescents and young adults are found. Roll out of HTC in schools should be done alongside educational programs that provide comprehensive SRH education.

Some of the participants in the study had little knowledge on how to navigate around issues of sexuality and reproduction. Specifically, concern was raised around issues of having healthy children in concordant HIV positive couples. Childbearing meant that young people could fulfil their dreams and happiness as they transition into adulthood. Although others have indicated that they preferred being with HIV positive partners as it was easy to disclose and have a non-judgemental relationship with them, others preferred HIV negative partners as they guaranteed that they will have healthy children and a partner who would outlive them. These findings highlight that the participants were not fully aware of the benefits of prevention of mother to child transmission (PMTCT), as well as the effectiveness of optimum adherence to ART in improving quality of life and life expectancy. HIV care programs should address childbearing intentions of AYPLHIV and provide comprehensive information on conception counselling.

#### **7.4 Conclusion**

Risky sexual behaviours are prevalent among AYPLHIV. Fear of rejection and blame contribute to young people engaging in risky behaviours. Lack of comprehensive SRH information and education tailored to the unique needs of AYPLHIV leaves them isolated and ill-equipped to deal with sexuality and the dynamics of relationships. This finding indicates a critical

need for holistic interventions targeting awareness of HIV risk reduction strategies such as PrEP for HIV serodiscordant partners, access to PMTCT services for young HIV positive couples, sexuality counselling, adherence to ART and condom use to minimise onward HIV transmission.

## CHAPTER EIGHT

### Copying mechanisms adopted by adolescents and young people living with HIV

#### 8.1 Introduction

The increased availability of antiretroviral therapy (ART) has drastically reduced mortalities among AYPLHIV. Thus, HIV has been transformed from a death sentence to a chronic condition (Kimera et al., 2019), characterised by an increase in life expectancy than in previous years. As a chronic condition, HIV requires long-term attention and a shift from cure to care and support (Mutabazi-Mwesigire et al., 2015). In the context of HIV, care and support entails provision of a comprehensive set of services, including medical, psychosocial, socioeconomic, nutritional and legal support to improve survival and the quality of life for PLHIV (UNAIDS, 2016).

In addition to living with HIV, AYPLHIV may experience challenges that affect their HIV treatment and care, including isolation and lack of social support (Bekele et al., 2013), HIV-related stigma (Logie et al., 2018), depression (Okawa et al., 2018), limited access to food (Weiser et al., 2010) and a negative body image (Blashill et al., 2014). Among HIV infected individuals, body dissatisfaction is associated with negative health outcomes such as poor adherence to ART (Blashill & Vander Wal, 2010) and low self-esteem (Hunt, Gonsalkorale, & Nosek, 2012). Heightened appearance concerns arising from real or feared bodily changes may lead individuals not to adhere to their ART regimen, especially if they are concerned that the treatment may cause further undesirable changes in body composition (Lamb et al., 2018). Additionally, appearance

concerns are associated with a myriad of negative emotions like loss of self-confidence and feelings of self-loathe.

If not addressed, the physical and psychological challenges resulting from living with HIV and taking ART are likely to affect the quality of life of AYPLHIV. This chapter sought to identify the coping mechanisms utilised by AYPLHIV in maintaining a positive body image and overcoming various challenges related to living with HIV.

## **8.2 Findings**

Following a data analysis process, the main theme comprised three sub-themes of individual, interpersonal and community resources. The identified individual resources included belief in God, emotional detachment, and exercise; interpersonal resources included peer and family support; and community resources included role of NGOs, food security and income. These sub-themes are presented in detail below, and appropriate quotations are incorporated for illustrative purposes.

### ***8.2.1 Coping mechanisms***

A diagnosis of HIV carries significant physical and psychological implications. Both the disease and the medication can potentially contribute to physical changes. As noted earlier, most of the participants had significantly lost weight which impacted on their body image. In addition to the effect of HIV on physical health, AYPLHIV commonly experience depression, fear, anxiety, anger, worry, and feelings of isolation. For some of the participants, living with HIV was aggravated by living under stressful and challenging conditions, food insecurity and lack of financial freedom. Some of the common experiences reported by participants include regrets on past sexual behaviour and suicidal thoughts:

*But at some point, I still think of all the mistakes that I have made in my past and I regret all the things that happened. Maybe, if I could just go back and change some things but now it is too late (Participant 16).*

*Sometimes I will walk to the river because there is some river across to get myself in there but then I know that I still have to live because there is a purpose I am here for, so yes, I want to finish my course and get a job to live alone and have my own money (Participant 2).*

The participants were asked on how they counteracted these physical, psycho-social and structural issues arising from living with HIV, and the following resources were identified.

#### **8.2.1.1 Individual resources**

##### ***Belief in God***

Spirituality and religion are an essential aspect of PLHIV and affects their HIV outcomes like disease progression, physical/mental health, and quality of life. The results indicated that most of the participants identified themselves as Christians and some as Muslims. Religion offers people a sense of identity and acts as a guide necessary for people to reflect on the meaning of life. The participants indicated that they believed that being sick and living with HIV was a result of fate and God's plan. They also mentioned that during times of difficulty, prayers and belief in God kept them strong and resilient:

*When I am alone, I do think to myself why God allowed me to be sick you know. But I believe that it is happening because I think it is in God's plans... I would be lying if I say I could be strong without the prayers from my pastor (Participant 10).*

*Sometimes my friends from school come to play but my auntie is always there for me, she does the encouragement and makes sure I keep on moving. When things are not going well, maybe I get too sick I pray a lot for God to give me strength and that is the only person that make me stronger in my life (Participant 17).*

### ***Physical exercises***

For others, engaging in sporting activities gave them a worthwhile activity, which also contributed to their physical well-being and boosted a sense of belonging. Physical exercises can potentially ameliorate a range of side effects associated with HIV infection, strengthen the immune system, and better equip the body to fight HIV. Furthermore, exercises can also help people with HIV-related weight loss by increasing lean body mass, which is likely to enhance self-esteem. The common sports/exercise identified by the participants were soccer, netball, and jogging.

*I am into playing football and I have won competitive events. My health has improved very much, and I have a very fit body. Only my close friend knows that I am sick, but all the guys do not know. When I'm not playing soccer, I go jogging everyday just to keep my body active and I know that I'm just like anyone else so me wanting to throw the towel thinking that it is the end because I'm sick is unfair (Participant 7).*

*I like sports. For example, like I am too good in netball. I play at school and everyone knows me even some school children from the other schools know my name...I know that there is something I am very good at and no one can stop me to do it (Participant 17).*

*My body looks way better now because I am in the soccer team now. It's 4 years now since I started playing soccer. I am not the only because my brother is also playing*

*soccer, so we train together, and I just want to have a strong body like him (Participant 15).*

Sport was identified not only as a hobby by the participants but also a form of exercise. Sporting activities helped the participants in regaining their physical fitness whilst at the same time allowing them to belong to a group.

### ***Emotional detachment***

Some of the participants narrated experiences where they had been hurt by comments and negative feedback from others about their bodies and their HIV positive status. It was noted that some of the participants resorted to emotional blunting to mitigate the impact of negative feedback. Emotional detachment seemed to save the participants from stress and emotional upset. They used different mechanisms of emotional detachment such as imaginary friends, diverting attention to unrelated things and shutting off as noted below:

*I do feel angry sometimes, but I have actually made a friend in my head, maybe you are going to say I'm off my head, but I have made a friend in my head who I talk to. If you are talking about me and looking at me in a funny way, I will talk to this person. About how I feel, I talk about my situation and how and what do you know like I know that I can do, like I tell myself positive things with this person it's like me talking to me and encouraging myself. Positive things. And it encourages me even when I am weak, maybe I am down in one day (Participant 16).*

*So, when other people laugh at me and if I take it into my mind then it ends up hurting me, but now I do not care anymore. I just find a way to separate myself away from that atmosphere and everything that they will say. I shut myself off, it is like I am standing*

*here, but I am not here. I will just be saying yes, yes, yes and I agree to whatever you say, but not actually listening. I am not there it is like my mind is somewhere else, I will be still here, but I will be in another place thinking of something else (Participant 2).*

### **8.2.1.2 Interpersonal resources**

Interpersonal resources were experienced in the form of social support from friends, romantic partners, and family. Social support is central in the lives of PLHIV as it mitigates the impact of HIV related stress, contributes towards the treatment against HIV and improves the quality of life for PLHIV.

#### ***Relationship/peer support***

Friends and romantic partners were commonly identified as a source of support by the participants. Romantic partners gave positive feedback on the body appearance of their partners and indicated that they were content with their partners' body appearance. Friends also showed support and encouraged the participants to be proud of themselves despite how they might perceive their body. In relation to the role of friends and romantic partner in her life, one of the participants stated that:

*Because he tells me that "I don't have a problem with the way you look, I just love you". When it comes to friends, I feel okay because they do not tease me on how my body looks instead, they motivate me not to undermine myself the way your body looks means nothing, it's in good shape, what I have to do is to apply those body cream that they recommend me to apply and try them (Participant 9).*

Non-judgemental approaches and unconditional support from romantic partners were also noted below from the experiences of two of the participants who indicated that:

*He doesn't have any problem with my body, but what can I say is; he also tells me perhaps if I have lost weight, he says "you are losing weight, you must try doing this and this". He is always complaining that you know at times there is nothing to be ashamed of, if you need help that is the reason why I am here, otherwise I would not have been here. So, if you feel that you need help in certain areas, come to me speak to me, if I cannot help you, we can find somebody to help you (Participant 5).*

*Our relationship has been normal, she's been very supportive, and she encourages me, she can see that maybe today I'm not myself, I'm not feeling my normal self, because I'm that type of person that's always joking and walking around and making jokes, so she can see you know things don't look right then she will sit me down and say what's wrong, what's the matter? (Participant 18)*

