

**“Adverse Childhood Experiences and Psychological Resilience among HIV Positive Youth in
South Africa”**

By

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PLAGIARISM DECLARATION

I, Nozipho Sigola (Student **Number, 852195**) am a student registered for the degree of Master of Art in Community-Based Counselling Psychology by Coursework and Dissertation in the year 2024 at the University of the Witwatersrand.

I hereby declare:

- I am aware that plagiarism (the use of someone else's work without their permission and/or without acknowledging the source) is wrong.
- I confirm that the work submitted for assessment for the above degree is my own unaided work except where I have explicitly indicated otherwise.
- I have followed the required conventions in referencing the thoughts and ideas of others.
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Signature:



Date: 26 June 2024

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LIST OF ABBREVIATIONS

ACES	Adverse Childhood Experiences
AIDS	Acquired Deficiency Syndrome
ART	Antiretroviral therapy
ARV	Antiretroviral drugs
CLWH	Children living with HIV
HIV	Human Immunodeficiency virus
IPV	Intimate Partner Violence
IPA	Interpretive Phenomenological Analysis
NGO	Non-governmental Organizations
PLWH	People living with HIV
WHO	World Health Organisation

OPERATIONAL DEFINITION

Adverse Childhood Experiences

The term Adverse Childhood experiences is a broad term used to account for childhood experiences. This includes experiences of physical and sexual abuse, neglect, acute and chronic illness, poverty and family distress. As forms of childhood trauma, they have an impact on the child's emotional, behavioural and overarching health (Kalmakis & Chandler, 2014).

Experiences

Lived experiences are classified as key object analysis to obtain an in-depth understanding of one's actions while considering the social environment in which they are placed. Experiences in this regard are understood as an individual's continuous process "known from within" (Dieumegard *et al.*, 2021, p.2).

Youth

To understand the social constructs and mechanisms that continually shape the lives of young people on varying levels, this research has adopted the use of the term 'youth'. Often referring to individuals between the ages of 15-25. There is an acknowledgement however of overlap, as the term can be interchangeable with adolescents, or teenagers considering the day-to-day experiences and encounters of this population (Evans, 2008).

Children

To understand mechanisms that shape the development and experiences of childhood, this research uses the term 'children'. Children in this regard refer to the early childhood development from birth up to 18 years. It is in the first few years of life that the quality of a child's early experiences makes a significant difference in foundational development (UNICEF, 2021).

ABSTRACT

Research has revealed and highlighted the plight of HIV and its effects on individuals, their families and larger communities. Through a qualitative research approach, this study sought to explore the experiences of black South African Youth who are living with HIV and their exposure to Adverse Childhood experiences. Experiences of stigma, inequality and disparity were also explored. The research was largely informed by the resilience theory (Garmezy, 1978) which enabled the researcher to make sense of the participants' experiences. The researcher then employed a non-probability purposive convenience sampling approach to recruit participants who were either born with HIV or contracted it while they were young. Interpretive Phenomenological Analysis (IPA) was then used to analyse the data that was derived from the semi-structured interviews conducted. Further, the use of IPA allowed the researcher to pay attention to the lived experiences of the participants. The themes extracted from this study suggest that children growing up with HIV in South Africa are often subjected to various adverse experiences that often challenge health and developmental outcomes. This is demonstrated by the dominant themes of navigating changes in identity, experiences of stigma, discrimination and marginalisation, exposure to poor socio-economic conditions and lastly resilience strategies employed to mitigate harm from the experiences.

Key Terms: Childhood Adverse Experiences, ACES, Lived Experiences, Resilience, Youth

CHAPTER 1: INTRODUCTION AND RATIONALE

1.1 Introduction

The focus of the study is on the Adverse childhood experiences encountered by youth living with HIV. In this study, adverse childhood experiences are conceptualised as highly traumatic encounters experienced in childhood, varying from all forms of abuse to more subtle long-lasting types of adversities (Pilking & Younan, 2020). Since the early 90s, ACEs have been continually linked to psychological and physical health-related issues in childhood (Hughes *et al.*, 2017). The primary research on ACEs emerged from the ACE study, conducted among adult members of health maintenance organisations to evaluate the effects of childhood stressors on various health-related outcomes in adulthood (Scheel-Jones, 2013).

Research on ACEs has been continuously criticised for providing varying examples of ACEs without a definite description. For example, Pilkinton & Younan (2020) describe adverse childhood experiences as “traumatic events in the first 18 years of life such as neglect, abuse, partner violence, substance abuse in the home and mental illness in the home” (p.3). Other researchers argue that there is no clear or agreed description of the phenomenon (Kalmakis, 2013). This has resulted in the concept of ACEs remaining challenged and unclear. However, this is a key point of analysis because it has been demonstrated that childhood is a fundamental yet delicate part of development, as a child’s genetics and experiences then begin to shape attributes such as self-control, emotions and even stress reactions (Hertzman, 2013). Suggesting an interplay of biological and environmental factors that begin to influence growth and development. Furthermore, by seeking out experiences of resilience and vulnerability this research study works to highlight how firstly, children are not often exposed to a single type of ACE. Secondly, adversity is often experienced in the context of a broader environment. Resolving the conundrum of an unclear definition of ACEs by demonstrating that ACEs can be broad and that early childhood exposure may often increase the risk of negative outcomes and susceptibility to various health challenges in adulthood.

Bowlby's attachment theory suggests that children need to feel safe knowing their parents will be there when needed. This is because children can potentially experience negative health challenges when they are deprived or neglected (Kalmakis, 2013). This theory confirms a key element of the study at hand: given that early childhood experiences impact an individual's health throughout their life, violation of a child's sense of safety potentially threatens their development (Kalmakis, 2013; Hughes *et al.*, 2017).

Another key element in this study is the experiences of living with HIV. Rydstorm *et al.*, (2013) describe HIV as one of the largest "social, economic and health challenges worldwide" (p.1358). With possible impacts on cognitive and physical development, low-income countries also see a compounded experience of impoverishment and disrupted family structures (Knizek *et al.*, 2017). The lived experiences of children and youth have been key in understanding developmental and growth outcomes from childhood to early adulthood (experiences of childhood (below 18 years) and experiences of youth up to the age of 25). Significant to this study is the experience of gender and race. In Southern Africa, women continue to experience the devastating effects of the epidemic with younger girls being infected at least 10 years earlier than boys (Ramjee & Daniels, 2013). For women living with HIV, various elements heighten their vulnerability to acquiring HIV, such as socioeconomic status, behavioural and cultural attributes (Rispel & Popay, 2009). In addition to the gendered power relations in determining health is the racial disparity. Since access to ART is vital in curbing the effects of HIV, for one to access treatment, one needs to have financial access to healthcare and be near health facilities (Bell *et al.*, 2016). Due to the historical effect of the apartheid regime, a significant number of black people have restricted financial resources, and as such the lived experiences of black people living with HIV are embedded in racial and economic experiences (Bell *et al.*, 2016).

Children Living with HIV (CLWH) in South Africa may be further subjected to these socio-economic challenges that determine the level of access they may have to medical care, education as well as housing. A significant number of South Africans live on the margins of poverty, with unemployment rates increasing to well over 30% (Francis & Webster, 2019). The high unemployment levels indicate how inequality in the country is both institutional and structural, its operations lying at the intersection of identities, whether it be race, gender or ascribed identities (HIV) (Francis & Webster, 2019).

The impending question then becomes, how are the youth exposed to ACEs resilient? By employing ACE theories and Garmezy's theory of resilience to gain meaning from the participants' experiences, there is an appreciation of the individual's experiences, particularly those who may be perceived to be at risk for undesirable outcomes. The theory of resilience refers to the "process of, capacity for, or outcome of successful adaptation despite challenging or threatening circumstances" (Masten, Best & Garmezy, 1990, p.3). The significance of the theory in this study lies in presenting knowledge of how children living with HIV successfully transition to adolescence and ultimately to being young adults, the contextual mechanisms at play, and how they all interlink to create environments where people can thrive.

These individual experiences being of paramount importance, the researcher has opted for the use of Interpretive Phenomenological Analysis (IPA). IPA allowed for an in-depth understanding of the experiences of living with HIV within the South African context. The emphasis on the stories and experiences allows for individual stories to be heard and given room (Smith & Osborn, 2007).

1.2 Rationale

Adverse Childhood experiences are a common encounter in both low and high-income areas (Manyema & Richter, 2020). South Africa recorded high rates of individual exposure to ACEs, with 41.6% of women and 39.6% of men reporting experiencing adverse events and, more significantly emotional neglect before the age of 18 (Manyema & Richter, 2020). With the description of ACEs expanding to include aspects such as parental separation, bullying, residing in unsafe neighbourhoods, chronic illnesses and job insecurity, there remains very limited research on the effects of ACEs on youth (Nazareth *et al.*, 2020).

Research has demonstrated that overexposure to traumatic childhood events can interfere with healthy development, with scholars highlighting the devastating effects on future health and life opportunities (Alumuneef *et al.*, 2018). Early childhood development theorists have further posited that the day-to-day experiences in a child's life are more prevalent and have the most adverse effects on development. It is argued that it is not one isolated instance of neglect, but long-term daily exposure to ill-treatment, and various difficulties that cause the

most harm (Hazel *et al.*, 2008). As a result of these long-term effects, Taghavi & Kia-Keating (2024) posit that ACEs pose a public health concern. These stressful and traumatic events encountered by children can lead to significant emotional stress, potentially impacting their lives even as adults (Vu *et al.*, 2022).

Hazel *et al.*, (2008) then posit that though there is not enough research to support a link between exposure to ACEs and depression, ACEs have been proven to be key indicators of maladjustment and depressive symptoms in adulthood. This has been further supported by trauma research pointing to a high possibility of psychopathologies such as depression and anxiety disorders in youth who were exposed to childhood adversities (Marackova *et al.*, 2016). Oeri & Roebbers (2022) advocate that given the quick rapid growth of the brain, and its property to be malleable during early development it becomes important to comprehend the impact of chronic adversity that one experiences from very early in life as it can be a predictor of pre-academic ability.

Alluding to the neurobiological and psychological impact of ACEs on development, Goddard (2020) highlights that a child may develop weak attachment, low self-efficiency, and become vulnerable to brain abnormality and stress dysregulation. To have a strong grasp of the effects of the trauma caused and chronic stress brought about the exposure to ACEs, is fundamental in understanding intervention plans suitable for the vulnerable youth. The trauma-informed care further suggests that the continual elevation of stress levels due to toxic exposure leads to unfavourable health outcomes (Goddard, 2020; Felter *et al.*, 2022). Black communities and communities from lower-income households face even higher chances of experiencing adverse childhood experiences (Oral *et al.*, 2016). Given the prevalence of ACEs in black marginalised communities, this exploration potentially leads to the unfolding and addressing of the social, historical and environmental factors perpetuating traumatic experiences.

Stats SA Mid-Year Population Estimates (2022) suggest that approximately 13.9% of South Africa's population live with HIV, which is an estimated 8.45 million people. 11% of South African children (0-14 years) acquired HIV in 2020. Although antiretroviral therapy (ART) treatment coverage for HIV is currently at 23% of children and adolescents who require it globally, it has allowed millions of HIV-positive infants/ children to live healthier lives by delaying the progression of the virus in the body (Stekler *et al.*, 2012). Bernays *et al* (2017)

describe the survival of HIV-positive children into adolescence and adulthood as a relatively novel phenomenon. This is because while facing a lot of complex challenges along the way such as confronting multiple social and material constraints, how these young adults continue to thrive remains in need of both delineation and emphasizing. In addition to the trauma of living with the virus, many HIV-infected children encounter challenges that are attributed to the effects of the epidemic (Burkholder, 2019). Children living with HIV are vulnerable to various biological challenges such as impaired health, and inadequate access to proper nutrition (Ashaba *et al.*, 2019). A certain level of disadvantage is accumulated for these children, and as such rendering them severely disadvantaged in comparison to their agemates who may not be exposed to HIV. Although adults also face social pressures, in part due to the pervasive stigma surrounding HIV, what children and young people can say and do regarding HIV is further limited by those in their immediate environment. This is due to their age-specific incapacity to make decisions regarding many important aspects of life, such as housing arrangements and legal and financial dependence (Bernays *et al.*, 2017).

Additionally, for children living with HIV, the effects of the disease and the antiretroviral treatment coincide with fundamental times of development, rendering them vulnerable to opportunistic infections which compromise their bodies and immune system (Flynn & Abrams, 2019). Furthermore, the role of HIV with respect to developmental outcomes has been largely associated with behavioural deficits which are in part linked to poorer neurocognition. (Bartlett *et al.*, 2020) . Similarly, deficits in key areas such as verbal IQ and executive functioning observed in children living with HIV often place them at a disadvantage, as they may struggle with transitioning to adulthood consequently leading to psychological challenges such as anxiety. (Lanyon *et al.*, 2020)

The exploration of resilience in youth living with HIV could strengthen interventions targeted at both the individual and environmental factors surrounding the development of vulnerable children. Therefore, one prominent thrust of this study is to aid the body of knowledge around resilience studies among HIV-positive youth. This research hopes to understand the challenges faced by children born with HIV in South Africa, taking into consideration the extreme levels of poverty, lack of access to vital resources and the struggles of stigma. The larger literature on mental health actively advocates for social support as it holds a positive impact on the mental health of children (Wang *et al.*, 2012). The support from family often acts as a buffer

to advocating healthy survival when faced with adversity (Wang *et al.*, 2012). Moreover, it has been argued that perceived social support, which is the view that one has enough social support from family and friends is significantly correlated with positive psychological well-being compared to the literal support provided (Casalle *et al.*, 2019).

Therefore, at a theoretical level, the research will add to an understanding of positive adjustment in the aftermath of trauma (Larsen, 2021). Through the theory of resilience, the research seeks to provide an understanding of human potential, and the ability to be resilient and thrive even in the face of adversity. A greater look into risk factors and how these are mitigated through the lens of resilience as postulated by theorists such as Garmezy (1984) will be essential to the conceptualization and understanding of the participants' experiences. Resilience is vital in helping children mitigate a variety of adversities, including poverty, abuse, violence in the community, parental divorce, and traumatic life events, and while previous studies have acknowledged the resilience viewpoint as a potentially useful paradigm for directing research and health promotion activities, there has not been a significant theoretical debate in this area to highlight resilience strategies due to HIV illness (Li *et al.*, 2015).

1.3 Aims and Objectives

The primary aim of this research study is to understand the experiences of Youth who have grown up with HIV. Within this primary aim, there are two secondary aims:

1. The researcher seeks to understand experiences of varying Childhood Experiences that youth living with HIV have encountered in their childhood.
2. Secondly, to understand the experiences around the resilience strategies applied by this group of individuals.

The Key Objectives of the study are:

Firstly, this research seeks to explore the lived experiences of youth living with HIV in South Africa. Secondly, the study explores the impact of childhood adversity on Youth development and well-being. Lastly, the research seeks to understand the various ways in which youth are resilient considering exposure to various childhood adversity.

1.4 Chapter Outline

Chapter 1 introduces the research by giving background information on the contextual experiences of HIV in South Africa. This section also sets out the rationale of the study.

Chapter 2 is a review of the literature on Adverse Childhood Experiences (ACEs). The chapter explores local and international literature regarding contextual aspects such as socio-economic status, stigma and identities. This extends to a review of the presence and understanding of resilience.

Chapter 3 explores the theories of Resilience, particularly Garmezy's theory of resilience, unpacking the application and relevance of the theory to the study.

Chapter 4 presents the research design and methods used in conducting the research. The Chapter highlights the researcher's sampling techniques and data collection methods. It is here, that the researcher presents an emphasis on the importance and relevance of IPA as a method of analysis. Lastly, ethical considerations and reflection are highlighted.

Chapter 5 presents and discusses the four main themes that emerged from the data. The chapter discusses the data as per the participant's experiences.

Chapter 6 renders the conclusion of the study. The summary of the themes identified, which translated to the recommendations, and strengths and weaknesses of the study.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

This chapter focuses on the international and local literature related to ACEs. The chapter reviews various experiences related to challenges encountered by those infected and affected by HIV. These include children living with HIV in South Africa. Among the challenges identified, include experiences of stigma, identities and poverty. Within this engagement with literature, is the understanding of core experiences of HIV and the impact that they hold on to the development and transitioning of children to adolescence and ultimately to being young adults. The critical period between the ages of 15-25 highlights greatly the day-to-day experiences and encounters of this specific population (Evans, 2008). Additionally, reviewing an interlink of various social determinants in the development of black children living with HIV in South Africa.

HIV-infected children continue to face an increased risk of physical and emotional abuse as compared to other children (Meink *et al.*, 2015). The physical and psychological trauma of growing up with a chronic illness such as HIV can be devastating. The emotional trauma coupled with a lack of access to resources, poverty, loss of loved ones and abuse can have detrimental effects on their growth and development, impacting how they navigate themselves in the larger society, securing careers and employment for themselves. With assured adversity, it is interesting to explore and seek an understanding of the lived experiences of such youngsters and understand their resilience in the face of such complex adversities.

2.2 Biological Challenges

In as much as antiretroviral therapy has had a significant impact on curbing the detrimental effects of HIV, children with chronic HIV often experience illnesses related to aging and premature aging, a weakened immune system and a continuous inflammatory process associated with difficult development (Dalzini *et al.*, 2020). Research has also revealed that children with perinatally acquired HIV who are on ART continue to be at a higher risk of “non-AIDS related morbidity” because of a higher chance of a variety of illnesses related to aging (Kalembo *et al.*, 2019). Nolwanga & Musiime (2022) assert that for lower-income countries,

particularly in Southern Africa the controlling of paediatric HIV infections continuously remains a challenge for healthcare professionals even with access to ART. Furthermore, in lower-income countries, there is an increased chance of food insecurity leading to malnutrition, and exposure to illnesses such as pneumonia, TB as well as ear infections (Merchant & Lala, 2012). This suggests that the interplay of psychosocial determinants has an impact on adherence to treatment. Additionally, their home environment affects children's adherence to treatment. Unlike adults, they are more vulnerable to family disruptions and the non-adherence of their parents, further compromising their already vulnerable immune systems (Kakka *et al.*, 2020).

Furthermore, children living with HIV are at risk of a neuropsychological deficit, which means that they are likely to develop cognitive and motor dysfunctions (Boivin *et al.*, 2018). Research highlights that despite the prevalence of antiretroviral treatment, neurocognitive disorders associated with HIV infection persist in those who are infected. (Walker & Brown, 2017). However, there is also an acknowledgement that various variables such as age, sex and immunological status modify the degree to which HIV affects some executive functioning in children. (Walker & Brown, 2017). Nonetheless, Wedderburn *et al.*, (2019) posit that a clear negative impact of HIV on child brain development has been established, with poor language and motor development, and a delayed cognitive impairment that unfolds as they grow older. Additionally, these developmental delays are evidenced in poor school performances in mathematics, a much lower IQ, and language and motor development which poses a greater risk for general academic learning (Nolwanga & Mesiime, 2022). In South Africa, a research study found that HIV exposure was linked to delayed language development and that in addition to the presence of HIV, numerous socioeconomic, environmental and biological aspects have an impact on a child's neurodevelopment (Wedderburn *et al.*, 2019). It follows that children living with HIV are susceptible to neurodevelopmental delays that can potentially impact their learning abilities.

2.2.1 Paediatric to Adult-healthcare

Antiretroviral therapy (ART) enhances the lifespan of children living with HIV. However, Duhouhou *et al.*, 2017 argue that the emerging group of youth still faces tremendous evolving challenges (). The period of youth reflects a transition not only denoted by puberty but also speaks to the formation of one's sexual identity and key aspects of social maturation (Mark *et al.*, 2017). Due to this stage's critical and delicacy, guidance is needed as they negotiate these challenging and rewarding milestones. As highlighted before, this cohort of youth is a vulnerable group who encounter various developmental and psychosocial issues as they navigate a stigmatised identity (Dahounou *et al.*, 2017)

One of the predominant difficulties is the transition from child or paediatric to more adult care centres, the youth being more accountable for their health and as such bringing up new challenges (Duhouhou *et al.*, 2017). Bailey *et al.*, (2017) state that in countries with a high HIV epidemic, youth transitioning from paediatric to adult HIV care experience challenges with adherence due to the level of healthcare access available and most importantly a lack of support from the immediate environment. Kung *et al.*, (2016) state that there have been global healthcare transition models suitable for high-income settings, but not applicable to South Africa as youth living in South Africa struggle with resource-limited adult care centres, often lacking staff members and key resources. Youth transitioning from paediatric care would benefit from youth-friendly services that will aid in their transitional process as the challenge of belonging and getting services that cater to their developmental needs poses a threat to their viral suppression (Zanoni *et al.*, 2020).

2.3 Cognitive Challenges

Cognitive challenges in children refer to the failure to gain cognitive abilities. Children with HIV are therefore subject to the potential impact of the virus as well as environmental factors that are known to stunt cognitive development. In their study on the cognitive challenges of HIV children, Sherr *et al* (2014) assert that one of the predictors/ indicators of poor cognitive performance is reduced stimulation. This will be more prevalent and evident in homes where there is poverty and sickness; this is because at this point even parental responsiveness may be reduced. Ravindran, Rani and Priya (2014) point out that during the period of rapid growth

development HIV infection may, through recurrent infections lead to poor general health. This is congruent with a research study on the neurocognitive impairment of HIV-infected children. (le Roux et al., 2018) assert that early severe HIV infection significantly increases a child's risk for neurocognitive impairment. The study found that children with perinatal HIV infections demonstrated greater delays in cognitive functioning than their peers who were not exposed to HIV (le Roux et al., 2018). Interestingly, in a study that was conducted in Cape Town, South Africa to assess the motor performance of HIV-infected children, the performance of the HIV-infected sample was significantly poorer than the age-matched sample (Madlala et al., 2020).

Living with HIV is often associated with a higher risk for a wide range of behavioural and psychological outcomes, when both individual and environmental resources that initiate positive outcomes are threatened (Kuo *et al.*, 2019). This indicates that poor health threatens one's system's functioning and encompasses processes of thriving in the face of adversity. The capacity to overcome difficulties is a result of various key factors which include being able to cultivate safe and healthy environments, however, living with HIV compromises this key factor as food security, physical health and poor peer relationships threaten the capacity to harness resilience factors. (Dow *et al.*, 2018).

Child displacement has been recognized as another reason why there could be developmental delays in children living with HIV. A significant number of HIV-infected children are often adopted or live in institutionalized homes, causing delays in development (Bruck *et al.*, 2001). More environmental issues such as low levels of maternal education, and poverty are more likely to aid the low levels of cognitive functions such as language development, motor skills as well as memory functioning (Ravindran, Rani & Priya, 2014). These cognitive impairments and challenges compromise the development of the infected children, worsening an already traumatic experience.