It was evident from the participants' experiences that friends and romantic partners were a source of support as they suggested ways for them to gain weight and listened to their worries and suggested solutions to these. It seemed that from the above experiences, most of the participants who reported support from friends and romantic partners had disclosed their HIV status, hence the friends and romantic partners were better positioned to support them as they were aware of their HIV positive status and understood the need to support them as they navigated life challenges. In relation to the link between status disclosure and support, one of the participants stated that:

*I can take them (ARVs) anyhow even some of my close friends know that and they are very supportive. I know everything about my condition, and I am comfortable with whom I am (Participant 2).*

### ***Family support***

The family was also key to providing support to the young people in the study. Feedback from family on body appearance was mostly positive and they reassured the participants that personality and attitude were more important than physical traits. As compared to other people in the participants' lives who could say hurtful remarks, family usually had encouraging feedback and inspired the participants to be positive. The role of family in providing support to the participants is highlighted in the following experiences:

*Because the body does not say much about you, you see. The spots too, say nothing, they just accept me the way I am, especially my friends and my family they love me a lot they say I have a good heart. Body appearance does not matter, but it is your personality or your attitude that can make people either accept or reject you (Participant 3).*

*People that I am close to have never said any nasty comments about my body, it's only those that I have no attachments to or relationship with, that keep saying bad things about me. The ones that I have a relationship with do not have any problems with me even my family. If for instance I have lost weight and I tell them that I feel like I have lost weight, they try to take that out of mind and say; "No, you haven't lost weight you are not thin, you are okay" (Participant 15).*

*My family knows well about me; they support me. So, they would not do something, or they would not think something bad about me. For example, my family, even my friends, there are few friends of mine who know and are supportive to me, so they are always complimenting my body. Okay, I have a boyfriend who knows my status, so he is also supporting me (Participant 10).*

For some of the participants, the mother played a more crucial role as compared to other family members. In most cases, the mother is the primary caregiver, and the onus and maternal instincts are likely to contribute to her providing unconditional support to one's child living with HIV. For some, the mother has been the only pillar of strength and without her the future is gloomy as indicated by the following participants:

*The only person in my life is my mother and if she has to go, I tell you the truth, if I don't get a job and a stable career, I will end up on the streets, that's the truth, I won't rely on my younger sisters... Even though I am HIV positive and ill, but I would end up on the streets (Participant 13).*

*I would like to say my mother because she has been a pillar to lean, I can say she always ask me are you okay, how you are feeling like what should we cook today, don't forget to take your medication, stuff like that (Participant 8).*

Irrespective of the financial, emotional and physically strain that youth living with HIV might be experiencing, it was the view of one of the participants' that familial support cushioned all these strains. He emphasized that appreciating the things one had in life especially family support was important and explained that:

*I just reflect on all the positives, although I may have financial strain or physical strain, I just sit and think of the support system that I have, and all that I still have in my life, because if you still have parents most people don't have parents, you need to sit and think of all the things that you have in life (Participant 16).*

The notion of the association between status disclosure, increased social support and improved adherence to ART is also noted below when one of the participants explains the role of his family support that:

*They support me, they tell me that I should always take my medication. They motivate me. They also tell me about other people's experiences, especially those who have the same situation as mine, but they have made it in life, which means that it is not the end of my life, I can keep living this life. It's up to me in terms of how to live it. So, there is that support that I get from my family and friends (Participant 4).*

Having a decent meal on a regular basis was one way that contributed to maintenance of a stable body weight among the participants. However, challenges were highlighted in securing a healthy nutritious meal on a regular basis. For one of the participants the challenge was worsened by staying with a stepmother. She narrated that:

*I am always hungry. When the food is there in the house, I have to ask for it first. I cannot eat what I want because she will be angry because the nice food is for the children for me, I have to eat whatever they don't like... but when I go to my aunt's house, I eat anytime I like, and she doesn't not say this is for the children (Participant, 5).*

### **8.2.1.3 Community resources**

One of the participants also mentioned that he had benefitted immensely from a support group that he used to attend at the BRLS centre. The centre provides a wide range of youth-friendly support services for AYPLHIV. He stated that, *"because in the group we were all here because we had the same problem, so the group was there to actually make us to be open with each other and get help together"* (Participant 2).

Although the participants did not directly highlight being employed and having regular meals as a coping mechanism, the narrative suggest that these were deemed as important. Getting a job and a source of income was essential for one of the participants to secure a decent accommodation. He stated that:

*If I don't get a job and a stable career, I will end up on the streets, that's the truth*  
(Participant 13).

The participants highlighted that they utilised various strategies to cope with the different stressors they experienced. These strategies were located within the individual, interpersonal and community level.

### **8.3 Discussion**

Youth living with HIV encounter a myriad of physical, psychological, social, and economic challenges that may affect their general well-being and quality of life. The study has indicated that among AYPLHIV, physical attributes such as weight loss and skin sores are associated with loss of self-esteem. Furthermore, fear of rejection, stigma and discrimination were also commonly reported as reasons for non-disclosure of an HIV positive status. Self-blame was also expressed as participants regretted their past behaviours that may have led them to be infected. As a result of learning about their HIV status as well as the challenges of living with HIV, suicidal ideation was reported by some participants to escape from the shame and suffering of living with a stigmatised disease. Suicidal ideation is a crucial phase in the suicidal process prior to completed suicide. Among PLHIV, suicidal ideation is a predictor of future suicidal attempt and completed suicide and it is associated with reduced quality of life (Kinyanda et al., 2012).

Understanding how PLHIV cope with distress is particularly important, as coping deficits have been related to psychological distress, sexual risk behaviour, and poorer physical health outcomes (Tate et al., 2006). Coping allows individuals to manage the problem that is causing distress as well as regulating the individual's response to the distress (Folkman et al., 1991). The narratives of the participants suggested that they employed different mechanisms to cope with the various stressors they encountered. Coping strategies in the current study were informed by personal resources such as religiosity and exercises; interpersonal resources such as peer and family characteristics; and community resources such as association with BLRS.

An engagement with spirituality and religion is an essential component of health and well-being. The search for meaning is common in people diagnosed with HIV as indicated by some participants who sought to understand why God allowed them to be sick. These kinds of questions can only be resolved by spiritual engagement with higher powers that allow people to heal by acceptance of one's illness and peace with current life. Participants indicated that they belonged to different religious groups but often practised non-organised religious activities such as prayer at home. These religious activities were a source of comfort and strength to cope with illness and life stresses. Several studies have highlighted the importance of religion in the lives of PLHIV, including providing renewed hope, comfort, and a sense of meaning in their lives (Szaflarski, 2013). The young people in the study relied on their spiritual belief systems to cope with adverse circumstances. They sought an intimate relationship with God through prayers and searched for answers about the meaning of one's life in the context of living with HIV.

Weight loss is common in AYPLHIV. Even in patients with widespread access to ART, wasting remains a significant complication and is associated with impairment of strength and functional status (Erlandson et al., 2016). Enhancing physical well-being and functional capacity

is paramount for youth living with HIV to achieve and maintain a sense of ‘normalcy’. The participants’ narratives indicated that weight loss was an undesirable manifestation. To counteract this physical manifestation of HIV, participants engaged in various physical activities and supplemented their diet.

Engagement in sporting activities such as jogging, playing soccer and netball was mentioned as a way of keeping fit and regaining control of their physical capabilities. Weight loss and a physically thin appearance is often associated with being unhealthy and living with HIV (Matoti- Mvalo & Puoane 2011). It seemed the main goal for engaging in physical exercises was to improve physical appearance, look good and healthy as well as conceal the notion of being sick. Similarly, a study on muscular strength training with PLHIV showed not only an improvement in physical function and well-being, but also psychosocial significance of avoiding being stigmatised (Ley et al., 2014). One study reported benefits of physical exercise training including improved quality of life, self-esteem, improved fitness, enhanced body image and functional capacity with respect to daily activities (Derman et al., 2010). Participation in sports is essential in boosting the physical well-being of youth living with HIV. Physical training interventions may also improve body image by encouraging AYPLHIV to focus more on the tenets of body appreciation that emphasize functionality of the body than physical appearance.

Furthermore, engaging in sporting activities had the additional benefit of boosting self-esteem and creating a group to associate with and belong to. This is particularly important considering that PLHIV may actively isolate themselves to avoid rejection. Participating in sporting activities creates feelings of belonging to a community, contribute to identity confirmation and self-image building (Walseth, 2006). Involvement in sport removed feelings of being different from other young people. The feeling of belonging to a team and being identified for a specific

talent was rewarding. Studies have indicated the benefits of sport engagement among the youth, including enhanced self-esteem, emotional development, and reduced health issues (Keegan et al., 2010; Stuntz & Weiss, 2009). Due to the nature of sports such as soccer and netball, young people learn social skills and teamwork behaviour through participation in sport. Sports helps young people to build confidence, relationships, and social skills that they can extend to various spheres of their lives. Sports groups can help adolescents in increasing their resilience through their social support system and a sense of belonging (Ruvalcaba et al., 2017). The findings highlight the benefits of encouraging AYPLHIV to engage in sport and to use sporting activities as avenues to increase positive development.

The study indicated that youth living with HIV may experience stigma or endure negative remarks on their illness or physical appearances, which may lead to negative affect. Some of the participants emotionally distanced (emotional detachment) themselves from these unsettling remarks whereby they chose not to pay attention to negative feedback as a way of coping. However, repressing these upsetting emotions can be overwhelming and stressful on the mind, subsequently leading to psychological distress. Greater use of avoidant coping strategies is associated with negative psychosocial and health outcomes, including poorer adherence to ART and quality of life (Weaver et al., 2005). Some of the participants talked to themselves as a way of dealing with an emotionally demanding situation. This finding may suggest lack of social support within the individuals' immediate environment as some of the participants explained that they had not disclosed their status and therefore had no one to talk to regarding their illness and experienced stigma. Previous studies have highlighted self-isolation as a common coping mechanism, which may have negative implications for mental and physical health (Audet et al., 2013). This finding

points to the need to encourage youth living with HIV to disclose their status so as to utilise available social coping resources.

The physical and psychological challenges including weight loss, anxiety, and stigma experienced by AYPLHIV, if not addressed often lead to self-isolation and avoidance of proactive behaviours that might improve their quality of life. Social support serves a positive role in promoting the health condition of PLHIV. Social support comes in different forms such as emotional support (empathy, caring, love and trust), instrumental support (actual aid in time, money and energy), appraisal support (evaluative feedback), and informational support (information, advice and suggestions) (House, 1981). In this study, these various forms of support were mentioned by the participants, however with emotional support being prominent.

Support from friends, family and intimate partners was frequently mentioned as a strategy of counteracting the challenges experienced by respondents. Several AYPLHIV spoke positively of the support and love (emotional support) they received from family, friends and romantic partners. Most of the narratives attested to the unconditional support which in most cases came in the form of positive feedback in terms of body appearances. It seemed most of the support from family was in the form of emotional support and this is somewhat consistent with previous findings among HIV outpatients, which found that emotional social support was slightly higher than instrumental social support (Pedrosa et al., 2016). In instances where the individual had lost some weight or the skin was not clear, they were encouraged to try different food choices and apply certain lotions (informational support). Support in this way also boosted the body image of participants as the suggested remedies by significant others proved to be effective in weight gain and removing skin sores. More importantly the knowledge that significant others gave them positive feedback (appraisal support) and encouraged them to look good contributed to coping. As

noted earlier, body image is not limited to an individual's bodily experiences but is also influenced by external influences. Hence a positive perception from others will likely lead to the development of positive body image. It is suggested that body image is elastic and changeable through new information and social experience (O'Dea, 2012). Within their unique communities, AYPLHIV are enmeshed in various ecosystems with each of these ecological systems interacting with and influencing each other. Hence, surrounding youth living with HIV with a supportive environment, particularly social support from family and peers is of great significance in the promotion of a positive and healthy body image.

Revisiting the socio-ecological framework, the interconnectedness between intrapersonal and interpersonal factors is evident. The negative or positive feedback from significant others (interpersonal) influenced body image and self-esteem (intrapersonal) among the participants. When participants received negative feedback, they developed feelings of self-doubt, despised their body, and lost self-confidence. In these instances, individual protective factors can be cultivated to foster resilience and improve body image. For example, self-esteem enhancement interventions can be particularly useful when they identify and appreciate individual differences in body shape and emphasize on individual strengths and building skills that are necessary for healthy coping and development (Alleva et al., 2015). Additionally, addressing the interpersonal factors that may contribute to developing a negative body image is equally important. Other researchers such as Merianos et al. (2012) reported that family and peer support was associated with higher levels of body image satisfaction. These results underscore the need to consider interpersonal factors such as social support when designing and implementing body image promotion interventions among AYPLHIV.

Some of the participants believed that if they were financially stable and independent, they would not worry about being rejected by potential partners and family members. In this case, a job and source of income will give them a sense of purpose and satisfaction that they can have everything else that money can buy. While it is believed that HIV causes poverty and worsens already existing poverty (Hecht et al., 2006), a form of occupation and economic empowerment can give youth living with HIV a sense of purpose and contribute to securing good nutrition. Sustainable nutritional and food security interventions would be beneficial for ART adherence among AYPLHIV (Becker et al., 2020). As most of the participants had completed matric and not pursued tertiary education, they may benefit from targeted skills development and empowerment programmes to amplify their employability and financial independence. Similarly, findings by Yakob and Ncama (2016) also suggest the need for well-coordinated interventions that aim to integrate short-term food support programs and create job opportunities to ensure self-reliance as a long-term target among PLHIV.

Most of the participants took their ART medication at the BRLS centre that doubled as a youth care centre offering different activities for AYPLHIV. Spending time with other youth living with HIV was recognised as comforting and facilitated a sense of belonging. Being members of a support group provided by the centre and participating in the various activities offered gave the youth access to a network of peers in whom they could confide and people they could identify with. Kumar et al. (2015) also observed that becoming part of support group networks with people with the same condition was one way of coping. Like most NGOs, BRLS understands the needs of the communities it serves and is more likely to attract community participation in HIV care efforts and social development (Kelly et al., 2006). With their existing structures for health service delivery, NGOs can partner with the government to deliver social protection programmes as

evidence highlights the efficacy of these programmes in promoting adherence to ART (Zungu et al., 2020). Thus, there is need for partnership and sustained financial investments in NGOs so that they continue to serve the needs of AYPLHIV.

#### **8.4 Conclusion**

Young PLHIV experience innumerable challenges within families and communities. Issues related to body image are central, with weight loss and skin sores generating negative feelings of self-hate and loss of confidence. These negative affects contribute to poor health and quality of life among this population group. Nonetheless, AYPLHIV identified several individual, interpersonal and community resources employed to cope with the various stressors. Young people are resilient and resourceful in their nature and bolstering these strengths with multi-level tailor-made interventions is essential.

## **CHAPTER NINE**

### **INTEGRATIVE DISCUSSION AND CONCLUSION**

#### **9.1 Introduction**

The burden of the global HIV epidemic remains highest among young people living in the countries within the Eastern and Southern African Region (ESAR). Adolescents and youth living with HIV (AYPLHIV) often face several significant challenges related to living with HIV. As antiretroviral therapy (ART) becomes more widely available in the developing world, challenges related to access of ART have been ameliorated, yet many AYPLHIV continue to struggle to cope with the physical and psychological burden of living with HIV. Alongside the social-structural issues that pose challenges to the ART related behaviour of young people living in South Africa, the success of ART in promoting health in this population is highly contingent on the individual choices young people make about treatment-related behaviour.

A wide range of reasons for non-adherence to ART have been reported among young people including body image concerns. Issues pertaining to body image have emotional, psychological and interpersonal implications for young people who associate attractiveness with social desirability, yet these issues have not been adequately researched in the African context among adolescent population groups. Therefore, in this doctoral thesis, the lived experiences of AYPLHIV with regards to body image concerns were explored, and the association between body image and various psychosocial factors including adherence to ART, internalised HIV-related stigma and social support were investigated. The convergent parallel mixed method research approach, which allows for the concurrent collection of both quantitative and qualitative data was adopted (Onwuegbuzie & Leech, 2005).

The key findings from the study were discussed in relation to relevant theories and pertinent literature on the body image experiences of AYPLHIV and centred around four broad but overlapping areas. These are: perceptions of body image; relationship between body image, adherence to ART and various psychosocial factors (including a mediational analysis conducted); SRH experiences; and coping mechanisms adopted by AYPLHIV. The implications of the key findings from this doctoral thesis regarding psychosocial interventions, clinical practice and research are highlighted. The limitations of the findings from this study and recommendations for future studies are also offered. The final part of this work presents an overall conclusion drawn.

## **9.2 Perceptions of body image among AYPLHIV**

The body is inextricably tied to HIV since it is through the body that people are exposed to the infection and experience the HIV epidemic. In this sense, the participants mentioned physical changes that they experienced from living with HIV as well as the psychosocial factors arising from these bodily changes. Weight loss was associated with concern about a small body size that did not correspond to the age of the participants. Adolescents and young people may be self-conscious or embarrassed about not being as developed as their peers. Later maturation is associated with risk for psychosocial problems, including lower self-esteem and depression, and may have implications for reproductive health (Brogly et al., 2007; Majaliwa et al., 2009). Hence, AYPLHIV may be more distressed about their actual or perceived maturational delay than about their underlying chronic illness. Among females, physical changes negatively impacted on perceptions of physical and sexual attractiveness. Within the South African context there is a cultural acceptance of curvier body types among females. Hence, a body type that does not closely resemble this is associated with low self-esteem and confidence. Whilst feedback from significant others highlighted that some of the participants had normal healthy weight, the participants

perceived themselves as underweight. Hence, the perceptions of body size expressed differed from the actual body size. This could have been as a result of knowledge of living with HIV whereby participants may have internalised the association of living with HIV with weight loss and wasting. This finding is not surprising considering that in a previous study the participants identified a thin figure as being representative of someone who is HIV positive (Matoti-Mvalo & Puoane, 2011).

Adolescents are particularly susceptible to social pressure associated with physical appearance, as this period is critical for the formation of one's identity and self-worth. Some of the participants expressed dissatisfaction with their bodies. Dissatisfaction with physical appearance is a common experience for many adolescents, with girls experiencing more dissatisfaction than boys (Biolcati et al., 2017). This finding suggests the need for gender specific interventions to improve body image. There was discrepancy between the desired body size versus the current body size and desired skin versus current skin condition. As explained by the self-discrepancy theory (SDT), the discrepancy between the current physical state (i.e., actual self) and the physical state one desires to acquire (i.e., the ideal self) resulted in feelings of disappointment and dissatisfaction with one's appearance. To alleviate such feelings, interventions aimed at changing perceptions of the ideal self might require correcting individuals' biased perceptions of their own bodies. Young PLHIV can be involved in cognitive behavioural programmes aimed at changing negative body images.

Lacking self-love, self-doubt, undermining themselves and concealing certain aspects of the body were issues reported in the study. Discrepancy between the ideal self and the actual self will likely lead to concealment as a strategy to cope with distressing body image thoughts (Cash & Smolak, 2011). However, concealment is a short-term fix for the anxiety caused by body concerns as in the longer term, it reinforces the belief that an individual's body is unacceptable.

Field (2004) suggests that adolescents who are dissatisfied with their bodies are more likely to perceive their health as poor and more likely to show low self-esteem and low social functioning. Furthermore, fears of rejection by families, peers and partners were common among AYPLHIV. These feelings can be amplified by the presence of symptoms indicating the presence of HIV such as deteriorating body weight and skin sores. A combination of nutritional counselling and exercise targeting youth living with HIV can counter the issue of weight loss and its accompanying effects. Physical exercise plays a vital role not only in improving physical appearance and well-being, but also has psychosocial importance. The promotion of physical exercise is desirable because it impacts on body image, psychological health, and overall well-being.