2.4 Psychological Challenges

Elevated levels of depression, anxiety, and ADHD have been associated with children who are infected by HIV (Visser, Hecker & Jordaan, 2018). Illustrative data from a study done on HIV-infected children showed that children who had depression and conduct problems and were HIV positive were significantly more likely to engage in suicidal behaviours than those who did not have HIV (Visser, Hecker & Jordaan, 2018). It has been established that, in the context of HIV, there is an increased risk of suicide (Kehide *et al.*, 2017). Research findings from a Youth Risk behaviour Surveillance showed that over 20% of adolescents living with HIV had suicidal ideation and an estimated 12% had already attempted suicide (Kehide *et al.*, 2017). In various research findings, it was recognized that clinical variables that have been associated with depression in children with HIV infection were found. A meta-analysis of 8 studies established a frequency of psychiatric disorders among teenagers with HIV infection and reported a 25 % prevalence (Kehide *et al.*, 2017).

The prevalence of psychological challenges is rooted in more than the experience of being infected, but the possibility of academic failure due to school absence does cause psychological distress, living with extended family/ friends rather than one's immediate family, and loss of family members. Vreeman *et al* (2019) highlight that perinatally infected children have the potential to have stunted growth and delayed bodily development, therefore these visible differences in appearance may be a source of anxiety and cause internalized stigma (Vreeman *et al.*, 2019). The added anxiety of frequenting the clinics to get medication, in sections that are marked and associated with HIV can cause shame and discrimination (Letamo, 2011).

In recent years, literature also focused on at-risk children and has made strides in attempting to understand their mental wellness and investigating traits that are linked with survival (Kathleen *et al.*, 2019). Research also points to the prevalence of childhood trauma among people living with HIV, reporting that it is often two times higher in people living with HIV (Bekele *et al.*, 2018). In addition, HIV exposure in the family has been widely linked to poor relational outcomes, hopelessness and depressive symptoms (Betancourt *et al.*, 2012). Therefore, it appears that for the adolescent affected, there may be an increase in anxiety levels regarding their health, and the negative stereotypes about HIV around them often

exacerbate this. Amid these challenges, research has found that families that are supportive play a critical role in promoting a sense of normalcy for these children, helping adolescents cope and mitigate depressive experiences (Willis et al., 2019)

2.4.1 The Self-Concept

It has been noted that HIV brings up a variety of social and psychological changes for the infected individual, leading to one feeling inferior and devalued (Rodrigues *et al.*, 2019). It is further argued that a low self-concept is a common experience among those living with HIV. Miskijan & Endriyani (2017) define self-concept as “all ideas, thoughts, beliefs and beliefs that individuals know about themselves and influence individuals in relation to others”(p.183). Early definitions of research into self-concept posit a multifaceted view of “thoughts, attitudes, images, schemas regarding the self”(p.304), further indicating that individuals observe other people’s opinions the use a variety of techniques to verify and validate their self-perception (Demo, 1992). However, more recent attention on self-concept in Southern Africa has focused on the self as a result of the logical relationship between an individual and their environment (Oppenheimer, 2005). Ke *et al.*, (2019) highlight that low levels of self-concept pose a significant threat to one’s mental well-being. This is a significant point of review as one’s view of oneself emerges and alters quite substantially during adolescence, and as supported by studies in Social Psychology that these emerging stages of youth, there are inclinations towards being more self-conscious and may worry more about other people’s views (Ke *et al.*, 2019).

Miskijan & Endriyani (2017) highlight four different components impacting the self-concept of individuals living with HIV.:

2.4.1.1 Self-Image/ Body Image

The first component is self-image/ body image. Defined as how one perceives their body (Bacchii & Magliulo, 2003), body image also encompasses how one experiences the appearance and purpose of their body. Maskin & Endriyani (2017) posit that this view of the body ought to be realistic so that the individual is void of anxiety particularly in adolescence. Nyamaruze & Govender (2020) further extrapolate that one’s view and experience of oneself is hugely influenced by their social experiences, and for the youth living with HIV, their body

assessments are compounded by living with a stigmatised identity. To date there has been limited research on body changes in youth living with HIV, however, more qualitative studies appear to indicate that individuals' perceptions of themselves are often found to be poorer after receiving an HIV diagnosis. (Nyamaruze & Govender, 2020). A related study found that an HIV-positive diagnosis was linked to a lower and inferior level of body image, consequently reducing one's life satisfaction (Huang *et al.*, 2006).

Because one's body is linked to HIV as it is via the body that individuals come to acquire the virus and experience themselves, the relationship with the body can easily become altered. It has been highlighted within the Southern African context, there is value placed on acceptance and social identity, most young people begin to worry about being physically developed, and for most young men lies the concern of having visible delays in maturation due to being HIV positive (Megan *et al.*, 2016). Male youth living with HIV have been found to be less impressed with their weight due to a desire to increase their body size (Lima *et al.*, 2017). Megan *et al.*, (2016) raise attention to the influence of cultural norms and beliefs that often link weight loss or as others often refer to "thinness" to being HIV positive. This is supported by a study conducted by Zanolenci, Ferreira-da Silva & Silva (2023) that shows that an individual's environment, cultural experiences and values play a role in how they experience and feel about their bodies. Ultimately, the key understanding of body image satisfaction is that the changes and perceived changes in physical appearance can potentially bring about severe behavioural issues. (Zanolenci *et al.*, 2020). Marengo *et al.*, (2018) assert that in attempts to cope with the negative emotions associated with body dissatisfaction, the youth then become at risk of unhealthy behaviours such as engaging in restrictive diets, taking part in vigorous and excessive exercise as well as illegal drug use. This proceeds to be a significant factor in their psychological adjustment. Furthermore, the role of social media in facilitating dissatisfaction is embodied in the youth manipulating their social media presentation, posting images and content that reflects an idealised self (Marengo *et al.*, 2018)

2.4.1.2 Self-esteem

First defined by theorist William James in the 80s, self-esteem has been understood as depicting a sense of self-worth that arises when individuals reach or surpass major goals in their lives (Zeiger-Hill, 2013). In more recent years, the definition still holds similar connotations and has maintained its relevance. Miskijan & Endriyani (2017) define self-esteem as the “judgement of personal value obtained by analysing how well one’s behaviour corresponds to the ideal of self”(p.184). From this definition follows that high self-esteem stems from one’s ability to accept oneself without reservation, even when experiencing setbacks and failures. As such, low self-esteem can lead to depression that can impair one’s immune function (Miskijan & Endriyani, 2017). For instance, a youth living with HIV who perceives themselves as carrying a stigmatised identity due to being grouped with other stigmatised individuals may have a negative view of themselves, leading to a low sense of self (Kalomo *et al.*, 2020).

Furthermore, Small, Huynh & Parchment (2020) posit that self-esteem is crucial for preserving one’s health, upholding hope and a good quality of life. However, a low-self self-esteem among the youth living with HIV can also be attributed to being rejected, isolated and experiencing physical changes in their bodies (Wani, 2020). A research study conducted in Ghana found that the female participants living with HIV who felt isolated had lower levels of self-esteem in comparison to their male counterparts. These results further allude to the literature on the gendered experiences of self-esteem, as HIV is often viewed as a feminine condition, establishing an association between self-esteem and gender (Agyemang *et al.*, 2020). A related study in Uganda found that there was a significant attachment to self-worth and observed female participants to exhibit lower levels of self-esteem (Amongin *et al.*, 2020).

Low self-esteem has also been linked to internalised stigma. Nyamaruze, Govender & Gowden (2021) suggest that when a young person internalises the negative perceptions related to HIV they may begin to have self-blame thoughts. They further suggest an inverse relationship, by positing that with lower self-esteem one can easily adapt or ascribe to an identity denoted by social norms and beliefs, and as such appropriate self-perceptions from others (Nyamaruze *et al.*, 2021). Small *et al.*, (2020) highlight that in South Africa, experiences of stigma have been proven to lead to psychological stress among adolescents. For HIV-infected children who

manage to live to see the adolescent stage, the normal developmental challenges of this stage such as sexuality, and the desire to fit in can be seriously complicated by HIV. This is when children may become withdrawn from social spaces in fear of being discriminated against and not “fitting in”. Peer support can be beneficial to HIV-infected children, so a threat to this support system can cause distress, low self-esteem and instability (Avert, 2020).

2.4.1.3 Perfoma roles

Miskijan & Endriyan (2017) propose that a significant part of one’s self-concept is the perfoma role: roles in this regard refer to a set of behaviours that the social environment expects individuals to demonstrate. They further allude that the role set is the function to which one has no control, whilst the role received is the one chosen by the individual (Miskijan & Endriyan, 2017). In his theory of role strain, Good (1960) posits that a connection is established between one’s observed behaviour and their assumed ideas as denoted by the larger society.

Within the perfoma role, Miskijan & Endriyan (2017) propose that youth living with HIV may have high self-esteem as a result of a particular role that embodies experiences of an ideal self. However, one’s position in society as an individual living with HIV can be viewed as a stressor to this role due to societal norms, expectations and beliefs around being HIV positive (Mumin *et al.*, 2018). Burke & Reitze (1981) in their early work on identity and role performance highlight our main preposition, which is to suggest that individuals are often driven to derive plans and reach benchmarks that validate and confirm their identities. Concerning perfoma roles, the common knowledge is that youth living with HIV may begin to operate in choosing behaviours and that these behaviours reinforce and support the self that is accepted by others (Santos *et al.*, 2005).

2.4.1.4 Self Identity

In this last component, Miskijan & Endriyan (2017) propose identity as “the organising principle of personality responsible for the unity, continuity, consistency and uniqueness of the individual” (p. 184). The social constructionism theory posits that the concept of the self lies on the premise that, the self is continuously moulded by the dominant social discourse and values, and as such for PLWH, the similia of HIV as deviant may be integrated into their

conceptualisation of the self-identity (Rohleder & Gibson, 2006). When an individual has HIV, they become subject to various social projections, compelling them to absorb the stigmatised features that are attached to the 'other', internalising this stigma and subsequently giving rise to a "spoiled identity" (Joffe 1995; Goffman, 1963, p. 127). Analysis of further research posits that one's positive response to these negative perceptions potentially serves as a protective factor that mitigates even the internalised stigma that is often harboured by those living with HIV (Zhang *et al.*, 2015)

When the infected person adopts this deviant identity, there is repulsiveness that comes from the larger society. As Judgeo & Moalui (2014) argue, people who are thought to exhibit discreditable qualities are tarnished and diminished in value. Now, the notion posited above is suggestive of the pronounced effects of societal attributions to stigmatised illnesses. HIV has been acclaimed to be a disease "whose charge of stigmatisation and whose capacity to create a spoiled identity, is far greater than that of other diseases" (Sontag, 1991, p.101). It has been argued that disclosure has an impact on identity, and as such placing disclosure at the periphery of a tainted social identity, with individuals who possess a stigmatising trait being identified as "deviant, having spoiled identities" (Frye *et al.*, 2009). Therefore, how PLWH navigate and occupy space in larger social connections becomes significant to their identity transformation (Tsarenko & Polonsky, 2010). Often, PLWH experience a shift from the "inner-directed personality" to othering, the "other-directed personality", with identification of one's place in the larger social network structure being influenced by community membership, affiliation to groups, and a sense of belonging (Tsarenko & Polonsky, 2010).

Because at the core of social constructions of identity lies labels, particularly for individuals who live with stigmatised identities (Tewksbury, 2000). However, in the same notion, it can also be argued that the ability to manage one's identity can reduce the implications that are associated with stigmatised labels (Stanley, 2002). Some may argue that possessing a marginalised identity impacts one's participation in social networks, which co-produce some aspects of their identity (Pantelic *et al.*, 2019).

2.5 Social Challenges

Stigma continues to be one of the largest obstacles in the social response to HIV because of the persistent attitudes and judgements about the virus (Chambers *et al.*, 2015). Latzoo (2015) describes HIV- related stigma as the “systemic social othering of people living with HIV based on their spoiled identity” (p. 240). HIV-related stigmatization is also oftentimes connected to moral convictions that view individuals as sinful or wicked, such labels then transfer negative ideals of the people living with HIV onto the ‘othering’, one who is then deemed defective or spoiled (Duffy, 2005). Furthermore, research has found that African youth with HIV seem to be more susceptible than adult HIV-positive individuals to depression and HIV stigma. Also, adolescence is a crucial developmental stage that has a great deal of potential to protect against negative consequences for one's physical and mental health in the future the impact can be adverse (MacLean & Wetherall, 2021). A community study conducted in South Africa among PLWH found that their stigma experiences included negative behavioural patterns and attitudes, the fear from their communities that they are infected and lastly, their negative self-judgement (Peltzer & Pengpid, 2019). These results are suggestive of key processes involved in stigma and these interpersonal processes can lead people living with HIV to either internalise the stigma and or anticipate it. Similarly, again in South Africa, the implementation of an integrated Youth Centre resulted in a significant number of adolescents testing for HIV, making use of the centre for learning and for most of the youth living with HIV it served as a safe space that enabled them to find support and cope with living with HIV (Enane *et al.*, 2019)

2.5.1.1 Disclosure

The disclosure of HIV status to children is a task for their parents or caregivers, however, when these children transition to adolescence, they face a great conflict of exposing themselves to the larger social community (Aurpibul *et al.*, 2012). This is a process whereby one reveals their status to those around them. Research highlights that though there are significant benefits to this, such as yielding social support, however, this potentially opens room for discrimination (Aurpibul *et al.*, 2012). Maseko & Madiba (2020) highlight a conflictual experience of brought about by disclosure, positing that disclosure has been linked to better ART adherence. In most cases much better treatment outcomes, however, disclosure becomes complex when it

presents a risk for stigma. A research study conducted on HIV status disclosure in Eswatini indicates that youth who had low knowledge of HIV were less likely to disclose their status, needing to maintain a certain level of secrecy to guard against stigma and discrimination (Dlamini & Mtshali, 2023). This correlated with a study by Abuba-Kar *et al.*, (2016) who highlighted that fear of rejection, stigma and discrimination were the key reasons for Youth living with HIV concealing status and avoiding disclosure.

2.5.2 Stigma and Marginalisation

Stigma theorist Goffman describes stigma as “an attribute that is greatly discrediting” (Goffman, 1963, p. 127). Through this definition, Goffman suggests a societal influence, a labelling that deems an individual as different. Birenbaum & Segarin (1976) posit that when discussing stigma “we are discussing the entire field of people who are regarded negatively, some for having violated, rules, others just for being the sort of people they are or having traits that are not highly valued” (p. 33). At the core of these definitions is the premise that stigmatised individuals carry markers that set them apart, leading them to be devalued by others. “Stigmatising marks” as Major & O’Brien (2004) describe them, can be attached to either behaviour, appearance or group membership, they can also be visible or invisible, but most importantly stigma exists in a social setting rather than the individual. In stigma, the very same stigmatising marks become interlinked with a devaluing or “discrediting disposition” leading to negative evaluations and stereotypes (Goffman 1963, p. 127; Jones 1986).

Stigma consequently implies a relationship. Stigma permits others to feel superior to others and the idea of superiority and inferiority asserts that there must be another person who is thought to be or who truly feels inferior for another person to feel superior (Coleman, 1986). Conceptually, then, for stigma to exist there needs to be a set societal range of human differences (Andersen, Vary & Folker, 2022). The existence of stigmatisation in social settings seems to posit that the value systems and beliefs of the larger society determine what is an acceptable identity and what is devalued or spoiled. Similarly, HIV-related stigma would be located in the contextual perceptions and understandings about being HIV positive (Serios *et al.*, 2022). People living with HIV may then experience a loss of social value and position, because stigma is produced and maintained by social structures and interpersonal processes, a social phenomenon that necessitates an “us” as opposed to a “them” (Turan *et al.*, 2016).

This experience of stigma potentially affects self-esteem, social relationships, happiness and a sense of purpose in people living with HIV (Anderson *et al.*, 2020). This further categorises and maintains inequalities between those who hold power and those who do not, disproportionately affecting individuals living with HIV as they exist on the peripherals of society (Anderson, *et al.*, 2020)

2.5.2.1 Internalised Stigma

Individuals living with HIV may experience internalised stigma when they take on perceived negative public perceptions about people who are HIV-positive and apply to themselves (Pantelic *et al.*, 2016). By so doing, they draw out feelings of being worthless (Pantelic *et al.*, 2016). Because they now belong to a group that they believe people view negatively, people living with HIV may feel less valuable, and as such internalized stigma can bring about negative reactions such as withdrawal, and isolation (Pantelic, Shenderovich & Boyes 2015). For the reasons stated above, internalized stigma could be highly damaging to one's well-being as it is a representation of their internal process, their acceptance that they belong to a socially devalued group (Fekete, Williams & Skinta, 2017). Furthermore, internalised stigma can heighten depressive emotions, higher levels of anxiety and to some extent even poor medical adherence (Mumin *et al.*, 2018). People with internalised stigma have been said to be more vulnerable to judgement and may also have limited resources to navigate the negative experiences. Because internalised stigma can hinder disclosure, it can potentially impair the individual's access to treatment and support from family (Crockett *et al.*, 2018). In their study, Pantelic (2017) highlight that South African adolescents are most likely to experience internalised stigma compared to the other age groups. Peltzer & Pingpid (2019) allude to the increased vulnerability of the age group, impacting greatly their view of themselves in relation to others in their age group. Individuals living with HIV may choose to absorb the stigma to evade being marginalised, and in the end, HIV stigma is heavily determined by a wide range of variables depending on the sociocultural and political context of HIV (Mumin *et al.*, 2018)

2.5.2.2 Enacted Stigma

Enacted stigma has been defined as “overt negative actions of verbal harassment, discrimination and or violence” (Balaji *et al.*, 2017, p. 228). Enacted stigma due to HIV has

been said to increase stress levels and is associated with missed clinic appointments (Earnshaw *et al.*, 2021). Enacted stigma can be done by various types of people, from family, and friends to strangers and even healthcare workers. Healthcare settings have thus become one of the main places where people living with HIV have reported experiencing stigma (Algarin *et al.*, 2020). This often occurs through refusing to touch patients living with HIV and denying them services. Research on stigma among African American women living with HIV, Fletcher *et al.*, (2016) showed that individuals may be more susceptible to stigma and discrimination when they visit clinics that exclusively treat patients living with HIV, which may then discourage them from receiving much-needed care. Research data from Southern Africa reports young people's experiences of violence due to their HIV status. Reports of abuse and victimisation, various types of maltreatment in comparison to their peers, emotional abuse and bullying were also reported to have had detrimental effects heightening depressive symptoms among the youth (Pantelic *et al.*, 2017).

2.5.2.3 Anticipated Stigma

Anticipated stigma, quite contrary to the other experiences speaks to the "expectation of repercussions in the future, these are beliefs by people living with HIV that others will treat them negatively due to their HIV status" (Turan *et al.* 2016., p. 284). Anticipated stigma has been hypothesized to encourage poor adherence to medication as it imperils a hesitation in medication and overall care, it is also heightened by the fears of disclosing and avoiding any support rendered (Camacho & Kather, 2019). When individuals are aware of the effects of an HIV diagnosis on their social identity, including the negative stereotypes and stigma attitudes experienced by people living with HIV around them, they may anticipate similar experiences and treatment should they ever get a positive diagnosis (Luseno *et al.*, 2020). The anxiety that follows the anticipated stigma can then have an impact on one's well-being. The shame and stigma that may often be anticipated by the public are often harboured within homes, where caregivers would be secretive about the child's status. This secrecy may often appear in the form of concealment, by keeping silent about the child's status to others and in some cases concealing it from the child (Hejoaka, 2009). How caregivers engage with disclosure and secrecy has an impact on how the child processes and accepts their illness (Hejoaka, 2009).

Studies and research on disclosure indicate that often caregivers manage disclosure by limiting access to the child in the home, however, that narrative cannot be controlled once the child leaves the home (Duffy, 2005). Research has found that the anticipated stigma can act as a hindrance for individuals who have a negative status to seek health care assistance (Liu *et al.*, 2020). When people are living with high levels of anticipated stigma, they may be less inclined to seek social support, and experience great difficulty in trusting the health care services due to the fear of being discriminated against (Turan *et al.*, 2016).

2.6 Socio-economic conditions

To comprehend and consolidate the dynamics of HIV in South Africa, it is imperative to know and identify the context in which the rate of infections is rising. Whilst there is wide research and data on the prevalence of the illness, context-specific experiences and data that take into consideration the wide range of socioeconomic influences and impact are rare in South Africa (Karim & Karim, 2010). Hunger, a lack of access to good education, unemployment and undesirable residential conditions are examples of prime social determinants that have a detrimental effect on health and well-being, and as such disadvantaged exposure can harm the biological and social development from childhood (Thornton *et al.*, 2016). Conceptually, the interaction of demographic attributes such as class and race would ultimately influence health, and health outcomes at all levels.

South Africa has been rated one of the most unequal countries in the world, with a majority of its citizens living on the margins of poverty (Francis & Webster, 2019). Regardless of the changes in policies post-Apartheid, the structural inequalities that persist in South Africa immensely place South Africans on the socio-economic and racial divide (David *et al.*, 2019). Research highlights that the state of the labour market in South Africa greatly affects those living in poverty and due to its inability to draw people from disadvantaged homes into labour the poor continue to suffer unimaginable difficulties (Leibbrandt, Finn & Ooisthuzen, 2016). With the majority of black people's land taken away from them, in post-apartheid, very few options for jobs and self-employment exist, with a poor education system confined to impoverished areas such as informal settlements it leaves a majority of individuals from disadvantaged homes in poverty (Seekings, 2007).

The majority of the countries impacted by HIV exist in the Southern Hemisphere and are mostly on the peripherals of poverty; however, the impediment of this correlation does not suggest that poverty inevitably leads to HIV (Mufune, 2015). In South Africa however, socioeconomic status tends to profoundly influence behaviour as it affects access to key resources and opportunities that can potentially influence health outcomes (Mabweazara, Ley & Leach, 2018). Generally, individuals who come from low socio-economic neighbourhoods tend to have limited resources and this impacts negatively on the form of health services that they can obtain (Mabweazara, ley & Leach, 2018). Children who are living with HIV are exposed to intense difficulties of poverty. In low-income and developing countries where access to basic services is limited, the experience of living with HIV can impact one's livelihood in tremendous ways (Islam, Minichiello & Scott, 2014). Epidemic illnesses can potentially exacerbate already existing levels of poverty, so, regardless of who is ill in a home, there is an increased need for a nutritious diet, medication and treatment that often requires more money from the families affected (Whiteside, 2002). Compared to other chronic illnesses, children born with HIV are usually born in homes that may already be experiencing the severe socio-economic significance of the illness (Reddi, *et al.*, 2007). The potential of being at a disadvantage from inception then renders the children vulnerable and susceptible to various developmental challenges.