### **9.3 Relationship between body image, adherence to ART and related psychosocial factors among AYPLHIV**

Both body image and adherence to ART are associated and influenced by several psychosocial factors. To examine the relationship between body image, adherence to ART and the related psychosocial factors among AYPLHIV a correlational statistical analysis was conducted. The findings of this study showed that the sub-scale of negative evaluation was significant and negatively correlated with social support from family, body appreciation, emotional well-being, general health and a significant positive correlation with internalised stigma was observed. Adherence to ART was significant and positively correlated with support from family, support from significant others, body appreciation, general health and a significant negative correlation with internalised stigma was observed.

A negative subjective evaluation of an individual's body as it relates to body size, shape and weight is common among AYPLHIV. Stronger perceived negative evaluation was associated with higher HIV-related internalised stigma. People living with HIV are likely to accept and

internalise the widespread stereotypes associated with their illness (Kim et al., 2015). The internalisation of negative messages and stereotypes contribute to an unfavourable perception of the self. When an individual has discernible physical features that may be attributed to living with HIV and distinguishes them as different from others, it may lead to the development of a negative body image. It seems that AYPLHIV with a negative body image are likely to be vulnerable to HIV-related internalised stigma, whilst individuals with elevated internalised HIV-related stigma are likely to experience a negative body image. A significant negative relationship between negative evaluation, emotional well-being and general health in AYPLHIV was noted. People with a negative body image frequently suffer from negative emotions such as depression and have a poor quality of life (Begovic-Juhant et al., 2012). Body appreciation which is an aspect of positive body image is likely to be protective of negative body image whilst positively impacting on emotional well-being and general health.

The results of this study provide an understanding of the importance of social support, especially from family and significant others, for AYPLHIV who have a negative body image and experiencing HIV-related internalised stigma. When support from family and significant others is readily available and positive in terms of tangible support, a sense of belonging, and social intimacy, it is likely to buffer the negative impact of HIV-related stigma and HIV-related harmful beliefs (Colbert et al., 2010; Larios et al., 2009) and lead to significantly higher levels of body image satisfaction (Merianos et al., 2012). In the context of body image concerns, social acceptance and support from family and friends is critical for AYPLHIV in buffering the effects of negative affect including body dissatisfaction. These findings were corroborated by results from the qualitative findings which revealed that support from family, friends and romantic partners

was pivotal in young people's perceptions of their bodies and in their efforts to maintain a positive body image.

Non-adherence to ART is a limiting factor in the successful treatment of HIV and can lead to the development of viral resistance and ultimately compromising the health of the person living with HIV (Robbins et al., 2014). Improving and facilitating patients' consistent adherence to ART has individual and public health benefits. The study findings suggest that internalised HIV-related stigma is a concern among AYPLHIV which is likely to lead to non-adherence to ART. For AYPLHIV, the perception and internalisation of HIV-related stigma, coupled with the lack of supportive social relationships, can lead to decreased engagement in healthcare and non-adherence to medication (Pantelic et al., 2020). Given the negative medical outcomes that AYPLHIV may experience due to the deleterious effects of internalised HIV-related stigma, it is vital to equip young people with the necessary skills and increase their access to the resources (e.g., social support) needed to combat the negative effects of internalised HIV-related stigma.

This thesis also examined relations between self-esteem, internalised HIV-related stigma, body appreciation, and adherence to ART. The results revealed that self-esteem and adherence to ART were linked indirectly through a sequential path of internalised HIV-related stigma followed by body appreciation. Evidence of a two-step indirect effect suggests that the sequential path of internalised HIV-related stigma and then body appreciation represents one mechanism that accounts for the relation between self-esteem and adherence to ART. This sequential pathway can be interpreted in the context of existing conceptual models that highlight the role of low self-esteem in precipitating health risk behaviour. Taken together, the two-step indirect effect found in this study suggests that AYPLHIV who receive support to reduce or protect against internalised HIV-related stigma may benefit by experiencing higher levels of body appreciation, which in turn

could lead to better adherence to ART. Previous studies have highlighted the importance of identifying mechanisms by which internalised HIV-related stigma is associated with adherence to ART to enhance the efficacy of treatment approaches for improving treatment adherence (Helms et al., 2017). Based on the findings of this study, intervention initiatives targeting internalised HIV-related stigma and body appreciation may offer viable pathways for improving adherence to ART.

#### **9.4 Sexual and reproductive health experiences**

In a country where young people are disproportionately affected by HIV, it is important to understand the SRH experiences and needs of AYPLHIV. Sharing an HIV status can help HIV positive individuals to cope with the stress of living with HIV. However, onward self-disclosure to family, friends, and romantic partners was a daunting task for most of the participants. This is similar to other studies which found that disclosure is low among young people (Nöstlinger et al., 2015) and when it happens it is usually to a selected few (Elopre et al., 2016). Some of the reasons cited for not disclosing included fear of rejection, stigma and discrimination, and fear of being accused of infidelity (Hogwood et al., 2013; Mburu et al., 2014). However, some of the participants mentioned that it was important to disclose to their current partners so that they could make an informed decision to continue dating them. Disclosure, particularly to romantic partners has the potential to play significant roles in both HIV prevention through reducing onward transmission and HIV management through greater social support and increased adherence to ART (Evangeli & Foster, 2014). The findings indicated that the prevailing norms and misconceptions regarding HIV were for the most part negative and this contributed to non-disclosure of an HIV positive status. More so these discriminatory norms and beliefs constructed and perpetuated within communities are subsequently perceived and internalised by individuals living with HIV.

Internalised HIV-related stigma may further militate against health seeking behaviour and adherence to ART (Turan et al., 2019).

Risky sexual behaviour is a major concern in the prevention and management of HIV in the general population. Among AYPLHIV, this may be aggravated by their compromised health condition. Results from the present study showed inconsistent condom use. The reported prevalence of inconsistent condom use was attributed to lack of sexual satisfaction with condoms, the desire to have children and fear of involuntary HIV disclosure. Subsequently, inconsistent condom use in HIV positive youth poses dangers for onward transmission and HIV superinfection. To promote the sexual health of AYPLHIV, it is key to promote consistent condom use through overcoming difficulties and beliefs that interfere with safe sex practice. These results highlight the need for strengthening HIV prevention interventions such as condom promotion.

HIV testing rates are low among adolescents and young adults living with HIV, and they are more likely to be unaware of their HIV infection than any other age group (Van Handel et al., 2016). In line with previous findings, this study indicates lower levels of HIV testing among the participants. Late diagnosis of HIV is associated with poor prognosis and treatment outcomes (Belay et al., 2017). These findings point to the need to roll out and promote HIV testing programs especially in schools where most adolescents and young adults are found. In planning to roll out HTC at schools, there is also a need for interventions and educational programs to provide comprehensive reproductive and sexual education that will also benefit AYPLHIV. Whilst developing these in-school programmes it is important to be cognisant that many AYPLHIV may not be in schools. Out-of-school young people are at greatest risk of poor sexual and reproductive health outcomes (UNFPA, 2020), including poor ART adherence. Therefore, stakeholders should

develop a separate guidance document focused on out-of-school CSE to effectively address their needs.

Young PLHIV also expressed their desire for childbearing. They had little knowledge on how to navigate around this issue. Specifically, concern was raised around issues of concordant HIV positive couples having healthy children. Childbearing meant that young people could fulfil their dreams and happiness as they transition into adulthood. Although others indicated that they preferred being with HIV positive partners as it was easy to disclose and have a non-judgemental relationship with them, others preferred HIV negative partners as they guaranteed that they will have healthy children and a partner who would outlive them. These findings highlight that the participants were not fully aware of the benefits of PMTCT, as well as the effectiveness of optimum adherence to ART in improving quality of life and life expectancy. HIV care programs should address childbearing intentions of AYPLHIV and provide comprehensive information on conception counselling.

### **9.5 Coping mechanisms adopted by AYPLHIV**

Young PLHIV encounter a myriad of physical, psychological, social, and economic challenges that may affect their well-being and quality of life. The study indicated that physical attributes such as weight loss and skin sores endured by AYPLHIV are associated with loss of self-esteem. Furthermore, fear of rejection, stigma and discrimination were also commonly reported as reasons for the non-disclosure of an HIV positive status. Self-blame was also expressed as participants regretted their past behaviours that may have led them to be infected. In such scenarios, coping allows individuals to manage the problem that is causing distress as well as regulating the individual's response to the distress (Folkman et al., 1991). Findings indicated that

participants employed different mechanisms to cope with the various stressors they encountered. Engagement in spirituality and religion was a source of comfort and strength to cope with illness and life stressors. The participants sought an intimate relationship with God through prayers and searched for answers about the meaning of one's life in the context of living with HIV.

To counteract weight loss, participants engaged in various physical activities and supplemented their diet. Engagement in sporting activities such as jogging, playing soccer and netball was mentioned as a way of keeping fit and regaining control of one's physical capabilities. It seemed that the main goal for engaging in physical exercises was to improve physical appearance, look good and healthy as well as conceal the notion of being sick. Previous research has reported benefits of physical exercise training including improved quality of life, self-esteem, improved fitness, enhanced body image and functional capacity with respect to daily activities (Derman et al., 2010). Furthermore, engaging in sporting activities had the additional benefit of boosting self-esteem and creating a group to associate and belong to. This is particularly important considering that PLHIV may actively isolate themselves to avoid rejection. The above findings highlight the benefits of encouraging AYPLHIV to engage in sport and to use sporting activities as avenues to increase positive development.

The study indicated that youth living with HIV may experience stigma or negative remarks on their illness or physical appearances, which may lead to negative affect. Some of the participants emotionally distanced (emotional detachment) themselves from these unsettling remarks whereby they chose not to pay attention to negative feedback as a way of coping. However, repressing these upsetting emotions can be overwhelming and stressful on the mind, subsequently leading to psychological distress. Greater use of avoidant coping strategies is associated with negative psychosocial and health outcomes, including poor adherence to ART, and

low quality of life (Weaver et al., 2005). Some of the participants talked to themselves as a way of dealing with emotionally demanding situations. This finding may suggest lack of social support within the individuals' immediate environment as some of the participants explained that they had not disclosed their status and therefore had no one to talk to regarding their illness. Previous studies have highlighted self-isolation as a common coping mechanism which may have negative implications for mental and physical health (Audet et al., 2013). This finding points to the need to encourage youth living with HIV to disclose their status so as to utilise available social coping resources. As previously noted, support from friends, family and intimate partners is essential in improving well-being and a positive body image. Surrounding youth living with HIV with a supportive environment, particularly social support from family and peers is of great significance in the promotion of a positive and healthy body image.

Revisiting the socio-ecological framework, the interconnectedness between intrapersonal and interpersonal factors is evident. The negative or positive feedback from significant others (interpersonal) influenced body image and self-esteem (intrapersonal) among the participants. When participants received negative feedback, they developed feelings of self-doubt, despised their body, and lost self-confidence. In these instances, individual protective factors can be cultivated to foster resilience and improve body image. For example, self-esteem enhancement interventions can be particularly useful when they identify and appreciate individual differences in body shape and emphasize on individual strengths and building skills that are necessary for healthy coping and development (Alleva et al., 2015). Additionally, addressing the interpersonal factors that may contribute to developing a negative body image is equally important. The findings underscore the need to consider a myriad of factors (intrapersonal and interpersonal) in the design and implementation of body image promotion interventions among AYPLHIV.

Some of the participants believed that financial stability and independence mitigated the negative effects of rejection by potential partners as a source of income will give them a sense of purpose and satisfaction that they can have everything else that money can buy. While it is believed that HIV causes poverty and worsens already existing poverty (Hecht et al., 2006), a form of occupation and economic empowerment can give youth living with HIV a sense of purpose and contribute to securing good nutrition. Furthermore, being members of a support group provided by the youth centre and participating in the various activities offered by the same centre gave the youth access to a network of peers with whom they could confide in and people they could identify with. Kumar et al. (2015) also observed that becoming part of support group networks with people with the same condition was one way of coping with living with HIV.

## **9.6 Practical implications for interventions and practice**

It is apparent that perceived physical changes such as weight loss are still common among youth living with HIV. Making improvements in diet can improve the physical health and well-being of PLHIV. There is an urgent need for renewed focus on nutrition counselling, care and support interventions for AYPLHIV as a fundamental part of the comprehensive package of HIV care at the country level. With worsening poverty and threats on household food security in South Africa (Chakona & Shackleton, 2019), there is a need for greater political will from government and private organisations to provide financial and technical support for improving dietary quality and increasing dietary intake in families infected and affected with HIV.

Furthermore, the findings from the qualitative study demonstrate that young PLHIV engaged in various physical activities as a way of keeping fit and regaining control of their physical capabilities. Development of community-based group exercise programs, which may include both

PLHIV and those not infected with HIV may increase social support, enhance engagement in social activities, and reduce isolation and the stigma associated with HIV. Given the concern of HIV-related stigma, ensuring confidentiality relating to HIV status disclosure is important to consider in such a program.

Physical changes such as loss of weight are often associated with significant psychological challenges including anxiety, worry, and stigma, which if not addressed often lead to self-isolation and avoidance of proactive behaviours. The findings highlight the importance of several coping strategies employed by AYPLHIV as they negotiate their body image and strive to live 'normal' lives. These include both negative and positive strategies. Support to young people in this regard may be vital especially in identifying the use of maladaptive coping strategies. This, therefore, may require regular training of clinicians and counsellors in counselling techniques, which would enable them to identify and examine patterns of coping and their impact on the health outcomes of AYPLHIV. Young people living with HIV may also benefit from group counselling and/or support groups where they can connect and share with other people who are also living with HIV and experiencing body image challenges. In this type of counselling, young people have the opportunity to share knowledge, build social capital, instil hope, catharsis, develop interpersonal skills and expand their support systems (Borek & Abraham, 2018).

In addition, findings from this thesis underscore the importance of social support as an invaluable social support system. Participants mentioned support from friends, family, and intimate partners as one of the key resources for coping with their illness and related stressors. There is a need for multifaceted interventions aimed at strengthening the social support systems of youth living with HIV to mitigate the negative consequences of negative body image and the negative psychosocial effects of living with HIV such as stigma. Although not closely related to

social support is the influence of individuals' religiosity and spirituality, which has important influences on their perceptions and understanding of the illness. Therefore, one can argue that supportive faith-based psychosocial interventions may further boost the faith of these young people that will assist them in coping with their illness.

Internalised HIV-related stigma acts as a barrier to beneficial HIV-related behaviours particularly adherence to ART. The findings from the mediational analysis suggest that intervention initiatives targeting internalised HIV-related stigma and body appreciation may offer viable pathways for improving adherence to ART. Several stand-alone interventions have successfully addressed internalised HIV-related stigma and negative body image in isolation. Cognitive behavioural therapy approaches have been effective in reducing internalised HIV-related stigma by challenging maladaptive patterns of thinking and building internal self-regulatory resources (e.g., coping skills) to manage stigma (e.g., Tshabalala & Visser, 2011). Cognitive behavioural therapy for body image and self-care (CBT-BISC; Lamb et al., 2018) and fitness training interventions (Ginis & Bassett, 2011) have been successful at improving body image perceptions, generalised self-efficacy and adherence to ART by encouraging people to focus more on the functionality of their body and less on their appearance. Many of these stand-alone approaches addressing internalised HIV-related stigma and body image concerns could be integrated together into interventions that incorporate other key components (e.g., social support) to provide a multi-pronged and more comprehensive approach to target decisions related to adherence to ART and related behaviours among AYPLHIV.

The social and sexual needs, behaviours and practices of AYPLHIV do not differ significantly from those of their HIV negative peers (Folayan et al., 2014). Thus, AYPLHIV also seek and initiate romantic and sexual relationships, some with the hope of marriage and having

children. However, unlike their HIV negative peers, AYPLHIV may encounter increased challenges as they negotiate their social and sexual lives. The findings indicated that the young people in the study were reluctant to disclose their status for various reasons including fear of being stigmatised, blamed, and rejected by sexual partners. HIV disclosure is a critical component of HIV prevention and treatment efforts, associated with positive outcomes such as increased emotional and instrumental support from family and friends, reduced risky sexual behaviour and adherence to ART (Atuyambe et al., 2014; Dessalegn et al., 2019). To realise the potential benefits of HIV disclosure, there is need to evaluate the effectiveness of current interventions designed to promote disclosure among young people and from these, develop innovative efficacious interventions tailor made for AYPLHIV in South Africa.

Access to SRH services is critical for AYPLHIV as engagement in risk sexual behaviours among this group is associated with detrimental individual and public health consequences. The current results demonstrate poor knowledge on SRH, inconsistent condom use and low HIV testing levels among participants. The findings highlight the importance of targeted research on the SRH needs of AYPLHIV, particularly ensuring the availability of adolescent-friendly age-appropriate information on SRH, offering family planning and counselling services. The provision and delivery of these services should be cognisant of the complexities and diversity of this group, which may include young people from key populations. Schools may also be conducive sites for delivery of comprehensive sexual education and HIV testing as they provide a safe environment accessible to many adolescents and young people.

## **9.7 Contribution to academic knowledge**

A crucial strength of this doctoral thesis is the use of a convergent parallel mixed-method approach (i.e., combination of both qualitative and quantitative methods). This mixed methods approach drew on the strengths of both qualitative and quantitative methods and allowed for a synthesis of quantitative and qualitative results to develop a more complete understanding of the topic under study (Creswell & Clark, 2017). The quantitative component of the study examined the association between body image, adherence to ART and various psychosocial variables whilst the qualitative phase offered an in-depth and contextualised understanding of body image experiences, SRH and coping strategies among AYPLHIV. Thus, these approaches have enhanced our understanding of factors that promote adherence to ART and reflected on the coping strategies utilised by AYPLHIV.

The use of a mediational method to analyse the role of body appreciation in adherence to ART, to the knowledge of the researcher, is the first study of its kind to provide preliminary information on the association between these variables. Whereas previous research has focused on the impact of negative experiences (e.g., body dissatisfaction) on adherence to ART (Blashill et al., 2014), the study adopts a positive psychology framework that focuses on positive events and influences in life including individual strengths and happiness (Snyder & Lopez, 2001). AYPLHIV who are likely to experience several stressors daily including negative body perceptions, are most likely to benefit from constructs of positive psychology that teach the power of shifting one's perspective to maximise the potential for happiness and well-being.

The study foregrounded AYPLHIV as research participants. Whereas previously most social research tends to illuminate issues relating to adolescents through the adult's lens (Fraser, 2004), thereby undermining the agency of young people, the current study acknowledges that

young people are not passive but active participants of their lives. The use of child-friendly methods ensured that the young people who may be perceived as marginalised because of their age and living with a stigmatised illness are given a voice and an invaluable opportunity to define their realities, and importantly share their own lived experiences regarding how they perceive their body image, their SRH and well-being. Findings from this study indicated that AYPLHIV are agentic and taking cognisance of that may positively impact health promotion interventions particularly those targeting SRH. Because young people are mostly affected by the global HIV epidemic, particularly in sub-Saharan Africa, studies in this group are not only pertinent, but also constitute best practice (Singh et al., 2006).

### **9.8 Limitations of the study**

This doctoral thesis has made some contributions to the field of health and well-being among AYPLHIV. It added knowledge on body image. However, there are some limitations that are worth highlighting. It is important for these limitations to be identified and explained in relation to the overall interpretation and application of the results. The cross-sectional nature of the quantitative component of this doctoral study limits the interpretations of the findings, as data were collected from respondents at one specific point in time, rather than over a period of time. Drawing conclusions about causality in the quantitative component is not possible. In addition to the above design, the use of a non-probabilistic sampling approach in identifying respondents for this study means that the findings cannot be generalised to all AYPLHIV in South Africa. Notwithstanding the limitations inherent in the use of a cross-sectional design, this design was the only practical approach to use considering resource constraints in terms of finances, personnel, and time.