Research further argues that there is a prevalent interlink between lower socio-economic status and HIV, for example, at a biological level poverty means a lack of access to sufficient food and consequently malnourishment (Cain, 2018). Furthermore, poverty can work in various ways in increasing the prevalence of the HIV epidemic, for instance, young women may exchange sexual relations for food and money, as such making them susceptible to Sexually transmitted infections and HIV (Krisch *et al.*, 2019). In South Africa, the economic challenges and high unemployment levels expose most young people to risky behaviours; transactional sex becomes a key source of HIV when sex is exchanged for money and favours (Kilburn *et al.*, 2018). This therefore serves as an experience that maintains HIV prevalence and exacerbates infection rates.

2.6.1 Unemployment

Many unemployed people in South Africa are the black population in informal dwellings (du Toit, 2018). The issue of unemployment is not just an economic crisis, but rather a danger to human worth. Research posits that structural inequality is a key driver to the rising levels of unemployment in South Africa and is also somehow prevalent amongst the economically disadvantaged (Cloete, 2015). Looking at aspects such as income poverty then allows for a closer view of the impact of a no to lower income on the well-being of families (Fox, 2010). Income poverty is often related to poor health, limited access to education and exposure to environments that endanger one's safety as money is required to access various services (Meinjtesa & Halb, 2002). Access to job opportunities is an important aspect of progression, however, the opportunity to work is a huge contributor to social and psychological wellness: it is a catalyst that improves self-esteem and brings about a sense of sufficiency (Abur, 2016). Therefore, one can conclude that if left unattended to, unemployment can have detrimental effects on the well-being of those afflicted.

Informal settlements have been reported to have higher rates of the HIV epidemic compared to urban areas (Steenkamp *et al.*, 2014). Fox (2010) asserts that the prevalence of poverty and unemployment is a great influence on risky sexual behaviours thus perpetuating HIV rates. Because HIV has an impact on the entire family and not just the individual, the impact spans out to the livelihoods of those within the household (Borus, Rice & Lester, 2007). A household affected by HIV may see a significant (40%) reduction in food consumption and as such putting the children in danger of malnutrition (Kibert, 2018). Consequently, the added load placed on the afflicted household members then sees a rise in health-related costs and sometimes job loss as well (Kibert, 2018).

A research study conducted in France on unemployment comparison between people living with HIV and the general population found that unemployment rates were significantly higher in people living with HIV in comparison to their counterparts, with the unemployment gap increasing in the last 10 years (Annequinn *et al.*, 2016). Now, unemployment in the family brings about hardship for the members, causing a strain in the relationships and subsequently leading to poor health outcomes, stunting the development of children (McClellan, 2023). Families with limited financial resources may experience adverse conditions such as poor

housing, living in neighbourhoods with fewer community amenities and investing very little in their children's education. These unemployment conditions could then bring about parental stress, and more stressed parents typically engage with their children in problematic ways (Gonzalez *et al.*, 2020). Research also seems to suggest that exposure to these adverse situations such as poor socio-economic status in childhood could have a significant impact on the child's opportunities later in life, including educational success and income (Wadsworth, Montgomery & Bartley, 2008). One can conclude that employment can provide families access to social networks, structure, a good sense of identity and a sense of purpose in their day-to-day living. People living with HIV can also lead seemingly "normal" lives if they can work and meet social, family and personal expectations for their financial security (Barrington *et al.*, 2017)

2.6.2 Health-Care Access

The significance of early and consistent involvement with HIC care services, from testing to antiretroviral medication is highly valued for its advantage in lowering the progression and spread of the disease (Mitchelle *et al.*, 2019). However, ART treatment for children has been reported to be significantly low and one of the main reasons for this has been socio-economic hindrances (Kimane-Murage *et al.*, 2012). Guardians and caregivers in a rural community in South Africa share that the accumulating expenses kept them from seeking help: It was discovered that ART was offered one public-private health centre, located far from the settlements and though the ARVs were free, people had to pay for enrolment fees, infection drugs and therefore considering the cost of ART exorbitant (Msellati, 2009). In South Africa, it may be challenging to follow up with a mother and child for at least a year after giving birth due to numerous reasons such as poor economic circumstances and geographical displacement (Msellati, 2009).

The scarcity of mental health services in the country makes it difficult for these children to navigate themselves in health-seeking. In South Africa, the World Health Organisation report showed that there are 0.28 Psychologists, 0.4 Social workers and approximately 0.28 Psychiatrists and associated mental health workers per 100,000 population (WHO-AIMS, 2011). Disadvantaged children who cannot afford health care and private mental health

services are left exposed to the only available practitioners who may not be experienced or equipped to provide adequate mental health services.

It can be acknowledged that there have been tremendous efforts made to increase care for children with HIV in the African continent, however, HIV in African countries also exist at the core of great inequality and disparity and as such disparities such as health care access persist (Mitchelle *et al.*, 2019). Because children and teenagers affected by HIV require extensive medical care for a variety of illnesses, it implies that those in low-income areas may need consistent transportation to medical institutions, and research has indicated that a significant portion of households may not be able to pay for these extra costs (Mugish *et al.*, 2020).

2.6.3 Education

The effects of HIV on schooling are quite robust, with children's schooling impaired because of illness. A significant portion of the literature has focused on the educational prospects of orphaned children due to AIDS, overlooking the experiences of children living with HIV and navigating the educational system (Zinyemba, Pavloa & Groot, 2020). However, literature has provided evidence that poor socio-economic conditions potentially stunt the development of children, with dropout rates measured to be twice as likely for poor children in comparison to their 'non-poor' counterparts (Chaudry & Wimmer, 2016). Since education is a privilege widely acknowledged to be vital for development because of its successful effect on communities, a lack of access to it for any reason could stunt development (Guo, Li & Sherr, 2012). In addition to this, victimizing experiences such as bullying can be quite prevalent within the school, with the stigma associated with HIV having a significant impact on vulnerable teenagers who are constantly being made fun of, bullied and talked about by their peers in school (Asikhia & Mohangi, 2016; Okumu *et al.*, 2017).

Adolescents residing in areas where there are high HIV occurrences face an even greater risk of not finishing high school due to HIV (Akinyemi, Fotso & Banjo, 2018). The supposition made here, suggests an intertwined experience or relationship between successful educational outcomes and HIV prevalence. Several studies have found that the effects of HIV on educational outcomes are determined by a variety of individual and contextual characteristics such as gender, the type of interaction with guardians as well as the family's poverty levels (

Walakira, Nyanzi & Nafigiri, 2014). Now, Hyde, Swainson & Bennell (2012) suggest that HIV has the following impact on the education system. Firstly that:

- The educational performance of children living with HIV and related illnesses may decline as the number of guardians and children who are infected increases.

Secondly that

- HIV will have a negative economic impact on parents, and as such parents will have less money to cover educational costs such as school fees.

2.6.4 Food Insecurity

There is an alarming number of children living in extreme poverty, constantly in situations that threaten even their basic human rights, and HIV only worsens their experiences. Food insecurity affects about 80% of homes where children live, with most children living in overcrowded spaces and sometimes with no water supply (Sherr *et al.*, 2014). Morobadi and Webber (2014) highlight that the impact of HIV on children is often multi-dimensional and simultaneously complex. This is significant because children are a key part of a physically growing population, they encounter various complex stages of development and have great prospects (Morobadi & Webber, 2014). This inaccessibility of resources and basic sanitation serves as a great disadvantage for the children infected with HIV (Smith *et al.*, 2012). Sherr *et al.* (2014) highlight that these are children that are at risk of facing developmental and behavioural challenges. This is an indication that the HIV epidemic is unfortunately one of the many struggles that will impact their development and growth (Hosegood, 2005). The significant historical socio-economic issues influence not just how the epidemic increases, but the consequences for the infected children, particularly access to nutrition (Chaudry & Wimmer, 2016).

Given the multiple socioeconomic, biological and environmental challenges encountered by youth living with HIV, research posits that environments such as the school are potential sources of support as young people spend most of their formative years there, and although schools have not provided adequate support, they have provided a sense of normalcy for most youth and helped many engage in behaviours that promote wellbeing such as sporting

activities (Kimera *et al.*, 2019). Furthermore, because the youth often have minimum to no control over their living conditions as they may be highly dependent on their caregivers, they often rely on maintaining meaningful friendships in the areas where they live to relieve stress (Willis *et al.*, 2018). How youth navigate their environments is critical as the experienced challenges and the supportive structures that help them manage their day-to-day functioning mostly come into effect in natural living environments, supportive family structures, and caregivers that create safe spaces are helpful sources of support. (Bhana *et al.*, 2020)

2.7 Conclusion

This chapter focused on available research and data that is relevant to the current research study. The focus was on the various challenges that children living with HIV experience which include the adverse childhood experiences related to biological, psychological, social and socio-economic factors. Importantly, the chapter also explored the understanding of disclosure experiences and their impact on identity changes and possible exposure to stigma. This extended to further exploring literature on the different aspects of stigma and the impact that it has on an individual's wellness. The chapter further discussed discrimination from the schooling environment, the community but more so from the family. Last, the chapter further discussed the socio-economic conditions, and the various literature on the role of poverty in hindering access to health care and job opportunities.

CHAPTER 3: THEORETICAL FRAMEWORK

3.1 Introduction

The concept of wellness for people living with HIV is important. It is achieved through the development of what has been termed “healthy personal environment systems, leading to the promotion of positive well-being which reduces dysfunction” (Cowen & Work, 1988, p. 11). Some theorists postulate that the way individuals position themselves in the face of difficulty, through creating healthy environments that promote, for example, medication adherence, social interaction and healthy relationships are integral in fostering resilience (Rutter, 2006, p.106). This research evaluates ACE theories and the ACE model and employs the theory of Resilience as a framework for conceptualizing the experiences of the research participants and gaining further understanding of how experiences of trauma and adversity can be mediated.

Resilience studies emerged during the 1970s and 1980 through the work of Garmezy, Rutter and Werner (1985). The early studies on resilience paid particular attention to risk factors for adult illnesses, and vulnerability in impoverished children (Pooley & Cohen, 2010). The adverse outcomes of adversity were an important element in understanding resilience and the outcomes of resilience. Garmezy, Masten and Tellegan (1984) advocated that people could not be resilient in the absence of problems or difficulty. Contemporary studies on resilience continue to focus on populations that are at risk of understanding resilience.

3.2 Adverse Childhood Experiences

The prevalence of HIV and associated Adverse Childhood Experiences is key in unravelling the challenges and experiences of individuals living with HIV. ACEs refer to the events that are experienced in a person’s childhood and are deemed as traumatic or adverse (McGloin & Widom, 2001). These events include violence in various forms, neglect in its different stages, exposure to or engaging in substance abuse as well as exposure to or having mental illnesses (McGloin & Widom, 2001). The United Nations Children’s Fund has noted through statistical research that there are over 40 million children across the globe who have been subjected to one or more types of ACEs which in turn increases the risk of emerging adults’ experiences of physiological, emotional, or mental disorders.

This research acknowledges an understanding of adverse childhood experiences which posit that: Adverse experiences when experienced at a young age become detrimental to the individual exposed due to the vulnerability of children and how that vulnerability makes it easier for said children to be prone to the effects of the trauma that they experienced (Sacks & Murphey, 2018). This then becomes a neurological phenomenon where the brain is still in its development stages and the exposure and experience of childhood trauma can infringe on the normal development of a child's brain. This research further argues that experiencing these traumas and adversities for long periods can negatively affect a child's learning development, decision-making process, attention span as well as the development of stress management skills (Sacks & Murphey, 2018). The danger does not always stop where the exposed individual is affected, however, these effects can become hereditary and affect children who are not exposed to the same adversities or traumas as their parents (Sacks & Murphey, 2018).

The ACE theories have shown significant interaction between adverse life experiences and important classes of emotional well-being, health scares and illnesses (Thabrew, de Silva & Romans, 2012). In their early work on childhood adversity, Perry & Pollard (1998) stipulated that the brain's ultimate functioning capability depends on both environmental and developmental encounters that impact the progression of the genome. Similarly, Teicher (2002) further stretches this conceptualisation by alluding that the expression of one's genome is susceptible to continuous and highly extreme stress experiences during crucial childhood development. An expanding body of research on the framework of ACEs continues to prelude that childhood stressors have significant long-term effects even on brain development (Anda *et al.*, 2016). In addition to the impact on brain processes, Thabrew, de Silva & Romans (2012) state that exposure to early childhood traumas potentially compromises key psychological self-regulatory capacities which are linked to psychiatric and behavioural challenges.

Furthermore, understanding early childhood adversity in this research study also calls for a focus on the social ecology of childhood as a contextual framework for assessing the adverse effects on long-term health and adaptability, Lopez *et al.*, (2021). Lopez *et al.*, (2021) state that the social ecology of childhood encompasses both positive and negative encounters, presenting a socio-biological framework to assess developmental goals. Earls & Carlson (

2001) share that social ecology implies the close grouping of family, school, neighbourhood and community spaces in which children mature. Furthermore, Rosenheim (2002) asserts that the well-being of children is influenced by various socioeconomic and historical systems. Therefore, to understand experiences encountered by a child, one must go beyond the personal attributes and encounters, and encompass more distant contexts and interactions found in church groups, communities and school environments.

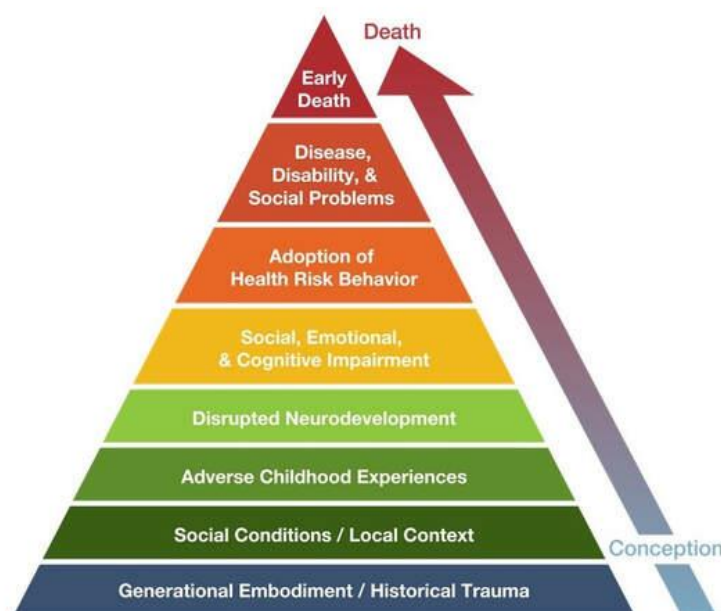
The framework further states that any disturbances to this ecology, including continuous stressors and trauma can have detrimental impacts on the child's wellbeing. Philosopher, Rosseau (1798) suggested that early childhood experiences continue to establish behaviour in adulthood. The preceding work on early childhood adversity has linked childhood experiences to behavioural, social, cognitive and psychological outcomes (Lopez *et al.*, 2021). Theorists adopting the same framework posit that child development is influenced by intricate encounters between the child and their environment, and failure to acknowledge this interactive approach ignores the layered systems within a child's environment (Sanchez, McCormack & Howell, 2015).

3.2.1 ACEs Model

The ACE framework rooted in the work of Felitti *et al.*, (1998) seeks to demonstrate then a risk-based concept, in which childhood exposure to adversities is conjectured to have an impact on health risk outcomes, developmental disturbances, mental and physical sicknesses in childhood that further expands into adulthood. The ACE model is a pyramid that illustrates the interlink between ACEs, illnesses and possibly early death (Boullier & Blair, 2018).

Figure 1.

ACE Pyramid



The 8 sections depicted in the pyramid above (**Figure 1**) show the systems through which adverse childhood experiences potentially affect one's health in their lifetime (Rides & Shaw, 2023). These systems are represented as historical trauma, social conditions, ACEs, Disrupted neurodevelopment, social, emotional and cognitive impairment, adoption of health risk behaviours, disease, disability and social problems, and lastly, Early death (Bernard *et al.*, 2020).

Historical Trauma

At the core of the pyramid lies a depiction of the shared traumatic experiences of a generation, the parents' history of trauma and how this generational trauma prompts psychological distress for future generations (Bernard *et al.*, 2020). Malin *et al.*, (2024) share that for infants there is a high likelihood of vulnerability to maternal stress and as such contributes greatly to brain development which affects learning and behavioural issues even in adulthood. Brewerton (2022) states that children can experience detrimental developmental delays even when they have no immediate contact with the distress, emphasising how historical trauma/generational embodiment such as apartheid, slavery, migration and even poverty is highly influential on the child's epigenetic systems. In South Africa, historical trauma is particularly fundamental to reflect on, and for black people in particular being exposed to violence and forced migration because of the apartheid government (Mufune, 2015). The system of apartheid disfranchised and persecuted black people, and as such reinforced the dehumanising of black people in South Africa (Mufune, 2015). Therefore, this historical legacy of apartheid is linked to the continued marginalisation of black people even in post-apartheid governments and as such sustaining inequality across all economic domains (Bernard *et al.*, 2020). Bernard *et al.*, (2020) state that historical trauma then informs the social conditions in which the youth grow and as such increases their likelihood of being exposed to ACEs. Considering historical trauma in this study is key in pointing out the contextual experiences embodied by the participants. Locating their experiences in this larger context emphasises the influence of larger structures on individual experiences.

Social Conditions/ Local Context

According to Brewerton (2022) one's environment is linked to the possible exposure to adverse experiences as well as the chance of posttraumatic stress and related adverse consequences). Social conditions paramount for consideration include vulnerability to violence in the family, poverty, disadvantaged communities, experiences of stigma, poor educational opportunities as well as inadequate healthcare support (Brewerton, 2022). This is a high encounter for historically disadvantaged populations as this is an extension of inter-generational struggle owing to racial discrimination which yields health challenges and, in some contexts, chronic diseases (Malin *et al.*, 2023). As highlighted before, in South Africa exposure to these adversities yields low maternal-child outcomes especially for children born with HIV (Zhang *et al.*, 2015). The model of ACE points us to the existence and impact of historical racism on what people currently have access to, such as adequate home structures and job opportunities which have a direct impact on exposure to adverse childhood experiences (Bernard *et al.*, 2020). Thus, children who grow up in these conditions experience unequal distribution of wealth, and as such impacts what they have access to and do not. Furthermore, significant literature points to the importance of interactions within the family environment in driving healthier health outcomes for children, for example, parents' emotional availability, and poor attachment to their children are critical mediators of the adverse impact on a child's wellbeing (Brewerton, 2022).

Adverse Childhood Experiences

A plethora of research has pointed to the severe impact of ACEs on the likelihood of psychiatric disorders and trauma-related disorders (Brewerton, 2022). Research has also demonstrated that when an individual is exposed to violence, their likelihood of encountering successive experiences of violence is enhanced. In the long run, such reflects on an individual's increased levels of impulsivity or even self-destructive habits. Similarly, the model posits that ill-treatment of children, and the presence of posttraumatic stress disorder are key indicators of chronic illnesses (Hughes & Ostrout, 2020). Therefore, the comprehensive evidence continuously proposes that children exposed to various stressors, traumas, abuse, family difficulties and life-threatening illnesses (such as HIV) cause a dose-effect relationship with psychological and physical health (Brewerton,2022).

Disrupted Neurodevelopment

Environmental stressors such as poor socioeconomic status and child neglect have been associated with variations in brain progression (Malin *et al.*, 2023). Researchers present significant correlations between reduced brain size and encounters with impoverishment and limited social support (Malin *et al.*, 2023). Here, the model argues that exposure to ACEs creates long-term alterations in the functioning of the Central Nervous System (Brewerton, 2022). Furthermore, it is demonstrated that changes in the nervous system and the HPA axis that is responsible for stress regulation start devastating damages that are influenced by environmental factors (Rides & Shaws, 2023). Likewise, youth who are either directly or indirectly exposed to ACEs may be subjected to changes in neurodevelopment, which in turn impacts their connectedness to others, how they regulate their emotions and subsequently their cerebral functioning (Bernard *et al.*, 2020). Consequently, these disruptions in neurodevelopment become predictors for risk behaviours such as the use and abuse of alcohol (Bernard *et al.*, 2020).

Social, Emotional and Cognitive impairment

Children who encounter ACEs have been shown to exhibit various social and emotional challenges such as struggles in maintaining relationships, exhibiting aggressive attributes and elevated chances for risk-taking (Malin *et al.*, 2023). Risk-taking behaviours such as alcohol abuse have ripple effects on the youth involved as they increase the likelihood of school dropout, motivation for violent activities and subsequent consequences such as unemployment (Huges & Ostrout, 2023). Moreover, this impairment in the ability to process social, emotional and cognitive cues does not just dent interpersonal relationships but causes significant challenges in recognizing and voicing one's own psychological experiences (Brewerton, 2022). The model states that children affected in this regard may continue to show deficits in socio-emotional and processing mechanisms. This is a potentially risky impairment as deficits in this regard could mean trouble processing trauma, difficulties recognising potentially threatening encounters, and most importantly for youth living with stigmatised identities, trouble receiving support from others, which is key to thriving (Bewerton, 2022).

Adoption of health risk behaviour

It has been demonstrated that ACEs are closely related to harmful effects on different health outcomes of the affected youth (Daja *et al.*, 2020). Liu *et al.*, (2023) state that exposure to adversity from infancy until the age of 4 has been linked to behavioural issues and poor academic performance, consequently leading to an increase in adolescent alcohol and marijuana use. As such they pose a risk of engaging in potentially risky behaviours. Prominent risky behaviours such as illegal drugs and risky sexual activities are common among youth who witness domestic violence in the home, live in gang-infested neighbourhoods, and come from impoverished homes (Thompson, 2017). In referencing Judith Harris's theory of child socialisation, Novak (2024) states that children who experience adversities at the home level may adapt to coping mechanisms that ensemble their home environments. Brewerton (2022) states that these risky behaviours are maladaptive coping strategies due to environmental exposures, however, they grow to become damaging behaviours that persist and if not curbed lead to chronic diseases. This can be demonstrated by the participants' experiences that translate even to the community environment, as the community environment for most of the participants is marked by basic disadvantages. Novak (2024) further suggests that when these children are in school, they may realise that their behaviours tend to be adaptive, falling short of their teachers' expectations and becoming vulnerable to rejection and even stigma.