The findings should also be considered alongside the small sample of participants in this study. HIV remains a highly stigmatised health condition in South Africa (Wadley et al., 2019) and is a sensitive topic for many young people who are transitioning to adulthood while navigating the psychosocial challenges of an HIV seropositive diagnosis (Cervia, 2013). Young PLHIV often have concerns about the possible consequences of participating in research on HIV, including the potential ramifications (e.g., discrimination, ostracisation) of having their HIV status further exposed (DiClemente et al., 2010) and the vulnerability of discussing their experiences of living with HIV to others (Poudel et al., 2016). Approximately 73% of those who were approached consented to participate in this study, with the others AYPLHIV offering the aforementioned concerns as reasons for declining to participate. Although there is a need for additional studies to determine the replicability of the current findings in larger samples of AYPLHIV, participant recruitment and research ethics challenges need to be factored into investigations on HIV in AYPLHIV (Govender et al., 2018).

Further, the sample size and the cross-sectional nature of the qualitative component may not reflect the entirety of the experiences of AYPLHIV over time. Future research is needed to longitudinally explore patterns of change in body image among a broader sample of AYPLHIV as adolescents' relationship to their bodies is likely to be fluid and changeable as they progress through adolescence. Despite these limitations, more than one in-depth interview was conducted with some of the participants, which allowed the researcher to extensively explore their feelings and perspectives on body image. The follow-up one-on-one interviews were productive as each participant had enough time and opportunity to share his/her feelings and experiences.

## **9.9 Recommendations for future research**

Firstly, there is the need for a longitudinal study to examine how body image changes throughout the life span of youth living with HIV. Body image is thought to be fluid and dynamic in nature. A longitudinal study would enable researchers to unravel the changes in body image and how these changes relate to adherence to ART. Thus, it would be possible for researchers to learn more about cause-and-effect relationships and make connections in a clearer manner.

This doctoral thesis provided information about the possible mediational relationship between self-esteem and adherence to ART among AYPLHIV. Within this broad group of AYPLHIV, they are also specific groups of, young key populations (YKPs) that are likely to have worse adherence outcomes as they face stigma, exclusion, harassment, and violence because of their HIV status and because they are from a key population. It would be important for future studies to determine the replicability of the findings in specific populations, particularly among vulnerable YKPs (e.g., young men who have sex with men) who may be at increased risk of sub-optimal adherence to ART (Lall et al., 2015).

It is possible that the findings of this study are confounded by the omission of relevant variables (Yeager & Krosnick, 2017) that might exert a stronger mediating effect on the relation between self-esteem and adherence to ART. Future studies might consider integrating additional variables into modelling procedures to explore the relative strength of alternative indirect mechanisms that link self-esteem with adherence to ART.

Future studies are needed to explore, in more detail, than examined in this doctoral thesis, how AYPLHIV cope with the negative experiences of body dissatisfaction. The study revealed that some of the participants had experienced feelings of body dissatisfaction, and a better

understanding of the coping strategies employed by AYPLHIV may help develop appropriate programmes that would support and promote the development of more constructive coping methods. For example, disengagement coping strategies such as social withdrawal and emotional detachment have been found to be positively related to psychological distress and worse well-being outcomes, whilst problem-focused and active coping, which involves taking steps to eliminate the source of stress has an inverse relationship with these psychological problems (McIntosh & Rosselli, 2012). A systematic review can synthesize available evidence of the research conducted in different contexts on the coping strategies used by AYPLHIV. Such a review may inform the design of efficacious interventions to promote positive coping.

## **9.10 Conclusion**

This doctoral thesis has investigated: (i) The relationship between body image, adherence to ART and various psychosocial factors (ii) The relationship between internalised HIV-related stigma, body appreciation, self-esteem, and adherence to ART; and explored: (i) Perceptions and feelings about body appearance and the strategies used in negotiating a positive body image and (ii) The lived experiences, intimate and SRH needs of AYPLHIV in Durban, South Africa, using a mixed methods approach.

Youth living with HIV face unique challenges when it comes to accepting their bodies which negatively affects their well-being and quality of life. AYPLHIV are not a homogenous group as they experience physical changes in the form of weight loss and body sores differently, which may lead to body image dissatisfaction. Interventions should be cognisant of this diversity and be tailor made to suit the unique needs of all AYPLHIV. The body image perceptions and experiences of AYPLHIV are not fixed but rather dynamic and changeable and require ongoing

discussion and attention as young people continually negotiate their identity. Enhancing existing coping mechanisms such as religious beliefs, support networks and physical exercises among AYPLHIV can counter the physical and psychosocial effects of living with HIV and improve well-being. The importance of developing a healthy body image for AYPLHIV should be emphasized in both family and health settings. The findings further raise the intriguing possibility of promoting adherence to ART among young people through targeted intervention initiatives that seek to resolve internalised HIV-related stigma and improve body appreciation.

Comprehensive SRH education and information that is tailor made to the unique needs of AYPLHIV is missing in family, community, and health-care settings. Therefore, most AYPLHIV are left to deal with sexuality and relationships entirely on their own, leaving them isolated and lacking adequate SRH information. This study highlights a critical need for holistic SRH education targeting awareness of HIV risk reduction strategies such as PrEP for HIV serodiscordant partners, access to PMTCT services for young HIV positive couples, sexuality counselling, and condom use to minimise onward HIV transmission.

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# APPENDICES

## APPENDIX 1: ETHICAL CLEARANCE CERTIFICATE



1 August 2018

Mr Patrick Nyamaruze (210551048)  
School of Applied Human Sciences – Psychology  
Howard College Campus

Dear Mr Nyamaruze,

Protocol reference number : HSS/0522/018D

Project title: An investigation of the relationship between body-image, body-appreciation, adherence to HAART and health related quality of life among adolescents and young people living with HIV (AYPLWHIV) in Durban, South Africa

**Full Approval – Full Committee Reviewed Protocol**

In response to your application received 22 May 2018, the Humanities & Social Sciences Research Ethics Committee has considered the abovementioned application and the protocol has been granted **FULL APPROVAL**.

Any alteration/s to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach and Methods must be reviewed and approved through the amendment /modification prior to its implementation. In case you have further queries, please quote the above reference number.

**PLEASE NOTE:** Research data should be securely stored in the discipline/department for a period of 5 years.

The ethical clearance certificate is only valid for a period of 3 years from the date of issue. Thereafter Recertification must be applied for on an annual basis.

I take this opportunity of wishing you everything of the best with your study.

Yours faithfully



.....  
Professor Shenuka Singh (Chair)  
Humanities & Social Sciences Research Ethics Committee

/pm

Cc Supervisor: Dr Kaymarlin Govender  
cc Academic Leader Research: Dr Maud Mthembu  
cc School Administrator: Ms Ayanda Ntuli

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Humanities & Social Sciences Research Ethics Committee

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Founding Campuses: ■ Edgewood ■ Howard College ■ Medical School ■ Pietermaritzburg ■ Westville

## **APPENDIX 2.1: CONSENT FORM FOR INDIVIDUAL PARTICIPANTS: SURVEY**

School of Applied Human Sciences  
College of Humanities,  
University of KwaZulu-Natal,  
Howard College Campus,  
Dear Participant

### **INFORMED CONSENT LETTER**

My name is Patrick Nyamaruze and I am doing PhD in Health Promotion at the University of KwaZulu-Natal, Howard College Campus, South Africa.

I am conducting a study investigating the relationship between body image, body appreciation, self-esteem and adherence to ART among adolescents and young people living with HIV (AYPLHIV) in Durban. To gather the information, I am interested in asking you some questions.

Please note that:

- Your confidentiality is guaranteed as your inputs will not be attributed to you in person, but reported only as a population member opinion.
- The questionnaire may last for about 40 minutes
- Any information given by you cannot be used against you, and the collected data will be used for purposes of this research only.
- The record as well as other items associated with the survey will be held in a password-protected file accessible to myself and my supervisors only. After a period of 5 years, in line with the rules of the University, it will be disposed by shredding and burning.
- You have a choice to participate, not participate or stop participating in the research. You will not be penalized for taking such an action.
- Your involvement is purely for academic purposes only, and there are no financial benefits involved.

I can be contacted at:

Email: 210551048@stu.ukzn.ac.za

My supervisor is Professor Kaymarlin Govender who is located at HEARD, Westville Campus, University of KwaZulu-Natal.

Contact details: Email: [Govenderk2@ukzn.ac.za](mailto:Govenderk2@ukzn.ac.za) Cell: +27 83 799 1773

You may also contact the Research Office through:

P. Mohun  
HSSREC Research Office,  
Tel: 031 260 4557 E-mail: [mohunp@ukzn.ac.za](mailto:mohunp@ukzn.ac.za)

Thank you for your contribution to this research.

**RESPONDENT'S DECLARATION**

**I..... (Full names of participant) hereby confirm that I understand the contents of this document and the nature of the research project, and I consent to participating in the research project.**

**I understand that I am at liberty to withdraw from the project at any time, should I so desire.**

**SIGNATURE OF RESPONDENT**

**DATE**

.....

.....

## **APPENDIX 2.2: CONSENT FORM FOR INDIVIDUAL PARTICIPANTS: INTERVIEW**

School of Applied Human Sciences

College of Humanities,

University of KwaZulu-Natal,

Howard College Campus,

Dear Participant

### **INFORMED CONSENT LETTER**

My name is Patrick Nyamaruze and I am doing PhD in Health Promotion at the University of KwaZulu-Natal, Howard College Campus, South Africa.

I am conducting a study exploring perceptions and feelings about body appearance and the strategies used in negotiating a positive body image by AYPLHIV in Durban, South Africa. I would like to speak to you only if you agree to speak to me.

This discussion will take 60 minutes. I will ask you to talk about the following: thoughts and feelings of the appearance of your body, experiences of intimacy and sexuality and lastly how you cope with living with HIV.

Please note that:

- Your confidentiality is guaranteed as your inputs will not be attributed to you in person, but reported only as a population member opinion.
- Any information given by you cannot be used against you, and the collected data will be used for purposes of this research only.
- The record as well as other items associated with the interview will be held in a password-protected file accessible to myself and my supervisors only. After a period of 5 years, in line with the rules of the University, it will be disposed by shredding and burning.
- You have a choice to participate, not participate or stop participating in the research. You will not be penalized for taking such an action.

- Your involvement is purely for academic purposes only, and there are no financial benefits involved.
- If you are willing to be interviewed, please indicate (by ticking as applicable) whether or not you are willing to allow the interview to be recorded by the following equipment:

	Willing	Not willing
Audio equipment		

I can be contacted at:

Email: 210551048@stu.ukzn.ac.za

My supervisor is Professor Kaymarlin Govender who is located at HEARD, Westville Campus, University of KwaZulu-Natal.

Contact details: Email: [Govenderk2@ukzn.ac.za](mailto:Govenderk2@ukzn.ac.za) Cell: +27 83 799 1773

You may also contact the Research Office through:

P. Mohun  
 HSSREC Research Office,  
 Tel: 031 260 4557 E-mail: [mohunp@ukzn.ac.za](mailto:mohunp@ukzn.ac.za)

Thank you for your contribution to this research.

**RESPONDENT'S DECLARATION**

**I..... (Full names of participant) hereby confirm that I understand the contents of this document and the nature of the research project, and I consent to participating in the research project.**

**I understand that I am at liberty to withdraw from the project at any time, should I so desire.**

**SIGNATURE OF PARTICIPANT**

**DATE**

.....

.....

### **APPENDIX 3: PARENTAL CONSENT**

School of Applied Human Sciences

College of Humanities,

University of KwaZulu-Natal,

Howard College Campus,

Dear Parent/Guardian

You are being asked to allow your child to take part in this study among 15-24 years old HIV positive adolescents who are receiving treatment at the Blue Roof Life Space. Your child will be asked about what their thoughts and feelings about their body image, body appreciation, and adherence to ART.

This study is being done as I want to know what HIV positive adolescents (15-24 years) think and feel about their bodies. They will be asked to fill in questionnaires assessing body image, body appreciation, ART adherence, social support, internalised HIV/AIDS-related stigma, and self-esteem. They will be interviewed about the perceptions and feelings held by young people living with HIV about their body appearance. They will also be asked about the strategies they use in negotiating a positive body image.

This information will enrich our understanding of adolescents' needs and how to best support them in achieving a healthy lifestyle and well-being. The findings will also have implications for policy makers and health professionals who are interested in providing psychosocial services to young people living with HIV aimed at improving adherence. Your child is selected to take part in this study simply because he/she is a client at the clinic. If you decide to allow your child to take part in this study, they will partake in audio recorded interviews. I will make sure that the child's information will not be shared with anyone else except the researcher and his supervisor.

All the forms and tapes will be stored in a locked cupboard in the Psychology Department of the University of KwaZulu-Natal. Keys will be kept by the researcher only.

If at any time during the project your child no longer wants to participate they are free to do so without any negative consequences and their name will not be disclosed. Help will be available if the child feels distressed or wants to talk more about any difficulties. Your child will only take part in this study if you and your child are willing to take part.

**DECLARATION**

I \_\_\_\_\_ (parent/guardian) give permission for  
\_\_\_\_\_ (child's name) to take part in the research. The research participation has been explained fully to me and I have had an opportunity to ask any questions. I am aware that there may be risks and benefits of taking part in this research.

SIGNED \_\_\_\_\_ Date \_\_\_\_\_

Signature of parent or guardian of the participant (agreement for the interview to be Audio-recorded)

\_\_\_\_\_ Date

## APPENDIX 4: QUANTITATIVE RESEARCH QUESTIONNAIRE

### SECTION 1: DEMOGRAPHIC CHARACTERISTICS OF PARTICIPANTS

#### 1. Gender

Male	1
Female	2

#### 2. What is your religion? [Please Tick (✓) one]

Christian	1
Moslem	2
Other	3

#### 3. How old are you? (In years)

#### 4. What is your highest level of education [Please Tick (✓) one]

No formal education	1
Matric	2
Tertiary education	3

#### 5. Race

African	1
Coloured	2
Other	3

#### 6. Mode of transmission

Horizontal	1
Vertical	2

## SECTION 2: BSIQ

**Directions:** The following questionnaire contains series of statements regarding your thoughts and feelings about you and your body (commonly called body image).

Please note that there are no “right” or “wrong” answers to this questionnaire. The most important concern is that your response should reflect what you really think or feel. Some of the questions may seem similar, but they are all slightly different. Please read each item carefully, so that you fully understand its meaning before you respond and respond as honest as possible.

Strongly Agree (1)	Agree (2)	Disagree (3)	Strongly Disagree (4)
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*Instructions for questions 1-27:* Statements 1 through 27 are all related to you and your body. Read each statement carefully, and decide how true the statement is for you. Use the rating scale below to indicate how true the statement is for you.

1. I think my body is unattractive. \_\_\_\_\_
2. How well my body is functioning influences the way I feel about my body. \_
3. Having a well-proportioned body is important to me. \_\_\_\_
4. My overall fitness level is high. \_\_\_\_\_
5. I compare my body to people I’m close to (friends, relatives, etc.). \_\_\_\_
6. I’ve often wanted to be taller. \_\_\_\_\_
7. I think my body looks fat in clothes. \_\_\_\_\_
8. My naked body makes me feel sad. \_\_\_\_\_
9. I pay careful attention to my face and hair, so that I will look good. \_\_\_\_
10. I look good in clothes. \_\_\_\_\_
11. I feel better about my body when I’m fitter. \_\_\_\_\_
12. Body size matters to me. \_\_\_\_\_
13. My body is healthy. \_\_\_\_\_
14. Being around good-looking people makes me feel bad about my body. \_\_\_\_
15. I wish I were a different height. \_\_\_\_\_
16. My body is overweight. \_\_\_\_\_

17. I feel depressed about my body. \_\_\_\_\_
18. I'm usually well-dressed. \_\_\_\_\_
19. My body looks good. \_\_\_\_\_
20. The way I feel about my body improves when I exercise regularly. \_\_\_\_
21. I care about how well-shaped my legs are. \_\_\_\_\_
22. My body is in shape. \_\_\_\_\_
23. I'm more aware of my body when I'm in social situations. \_\_\_\_
24. If I were a different height, I'd like my body better. \_\_\_\_
25. I wish I were thinner. \_\_\_\_\_
26. Most days I feel bad about my body. \_\_\_\_\_
27. I spend time making my appearance more attractive. \_\_\_\_\_

**SECTION 3: BAS-2**

**Directions for participants:** For each item, please circle the number that best characterizes your attitudes or behaviors.

	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
	<b>Never</b>	<b>Seldom</b>	<b>Sometime s</b>	<b>Often</b>	<b>Alway s</b>
<b>1 I respect my body.</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>2 I feel good about my body.</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>3 I feel that my body has at least some good qualities.</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>4 I take a positive attitude towards my body.</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>5 I am attentive to my body's needs.</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>6 I feel love for my body.</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>7 I appreciate the different and unique characteristics of my body</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>8 My behaviour reveals my positive attitude toward my body; for example, I walk holding my head high and smiling.</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

<b>9 I am comfortable in my body</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>10 I Feel like I am beautiful even if I am different from media images of attractive people (e.g. models, actresses/actors).</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

**SECTION 4: MMAS-8**

Individuals have identified several issues regarding their medication-taking behaviour, and we are interested in your experiences. There is no right or wrong answer. Please answer each question based on your personal experience with your HIV medication.

Please circle the correct

number

	No=0	Yes=1
1. Do you sometimes forget to take your HIV pills?		
2. People sometimes miss taking their medications for reasons other than forgetting. Thinking over the past two weeks, were there any days when you did not take your HIV medicine?		
3. Have you ever cut back or stopped taking your medication without telling your doctor, because you felt worse when you took it?		
4. When you travel or leave home, do you sometimes forget to bring along your HIV medication?		
5. Did you take your HIV medication medicine yesterday?		
6. When you feel like your HIV symptoms are under control, do you sometimes stop taking your medicine?		
7. Taking medication everyday is a real inconvenience for some people. Do you ever feel hassled about sticking to your HIV treatment plan?		

8. How often do you have difficulty remembering to take all your medications? (Please circle the correct number).

- Never/rarely 0
- Once in a while 1
- Sometimes 2
- Usually 3
- All the time 4

### SECTION 5: MSPSS

**Instructions:** Please rate the extent to which you agree/disagree with the following statements by circling the appropriate number on the 1 to 7-point scale provided.

	Very Strongly Disagree	Strongly Disagree	Mildly Disagree	Neutral	Mildly Agree	Strongly Agree	Very Strongly Agree
1. There is a special person who is around when I am in need	1	2	3	4	5	6	7
2. There is a special person with whom I can share my joys and sorrows	1	2	3	4	5	6	7
3. My family really tries to help me	1	2	3	4	5	6	7
4. I get the emotional help and support I need from my family	1	2	3	4	5	6	7
5. I have a special person who is a real source of comfort to me	1	2	3	4	5	6	7
6. My friends really try to help me	1	2	3	4	5	6	7
7. I can count on my friends when things go wrong	1	2	3	4	5	6	7
8. I can talk about my problems with my family	1	2	3	4	5	6	7
9. I have friends with whom I can share my joys and sorrows	1	2	3	4	5	6	7
10. There is a special person in my life who cares about my feelings	1	2	3	4	5	6	7
11. My family is willing to help me make decisions	1	2	3	4	5	6	7
12. I can talk about my problems with my friends	1	2	3	4	5	6	7

### SECTION 6: Rosenberg's Self-Esteem Scale

**Instructions:** Below is a list of statements dealing with your general feelings about yourself. Please indicate how strongly you agree or disagree with each statement.