Disease, Disability and Social Problems

The ACE model through this level highlights how ACEs cause progressive physiological changes that often last into adulthood and progress to diseases and disabilities at a later stage (Malin *et al.*, 2023). Diseases and social challenges often occur as a result of the health risk behaviours that are used as maladaptive coping mechanisms, leading to a much poorer quality of life (Brewerton, 2022). This suggests that a vast variety of both physical and psychiatric illnesses that span from mood disorders, anxiety disorders and personality disorders have been continually reported as direct outcomes of ACEs (Brewerton, 2022). The severe impact of ACEs on youth health is an increasing one which correlates with the intensity of the ACEs exposed to (Brewerton, 2022). This study highlights the various ACEs encountered by youth living with HIV, exposure which is compounded by multiple ACEs for each participant.

Early Death

For adults living with chronic illnesses such as HIV, it is postulated that risky behaviours and unhealthy lifestyles intensify the danger of avoidable early death (Brewerton, 2022). However, a key distinction is proposed in this regard, Zarnello (2018) proposes although unhealthy lifestyle choices add to the progression of chronic diseases, a significant amount of research indicates that exposure to ACEs in childhood creates “biologically embedded changes”(p.8). This is because exposure to early childhood adversity produces persisting biologically engraved alterations and neuro-developmental impairments and poor health outcomes are expected (Zarnello, 2018). Brown *et al.*, (2009) postulate it is therefore sufficient to conclude continuous exposure to ACEs potentially accelerates a child’s disease experience and as such makes them vulnerable to early death. However, Stillerman (2019) argues that although the nature of the relationship between ACEs and mortality has been demonstrated as causality, there is more evidence for considering that ACEs serve as the root cause of negative health outcomes. Anda *et al.*, (2009) propose the view that if anything, early childhood adversities are key pointers of messy family structures, unequal societies and structural challenges that lead to early death among individuals. These differing views on how ACEs lead to premature death allude to the same principle and understanding which appears to stem from the fundamental understanding of the detrimental effects of ACEs on health outcomes.

Furthermore, a contextual framework highlighting early childhood adversities on functioning has also been considered to understand the participants’ experience of adversity in development.

Early Childhood Adversity and Physiological Function

Taylor, Way & Seeman (2011) state that exposure to childhood adversities has an impact on a child’s physiological functioning. Being neglected in childhood, encountering abuse and exposure to violence both within the family home and community has been particularly linked to health outcomes such as premature mortality, types of addictions and cancer (Berens, Jensen & Nelson, 2017). Lopez *et al.*, (2021) further add that these health outcomes can be significantly accounted for by the interaction between a child and their immediate environment. Berens *et al.*, (2017) highlight that biological processes are a significant point of

analysis as early childhood encounters occur at quite intricate periods of development where a child's responsiveness to experiences is heightened, and exposure to any kind of adversity at this point causes impairment on gene expressions.

Furthermore, exposure to trauma or continuous traumatic experiences impacts one's response to various stress challenges even after adopting to new environments, the risk of demonstrating dysregulation of the body's communication system in response to stress (Taylor *et al.*, 2011). Chian, Taylor & Bower (2015) state that abusive encounters and a lack of support from one's family in childhood have been linked to poorer reactivity to interpersonal danger-related cues in adulthood. In addition, a history of sexual violence in childhood has been associated with an impairment in the "hippocampal-dependent", learning and retaining of information such as short-term memory and slow learning (Chian *et al.*, 2015)

Early Childhood Adversity and Psychological Well-being

Taylor, Way & Seeman (2011) posit that rough early environments impair the development and form of a child's psychosocial disposition. Although researchers have argued that there is insignificant evidence to support how childhood adversity can be linked to depression (Hazel *et al.*, 2008), there is a huge body of literature that demonstrates that exposure to early childhood adversity has shown that early negative life events are key conjecturers of depression in adolescents, as adversity changes a child's psychosocial disposition leading them to be more informed to the impact of stressful situations (Hazel *et al.*, 2008). The theory on childhood adversity further asserts that mental health challenges are observed to surface during adolescence, potentially translating to depressive disorders and drug abuse later in adulthood (Fothergill *et al.*, 2016). Similarly, Bethell *et al.*, (2019) state that troubles with regulating one's emotions are found in the same neurological pathways that are associated with early exposure to adverse environments. Tayler *et al.*, (2011) posit that children coming from rough home environments, where domestic violence may be prevalent often demonstrate exaggerated reactions to environments perceived as dangerous, reacting aggressively to slightly stressful instances. While highlighting the value of constructive and positive communication, Sege (2017) shares that increased levels of anger and distress in a child's home have been found to impair a child's understanding of other's emotions.

3.3 The Theory of Resilience

The theory of resilience seeks to provide a theoretical explanation for positive adjustment as the result of trauma or adversity (Masten, 2016). The theory is also used to explain the phenomenon of how human ability permits individuals to endure and thrive after experiencing life's challenges (Johnson & Wiechelt, 2004). Constructs of Resilience have expanded over time with some researchers describing the concept as one's capacity for successful adaptation to environments that threaten system functioning, acknowledging that an individual's capacity for adaptation depends on more than a single trait (Larson, 2021). Subsequent definitions of resilience focus on one's ability to "withstand difficulty".

Masten *et al* (1999) postulate that two key assumptions need to be made to infer resilience. First, that the individual is "doing okay and secondly that there is no or has been significant risk or adversity to overcome" (p.4). According to Masten *et al* (1999), a resilient individual ought to be different from others with expectations of being functional on most occasions. Masten *et al* (1999) attest that resilience cannot be seen as an individualistic trait but rather people can exhibit resilience in how they behave. Various difficulties such as poverty and illness that can be experienced by a child have been studied in topics of resilience. In assessing resilience in the lives of youth who grew up with HIV in South Africa it is imperative to look for those processes that are protective of the child's development, for example, the variable focus approach has been one of the focal points of resilience studies (Masten *et al.*, 1999). The variable-focused approaches tend to assess the relationship between competence and adversity. The approach also incorporates many protective factors that would account for the differences in how children react differently and how they interact with the world in which they are. Variable models include protective factors which can be used as intervention tools for adolescents who grew up with HIV. Consequently, if social support is increased for example, it can help in negating the impact of stigma such that adolescents have much better outcomes (Masten *et al.*, 1999).

In as much as there has been a lack of consensus regarding the definition of resilience, there are specific traits that have been predicted to be protective thus leading to resilient outcomes (Larson, 2021). A factor is considered protective if it buffers a risk factor, both the internal and external aspects of one's life (connecting to others, self-efficacy, and socioeconomic advantages) (Braveman & Gottlieb, 2014). Carvalho (2007) points out that cognitive coping and acceptance of one's HIV status serve as protective factors that contribute to health and wellness. These traits and abilities allow for one to have resilient outcomes even in the face of stigma.

Resilience theory is centered around the concepts of adversity and competence, competence despite exposure to adversity. Tuppet, Fanta, Tyrell and Masten, (2015) point out that the theory seeks to observe resilient processes even at the broader levels of development because a person's capacity for adaptation is dependent on various systems, not just a singular trait that an individual mass possesses. For a child or an adolescent who grows up with HIV, their ability to be resilient is not just dependent on character disposition, but family cohesion and external structures such as the community. The support they get from their schooling, the broader system, and access to adequate health care all play a role in their experiences.

Adversity and Competence

Adversity is defined as negative experiences that can potentially challenge one's adaptive development (Obradovic *et al.*, 2012). These adversities can be chronic or acute. Chronic adversity tends to extend over time and may potentially have detrimental effects on an individual's life (Breda, 2018). Being infected with HIV may extend from childhood to adulthood. Acute adversities on the other spectrum have a defined starting point, usually a brief duration and very limited implications on the individual's life, such as an accident (Breda, 2018). The participants in this study all experience a chronic experience of living with HIV, extending from childhood to their youth. Acute adversities allow an individual to view resilience as 'bouncing back to the pre-trauma state of functioning, while chronic adversities do not, there is not before and hence the patterns of sustained coping may be more relevant and likely (Bonano & Diminich, 2013).

At multiple levels of functioning and through various mechanisms of process, adversity has the potential to threaten the stability and the development of adaptive systems and in the process undermine positive adaptation (Chatsworth, 2006). This was observed as the participants in this study experienced adversities that threatened academic and social development. Despite all this, when capacities for competence persist, and when expressed in contexts of adversity they characterize resilience (Coatsworth, 2006). For resilience to manifest in adversity, competence is key and necessary. Competence in context has been defined as “the capacity to adapt successfully and meet contextual developmental and cultural expectations for a particular individual, group or social structure” (Yates *et al.*, 2015, p.775).

3.3.1 Garmezy’s Theory of Resilience

Garmezy (1997) defines the construct of Resilience as “not necessarily impervious to stress”. In his or her view, resilience is designed to reflect the capacity for recovery and maintained adaptive behavior that may follow initial retreat or incapacity upon initiating a stressful event” (Garmezy, 1997., in Shean (2015, p.8). To be resilient, Garmezy states that one must be able to show functional adequacy as the standard of resilient behavior (Garmezy *et al.*, 1984).

For this study, employing Garmezy’s view of resilience, which is ecological, is important as it acknowledges protective factors at the individual, family and external family levels, and how this all influenced resilience (Shean, 2015). At the individual level, one recognizes the dispositional attributes of the child, and how the child can meet situations, such as coming to terms with their HIV status. This is seen in this study as the participants experience an interplay of family, society and their characteristics in mitigating some of the adverse encounters. Some of the family factors seen allude to family cohesion and the presence of an emotionally available family member despite HIV status. Lastly, an external support system, such as a supportive teacher, or a religious organization that does not discriminate against individuals living with HIV (Garmezy *et al.*, 1984). His theory of resilience has been further explained in three models.

Compensating Model

This model functions on the notion that stressors lower competence and personal attributes improve adjustment (Garmezy *et al.*, 1984). As illustrated in this study, an adolescent living with HIV for instance, may experience a high-conflict home environment and a warm close relationship with their extended aunt. The model suggests that, if this adolescent is resilient, it is due to the aunt's relationship that can compensate for the home relationship (Shean, 2015).

Protective vs Vulnerability

An interactive relationship exists between stressors and personal attributes, whereby the relationship between stress and outcome differs based on the level of the attribute being considered (Garmezy *et al.*, 1984). In this study, it was observed that an HIV-positive child who lives in extreme poverty may have a cohesive home environment which interacts with poverty to decrease risk.

Challenge Model

Stressors enhance adjustment and high levels of stress lead to lower levels of competence. Some stress such as encountering bullying may be helpful for children to develop skills that will encourage them to mobilize internal and external resources (Garmezy *et al.*, 1984). The model proposes that provided the risk factor is not too extreme, it can enhance one's adaptation. As participants were exposed to bullying in the school environment, it enabled them to mobilize their internal resources to thrive in that environment. The experience prepares one for the next challenge, rendering them adaptive to potential challenges.

3.3. 2 Evolving Theories

Garmezy's theory is congruent with the evolving theories of resilience. This research study also considers evolving research on resilience with a particular focus on resilience as a transactional process which relies on ecosystems that involve young people moving towards support structures, with communities and families reciprocating (Theron & Theron, 2010). The study acknowledges the context in which the participants exist and the systems that interact to create an impact.

Various scholars have conceptualized resilience as an individualized theory, and this has brought about criticism as researchers oppose the notion that individuals are responsible for developing themselves with little to no support from the state and external support systems and deeming this as problematic (Van Breda, 2018). Van Breda (2018) further states that the expectation of HIV-positive youth to deploy their dispositional attributes to mitigate challenges without the assistance of external support systems is flawed. If an individual is responsible for their well-being, then the state is free to disregard adverse social systems such as poverty and poor health care services (Theron & Theron, 2010). Resilience to chronic adversity, such as living with HIV in a poverty-stricken environment as seen with the participants in the study tends to draw for longer periods, drawing from a pool of limited resources (van Breda, 2018). Hence, conceptualizing and framing resilience outside social structures perpetuates adversity.

Recent theories on resilience have adopted a "dynamic process that is influenced by both neural and psychological self-organizations, as well as the transaction between the ecological context and the developing organism" (Vella & Pal, 2018, p.811). It follows therefore that resilience is conceptualized contextually. Recent literature has also emphasized three fundamental components of resilience, firstly, the presence of adversity, secondly the impact of protective factors that surpass the said risk, and lastly more positive outcomes than anticipated (Stainton *et al.*, 2019). Although the historical and cultural development of the concept has evolved with varying meanings, more consistent is the understanding that resilience is more than one's ability to continue developing skills despite adversity, it is rather the ability to react positively despite difficulties (Sisto *et al.*, 2019).

It follows from contemporary conceptualizations that resilience as a dynamic process occurs as change that enables one to explore a new balance and evolve positively, it is during this process of change that one can advance new skills and have a transformed feeling of personal efficiency and adapt to change that is precluded by the environment (Sisto *et al.*, 2019).

Concerning individuals living with HIV, it is believed that resilience resources potentially protect their health by encouraging positive health behaviours such as medication adherence and can buffer them from adversity such as poverty (Stainton *et al.*, 2019). Furthermore, the complex adversities that are experienced by youth living with HIV require a dynamic and multisystemic approach to resilience. To conceptualise resilience as purely an individual phenomenon in this regard ignores greatly the social context in which the individuals exist, and the social systems in which resilience occurs (Dulin *et al.*, 2018). For the purposes of this research study, the multilevel ecological experiences were acknowledged, as the interlink of personal and contextual factors in encouraging resilience.

For this reason, the perspective of resilience as an ecosystem has encouraged the researcher to consider contextual and cultural forces that are key to studying participants' experiences and to draw on theories of Resilience that are cognizant of cultural antecedents (Theron & Theron, 2010). As demonstrated in the most recent studies, the concept of resilience is viewed as a dynamic, context-based transaction, the focus is shifting from protective factors to acknowledging the contextually specific mechanisms that yield advanced resilience (Theron & Theron, 2010). Therefore, to understand resilience among HIV-positive youth studies have to continually conceptualize resilience as contingent on personal, community and cultural protective factors.

3.4 Aspects of Resilience

The RYSE study- The Resilient Youth in Stressed Environments which investigates the resilience among youth that live in stressed environments acknowledges both internal and external indicators as key elements for fostering resilience (Ncube, 2020). The study postulates that youth who are exposed to adverse environments have various biological, psychological, social and environmental aspects that support resilience (Ungar *et al.*, 2023). Ncube (2020) highlights that with respect to one's ability for 'constructive meaning-making' is dependent

on how one experiences challenging situations and individual emotional and cognitive resources which will influence how one constructs meaning from adversity. This indicated their ability to tap into internal resources, and how they demonstrate an ability to reframe negative and adverse encounters enabling them to view adversity optimistically (Ncube, 2020). Similarly, external indicators foster resilience strategies. Zhange (2023) posits that positive family interactions enable adolescents to find positive ways of adapting to challenging situations, and because resilience is a process of adaptation, developing qualities such as positive coping skills can be modelled through meaningful relationships within one's immediate environment.

3.4.1 Individual aspects of resilience

There are certain personal traits documented to be shared by individuals who have demonstrated resilience (Leune, 2022). It has been asserted that an individual's response to stress or adversity impacts their well-being, suggesting that resilience is an available inner quality, a resource within an individual that propels positive emotional wellness: within this conceptualisation, resilience is then defined as “an energy or force that drives a person from survival to self-actualization” (Richardson, 2002, p. 315). Postulating resilience then as an internal process that can be tapped into, to enable successful recovery from ACEs identifies individuals as ‘sources’ of resilience (Grafton *et al.*, 2010). Research subscribing to this conceptualisation suggests that resilience can be learnt and harnessed (Jackson, Firtko & Edenbough, 2007). Similar findings indicate that the presence of optimistic traits can build hardiness and serve as a protective mechanism against difficulties (Jackson *et al.*, 2007). However, further research could help assert the impact of the relationship that is hypothesized here.

In their study on the trait and process of resilience, Jacelon (1997) found that adolescents who had resilient characteristics confirmed an understanding of themselves, possessed an innate ability to reflect on changes occurring in their immediate environment, they were also seen to be able to solve problems and be independent thinkers. Subjects in a similar study living with HIV demonstrated that possessing a “sense of meaningfulness, and purpose in life” would yield a more positive adjustment compared to those who had a diminished sense of

purpose (Farber *et al.*, 2000). This is a phenomenon observed with participants in this study who reflected on their experiences, tapping into their resilience traits.

When considered with previous research studies, there appears to be a significant relationship between positive adaptation and personal reactions to adversity. Among research studies looking into individual resilience traits in those living with HIV, it was found that the characteristics that the participants demonstrated may not have had a direct impact on their health, however, drove them to resource centres where they received the necessary help and care. In addition, the individuals who demonstrated a hands-on approach to managing their wellness by reaching out for help showed to possess tremendous resilience traits (Liboro *et al.*, 2002).

3.4.2 Environmental factors

Mbad *et al.*, (2013) describe Resilience as an interactive phenomenon that exists between the personal, interpersonal and community levels. Positive family interactions, namely, good communication, experiencing love and being seen in the family, and regular support within the family have proven to perpetuate positive adaptation in African families (Crowley *et al.*, 2022). Research has also identified guardian characteristics and **emotional support** as key contributors to a child's resilience (Bireda & Pillay, 2018). One of the key elements to ensuring that social support is sustainable is an emphasis on consistency. Consistency in accessing this trusting social support only ensures better adjustment for adolescents in the future (Barenbaum & Smith, 2016). This suggests that inconsistency potentially produces mistrust which leads back to maladaptive behaviours later on. Consistent healthy interactions with caregivers are fostered firstly, through the adolescent's ability to experience their caregiver as trusting and accessible, and without this attachment, the child becomes vulnerable to complicated and often unattended grief which could result in mental health challenges (Barenbaum & Smith, 2016).

It follows therefore that, an adolescent may be able to demonstrate resilience when adequate and significant resources are made available and used in a manner which influences adaptive functioning regardless of exposure to adversity (Holte, Theron & Ungar, 2022). This suggests that an individual may be able to demonstrate resilience provided they can assist themselves as well as receive social support. By acknowledging that resilience occurs in a multisystemic space, researchers can note the vigorous interactions within and between systems, therefore, rather than focusing on single predictors, it is necessary as the current research has demonstrated to investigate resilience supporting-interplay of resources that gives rise to positive development in adverse environments (Ungar *et al.*, 2023) As Cowen & Work (1988, p.11) asserts that the development of “healthy personal environment systems, leading to the promotion of positive well-being reduces dysfunction”. By this, Cowen suggests that the way individuals position themselves in the face of difficulty, through creating healthy environments that promote, for example, medication adherence, social interaction and healthy relationships are integral in fostering resilience (Rutter, 2006, p.106).

CHAPTER 4: METHODS AND METHODOLOGY

4.1 Introduction

This chapter discusses the research questions of the study. It is here where I describe the method used in answering the questions, taking into consideration the principles of ethics and the notion of constant reflexivity throughout the study. The chapter also presents the sampling process in detail. In addition to this is a description of the process that was used to collect the data. The process of IPA (Interpretive Phenomenological Analysis) is explained as the process of data analysis. How quality was ascertained, followed by a description of ethical consideration and lastly how the researcher positioned themselves on the continual process of reflexivity.

4.2 Research Questions

1. What are the lived experiences of HIV Positive Youth?
 - a) What has been the experience of HIV-positive youth with varying Adverse Childhood Experiences?
 - b) What are some of the resilient strategies employed by HIV Positive Youth to strive?

4.3 Research Design

The research assumed a qualitative paradigm. In qualitative research, the research aims to explore and understand the meaning that individuals ascribe to a social phenomenon (Demuth & Mey, 2015). Sofaer (1999) alludes that the use of qualitative methods enables researchers to get rich descriptions of somewhat complex phenomena, enlightening not only the experiences but also the interpretations of those experiences. By emerging questions and procedures, the researcher can make interpretations of the data (Jackson, Drummond & Camara, 2007).

Islam (2022) clarifies that qualitative studies enable the researcher to draw meaning from the participants' context and experiences. Therefore, this approach enabled the researcher to comprehend the context in which the participants navigate their experiences. The use of a qualitative approach allowed the researcher to see the world of a societal truth from the

participants' view without asserting an agenda (Hak, 2015). With this type of research, researchers are interested in the interpretive and realistic method of the participants' views, while giving them room to express themselves accordingly (O'Day & Killen, 2002).

Qualitative research is flexible and dynamic in its approach and allows researchers to employ designs suitable for the work being pursued. This research assumed a phenomenological design which is concerned with attaining data about a specific experience by exploring the participants' "personal experiences" (Turhan, 2019). Phenomenological research explores in detail how participants make sense of their personal and social world (Smith, Flowers & Lurkin 2009). Yildirim (2010) describes phenomenology as a "type of research that focuses on phenomena that we are aware of in our daily lives but do not have detailed information about" (p. 80). Therefore, with the focus of the design being to understand phenomena from the participant's perspective, the researcher applied this design to understand the lived experiences of individuals living with HIV (Groenwald, 2004). Using Phenomenological research, the researcher employed in-depth qualitative analysis and focused on how the participants think and make meaning of their experiences.

The researcher was intrigued by the existence of a dialogue between an individual and their world, and how that is described to derive understanding and meaning. Thus, Interpretive Phenomenological Analysis (IPA) was used in the analysis of data. Hood (2005) asserts that IPA is solemnly interested in the "unique meanings that people assign to certain experiences and examines how those meanings relate to the person's individual and cultural context and experience of others". Demuth & Mey (2015) point out that the process is composed of a series of factors that aim to interpret the account of people and their personal lived experiences. Therefore, attention to an experiential approach was imperative in ensuring that meaning was not lost in translation, that reality based on the participants' perception was retained, and ultimately that the integrity of the study was also maintained.

4.4 Participants

The focus of this study is on the experiences of HIV Positive youth, hence the sample from which the data was collected comprises of youth who grew up with HIV. The research adopted the definition of youth by Evans (2008), classifying youth as young people between the ages

of 15-25. The study consisted of 3 Black female HIV-positive South Africans who grew up with HIV in marginalized communities. Alase (2017) states that in phenomenological research, the sample size can be between 2 to 25. IPA further emphasizes the homogeneity of the participants rather than size, stating that having a homogenous sample group enables the researcher to get a better sense and understanding of the lived experiences (Alase, 2017). All participants who had been exposed to and experienced some adversity in their childhood were also currently either graduated, in university or working. All three of the participants are from disadvantaged communities that still do not have access to the most basic services.

Restrictions on race and class were mandatory for the selection of the participants to obtain data relevant to the research objectives. Research highlights that of the 6.4 million individuals approximated to be living with HIV in South Africa in 2014, almost 6.2 million of those were black people (Bell *et al.*, 2022). Mabaso *et al.*, (2019) point to the racial disparities in the HIV epidemic in South Africa, stating that these racial and gender differences are embedded in structural inequalities that persist 30 years into democracy. The experiences of black people in South Africa are embedded in the stratifications of inequality and poverty (David *et al.*, 2019). Therefore, participants who were black and grew up in impoverishment were the inclusion criteria. As highlighted, this was an important exclusion criterion as it speaks to the many aspects of inequality, socio-economic distress and discrimination that are often the experience of historically marginalized populations in South Africa. The study explored their experiences of growing up with HIV in the context of poor socio-economic conditions. Notably, were their experiences of navigating themselves in community and educational spaces, and the kind of impact it had on their understanding of themselves to others. All three participants could communicate effectively in English, and as such, language was not a barrier to the study.

Table 1: Participants

Race	Gender	Age	Current Occupation	Residence in childhood
1. Black	Female	24	Student	Soweto
2. Black	Female	25	Student/ Working	Alexandra
3. Black	Female	25	Employed- Graduate	Boysens informal settlement

The sampling technique that was employed is non-probability, convenience purposive sampling. Banerjee & Chaunhury (2010) state that in non-probability sampling the research subjects that are chosen are selected using non-random models. This technique often leans towards exploratory and qualitative research. Therefore, the purpose of this method of sampling was to bring light to an under-researched population. Young adults who were available and willing to participate were used in the study, hence a convenience sampling method was employed. Since the study was explicitly looking for HIV-positive youth, a specific criterion was met. For this reason, purposive sampling was used as it works on a specific criterion to get the most suitable individuals for the study (Banerjee & Chaundhury, 2010).

The participants were above the age of 18, and this is vital as the study seeks to understand the resilience of the youth who were either in tertiary or working and how they were able to mitigate the ACEs. As indicated before, race and class restrictions were imposed. Black, HIV-positive youth, who grew up in poverty became the defining criterion for participation. This is because of the alarming number of children who live in extreme poverty who are constantly in situations that threaten even their basic human rights, and HIV only worsens their experiences. Previous research has been quite prolific on the issues surrounding medical adherence and the cost of HIV treatment (Mufune, 2015). In a context like South Africa where inequality is significant, previously marginalized groups tend to lack resources and are unable to access adequate healthcare thus exposing them to much more challenging encounters in living with HIV (Smith et al., 2012).

The target sample size was 5 HIV Positive youth who were either born with the virus or contracted it at a young age. This is because the main concern in IPA is with a thorough account of individual experiences, it is not about quantity but rather quality, and given the vast complexity of human experiences IPA benefits from a concentrated focus on a small number of cases (Smith, Flowers & Larkin, 2013). After conducting 3 interviews, the researcher felt that she had adequate accounts for the research. Pietkiewicz & Smith (2014) state that the sample size in IPA research is often small enabling a much more detailed, immersed thorough analysis. Pietkiewicz & Smith (2014) state that “the depth of analysis, the richness of individual cases, how the researcher wants to compare and contrast single cases” (p.9) determines the size which is appropriate for the study. Additionally, Vasileou *et al.*, (2018) state that to avoid the qualitative data collection being overwhelming, IPA researchers ought to put more focus on depth rather than scale of data. Therefore, the researcher finds that a detailed analysis of a case is justified as original problems, mechanisms and experience have been identified (Pietkiewicz & Smith, 2014).

4.5 Procedure

Upon obtaining ethical clearance from the University of Witwatersrand, the researcher approached various NGOs that work with or assist individuals living with HIV. Through written communication in the form of a letter (Appendix A), The researcher sought permission from Directors or Program Managers of NGOs to approach and interview participants. NGOs such as Nkosi’s Haven and Sister Mufura’s Foundation were engaged as they have accommodations and services for the target population and access to the individuals would have been easier. Though most NGOs were protective of their database and restricted access to individuals who either lived on the premises or accessed the services frequently, ultimately, the researcher was able to gain access to a participant through Nkosi Haven’s database, from there on, snowballing was used to access other participants who fit the research criteria and were interested. As Lewin (2005) alludes, the process of snowballing helps in identifying people who fit the criteria of a particular population and thus using them to gain access to others who are like them and may be willing to partake in the study. This enabled the researcher access to the target population.

The researcher telephonically contacted participants to explain her research project wherein she stated the purpose of the study. Upon reaching a verbal agreement the researcher set an appointment to meet the participants. For some participants, contact was made via email to set either a face-to-face session or an online meeting via Microsoft Teams. Two of the interviews took place via Microsoft Teams and one was conducted face-to-face. The interviews took place in a controlled environment with minimal distractions and were of comfort to the client (On campus for one face-to-face). The Participation Information letter was given to the participant to read and ask any questions that may arise. (**Appendix B**). Before the interview commenced the participants were given consent forms to sign (for participation and audio recording) (**Appendix C**). The interview only commenced once the participants had read, understood and signed the participation letter and relevant consent forms.

Semi-structured interviews were used as a means of data collection. This instrument allowed the researcher to obtain in-depth information which was imperative for the use of narrative analysis as a way of analyzing data. McIntosh and Morse (2015) point out that semi-structured interviews tend to use relatively detailed interview guides and may be used when there is enough objective knowledge about an experience, but subjective knowledge is lacking. This is true and relevant for this study; the intention is to obtain the subjective experiences of the participants. This instrument of data collection allows for the participants to freely express themselves, allowing the researcher to probe further.

The interviews lasted approximately sixty to ninety minutes per interview session. The time duration for the interviews per session is longer as Interpretive Phenomenological studies are known for providing rich and descriptive research data (Smith *et al.*, 2009). The interview process also allowed the researcher to engage in conversation with participants where the initial questions were modified considering the participant's response, allowing the researcher to enquire more from the responses provided (Smith *et al.*, 2009). The data collection procedure followed a one-interview-per-participant approach.

For the interviews that were conducted face to face, a good quality recorder was used to record the interview, to ensure that data was clear and saved accordingly. For the interviews conducted online, a Microsoft Teams link was sent to the participants and the sessions were recorded and saved for transcription purposes. After each Microsoft Teams recording was

downloaded and transferred to the researcher's laptop the audios were secured in a password-protected folder and the original audio files from teams were deleted. The same was done for the interview conducted face-to-face, audio was deleted from the researcher's recording device and stored securely in a password-protected folder.

4.6 Data Analysis

IPA (Interpretive Phenomenological Analysis) is a method of data analysis that gives the researcher a great opportunity to make sense of the innermost deliberations of the lived experiences of their participants (Alose, 2017). The process of IPA is concerned with examining the subjective experiences of the participants (Smith *et al.*, 2007). Smith *et al* (2009) argue that IPA is participant-oriented, asserting that making sense of what is being said requires a close interpretative engagement by the Researcher. This method of analysis allowed the researcher to use the experiences of the participants to answer the research questions. This method not only engages the respondent with the research problem, as an extension, but the researcher also had real-life experiences and interpretations from the subjects to compile data on the research question (Alose, 2017).

An IPA analysis allows for a focus on the interpretation of meaning. Frechette *et al.*, (2010) assert that the fundamental principle of an interpretive approach lies in the relevant interpretation of the person, as a simple descriptive approach will not provide efficient analysis. Smith & Osbourn (2015) posit that IPA operates as a "double hermeneutic" as it is a process of the researcher attempting to make meaning of their participants' attempt to understand their world.

For accurate data interpretation, the four-stage process by Smith & Osborne (2007) was used.

The initial stage involves the transcription of the audio files. The researcher listened to the audio several times, read the transcriptions several times and allowed herself to be immersed in the data as each reading seemed to provide new insight (Smith & Osborn, 2007). With each audio transcription, the researcher allowed herself to identify nuanced meanings. In this process, she also made notes of the choice of words and descriptions that the participants provided. By being attentive to each participant's experience, the researcher was able to draw meaningful insight into their lived experiences.

The second stage involved transforming notes into emergent themes. Pietkiewicz & Smith (2007) highlight that when the researcher has taken notes from the transcripts, the very same themes can then be converted into themes that will be intended for short phrases. The researcher then made use of these emergent themes in answering the research questions. Additionally, these themes were grouped around the theme of resilience, such as ways in which resilience was fostered for each participant in their different experiences of adversity.

The third stage entails identifying connections between emerging themes, grouping these themes to conceptualize similarities then providing each cluster with a descriptive label (Pietkiewicz & Smith, 2017). By grouping the related themes, the researcher actively interacted with the transcripts to ensure that the themes were recorded accordingly and most importantly, verbatim.

The last stage involves a summary of superordinate themes that are labelled and quotations from the interview are added (Smith & Osborn, 2007). This researcher then included the participants' verbatim quotes in the analysis to ensure the reliability of the data.

4.6.1 Methodological Integrity

Franklin & Ballan (2001) describe reliability as the extent to which data findings would yield similar outcomes on different occasions. This concurs with Kirk & Miller (2000)'s view that if other researchers conducting a similar research study by making use of the transcribed data used here should reach similar conclusions. Trochin (2005) further alludes that reliability in the qualitative study also means dependability which involves a researcher's efforts to justify changing conditions in their observations. Based on that, therefore, this research was able to achieve reliability. However, as Willig states, researchers employing a qualitative paradigm do not dwell on reliability as much as quantitative research does. The research at hand seeks to demonstrate reliability through assessing credibility, dependability, confirmability, commitment and rigour (Cope, 2014)

Cope (2014) states that **credibility** in research refers to the accuracy and truth of the data captured and how it is represented by the researcher. Chowdhury (2015) states that this is also a measure of the trustworthiness of the results. This has been achieved in this study as the researcher continually described her experiences as a researcher and demonstrated

engagement with the data. Moreover, the researcher demonstrated an ability to be empathetic while working with people's vulnerabilities. The process of constant reflexivity allowed the researcher to engage with the accurate interpretations of the participants' experiences. Furthermore, she remained as close to the data as possible, making sense of the participants' expressions in every possible way.

Regarding **dependability**, Polit & Beck (2012) share that this is the consistency of results even in similar conditions. This has been achieved through supervision when her supervisor corresponded with the decisions that were made at each stage of the research. The supervision provided throughout the research aids to the dependability of the research findings.

Cope (2014) describes **confirmability** as the researcher's ability to show that the research findings depict the participants' true responses and not the researcher's own opinions on the subject matter. The researcher was able to achieve this by showing how she reached conclusions and made interpretations. Verbatim quotations from the transcripts were used to demonstrate the emerging themes.

On commitment and rigor, Polit & Beck (2012) state that commitment refers to the researcher's ability to be attentive through the interview process, and her dedication to analyzing each transcript thoroughly. Again, the researcher leaned on the guidance of her supervisor to construct semi-structured interviews that would be used on a homogenous group as stipulated by the IPA guidelines. In addition to this was the researcher's continual observation and reflexivity throughout the process to ensure thorough explorations.

In addition to the process of ensuring reliability is the precept of *authenticity*. Cope (2014) states that the degree to which a researcher can faithfully express the participants' emotions allows other readers to feel the essence of the experiences shared. The researcher was able to achieve this by reporting the participants' experiences without alteration.

4.7 Ethical Considerations

Ethical clearance was granted by the School of Human and Community Development ethics committee at the University of the Witwatersrand (PROTOCOL NUMBER: MACC/22/10).

The research participants were given a brief overview of the specifications of the study, after which they gave their informed consent to participate. The research participants took part in the research voluntarily. This was essential to ensure that they were forthcoming in their interaction, and honest. There were no coercion strategies used to convince the research participants to engage in the study, and they were informed that should they wish to withdraw from the interview process they were free to do so. Participants were assured that their participation in the study would be anonymous should they choose to due to the sensitive nature of this research study. This was important to create space that allowed them to be more open knowing that their identity would not be compromised.

Details of their lives were not shared with anyone to maintain confidentiality. The researcher also used pseudonyms in the report writing to protect the identity of the participants. Any documents with information containing the participants' details were password-protected to ensure maximum security.

There was no harm inflicted on the participants, however, the researcher acknowledges that discussions of lived experiences may be distressing to participants, for that reason, the researcher provided the participants with the lifeline 24-hour counselling contact line. Details and contacts of the helpline were provided in the Participation Information Form (Annexure B). My research supervisor is experienced in both research and clinical work with HIV populations, the researcher also relied on this for support.

Should the participants require details of the research data after completion of data analysis, they will be allowed to ask any questions that they may have.

4.8 Reflexivity

Dowling (2006) describes reflexivity as the detailed focus on the researcher's role in qualitative research. There is a collective consonance that engaging in qualitative research has an effective change on the researcher, and as such the researcher acknowledges how she potentially shapes or has been shaped by the process. As Reid *et al.*, (2018) highlight, the role of a researcher requires one to have a practical understanding of the study and, even more significantly to demonstrate sensitivity to any conflicting priorities that may arise. Palaganas *et al.*, (2017) share that reflexivity requires an intentional process of reflecting on the role of

subjectivity in the research, continually reflecting on one's values, and acknowledging how their history and assumptions impact the study. In this research study, the researcher needed to become aware of her assumptions and how her social background filters through the work being done. In a nutshell, allows individuals to own up to their prejudices and acknowledge how opinions may impact the way data is processed (Alose, 2007).

4.8.1 Introspective Reflexivity- Before data collection

Patnaik (2013) highlights that the notion of introspective reflexivity speaks to the researcher's "consciousness of the self to understand how their own experiential location might influence the choice of subject, methodology and themes"(p.9). Approaching the data collection process of the research, I assumed that my race, gender and age, as a black female in her mid-twenties would make the participants more comfortable in opening up about their experiences. I thought that my positionality in these shared areas of identity would make the process less anxiety-provoking even for me. However, I felt anxious about my position as an individual who was not born with HIV nor is living with HIV, I worried about how that would be a barrier to fully comprehending and conceptualising the lived experiences of these participants. However, through the review of the interview schedule, and receiving guidance through supervision I was able to manage my anxieties, though it was not easy.

4.8.2 Introspective Reflexivity- Data Collection & Analysis

My data was collected using both face-to-face and online, via Microsoft Teams. This mixed approach brought some anxiety. I presumed that the anxiety was related to the online interviews, as I worried about the barrier of the screen, and not being able to build adequate rapport such that the participants were comfortable enough to disclose their own experiences. However, I soon realised that the participants were in their own spaces, spaces that were familiar to them and this made them feel comfortable and at ease. I observed that they did not demonstrate any anxieties in this state and were eager to engage in the process.

Although I was relying on my position as a young black female to ease the anxiety of interviewing this group of young people. I also realised, by the first interview which was conducted online, I became aware of my privilege both in health and socio-economic status. I then became highly anxious to probe into some experiences of their HIV status, and this was

demonstrated by my careful choice of words so as not to come off as insensitive or one without knowledge. However, as I continued to ask questions, the first participant would be explicit, descriptive and straightforward in using terms I was shunning away from in fear of being insensitive. Greenaway (2010) points out that outsider experiences often fall into the difficulty of experiencing language sensitivity. By attempting to be thoroughly cautious I was missing the contextual experiences that the participant was bringing to the table. This allowed me to not shun away from appropriately probing in the interviews that followed.

At the same time, my identity brought a certain closeness to the data collection, being able to relate to some of the experiences brought a certain level of closeness to the data collection. As the interviews continued, I occasionally found myself caught off-guard due to some sudden familiarity with an experience that was being described. I began to realise that one of the participant's descriptions of a school experience took me back a little to a time in primary school. However, these descriptions revealed how close yet far I was from their narrative and that the experience I resonated with at that time may not be the same as the experience. This became more evident as I was tracking back to my data during the write-up as I noted the varying undertones used and implied. Furthermore, it is worth noting that every research study has its confounding variables, and a confounding effect cannot be completely avoided. The researcher acknowledges that belonging to the same demographic as the participants provided a non-judgmental and accepting environment, however, she also was aware of all potential sources of bias in this regard and undertook all possible actions to minimize the deviation from the participants' true experiences. By ensuring that research questions and necessary probes were adhered to, the researcher worked to ensure that the responses recorded were matched to the questions and answers given.

Reflexivity of data analysis

As Patnaik (2013) posits, keeping a reflective journal in the process of making notes of observations and thoughts enabled me to continually have something to revert to in understanding the experiences in context. However, the write-up of the data analysis and discussion segment of the research was to be thorough and required that I continually revisit the data and engage with it case-by-case. I realised that it would be a challenging task to get to a thorough reflection of the participants' lived experiences and not mere general

descriptions. My supervisor gave me continuous feedback as I worked closely with the data, and this guidance enabled me to pay close attention even to the undertones of the language used by the participants. Moreover, the use of IPA enabled me to be able to extract the lived experiences, and though attempts have been made to stay as close to the participants' descriptions as possible, the analysis holds some elements of subjectivity. Engaging in qualitative research, particularly phenomenological analysis often requires that the researcher become immersed in the work. Though there is a plethora of research in this field of research I believe that this exploration adds to an understanding of childhood adversities and resilience.

4.9 Conclusion

This chapter of the methods section provided an outline of the research process regarding how the research study was carried out. The research questions were presented and discussed first, this was then followed by the description of the research approach and paradigm and the applicability thereof, given the context and nature of the research aims. The selection and description of the participants were then presented, and the sampling method used was further elaborated. The research tool used to obtain data and the procedure thereof were described to account for how the data was collected. The researcher then alluded to the process of data analysis (IPA). The relevance of the approach and its applicability in analyzing data was presented. How the themes were brought out and analyzed. Followed by a review of the ethical proceedings and reflexivity throughout the study.

CHAPTER 5: FINDINGS AND DISCUSSION

5.1 Introduction

This chapter presents a discussion of the themes that were derived from the interview transcripts. An Interpretive Phenomenological analysis was employed in examining the themes and the sub-themes thereof. The experiential themes were identified and under these were sub-themes namely: identity, stigma, discrimination and marginalisation, socio-economic conditions and resilience. The first theme seeks to explore how one's identity is shaped and impacted by their HIV status. By this, I mean the challenge of defining self-outside of their HIV status, both as an internalised experience and as a social identity by being. The second theme highlights the experiences of stigma, both enacted and perceived stigma. The aim is to understand how the larger societal experience of stigma impacts one's experience of their HIV status while highlighting the experiences of being marginalised because of being HIV. The third theme is a very significant aspect to the study for highlighting the impact of socio-economic status. This sought to analyse the participants' experiences from low-income to unemployment backgrounds, and the impact of not having access, to proper medical aid and education. Lastly, and equally significant to the study, are the experiential elements of resilience. These looks at what fosters resilience, the various protective factors, and how various environments can both be precipitators of stigma and foster resilience at the same time.

5.2 Theme 1: Identity

The theme of identity seeks to highlight how disclosure experiences often lead to what Frye *et al* (2009) have termed "Interactions that challenge an individual's self-concept as normal or a non-deviant individual" (p.4). When individuals living with HIV are confronted with this new identity, they are often compelled to adopt a social identity as someone who is HIV positive. Having a certain social identity often means one becomes one with that group and begins to see things from the group's perspective (Stets & Burke, 2000). The participants in this study share varying experiences of identity transformation and in the process employ some strategies that help to navigate some of the identity impacts linked to living with HIV. Tajfel (1971) emphasises this process by alluding to what is now understood as social

identification. For individuals living with HIV, this can mean that one may have a cognitive awareness that, they can be included in a particular group, while, taking into consideration the emotional significance of that group membership for the self. The emotional gravity of identifying becomes a significant element even to one's emotional wellness.

5.2.1 A Spoiled Identity

An individual who experiences stigma is often seen as possessing 'undesired deviance', and difference, thus creating what Goffman (1963) terms a "spoiled identity" (p. 128) Looking at these socially constructed meanings of being HIV-positive, they are often masked in derogatory descriptions such as a plague, otherness, and punishment (Rohleder & Gibson, 2006). When these descriptions become a huge part of the language used to understand HIV as an illness, they simultaneously create the process of othering, those who are infected and the self who is not. When the participants in the study share the experiences of beholding a spoiled identity, they are highlighting the social discourse of the communities' HIV understanding, their experiences of being categorised into various deviant experiences, puts the individuals and their families at risk of being seen as villains.

Nomfundo:...It's an informal settlement and everyone is in everyone's business. Everyone talks to everyone, and now our household, our little, the small home we live in, in that settlement, was looked at as a place with a plague, of course, I'm sure there were some people who also had the virus in that community, but because it's not something that they exposed It became a thing of. It's happening in our household, now it's her parents and their siblings.

The situation I ended up putting my family in a position where they now had to. You know, be be isolated from the rest of the community. I felt very bad for my siblings cause their friends weren't playing with them because their parents told them to stop playing with them.

Nomfundo takes us through a depiction of stigma as a central force in the lives of those living with HIV. The socially constructed meanings are seen to be hugely impacting how the self then is shaped. The use of words such as 'isolated' indicates the extent of the discrimination on her livelihood. Nomfundo may have incorporated these descriptions into the construction of her identity. The metaphors used in her description of the experiences allude to a greater understanding of an internalised impact. Her experience of a spoiled identity exemplifies the impact of ACEs as expressed through the ACE theories, which posit that youth ought to learn abilities essential to circumnavigate duties of adulthood, however, strong identity formation can be deterred by exposure and experiences of adverse encounters (Hosey, 2019). All the participants shared similar sentiments about how they had been located in various spaces by being HIV positive. Consistent with the studies on ethnic identity and resilience, which state that being an active member of a community of individuals can enhance the understanding of the self, ultimately buffering against stressful outcomes (Chlause- Ehlers, Yang & Chen, 200), one's HIV status is already socially attached to various negative stereotypes, consequently serving as a target of discrimination, it bears emotional consequences that often are a testament to the gravity of the perceived discrimination (Kang, 2015).

Simphiwe: Uh, I, I, I don't think anyone was brave enough to say anything. But you know it's just how people behave. I know some of the mothers knew because, for example, the one lady used to work at school and I know my teachers knew about it. So I think I am. I'm I'd like to think that maybe somehow she told some of her friends from the neighbourhood, so some of the kids started to act different and you could just see that they didn't want to include me in the circles when they played and Uh, yeah..