STATEMENT		Strongly Agree	Agree	Disagree	Strongly Disagree
1.	I feel that I am a person of worth, at least on an equal plane with others.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2.	I feel that I have a number of good qualities.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3.	All in all, I am inclined to feel that I am a failure.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4.	I am able to do things as well as most other people.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5.	I feel I do not have much to be proud of.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6.	I take a positive attitude toward myself.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7.	On the whole, I am satisfied with myself.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8.	I wish I could have more respect for myself.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9.	I certainly feel useless at times.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10.	At times I think I am no good at all.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

### SECTION 7: SF36

**Choose one option for each questionnaire item.**

1. In general, would you say your health is:

- 1 - Excellent
  - 2 - Very good
  - 3 - Good
  - 4 - Fair
  - 5 - Poor
- 

2. **Compared to one year ago**, how would you rate your health in general **now**?

- 1 - Much better now than one year ago
- 2 - Somewhat better now than one year ago
- 3 - About the same
- 4 - Somewhat worse now than one year ago
- 5 - Much worse now than one year ago

The following items are about activities you might do during a typical day. Does **your health now limit you** in these activities? If so, how much?

---

	Yes, limited a lot	Yes, limited a little	No, not limited at all
3. <b>Vigorous activities</b> , such as running, lifting heavy objects, participating in strenuous sports	1	2	3
4. <b>Moderate activities</b> , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	1	2	3
5. Lifting or carrying groceries	1	2	3
6. Climbing <b>several</b> flights of stairs	1	2	3

- |   |                         |                         |                         |
|---|-------------------------|-------------------------|-------------------------|
|   | <input type="radio"/>   | <input type="radio"/>   | <input type="radio"/>   |
|   | <input type="radio"/>   | <input type="radio"/>   | <input type="radio"/>   |
| 7. Climbing <b>one</b> flight of stairs | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 |
| 8. Bending, kneeling, or stooping       | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 |
| 9. Walking <b>more than a mile</b>      | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 |
| 10. Walking <b>several blocks</b>       | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 |
| 11. Walking <b>one block</b>            | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 |
| 12. Bathing or dressing yourself        | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 |

---

During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of your physical health**?

- |   | Yes                        | No                         |
|---|----------------------------|----------------------------|
| 13. Cut down the <b>amount of time</b> you spent on work or other activities                          | <input type="radio"/><br>1 | <input type="radio"/><br>2 |
| 14. <b>Accomplished less</b> than you would like  | <input type="radio"/><br>1 | <input type="radio"/><br>2 |
| 15. Were limited in the <b>kind</b> of work or other activities                                       | <input type="radio"/><br>1 | <input type="radio"/><br>2 |
| 16. Had <b>difficulty</b> performing the work or other activities (for example, it took extra effort) | <input type="radio"/><br>1 | <input type="radio"/><br>2 |

---

During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of any emotional problems** (such as feeling depressed or anxious)?

- | Yes  | No  |
|--|-----|
| 17. Cut down the <b>amount of time</b> you spent on work or other activities | 1 2 |
| 18. <b>Accomplished less</b> than you would like                             | 1 2 |

19. Didn't do work or other activities as **carefully** as usual

1  2

---

20. During the **past 4 weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?

1 - Not at all

2 - Slightly

3 - Moderately

4 - Quite a bit

5 - Extremely

21. How much **bodily** pain have you had during the **past 4 weeks**?

---

1 - None

2 - Very mild

3 - Mild

4 - Moderate

5 - Severe

6 - Very severe

---

22. During the **past 4 weeks**, how much did **pain** interfere with your normal work (including both work outside the home and housework)?

1 - Not at all

2 - A little bit

3 - Moderately

4 - Quite a bit

5 - Extremely

These questions are about how you feel and how things have been with you **during the past 4 weeks**. For each question, please give the one answer that comes closest to the way you have been feeling.

---

How much of the time during the **past 4 weeks**...

- |   | All of<br>the<br>time   | Most<br>of the<br>time  | A good<br>bit of the<br>time | Some<br>of the<br>time  | A little<br>of the<br>time | None<br>of the<br>time  |
|---|-------------------------|-------------------------|------------------------------|-------------------------|----------------------------|-------------------------|
| 23. Did you feel full of high spirits?                                  | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3      | <input type="radio"/> 4 | <input type="radio"/> 5    | <input type="radio"/> 6 |
| 24. Have you been a very nervous person?                                | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3      | <input type="radio"/> 4 | <input type="radio"/> 5    | <input type="radio"/> 6 |
| 25. Have you felt so down in the dumps that nothing could cheer you up? | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3      | <input type="radio"/> 4 | <input type="radio"/> 5    | <input type="radio"/> 6 |
| 26. Have you felt calm and peaceful?                                    | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3      | <input type="radio"/> 4 | <input type="radio"/> 5    | <input type="radio"/> 6 |
| 27. Did you have a lot of energy?                                       | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3      | <input type="radio"/> 4 | <input type="radio"/> 5    | <input type="radio"/> 6 |
| 28. Have you felt downhearted and blue?                                 | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3      | <input type="radio"/> 4 | <input type="radio"/> 5    | <input type="radio"/> 6 |
| 29. Did you feel worn out?  | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3      | <input type="radio"/> 4 | <input type="radio"/> 5    | <input type="radio"/> 6 |
| 30. Have you been a happy person?                                       | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3      | <input type="radio"/> 4 | <input type="radio"/> 5    | <input type="radio"/> 6 |
| 31. Did you feel tired?   | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3      | <input type="radio"/> 4 | <input type="radio"/> 5    | <input type="radio"/> 6 |
- 

32. During the **past 4 weeks**, how much of the time has **your physical health or emotional problems** interfered with your social activities (like visiting with friends, relatives, etc.)?

1 - All of the time

- 2 - Most of the time
  - 3 - Some of the time
  - 4 - A little of the time
  - 5 - None of the time
-

How TRUE or FALSE is **each** of the following statements for you.

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
33. I seem to get sick a little easier than other people	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5
34. I am as healthy as anybody I know	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5
35. I expect my health to get worse	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5
36. My health is excellent	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5

---

## SECTION 8: IA-RSS

**Instructions:** Read each statement carefully, and decide how true the statement is for you. Use the rating scale below to indicate whether you agree or disagree.

	Agree 1	Disagree 0
1. It is difficult to tell people about my HIV infection	1	0
2. Being HIV positive makes me feel dirty	1	0
3. I feel guilty that I am HIV positive	1	0
4. I am ashamed that I am HIV positive	1	0
5. I sometimes feel worthless because I am HIV positive	1	0
6. I hide my HIV status from others	1	0

*Thank you for your participation*

## **APPENDIX 5: INTERVIEW SCHEDULE**

### **First Layer of Questioning**

Thoughts and feelings of AYPLHIV on the appearance of their body will be examined by probing the following:

- Description of how one perceives one's body image.
- Thoughts on how one evaluates one's body appearance.
- Thoughts of how others' perceptions on appearance affect mood.
- Meaning of being satisfied with one's body image.
- Body changes and ART adherence behaviour

### **Second Layer of Questioning (asked after first layer has been exhausted)**

Perceptions of how body image influence attachment with significant others will be explored by probing the following:

- Concerns about what significant others think of one's body appearance.
- Acceptance/rejection by peers based on one's body appearance.
- Effect of positive or negative feedback from significant others on body appearance.
- Impact of body image on initiation and maintenance of relationships.
- Significant others influence on body image satisfaction.

### **Third Layer of Questioning (asked after second layer has been exhausted)**

The strategies utilized by AYPLWHIV to negotiate a positive body image (guided by three sources of resilience adapted from Grotberg, 1995) will be explored by probing the following:

- Inner strengths
- Interpersonal, problem-solving skills
- External supports/support networks

## APPENDIX 6: GATEKEEPER LETTER



Telephone Number: 031 461 3101 Fax: 031 461 1713  
Address: Blue Roof Life Space | 74 Lubbe Road | Austerville | Durban | RSA  
Postal Address: P O Box 14124 | Austerville | Durban | 4001 | RSA

02 February 2018

Mr Patrick Nyamaruze  
School of Psychology  
Office 02-016 TB Davies Ext, MTB  
University of KwaZulu-Natal  
Howard Campus  
Durban 4041

Dear Mr Patrick Nyamaruze

### **Permission to undertake research and conduct interviews**

We hereby acknowledge your request for permission to conduct research among adolescent' clients receiving treatment at Blue Roof Life Space and are happy to inform you that permission has been granted.

We expect your study to bring interesting insights into the lives and experiences of adolescents living with HIV and look forward to receiving feedback when the process has been completed.

We wish you all the best with your project entitled: **"An investigation of the relationship between body-image, body-appreciation and adherence to HAART among adolescents and young people living with HIV (AYPLWHIV) in Durban, South Africa"**.

Kind regards,



Tom Butterworth  
General Manager



## APPENDIX 7: CHANGE OF THESIS TITLE



07 December 2020

Mr Patrick Nyamaruze (210551048)  
School of Applied Human Sciences – Psychology  
Howard College Campus

Dear Mr Nyamaruze,

Protocol reference number : HSS/0322/018D  
New Project title: Body image and antiretroviral therapy adherence among adolescents and young people living with HIV in Durban, South Africa

### Approval Notification – Amendment Application

This letter serves to notify you that your application and request for an amendment received on 03 December 2020 has now been approved as follows:

- Change in title

Any alterations to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form; Title of the Project, Location of the Study must be reviewed and approved through an amendment /modification prior to its implementation. In case you have further queries, please quote the above reference number.

PLEASE NOTE: Research data should be securely stored in the discipline/department for a period of 5 years.

All research conducted during the COVID-19 period must adhere to the national and UKZN guidelines.

Best wishes for the successful completion of your research protocol.

Yours faithfully



Professor Dipane Hlalele (Chair)

/dd

Cc Supervisor: Dr Kaymarlin Govender  
cc Academic Leader Research: Dr Maud Mthembu  
cc School Administrator: Ms Ayanda Ntuli

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Humanities & Social Sciences Research Ethics Committee  
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Website: <http://research.ukzn.ac.za/research-ethical/>

Founding Campuses: Edgewood Howard College Medical School Pietermaritzburg Westville

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