Similarly, Simphiwe reflects on her struggle with being the bad child. Earlier in the interview she highlighted how when diagnosed with HIV she found herself reflecting on how that could have possibly happened. She sees how 'different' the other children begin to act around her and observes the unwanted acts towards her. Her attempts to accept this experience become difficult when in reality she is grouped into a category of the deviant group. The ACE model highlights how one's environment is linked to the possible exposure to adverse experiences (Brewerton, 2022). Consequently, her experiences with these challenges speak to the struggle of belonging as an individual, to tap into that innate and progressing self that is essential to develop a sense of autonomy even in the face of this adversity (Aranda *et al.*, 2012). Now, this

process of othering as alluded to earlier seems to take place even for Simphiwe, splitting into the bad and contaminated child and the clean child. As Rohleder (2016) posits, a huge aspect of the reported challenges of living with HIV is in one's sense of oneself as a social being, particularly a social citizen. Feeling like an outcast and as Nomfundo put it, a plague. Because experiences of early childhood adversity are located in the child's social ecology, negative encounters from the child's environment outside the home potentially devastate their identity formation (Lopez *et al.*, 2021). As such, there is a felt stigma, that Lekas *et al* (2011) describes as the shame that is associated with being HIV positive or the fear of being stigmatised. Felt stigma comes from one's identification with a group that may have a socially negative connotation, thus subduing the members to discrimination (Lekas *et al.*, 2011).

5.2.2 Rejected Identity

Living with HIV can be an incredibly challenging experience, especially when faced with the harsh reality of rejection from society. The participants in the study share a similar experience of embodying an identity that is often rejected. As such, the ACE model proposes recognising the systems involved in child development as they contribute to forming social identities (McComark & Howell, 2015). For individuals belonging to a 'stigmatised' group, a slight perception of rejection by the dominant group can impact one's psychological well-being (Schmitt *et al.*, 2003). Schmitt *et al* (2003) further extrapolate that being discriminated against also suggests that one's identity is excluded from what is seen as 'normal'. Nomfundo's experience below demonstrates how exclusion can feed into perceptions and experiences of rejection.

Nomfundo: You know like I said, the place that we lived in neh? It was so small and very intimate. If you know firstly how informal settlements are, shacks are close to each other, and everyone knows everyone, like if someone did something to wrong someone it would be very easy to know who did it. So you can imagine living in such a place, everyone began to give our household dirty looks, lol a plague! You know a plague? like our home became something that people like detested, and I think because people knew about it, which I think was the first mistake, for people to know what was happening at home. And I think that, you know because my father drank a lot he probably said something while drinking with his friends, because like I said he hated how I was bringing attention at home, so yeah it was

not pleasant you know, like I did not like it at all... you know I hate even now being the focus or center of anything because it is suffocating.

Living in a close community where there seems to have been little to minimal autonomy over disclosure, Nomfundo's experiences of living with HIV brought about exclusion for her siblings and entire family demonstrating the perceptions of HIV from the surrounding community. Experiences of community interactions motivate what, Berens, Jensen & Nelson (2017) highlight in the ACE framework as physiological and emotional determinants of well-being for the affected child. Additionally, acknowledging that an 'outgroup' experiences an inescapable level of discrimination implies the rejection of those individuals from the larger social context and sometimes even from positions of status (Giamo, Schmitt & Outten, 2012). Nomfundo seemed to have been experiencing seclusion from the larger community, the othering of her and her family which brought about feelings of isolation, and inferiority. As highlighted by the resilience theory and the ACE framework, embodying a stigmatised identity informs heavily responses to depressive experiences (Boardman *et al.*, 2011., Taylor *et al.*, 2011).

Nomfundos' description of her experience as a plague, isolated, resented and ruining of the image is suggestive of her experiences of seclusion, being treated as though they did not belong and feeling like an outcast, not only from her community but her father as well. The ACE theory states that abusive experiences and a lack of support from one's family in childhood can lead to an impaired reaction to threat-related experiences (Chiang *et al.*, 2015). Similarly, the theory of resilience suggests that this social rejection can bring about stress that is linked to a loss of social resources, subsequently denting the social aspect of the ecology that ought to work and serve as a buffer to negative experiences (Major & Gross, 2020). Research has also argued that personal relationships between families and friends can potentially be fractured due to an HIV diagnosis (Schmitt & Crystal, 2000). Because discrimination can impact supportive social interactions, negative perceptions of an HIV diagnosis can dent that support and render individuals lonely. For Nomfundo, she experiences the reaction from her father and community as harmful.

Gilbert and Walker (2009) highlight that the community's views of HIV are often based on subtle malicious beliefs which are often towards women, and in turn, people then fear existing in contexts where they are identified as being HIV positive, seeking to avoid the gossip from around them. Now, the capacity of the social system to change and alter while maintaining its relevance becomes challenged, as its inability to actively develop new wellness and resource dynamics is inadequate (Berkes & Ross, 2020) Nomfundo finds herself subject to possible malicious gossip from her neighbours, peers and people in the community. As Taylor, Way & Seeman (2011) posit, a negative encounter at the community level, particularly at the sensitive periods of development impairs the development of key mechanisms integral to interpersonal relationships. This exposure almost deems her and her family subject to various kinds of verbal abuse. In most African cultures the family is often held accountable for the behaviours and the lifestyle of the individuals within the family, therefore, "unhealthy behaviours" may then be viewed as traits that are characteristic of the entire family and their inability to correct the so identified risk behaviours (Lili *et al.*, 2008)

Nomfundo found herself being the victim of the same narrative around her family image and perceived unhealthy behaviours that were seen as indicative of the family's inability to control themselves. Moreover, keeping psychological steadiness while living with a chronic illness such as HIV can set significant difficulties to people's abilities to be adaptable (Schmitt & Crystal, 2000). The ACE theories have revealed an integral interaction between adverse life encounters and emotional well-being and health threats (Thabrew, de Sylva & Romans, 2012). Life proved to become a stressful challenge for Nomfundo due to the stigmatization, and limited social support, which meant that her ability to endure the challenges had become slightly impaired. Garzmezy posits that "the more protective factors that are present in a child's life, the more likely they are to display resilience" (Howard & Johnson, 2010, p309).

Nomfundo: See, and I knew that it's something that I can handle something, that I can deal with something that I can overcome and that it's not going to kill me and that there are things that I can do to make sure that I protect even the people who are around me and with that information as I grew in my in high school, I was able to Umm builds some form of mental resilience

When it comes to Internal protective factors, research has demonstrated some characteristics of a resilient child, and these often include 'social competence, problem-solving skills, autonomy and a sense of purpose and a future (Garmezy, 1985. p) Nomfundo's ability to be adaptable and think of a wide range of possible outcomes while manoeuvring a rejected identity demonstrates her ability to build resilience even outside of external protective factors.

5.2.3 Devalued Identity

The various manifestations of stigma often result in one losing their social status, being devalued and sometimes unfavourable outcomes for those who are at the receiving end of the stigma (Hover *et al.*, 2019). When one's social identity calls into question their humanity, the individual is "spoiled, flawed and essentially devalued" (Goffman, 1963, p. 128).

Simphiwe: "Because of the stigma, I decided to accept my fate. Umm, I decided to accept my fate because of the lack of information and knowledge I had about my status, and there wasn't anything I could do to combat it. But I was facing the stigma I was facing, so I decided to just accept that I would have to be alone in every sense of the word"

For Simphiwe, there was a sense of hopelessness, loneliness and defeat in her realisation of what it meant to be living with HIV. The experiences of stigma bring about a sense of isolation and more significantly taking on an identity that invites scrutiny and devaluation. To further address the relationship between childhood adversities and interpersonal relationships, Lopez *et al.*, (2021) state that childhood stressors have an impact on one's psychological self-regulatory abilities. Simphiwe's experiences of stigma highlight a significant experience. Reinka *et al* (2020) echo a similar narrative, by highlighting that though an individual possessing a 'devalued' identity may estimate the possibility of being stigmatised, individuals with a visible identity (in this case, a known identity) may be certain of other people's reaction

to them. The sure certainty of other's reactions and possible discrimination in itself is a catalyst for ascribing to identities that bring about the experiences of isolation. Simphiwe's experience of self is also experienced through Garmezy's challenge model, though her experience of self is progressive and at different points, is impacted by the level of understanding and acceptance that she gradually ascribes to, as she encounters higher levels of stress it yields her to lower levels of competency (Garmezy *et al.*, 1984).

Rohleder and Gibson (2005) have argued that women living with HIV and other sexually transmitted diseases are often faced with the stigma of being viewed as being dirty, damaged, and sometimes deviant. Therefore, the experiences of feeling undesirable all seem to stem from the core feelings of not being validated, valued, or seen. The three participants share similar experiences of stigma (as described). In their pursuit to belong, and form meaningful relationships, the participants were often met with the negative stereotyping of their stigmatized identities, and this, in turn, has left a common theme of feeling undesirable, due to the 'spoiled identity'. Such stereotyping encounters have also been identified as key contributors to adopting health risk behaviours as a way of coping with environmental stressors (Brewerton, 2022). When asked about her experiences of being HIV, Nomfundo expresses it this way.

Cindy: "Ohh!! But I still remember when things changed for me, I remember when what I thought would be my worst nightmare happened. I have always been a huge fan of social media, watching and posting. So at some point, I started thinking of ways I could make sense of my my status, I couldn't talk to my family because clearly there was shame, so I needed a platform to have these conversations. When I started on YouTube, I received encouraging comments, but there were also very mean ones, people asking me if I had been sleeping around, all of a sudden I felt as though the world was seeing me differently, I had done something to deserve this?"

Both the participants take us through the journey of their experiences of feeling judged, criticized and undesirable. This is consistent with the literature on facing stigma, which highlights that the feeling of prejudice against people living with HIV results in the social exclusion of the people who suffer from it (Arias-Colmenero & Perez Morento, 2020). The review of literature also reveals that the experiences of stigma can have a devastating effect on the lives of those who are stigmatised, being imperilled to a plethora of unpleasant treatment including but not limited to social ostracism (Jugeo & Moalusi, 2014)

5.2.4 An identity that is always under surveillance

Lebel (2008) asserts that often people experience stigma, such that others exclude them by posing an assumed threat to others, assumed to violate social standards and consequently bringing about aversive emotions in others—the responsibility of evoking undesired emotional reactions from others by carrying a marred identity. Lopez *et al.*, (2021) highlight that this interaction as occurring within the societal context of the child, can inhibit their developmental goals, as this layer is a key aspect in the child’s social ecology of interaction. In particular, Nomfundo’s experiences highlight the notion of the assumed threat to others. The stigma that is associated with her lived experiences speaks to the notion of being scrutinised.

Nomfundo: OK, so um, most of the kids in the community went to the same school, so, of course, my status was broadcasted in the school, and you know the little friends I had started ignoring me. I was isolated in class and teachers never really took an active role to try and stop the bullying and all of that. It's something that they just ignored. You know, they just did.

The teaching and then they moved on with their days. So sometimes I'll be pushed around, sometimes I'll be laughed at like publicly. Or when I'm walking around, people past remark or call me names or, you know, they. They took my status and made it my label. They would either call me HIV or they'll call me a ghost because you know, the misinformation makes people think that if you have HIV, you will die and whatnot.

Though disclosure often can open spaces for social support which in turn can foster resilience and enable individuals to live life without the fear of discrimination, disclosure can also open one to possible experiences of bullying and social exclusion (Murphy *et al.*, 2009). When

disclosure happens, one risks being exposed to all forms of harm as well, which oftentimes can be detrimental to one's well-being and ability to exist as a social being. The fear of disclosure in this instance alludes quite significantly Malin *et al.*, (2023)'s position on historical trauma as a key moderator to vulnerability to ACE exposure, hindering the health trajectories of the affected youth. Disclosure for Nomfundo demonstrates how the interactive relationship between the stressors in her life and her personal attributes becomes strained, threatening her capacity to recover from this experience (Garmezy, *et al.*, 1984).

Nomfundo finds herself subject to possible malicious gossip from her neighbours, peers and people in the community. This exposure subjects her and her family to various kinds of verbal abuse. In a study involving African Immigrant women in the USA, it was found that the women did not disclose their positive status for fear of being socially excluded by other Africans. This is because HIV is often considered a moral issue, and this may pose a threat to the entire family's status (Korner, 2007). Disclosure in minority and closely related communities is also influenced by the need to be acculturated into the larger group and maintain a sense of belonging. In expanding on the ACE model, Bernard *et al.*, (2021) state that by overlooking the exclusive stressors encountered by minority groups, there is a missed opportunity to integrate traumatic experiences of specific significance to marginalised populations. However, as evolving theories of resilience posit that individuals are responsible for developing themselves, the expectation of Nomfundo to organize her dispositional attributes to mitigate her disclosure experiences without the assistance of her community becomes challenging (Theron & Theron, 2010).

In most African cultures the family is often held accountable for the behaviours and the lifestyle of the individuals within the family, therefore, "unhealthy behaviours" may then be viewed as traits that are characteristic of the entire family and their inability to correct the so identified risk behaviours (Lili *et al.*, 2008). Hence, Bernard *et al.*, (2021) argue the imperativeness of acknowledging racial and ethnic experiences as formative to how ACEs unfold within different population groups. Nomfundo found herself being the victim of the same narrative around her family image and perceived unhealthy behaviours that were seen as indicative of the family's inability to control themselves. An interplay of what Garmezy explores as protective vs vulnerability, which in this case is Nomfundo's family vs the stressor – social rejection and vindication (Garmezy *et al.*, 1984). However, one notices how there

becomes a shift in perspective in the presence of supportive structures, Nomfundo, growing up in a seemingly judgemental environment, experiences a shift in support as she moves in with her aunt.

Nomfundo: my support system became then my aunt where it was now a strong support system because there was. An environment of open communication that she created. She was not married. She did not have kids of her own, so it was always just me and her, and she wanted to make sure that I knew that it was always safe for me to speak to her about experiencing something difficult. And if I didn't understand something it was OK for me to bring it up with her and then she would help as much as she can wherever she can. When she came to my status, I learned about...What is HIV really mean from her, So whatever emotional distress I experienced while discovering my status and learning how to live with that. She was there to help me through the process. The process of understanding and the process of learning how to live with it.

Howard and Johnson (1990) highlight that the consistency, quality of care and support that a child receives plays a significant role in fostering resilience. Nomfundo experienced the availability of a caregiver who was able to provide reasonable attention to her, consistent with the ACE model, acknowledging her experiences outside of her illness such as academic excellence and helping to foster meaningful relationships allowed her to thrive in reality of her illness (Chiang *et al.*, 2015). When an identity that is often under surveillance or scrutiny is protected by spaces such as family and friendships and structures are put in place during adolescence, it creates an environment that enables and fosters resilience.

5.3 Theme 2: Stigma, discrimination and Marginalisation

5.3.1 Stigma

Living with HIV often carries severe social ramifications, amongst which is the experience of being stigmatised, and that is devaluing. Stigma theorist Goffman (1963) defines stigma as “an attribute that is deeply discrediting” (p. 127). In this definition, Goffman posits an experience of a damaged character, tainted to say, particularly in social relationships. Additionally, Herek (2009) defines stigma as “the negative regard, inferior status and relative powerlessness that society collectively accords to people who possess a particular characteristic or belong to a

particular group” (p.441). Now, these descriptions of stigma share a common source of stigma, which is not the stigmatised individual, but rather the larger societal stance. Individuals living with HIV ACEs are often linked to poor health outcomes (Wolf *et al.*, 2019). Participants in the study share common experiences of feeling inferior and powerless due to their HIV illness. HIV stigma often is dependent on the discourses around the HIV illness, Ideas that are commonly shared in communities hugely impact interpersonal relationships with those who live with HIV.

Participants in this study demonstrate an experience of both enacted and internalised stigma, Fuster-Ruizdeapodaca *et al* (2104) describe enacted stigma as the actual social process of discrimination, prejudice and exclusion as experienced by the stigmatised individuals, while internalised stigma speaks to the individual’s acceptance of stigma as a part of who they are. Now, Santos *et al.*, (2005) express that one cannot understand stigmatisation outside of identity changes. It became prevalent in this study how tragic the impact of stigma is on one’s self-concept, quality of life as well as social support. Rohleder and Gibson (2005) assert that women living with HIV and other sexually transmitted diseases are often faced with the stigma of being viewed as being dirty, damaged, and sometimes deviant. Consistent with ACE studies, which highlight that exposure to childhood adversities increases the likelihood of psychological distress, and in this regard stems from not being valued (Brewerton, 2022). Moreover, the experiences of feeling undesirable all seem to stem from the core feelings of not being validated, valued, or seen. The three participants share similar experiences as described. In their pursuit to belong, and form meaningful relationships, the participants were often met with the negative stereotyping of their stigmatized identities. The review of literature also reveals that the experiences of stigma can have a devastating effect on the lives of those who are stigmatised, being imperilled to a plethora of unpleasant treatment including but not limited to social ostracism (Jugeo & Moalusi, 2014).

5.3.2 Stigma in the homeplace

It is one thing for an individual to be subject to victimization by the larger community, however, the utter rejection and abuse from within the family made it more difficult for Nomfundo to develop internal resilient strategies. ACE studies have revealed that the lack of support and acceptance from one's family renders one vulnerable to psychiatric and behavioural difficulties (de Sylva *et al.*, 2012). Centuries post the outbreak of HIV, the fear of being labelled by being HIV positive still stands. The participants' experiences allude to the importance of maintaining a family image that is not tainted by an association with HIV. For Nomfundo, the experience of being HIV meant shame that was carried by her father, shame that grew resentment. Wethington & Kessler (1989) argue that the point here is that even the perception of support can enhance one's health as the perception can mitigate stress by adjusting the severity of the adversity. Nomfundo alludes to her experiences of living with HIV in a home where she is the only one infected. The feelings of shame, and experiences of isolation as she lives in the reality of being the only one different from everyone in the home.

Nomfundo:... My father was also someone who drank. So even if you hide yourself sometimes you'll come and he would be violent and throw things around. Wake us up, beat us up. Hurts my mom or you know, stuff like that. And the one nice way we would have to stay outside because things would get dangerous and my mom would take me and my siblings to sit outside the house I can't really call it a house, but we would still have quite the House just to..to protect us because you know the way it is and my dad would really be enraged and I couldn't help but feel like it was all because of how I handled everything. But I was young. Of course, I was still a child, but I didn't know any better than to blame myself for the state of our home...

For Nomfundo, the day-to-day struggles included surviving her abusive father who often blamed her mother for Nomfundo's diagnosis, thus causing conflict within the family. Link and Phelan (2006) posit that abusive behaviours targeted towards individuals living with HIV are often influenced by the social context. Nomfundo was subjected to her father's anger towards her mother for causing disgrace to the family, a rage that is then expressed through physical and verbal abuse. An experience that contrasts with what Dlamini *et al* (2007) have described as a common experience in households with individuals who have HIV. Research also suggests

that women living with HIV have a significant chance of being in an abusive relationship as an HIV diagnosis is a potential trigger to violence and conflict within a household (Hatcher *et al.*, 2015). Developmental theories further highlight that the family is a natural space for children to grow and develop, children spend a significant amount of time with family, and as such they see a lot of attitudes and behaviours in the family, thus it is the family environment that shapes the child's attitudes and behaviours, they absorb from their environment (Tanju *et al.*, 2024)

The absence of positive family interactions and experiencing irregular support within the family are yielding towards negative adaptation for Nomfundo, (Crowley *et al.*, 2022). A contextual experience that Bernard *et al.*, (2021) argue should not be viewed outside systematic inequalities, positing that experiences of ACEs in the home for many black people, such as violence cannot be conceptualised without the acknowledgement of the unequal distribution of the economy which affects the education of those in lower-income homes. Here, Bernard *et al.*, (2021) suggest that the violence that is predominant in most black homes is often a result of structural and systematic failures on black children and communities.

Domestic violence has a greater impact on the family system, resulting in various behavioral and emotional adjustment difficulties for the children (Howell *et al.*, 2016). When Nomfundo and her younger siblings witnessed the violence in the home it brought about feelings of guilt and a diminished sense of safety. When a child becomes aware of their caregiver's ill-treatment it can cause permanent damage that then interferes with both emotional and physical development (Walker-Descartes, Ingrid *et al.*, 2021). This experience is supported by the ACE model, which acknowledges the value and impact of one's social and local context on their vulnerability to violence and family distress (Brewerton, 2022). The trauma of being ascribed a marred identity becomes compounded with the trauma of being subject to abuse within the home. Martinez- Torteya *et al.*, (2009) state that in children exposed to violence this may likely disturb the development of adaptive systems and in the process undermine positive adaptation. When individuals living with HIV experience stigma and discrimination outside of their household, many may resort to running away from home for safety and assurance. However, a compromised sense of safety in the home becomes detrimental to one's survival. Further, research show that Intimate Partner Violence exposure is a significant risk factor for internalizing violence (Menon *et al.*, 2018). Nomfundo was already suffering a

great deal of internalized guilt and shame, and as such the added exposure to violence seeks to perpetuate the guilt and does not help foster resilience.

When children are exposed to such adverse home environments, it can pose a risk to both their mental and psychological health (Boyce *et al.*, 2021). Research on childhood development highlights that it is imperative to pay attention to children's health from an early age because it will impact their psychological development, as it is in childhood that nerves are more vulnerable and easily damaged by toxic chemicals than adults (Tanju *et al.*, 2024)

For Nomfundo, a potential risk of a shortened life is eminent, as her experiences are compounded by exposure to abuse. The presence of her academic achievements and self-regulation skills suggests that at times resilience comes from ordinary protective processes, common but powerful protecting one's development under adverse conditions (Lopez, Shane & Snyder 2009). Resilience can arise from ordinary processes that enable individuals to thrive. In addition, the home environment as one of the roots of the ecological system in building resilience becomes a stressor rendering Nomfundo's multisystem of resilience threatened (Twum-Antwi, Jefferies & Ungar, 2020).

5.3.3 In the Families.

Participants discuss similar experiences of disclosure as a requirement to access care and how that can facilitate shame within individuals. With the level of stigmatization that exists, Researchers also posit that there is a corresponding secrecy that supports the silence, with the subject of HIV being completely avoided in some families. (Duffy, 2005). Cindy's encounter in particular highlights the significant levels of shame that she had to navigate to make sense of her illness. A hidden diagnosis masked in the mars of another sickness, an expression of shame within families.

Cindy: "No, growing up I feel like it was different you know, remember I said I didn't even know why I was taking the medication that I was taking, so my parents would constantly fight about money and I would hear them mentioning my medication and health and how it was costly, so I felt bad because I thought that these kidney stones were costing my family soo much money mos,. I would get the medication, but it felt like it was a struggle or there were tensions in that, so because I was young I did not want to ask too many questions, you

know, in black families, you don't ask too many questions because maybe they will think that you are being rude or ungrateful"

When a health condition is concealed, it may potentially limit an individual from learning about it, learning about the possible effects and treatment thereof (Smith & Niedemyer, 2009). When families perceive that disclosing a family secret may result in violence, from others, one's willingness to disclose the family secret then becomes disgruntled (Afifi & Olson, 2005). As research and ACE studies have alluded, there is often an unwillingness to disclose an individual's status to those outside of the family for fear of discrimination or tarnishing of the family name. In Cindy's case, the difficulty arose in that her HIV status was concealed from her. Cindy shares that as a child she took HIV medication that her family disguised as Kidney Stones medication. Dube (2014) shares that children are often reliant on their parents/caregivers to offer guidance through significant times such as death, and HIV, however, the silence and hidden information from parents' sows seeds of mistrust. Research has found that children who often receive 'partial disclosure' from their parents are told limited information about the severity of the illness however, the term HIV may not be used, and the challenge often exists in complete non-disclosure when the parents deny the existence of the illness and hide it behind other health conditions (Maureen & D'Angelo, 2006).

At the age of 15 years, she discovered that she was living with HIV, this revelation occurs at a stage that Erickson highlights to be a point of identity achievement, where Cindy assesses her strengths and weaknesses and determines how she wants to deal with them, how she wants to deal with this stigmatised identity, answering key questions of who is she? And who does she want to become? Erickson's developmental theory posits that "identity is not readily given to the individual but, it must be acquired through individual effort"(Erikson, 1959,p.51).

Cindy's self-discovery of her HIV status meant sitting with a lot of emotions, self-blame, and a lot of questions. Dyk (2012) alludes to this notion, by highlighting that often parents may struggle to tell their children about their own HIV status hence it becomes even more challenging to tell their children they are HIV positive. Much of this hidden status appears to be rooted in a lot of shame, rather than perceived shame from others, outside the family structure. The need to protect the family from being discriminated against, and to maintain a particular view of the family structure could potentially be compromised by a disclosure to

others. However, the fear in itself comes at a cost to the child's well-being, and the right to make responsible choices in their interactions outside of the home. Dube (2014) shares that disclosure to children reduces the adolescent's careless and risky behaviours such as stopping medication or going out of their way to infect their sexual partners.

Research suggests that oftentimes, family members have similar feelings as to those living with HIV, they carry the same, fear, anger, and uncertainty of the illness and consequently, the stigma that comes with being HIV positive (Iwelumone *et al.*, 2008). As such, these individuals may seek to protect themselves from possible violence and discrimination. For Cindy, being in an environment where her status was not discussed with her, hidden from her and being lied to exacerbated her fears and uncertainty around her diagnosis. The fear of the unknown would then impact how she relates with her family, her peers and ultimately herself. What does this newfound diagnosis mean for her, and why is it that her family has hidden such an important aspect of who she is? There is an enacted shame that is experienced, a social identity and construct that translates to families and holds people on guard of the life that they can live and how they can live it.

Concealing status can hurt those who conceal as social support from other family members can be limited, however for the child this can undermine their well-being as well as mental health (Daniel, 2015). The crisis of confidentiality, which refers to the fear of one's status being shared with everyone and as such resulting in discrimination and/or rejection becomes a huge factor in determining disclosure to the infected child or adolescent (Fombad, 2001). As Cindy goes through the different phases of confusion and denial, she begins to feel the feared emotions and experiences leading to secrecy. She begins to blame herself, feels shame for carrying an identity that the family feels shame for identifying with, and internalised stigma, and for a while, she begins to isolate herself from her friends in fear of being seen and possibly passing on an illness that she carries. The secrecy then carries double-edged harm of potentially perpetuating internalised stigma in efforts to protect the family image. Once learning about her diagnosis, Cindy, like many young people living with HIV needed to make difficult decisions about whether she was going to stay silent or disclose her status to her friends, possible sexual partners and other significant people in her life. Cindy appears to have felt such tremendous pressure around the decision of disclosure. In her interview, she used words such as fear, terrified and confused when she spoke about her feelings around

disclosure and her silence for the early days of discovery was heavily located within the context of personal family relationships.

5.3.4 In the Schooling Environment

Asikia and Mohangi (2016) highlight that one of the major difficulties in South Africa is how adolescents can be protected, particularly those impacted by both the psychological and emotional risks. Similar to the home environment, the provision of a safe schooling environment with adequately trained teachers and adequate resources would enable these adolescents to reach their full potential. The ACE theories have demonstrated the importance of a social-ecological view in discussing childhood experiences, and pivotal to the ecology is the school environment which fosters significant developmental goals and milestones (Thabrew *et al.*, 2012). Simphiwe takes us through the experiences within the schooling environment how that potentially impacted her ability to exist in the classroom, and what that meant even for peer relationships.

Simphiwe:...The teaching just went on, and then they moved on with their day, without reprimanding it or anything, sometimes even giggling at jokes made by the other kids. So sometimes I'll be pushed around, sometimes I'll be laughed at like publicly. Or when I'm walking around, people past remark or call me names or, you know, they. They took my status and made it my label. They would either call me HIV or they'll call me a ghost because you know, the misinformation makes people think that if you have HIV you will die and whatnot. So they call me a ghost So the word, you know, push me around, trip me in the hallways and it was a very lonely experience because there was no one to turn to and things at home were now difficult because of me.....

Simphiwe provides a seemingly distraught experience of being an HIV Positive learner, and what that entailed with regards to her interactions with other learners. Children living with HIV are often susceptible to experiencing stigma at school. For children who are at the school-going age, the schooling environment is a significant factor in fostering resilience (Sharp *et al.*, 2019). School connectedness has been defined as “the belief by learners that adults in the school care about their learning as well as them as individuals” (Sharpt *et al.*, 2019, p.102). It appears that it is at this level that children can be tempted to adopt unhealthy lifestyles or

health-risk behaviours due to a lack of connectedness anticipated by the child (Brewerton, 2022). It has been established that schools are quite central to the lives of children and youth as they spend a large proportion of their time in schools. Njuguna *et al* (2003) highlight that enacted stigma or even felt stigma can potentially minimize one's academic performance and create social disparities amongst the learners, and consistent with the ACE theories, vulnerability to behavioral issues becomes a cause for concern due to this (Bernard *et al.*, 2021). Behaviors and attitudes that perpetuate stigma, particularly by teachers, can influence the attitudes and behaviors of other peers (Martin *et al.*, 2020). Teachers often have an important role to play in the classroom, to support all learners, even those living with HIV, therefore, how they treat those living with HIV may have huge implications (Chao *et al.*, 2010). Simphiwe experienced stigmatized attitudes in the form of bullying from her peers. Simphiwe was subject to name-calling and being laughed at by her peers. An experience that was both daunting and distressful for her.

Simphiwe: "I was scared, because, at school and they spoke about it, didn't sound like something nice, like something you would not want to have with sound, You know, so to now know that it was something I have and it's. It's something that other people can't have, they couldn't. They didn't seem to understand it, it seemed, so it was scary because you feel like it's a secret you're keeping and everyone else is, like, you know, scared of it. But you know you have it and nobody else knows"

Children always experience these augmented challenges particularly at school simply because it is often a place of extreme scrutiny particularly by peers, there is very little privacy as well, and this increases stigmatized experiences as one may have little autonomy over disclosure (Johnson-Perez, 2022). Furthermore, children become vulnerable to anxiety disorders due to this fear, exposing the affected children to a cumulative experience of psychiatric illnesses as stipulated by the ACE model. (Brewerton, 2022) Disclosure in the school environment can also mean a loss of friends, being bullied, and sometimes being socially excluded from various activities such as sports (Johnson-Perez, 2022). 'Ghost' is what they used to refer to Simphiwe and that itself is indicative of the social context. The use of these and other related words allude to the attitudes and beliefs that the learners hold about experiences of being HIV positive. The home and teacher attitudes among children and adolescents often influence beliefs and knowledge of HIV. Ashaba *et al* (2018) highlight that bullying is a significant

concern for adolescents living with HIV as this marks a critical time in their life where there is great value placed on peer relationships and interactions. Considering that the school environment plays a pivotal role in the development of competence and adaptive systems needed to foster positive adaptation, a negative experience in this environment compounds negative emotional outcomes (Obradovic *et al.*, 2012). Malin *et al.*, (2020) suggest that Simphiwe's experiences in the school environment can cause progressive physiological changes that can potentially last adulthood and bring about psychological distress later in life.

The mileage of difficulties encountered by children living with HIV as experienced by Simphiwe, alienates individuals as they are seen and experienced as different (Nginya *et al.*, 2016). This experience then led children and youth to withdraw, as Simphiwe began to isolate herself from various activities and interactions with her peers. Now, we can begin to then trace poor participation in activities due to withdrawal. In her choice of words in the interview, she describes feeling shame, feeling diminished and different from her peers.

Cindy: You know when I found out about my status, that I was HIV positive, hay, my high school experience changed. Like even though my teacher did not know, and classmates did not necessarily know, I became scared, that people will find out. Will I lose friends? I was also a well achieving student so I worried that people would treat me differently, I mean I would sit in class and hear jokes about HIV, like one time this girl in my class was sick and she had lost some weight, people would make fun of her and ask her if now has the three letter sickness, at that moment my heart would sink a little, because, I myself am still coming to terms with this big thing.

The schooling environment also appears to have perpetuated self-stigma for the participants, particularly being nervous about being stigmatised, consequently leading to one internalising some of the negative stereotypical beliefs about individuals who live with HIV. The fear and shame that continued to build for Simphiwe and Cindy did not make school any better or safer for them to exist freely. Importantly, due to generally high levels of school dropout in high schools, learners who are affected by HIV could be at a higher risk of leaving school, and educational support could be a key moderator to instilling hope and encouraging grit and resilient outcomes among the learners (Watkins *et al.*, 2014).

5.3.5 Friends and Peers

In their pursuit to belong, and form meaningful relationships, the participants were often met with the negative stereotyping of their stigmatized identities, and this, in turn, has left a common experience of stigma within friendships and peers. When asked about her experiences of being HIV, Nomfundo expresses it this way;

Nomfundo: "So um, I stayed away from people. I avoided people as much as possible when I was home, I made sure that I did not bring too much attention to myself when my father was at home because I didn't want to watch him react to my presence, and so that there would be some form of peace in the house and it could be mean having accepted. Or it could have been fear. But I made sure that I was being excluded, I embraced it and I isolated myself even further. I made sure that when I was at school, I did what I needed to do at school and I left school immediately. I just felt like people didn't want me, and I did not want to make them feel uncomfortable, I felt like shit you know, unwanted, and I was not going to be a bother."

Nomfundo's experiences are a testament to the experiences of isolation as a measure of protecting one's self from possible discrimination. As highlighted before, social support from family, community and peers will impact greatly learner resiliency and perception of good health (Stewart & Sun, 2004). The process of shrinking so as not to make those around her uncomfortable. In similar accounts, Cindy shares that

"Ohh ohhh! There was a time when my friend circulated my TikTok video to my other friends, so there was no conversation it was the video where I talked about my experiences doing rounds all around everyone. So my one friend asked me about it and that's when I said something, otherwise, everyone watched the video and just gave me looks and weird vibes. I guess what hurt me was how the person delivered it and circulated it, and sadly, that was never my intention. I intended to spread awareness and not for it to become a thing. All of a sudden things changed a bit around me, I know I'm not too bad looking, but it felt like my people, I mean the people I knew, felt and thought differently of me like I wasn't it." (Cindy)

Both the participants take us through the journey of their experiences of feeling judged, criticised and undesirable. This is consistent with the literature on facing stigma, which highlights that the feeling of prejudice against people living with HIV results in the social exclusion of the people who suffer from it (Arias-Colmenero & Perez Morento, 2020). The review of the literature and ACE studies also reveal that the experiences of stigma can have a devastating effect on the lives of those who are stigmatised, being imperilled to a plethora of unpleasant treatment including but not limited to social ostracism (Jugeo & Moalusi, 2014). In a study conducted in rural Eswatini researchers found that the young women interviewed had experienced various negative psychological effects after being diagnosed with HIV, including unresolved grief, fear of stigma and discrimination, rejection, isolation, loneliness, and suicidal ideation (Nsibandze *et al.*, 2021). Cindy's experiences of feeling rejected and judged stem from the fear of perceptions and possible changes in interactions once her classmates find out about her status. The ACE theory then suggests that disruption in this system of support that she had built before her status was disclosed becomes threatened and the fear of being taken away brings about anxiety, the anxiety of living with HIV (Lopez *et al.*, 2021).

Both Cindy and Nomfundo share very similar yet different experiences of being undesirable, rejected and discriminated against based on their HIV status. The fear of being discriminated against may cause one to isolate before they are isolated and withdraw to protect themselves from the possible harm of being actively exposed. The ACE model recognises experiences of discrimination as one of the key determinants of vulnerability to emotional difficulties in children exposed to ACEs (Bernard *et al.*, 2021). Self-isolation can occur for numerous reasons, some of those being feeling inferior, self-blame for having a positive HIV status, and internalised stigma as a result individuals can ultimately condone the discrimination and as such avoid social interactions (Xie *et al.*, 2017). For both Nomfundo and Cindy, their ability to be resilient is not just dependent on their character dispositions, but their experiences of family cohesion and external structures such as the community (Tuppet *et al.*, 2015).

It also appears that in the two interviews, both Nomfundo and Cindy experience anxiety from a lack of control in how the information is disseminated to others, the lack of control in how their HIV status is shared with others means that one has no control over the narrative that comes out of the information that is shared. Chaudoir, Fisher & Simoni (2011) highlight that

though disclosure is important to increase one's social support, it may consequently place them at the risk of being discriminated against.

It appears that for the participants disclosure of status and exposure to others was associated with being unwanted and undesired. As such, the participants' reaction of self-isolation, withdrawal and avoiding social interactions served as a protective mechanism towards the perceived harm that would potentially come with being discriminated against. Quite interestingly to the study is the need to control disclosure, to disclose or not to.

5.3.6 In the Community

Gilbert and Walker (2009) highlight that the community's views of HIV are often based on subtle malicious beliefs which are often towards women, and in turn, people then fear existing in contexts where they are identified as being HIV positive, seeking to avoid the gossip from around them.

Nomfundo....And you know like I said, where I lived people did not have the luxury of things being private, so the fact that the surrounding neighbours and the whole community was making unkind statements about us did not sit well with me. See, in the beginning, I thought people were just being mean, but I came to realise that It was because of us, my family that's why they were speaking so much. So being part of like a community like that can have its advantages because you ask each other for help, like mealie meal, or sugar or babysitting, or if the church people had arrived, people would know to call each other to collect food, but It also meant that when you felt isolated and looked at it was also just as intense and like heavy, so it wasn't nice you know? Like I just wanted people to forget about us, because as child you never understand mean statements.

Nomfundo takes us through an experience of being visible and yet isolated, an emotive experience of a 'plague' something to be discarded with and considered filth. The experience of being the only one in her family living with HIV, the burden of putting her family in shame, even in an experience that she had no control over. The various manifestations of stigma often result in its losing status, being devalued and sometimes unfavourable outcomes for those who are at the receiving end of the stigma (Hover *et al.*, 2019). Nomfundo's status poses a threat to the loss of these communicable experiences not just for herself but her entire family

as well. Conversely, one can choose to conceal the information to fit in as 'normal' to avoid the possibility of being discriminated against (Deanna, 2006).

Nomfundo finds herself subject to possible malicious gossip from her neighbours, peers and people in the community. This exposure subjects her and her family to various kinds of verbal abuse. In a study involving African Immigrant women in the USA, it was found that the women did not disclose their positive status for fear of being socially excluded by other Africans, as HIV is often considered a moral issue, and this may pose a threat to the entire family's status (Korner, 2007). Disclosure in minority and closely related communities is also influenced by the need to be acculturated into the larger group and maintain a sense of belonging. In most African cultures the family is often held accountable for the behaviours and the lifestyle of the individuals within the family, therefore, "unhealthy behaviours" may then be viewed as traits that are characteristic of the entire family and their inability to correct the so identified risk behaviours (Lili *et al.*, 2008). Nomfundo found herself being the victim of the same narrative around her family image and perceived unhealthy behaviours that were seen as indicative of the family's inability to control themselves.

Simphiwe.. Uhhh, I, I, I don't think anyone was brave enough to say anything. But you know it's just how people behave. I know some of the mothers knew because, for example, the one lady used to work at school and I know my teachers knew about it. So I think I am. I'm I'd like to think that maybe somehow she told some of her friends from the neighbourhood, so some of the kids started to act different and you could just see that they didn't want to include me in the circles when they played and Uh, yeah..

Simphiwe's experiences take us through the loss of friendship because of disclosure. Though disclosure often can open spaces for social support which in turn can foster resilience and enable individuals to live life without the fear of discrimination, disclosure can also open one to possible experiences of bullying and social exclusion (Murphy *et al.*, 2009). When disclosure happens, one risks being exposed to all forms of harm as well, which oftentimes can be detrimental to one's well-being and ability to exist as a social being.

Disclosure in minority and closely related communities is also influenced by the need to be acculturated into the larger group and maintain a sense of belonging. In most African cultures the family is often held accountable for the behaviours and the lifestyle of the individuals within the family, therefore, “unhealthy behaviours” may then be viewed as traits that are characteristic of the entire family and their inability to correct the so identified risk behaviours (Lili *et al.*, 2008). Simphiwe finds herself being the victim of the same narrative around her family image and perceived unhealthy behaviours that were seen as indicative of the family’s inability to control themselves.

5.4 Theme 3: Socio-economic conditions

Research highlights a distinct relationship between socio-economic difficulties and communicable diseases such as HIV, particularly the potential to exacerbate already existing poverty (Whiteside, 2002). Though there is still a significant gap in the literature in making links between poverty and HIV, researchers have argued that HIV can worsen poverty by making it difficult for those in much poorer spaces to mitigate the impact (Tladi, 2006). Those mostly impacted by poverty are society’s most vulnerable population, the children, and this impacts their access to adequate housing and nutrition, medical access as well as education (Royce, 2021). The participants in this study all shared a similar experience of growing up in unfavourable economic conditions, lacking access to the most basic services, such as proper housing as well as adequate food supply. The ACE model recognizes this and suggests that social conditions such as poverty, and living in disadvantaged communities particularly limit healthcare access. There is also an inter-generational struggle for the previously disadvantaged communities (Malin *et al.*, 2021). Now, one’s socio-economic status can have a significant impact on their ability to navigate other stressors that may be beyond their control, such as the health implications of being HIV positive. Those living on the margins of society, often have limited access to health facilities, and this itself increases their likelihood of infections such as HIV (Bunyasi & Coetzee, 2017).

5.4.1 Food Insecurity

It has been found that food insecurity poses an incredible challenge particularly among those living with HIV (Nagala *et al.*, 2012). Coates, Swindle & Blinsky (2002) describe food insecurity

as “insufficient quantity or quality of food, reductions in intake, feelings of uncertainty or anxiety around food (p.17). For the participants, there appears to have been a significant amount of anxiety around the quantity of food, which would in turn impact on how they were able to take care of themselves and their families. Though urban informal settlements are often located close to some kind of business activity and housing areas, the reality of the informal settlements is a lack of basic services, such as clean water, electricity, and food (Steenkamp, Venter, Walsh & Dana, 2014). As the ACE model postulates, historical racism and inequality continue to impact what Nomfundo and her family have access to and have a direct impact on her exposure to ACEs (Bernard *et al.*, 2021). Nomfundo’s experiences living in an informal settlement, with an unemployed mother, an abusive father and three other younger siblings meant being exposed to compounded stressors beyond her diagnosis.

Nomfundo: Access to food was not easy. It was. It was. It was something very difficult. My parents depended on grants from the kids that they had so it. Was. We sometimes went to bed without food. We sometimes, Umm, you know, spent a day without food when we were at home but at school there was a feeding program, so it was, a good thing when me and my siblings and were all in school because we knew that even if there is no food at home, we would be able to have at least one meal at school and will it will sustain us for the day. So that was the way that I had to navigate. Food insecurity because there was no other way to access food. I remember that there were churches and, Charity groups who would visit the settlement to donate food or to run a soup kitchen, or who have a program and they donate groceries to some of the households and stuff like that. So there few times, were times, very, very, very few times throughout my childhood when groups like they would come and give a meal for the day or give groceries, to the community, but other than that, most of the families in my community were struggling to get food and because most of the people in the community were not working and so if my father didn't manage to find food, we would go to bed without eating because my mom stayed at home to make sure that all of the kids were taken care of because my youngest siblings were still very young at that time”

Verster (2012) describes poverty as a life in which individuals do not have access to necessities to cope with their lives, such as food, health care and adequate living. Nomfundo's family often went to bed on an empty stomach, with minimal food to accommodate the family. Developmental theories highlight the need for consistency and steadiness in early childhood care, noting the need to pay attention to firstly maternal health and secondly, food consumption so as to produce good brain development, this is important as brain development will influence cognitive development. (Tanju *et al.*, 2024)

Nomfundo shares her reality of experiencing food insecurity. The reality of living in an informal settlement and relying on a social grant from the government to take care of her entire family reflects the lives of many South Africans. The presence of even one individual with HIV can potentially threaten the food security of the entire family (Nagata *et al.*, 2012). This food insecurity occurs within a context of poor community-level income inequalities, among families that have low to no income (Kalichman *et al.*, 2019). The presence of an individual with HIV in a heavily disadvantaged home presents a unique crisis for nutritional deficiency and further scarcity in the home (Patel *et al.*, 2018). Nomfundo's experiences lie in what the ACE model identifies as the centred experiences of marginalisation which have an influential impact on her epigenetic mechanisms key for development (Brewerton, 2022). The need for individuals to have access to frequent healthy and adequate meals can cause a financial strain, particularly in low-income households. Being HIV Positive can potentially worsen one's nutritional status often leading to a deficiency in important nutrients. Gillespie (2009) alludes that the decreased food intake due to poverty highly impacts one's overall clinical outcome. It then becomes apparent that nutrition plays such an integral part in balancing food insecurity and health security. Brewerton (2022) adds that poverty as a common experience of ACE has detrimental long-term consequences on the functioning of the child's central nervous system.

Quite significantly is the distinction of unemployment as a result of generational traumas such as the apartheid system, and in South Africa, a system that disenfranchised black people (Mufune, 2015). Statistics highlight that in South Africa approximately 39% of the country's population lives on the margins of poverty and approximately 12% is susceptible to multifocal poverty (unemployment and lack of housing) (Adetoro, Ngidi & Dabso- Abbeam, 2023).

The challenge that exists for Nomfundo and her family is the dual challenge of firstly being vulnerable and lacking the opportunities to make things better for the family. The socio-economic impact of HIV appears to pose significant challenges, often pushing households to further poverty. Ijumba (2019) posits that the worst impact of HIV is at the individual and household level. Nomfundo's family already navigating unemployment and lack of housing as they live in an informal settlement and an uncondusive living environment made her susceptible to multiple vulnerabilities and challenges. Developmental theories highlight that favourable conditions are conducive to the development of the child's brain. A brain that develops optimally will influence children's cognitive abilities which will then enable the child to receive and process information well, so conditioning the child and the environment will be easy for the child. (Tanju *et al.*, 2024). Not only did she have to navigate the reality and impact of living with HIV in a small community but had to navigate poverty and a lack of access to basic services to help alleviate the challenges that she is exposed to.

..and it kind of, explains why I got sick, because, was because I was not getting enough nutrition in my body, not even to mention water because access to clean water was also difficult and the, the, the, the, the toilets that were used were community toilets. And you know, because it's an informal settlement, they're not sustained, they're damaged or you know, never clean...

Being malnourished can aggravate the effects brought about by being HIV positive and sometimes quicken AIDS-related symptoms (UNAIDS, 2010). Nomfundo needed access to adequate nutritious food and sanitary living conditions to avoid exacerbating her health conditions. However, constantly being exposed to unsanitary conditions and being malnourished put her health at risk. Ivers *et al* (2009) posit that a key contributing factor to ill health among those living with HIV is being malnourished. Her experiences pose integral questions of how one can mitigate the impacts of systematic issues that influence day to day experiences of the average individual who lives on the margins of poverty. Now, there is often a physiological aspect that is hugely important in monitoring one's well-being and the insufficient consumption of a poor diet heavily impacts one's immune system, compromising their ability to fight diseases and infections (Ivers *et al.*, 2009). The compounded vulnerability that comes with being physically weak can make individuals more susceptible to other health challenges and that itself is a risk to one's health. Nomfundo's difficulties around accessing

sufficient food to the point of relying on the school feed scheme to meet her daily health needs are indicative of the dire impacts of poverty on the livelihoods of the vulnerable, particularly those with health risks such as her.

5.4.2 Medical Care

The struggle of navigating compounded stressors is a common experience among the participants in this study. Poverty being such a significant element is suggestive of its impact on the livelihoods of those who live on the margins of poverty and inequality and how that itself is a perpetuating factor to the ill health and constant vulnerability of living with HIV or being impacted by either association or direct impact in the household. However, the lack of access to adequate medical care exacerbates what the ACE model describes as neuro-developmental impairments, which have a direct impact on one's connectedness to others and their own emotions (Bernard *et al.*, 2021).

Uh, so luckily I had I well my aunt, but she moved away. Uh, but now I'm old enough to be able to do it by myself, but when I was younger I had an aunt who worked at the hospital and the hospital is quite close to home. Uh, when I couldn't personally get my medication, she would bring it sometimes or it it was very close. And like I also said, my mom was very supportive and my sister, so I could go with my sister. She would accompany me. My mom would go with me also. And the thing is, I had to eat you know because of the medication, but when there was not enough food at home and worse my sister also got pregnant so it became very hard. There was a time when I was very sick, and my mother could not afford to take me for all the tests and pills, I remember her crying one time in her room and I thought maybe I was going to die. We could not afford to go to the doctor, and you know at the hospital sometimes you start at the clinic and usually no doctors there, whatever medication they say you must take you must go buy it and it was expensive. But you know sometimes it was also embarrassing to go to the clinic, sometimes the nurses would say, in the corridors, that there is a different queue for HIV medication, and now everyone sees you walking in that direction, eish, it just felt like the whole world was seeing us.

It has been estimated that approximately, 3.7 million children are orphaned in South Africa, and of those, about half are due to the HIV/AIDS epidemic (Frood & Pursell, 2020). Now, compounded on these prevailing conditions is the reality of living in the townships, where they have poor access to health care services and limited access to nutrition, this consequently leads to further illness, and a possible forced labour for these children (Frood & Pursell, 2020). Simphiwe's account of the struggle to access healthcare is a testament to the reality of the many marginalised individuals whose access to healthcare is stunted by financial availability, and synonymous with ACE theories which identify access issues as due to location. Poor and limited access to HIV Care is the key barrier to taking part in HIV Care, and that is poor attitudes from healthcare providers (Geter, Sutton & McCree, 2018). Simphiwe's difficulty in accessing medical care appears to be stunted by three main experiences: **Affordability** of medication due to financial limitations. Shisana, Zungu and Pezi (2009) state that to make sense of the interlink between poverty and HIV it is key to understand the socio-economic processes that are deeply entrenched in the schism of the African economy. Considering single-parent households are a key example of this, as these are very common within the South African culture. Raniga, Boecker and Mthembu (2019) state that 23% of the total population in South Africa belongs to single-parent homes. Single-parent households are therefore most likely to face higher costs than those in dual-parent homes (Morelli *et al.*, 2022). **Interaction with service providers** often appeared to be engulfed in stigmatised experiences. Healthcare professionals ought to be empowering and working to enable the children and their families to adapt to the new life of being HIV-positive. Lastly the **availability** of the health care services within her area, which was limited and centralised in the same area.

5.4.3 Education

The education system in South Africa is embedded in racial segregation, with funding being previously distributed in favour of predominantly white schools, such distribution would often result in poor quality in black schools and as such learners attending schools in townships or low-income schools would struggle with making payments (Dass & Ringwest, 2017). The school environment is a critical aspect of development, the Quantile ranking has allowed poor schools to receive funding such that learners are not discriminated against due to income disparity (van Dyk & White, 2019)

Although there have been more stringent rules on access to education for all, most schools, such as the one Simphiwe went to, are reliant on the school fees money to cater for the needs of the learners as the funding often may not be adequate to cover the costs. Van Dyk and White (2019) state that the poverty scores may only reflect based on the geographical area within which the schools are located, as such poor learners may be found in schools ranked according to higher quintiles. Therefore, for the participants, it meant that these barriers to access to education meant that sometimes there were school days that were missed and learning stunted.

Simphiwe: OK, uh, growing up was, it, it was a bit difficult. Like I said, my mother is a single mother, so, uh, she had to raise me and my siblings by herself. So, I think it was hard because there was no father figure and umm like I said, I stay in the South of Johannesburg so it's not too safe, so you can imagine having a single mother and she's always at work and it's just us as girls..... there's, there's quite a lot. Uh, like for example? I remember being sent home from school, because we had, well, both me and my sister, hadn't paid school fees, so sometimes we had to come back home because they had the system where if you hadn't paid your school fees, you had to come back home. But my mom would try and pay when she could. So sometimes they'll be some months, really can't go to school because school fees aren't paid.....Another thing is that my sister also had a child at a very young age, and I think that that makes finances even more strained because babies are expensive. So now we have a small child to look after and, Yeah, Pampers, the formula is really expensive and my sister also had to start working, so she dropped out of school and she had to start working and, yeah. So, I would have to look after the child also. You know, now we had to pay for daycare because sometimes I'd have to go to school. Yeah. So finances were very tight....

The compounded stress of being subject to the unequal distribution of resources, denial of resources and in this case being denied access to education, limited access to employment opportunities and as such an impact on the entire family (Shisana *et al.*, 2009). Being denied access to education due to financial constraints meant that she was exposed to more vulnerabilities and as such at risk of not being properly equipped to manage her health. Apart from limited access to education, she had to take extra responsibilities in the family by looking after her sister's child and taking care of the household while her mother was at work. These

responsibilities deprived her of childhood experiences such as interacting with her peers. As ACE theories have posited, a lack of access to social spaces that may foster interpersonal relationships and provide added support for Simphiwe meant that she was isolated and had minimal friends with whom she could interact (Malin *et al.*, 2023).

5.5 Theme 4: Resilience

Literature has highlighted the weakening impact of HIV on one's wellness, however, it is also apparent that not all children growing up in adversity will exhibit poor outcomes (Bireda & Pillay, 2018). Some individuals seem able to demonstrate incredible resilience in the face of adverse situations. Despite the challenges of living with HIV as highlighted in the themes above, and exposure to various ACEs, the participants in this study have demonstrated tremendous resilience in their ability to successfully manoeuvre the challenges and ultimately experience better. Being exposed to poverty, discrimination and other health disparities can potentially pose a risk of a shortened life span. However, understanding various protective factors, resilient strategies and influences can be pivotal in understanding the concept of resilience in children living with HIV. Guided by Garmaezy's (1984) ecological approach to resilience, the following themes related to the multisystem that the participants exist in, and their interaction to foster adaptive mechanisms.

5.5.1 Own aspects of resilience

Though exposure to HIV, often confers risks to both development and well-being throughout one's childhood, consequently impacting their quality of life in adulthood. Expanding on the effect of ACEs on autonomic functioning, Berens, Jensen & Nelson (2017) state that experiencing abuse or being neglected in childhood can lead to premature mortality. Therefore, it is interesting to note how these individuals develop coping mechanisms and strategies that foster resilience in their adulthood (Serios *et al.*, 2022). Because it is at multiple levels of functioning and through various mechanisms of process that adversity has the potential to threaten stability, individual traits have been identified:

Cindy: When I finally found out what the medication I was taking was for, I was confused, and I didn't understand why or even how, because I had not even heard it in the house, you know, just how? Like I didn't understand. So because it was hidden from me, I spent so much

time on the internet googling about HIV, how long I had to live and if I was going to die anytime soon. I was doing this all alone and didn't ask anyone for a little bit. But I think coz like I was a bit angry, at some point I lashed out at my parents, and I was met with just being dismissive. Typical of black parents you know? To act like something was not happening, but nana (me) I prevailed, I even started a TikTok account to spread awareness, I decided I was going to emotionally show up for myself, and live my life without fear. After I finished high school and got accepted at UJ, I moved out of home and stayed at res, my parents were a bit worried, and I was too, but life has to be lived right? I'm still scared, but I have accomplished so much in my life so far, passed grade 12, like it's happening you know?

'Life has to be lived'. Cindy shares how she had to make sense of an experience that was not just hidden from her, but a scary discovery that she made without the guidance or support of her immediate family. Her ability to manoeuvre adversity speaks to the innate aspect of resilience. Adversity as described by Gartland *et al* (2019) is "exposure to hardship as a result of social circumstances" (p.1). Children who are subjected to adversity are said to be likely to experience various developmental challenges, both emotionally and behaviourally, with an overall impact on well-being (Berens *et al.*, 2017). Navigating financial difficulties due to the medications and frequent doctor visitations, to carrying an identity that makes her vulnerable to stigmatisation, and regardless of these mass challenges, the majority of the young people living with HIV do not just 'strive' but they 'thrive', they attain their educational goals and can transition to adult roles without much difficulty. (Harrison & Li, 2019).

Research has found that "self-efficacy, motivation, and even more nuanced cognitive factors, such as having a positive outlook on life and a belief in one's sense of purpose" (Harrison & LI, 2018) play a significant role in facilitating resilience amongst the young people living with HIV. For Cindy, this is demonstrated by her choice of words in describing how she chose to navigate what may have been one of the most difficult realities. Cindy's experiences allude to what the ACE theory denotes as rough early environments which potentially impact the development of one's psychosocial dispositions (Taylor, Way & Seeman, 2011). Transitioning into independence and more adult roles appears to have been a stepping stone to understanding herself better.

Having a sense of meaning in one's life has been linked to a better state of mental well-being, and consequently, a reduced level of risky behaviours, for Cindy this sense of meaning served as a protective factor against the detrimental effects of adversity on health outcomes (Du *et al.*, 2017). It has been demonstrated that children often develop their resilience, i.e., optimism, persistence, and capability based on their experiences in coping with difficult life experiences (Chi *et al.*, 2019). "High levels of resilience mean that children may be able to find meaning in their lives" (Du *et al.*, 2017, p.1). This became the experience for Cindy, being able to find meaning in life, and having resilience, was an experience that helped her mitigate any possible mental health effects such as depression. Outside of an individual's ability to tap into innate necessities that drive positive outcomes is their interactions with family.

5.5.2 Family

Family can play an important role in fostering resilience among individuals. Simphiwe describes her family, particularly her mother as a significant support system that played a role in being able to navigate bullying at school and within her community, and ultimately being able to show up in various ways. When families create conditions that promote the well-being of the individual and family, buffering and mitigating the risk of abuse while simultaneously promoting resilience they foster an ability to successfully adapt to conditions and situations that potentially threaten the well-being of the individual (Benzies & Mychasiuk, 2009). The family unit can often become a significant advocate for the wellness of individuals living with HIV.

....Umm I think the experience was..Uh, I'm grateful for the fact that my mother was a big to support me. I think she got a lot of information that she needed so she was able to help me and she was very supportive of even just, you know. When you live in a very like community that is close people hear things and when they end up knowing then there are rumours and people start to treat you funny and they talk about you. But my mother was always very supportive, and she would remind me that, you know, it doesn't define who you are. So, I'm grateful that she was there. Even my sister was a very good support system because she didn't judge me. Sometimes I would I'd become stressed and discouraged because people would say things and they weren't too nice about it. But you know, other

kids, wouldn't want to play with me because maybe their mothers had heard or something and rumours were going around. But my family was very supportive and yeah...

Simphiwe acknowledges the challenge of navigating life under the conditions that she describes in the interview, however, there is a particular experience that is fostering an ability to adapt to her diagnosis and navigate life quite successfully outside of the stigma that she may be susceptible to. Hardaway *et al* (2015) highlight that adolescents often experience incredible levels of autonomy and independence from the support of their nuclear families. Young adults living with HIV may be at risk of being suicidal, defaulting on medication and being subdued by stigma, however, parenting behaviours can be impactful in mitigating any damages (Hardaway *et al.*, 2015). Simphiwe's relationship with her mother served as a buffer to the various challenges that she was exposed to. Murphy *et al* (2009) posit that open family communication, particularly about HIV/AIDS is a significant factor in fostering support for adolescents. This, therefore, suggests that communication in the family can have a positive impact in providing space to discuss even the salient fears of those affected (Marsiglia, Nieri & Stiffman 2006), for Simphiwe having her mother talk her through medication. Debunking myths about the virus became an incredible element of fostering resilience.

The first and probably closest element to the child is family, which often entails relationships with caregivers/parents. Therefore, the strength and closeness of this unit can act as a buffering mechanism (Meinck *et al.*, 2015). Simphiwe relied on the nuclear family which consisted of her mother and older sister. The presence of these, and an ability to openly communicate facilitated an openness even within herself. Brieda & Pillay (2018) share that the parental characteristics of the caregiver play an important role in promoting resilience, their ability and willingness to provide emotional support become a cornerstone in how the adolescents view themselves about others. Nomfundo provides an experience that highlights this.

But the older I got while I was living with my aunt she was the one who explained to me what it is that I'm carrying and Umm how it affects the body and what I can do to make sure that I didn't, umm didn't get sick or my immune system didn't deteriorate. So my mom sending me to my aunt's place was a huge blessing that I know was the turning point of my

life. The more information I got the more understood what my status was as someone who was living with HIV.

Nomfundo's account is a testament to the experiences of feeling held and supported and building her ability to navigate the challenges, either within the schooling environment or in social spaces where her identity may often have been challenged. Her aunt's ability to provide emotional support and be emotionally present was a pivotal part of building her confidence. Nomfundo sees the impact of the shift in her life as it provided her with a new perspective on her lived experiences while exposing her to possibilities of what more she could potentially experience, outside of the poverty and constant abuse that she was exposed to. As a result, one can attest that resilience is not just dependent on a child's unique traits, but rather, the connections in their life that support them, as well as the environment in which they live, which offers the resources needed for healthy growth even in the face of adversity (Bhana *et al.*, 2017). Families, almost often exist in the larger space of community and social norms and experiences, and that experience can not be ignored as stigma experiences are often socialised (Stewart & Sun, 2004).

5.5.3 Community Support

Turan *et al* (2016) highlight that when individuals experience perceived stigma in their communities it can lead to internalised experiences/stigma and as such lead to adverse psychosocial health outcomes. However, community structures can also play a significant role in fostering resilience through supportive structures and organisations.

Food insecurity because there was no other way to access food. I remember that there were churches that would often come to the settlement where we lived. I remember they would usually come on Saturdays maybe once in a few months and they would bring like cooked for that day, and sing songs for the people there. This happened once in a while though, and they would also give us the food packs, small ones, and at least we knew that for a day or two, there would be something decent to eat at home. I mean oftentimes times my father would come home empty-handed and im sure he could have tried to find something but it's not easy you know? So, my siblings and I sometimes would join some Sunday church

programs of people who came because they usually gave out sandwiches afterwards so we would look forward to that hehehe.

The roles of religious groups in working to provide food parcels in informal settlements seek to relieve temporary hunger for the families in distress, though not a permanent solution to the dire impact of living in poverty. Communities often offer resilience resources. Dulin *et al* (2013) define resilience resources as “positive psychological, behavioural, and/or social adaptation in the face of stressors and adversities that draws upon an individual’s capacity, combined with families’ and communities’ resources to overcome serious threats to development and health” (p.57). Simphiwe’s experience of social support from local organisations and neighbours indicates a relief to the family’s challenge of meeting their nutritional needs. Social support can promote resilience in individuals through a functional outcome. A person's community's social support system can also aid in building resilience in them, the coping mechanisms employed by other community members as well as the ability of the community to anticipate and respond to unfavourable circumstances and events have a significant impact on community members (Southwick *et al.*, 2016). In his early work, Holling (1973) threaded this interaction between vital systems showing how the stability of these systems fosters positive adaptation in the face of resilience.

Simphiwe: I had a few friends. I told one friend about it. Umm. And I think she was nice about it. She didn't really treat me differently and everybody else. Uh, I don't know if they knew, but it's it was. It was something they seemed to suspect, but nobody really asked me about it. But I told my one friends and, Yeah, I I don't think people were super mean about it at school, my friends actually made things a bit more bearable you know.

In light of the above, there is evidence that social support can act as a protective factor, especially for the youth’s mental health. Social support in this regard encompasses both tangible and experiential aspects, such as emotional support. A case in point is Simphiwe’s experiences through her friendships feeling understood, accepted and appreciated. This ultimately, helps her feel less psychologically pressured, suppressing negative feelings, feeling better emotionally, and maintaining her mental health (Liu, Jiang & Yang, 2021).

5.5.4 Posttraumatic Growth

It has been highlighted that the stages of adolescence through to adulthood can be complex, marked by vast physical changes and different psychosocial challenges, and for those living in stressed environments, the compounded impact of adversity can add more stress (Geup *et al.*, 2018). An HIV diagnosis and identity during this unique developmental phase can disrupt the attainment of key milestones and possibly have long-term effects (Liu, Jiang & Yang, 2021). Therefore, positive adjustment in this regard demonstrates an interplay of various resilience strategies.

Simphiwe: So it was a defining moment because Uh, I also managed to, you know, finish and I graduated. Also I think that was Umm a great experience for me because It it felt like, you know. I I could see actual results of all the hard work, yeah, so, Umm that was a great moment for me. Like i don't even know how to describe it, growing up does so much for you and I am thankful for those experiences you know? Like now when think of myself I don't think of my status first, I think of my abilities, ambitions and all the fun stuff.

For Simphiwe, monitoring of her affective state has been crucial, it is apparent that there has been a time when she was preoccupied with her HIV status, economic status and challenges and the distress that came with it. Rzeszotek *et al.*, (2019) highlight that one's positive changes in relation to others and their own existential beliefs in the form of greater appreciation for life in attempts to deal with highly stressful encounters is also an indicator of resilience forged.

Cindy: i used to get angry you know? Like when I think about it I would get so angry in my room and think to myself, what if I had sex with someone and didn't know that I had HIV? I disliked my parents for a while. But now? Now, I have social media accounts that are dedicated to talking about HIV, my status and I make fun of my own experiences so to teach others and make light of a seemingly heavy topic in most black families.

“The psychological change that appears following significantly traumatic or burdensome life events” (Geup *et al.*, 2018, p.2). This experience of Posttraumatic growth speaks to positive changes that were also observed among the participants in, changes that may entail important clinical as well as psychological advantage.

5.6 Conclusion

This chapter presented the findings of the research through an Interpretive Phenomenological Analysis. Four main themes were identified which demonstrated and highlighted the nuances of the vast lived experiences of the participants. From the start of the analysis, it became apparent that the participants had experienced various adverse childhood experiences which were compounded by living with HIV. Similar, yet diverse experiences that highlight different forms and depths of adversity. However, it also became apparent how the participants have come to be resilient. A range of external and internal factors have played a role in fostering resilience.

CHAPTER 6: CONCLUSION

This chapter provides a summary of the research undertaken, and the main themes and addresses the implications of the findings. These include a highlight of the significance of resilience, and the resilience theory in understanding the lived experiences of Black, HIV-positive youth from marginalised communities, with various adverse experiences. Furthermore, the chapter provides possible impacts of the research on future research explorations and closes off by giving recommendations for these.

6.1 Synopsis of Findings

The primary aim of this research was to delve into the lived experiences of young adults living with HIV, primarily subjected to adverse socio-economic conditions in their childhood. The researcher employed an interpretive approach (IPA) to derive meaning from each participant's experience. The use of this design was relevant in directing the researcher to even more nuanced experiences of resilience.

Through providing the context in which the participants experience these various challenges the research sought to highlight the severity of the experiential process. The youth living with HIV in South Africa navigate their illness first in the context of inequality and secondly in communities with negative stereotypes about people living with HIV. The experiences of navigating a social identity crisis are demonstrated through their knowledge and perception of self to others. It became evident in the study that disclosure, either willing or forced, impacted interpersonal relationships and hurt their ability to access social support outside of their families. Interestingly, the participants did not just survive but were thriving and easily transitioning to adult roles without much difficulty.

Society has been said to group individuals according to implied norms of what is acceptable and what is normal behaviour or deemed deviant. The participants found themselves trapped with social identities that were discrediting and devaluing by living with HIV. Some of them struggled with existing with a devalued identity as it meant a loss in status, an internalised stigma and most significantly enacted stigma. One participant shared her experience and referred to her home environment as a 'plague' and this was due to the experiences of enacted stigma, being rejected by her community because of the new identity that separated

her family from others. The impact of this was seen to be feelings of isolation, being withdrawn and sometimes hiding to avoid being seen. It was apparent that youth living with HIV face numerous challenges, including the challenge of navigating discrimination which often leads to experiences of stigma. Living with a stigmatised identity often leads to a low self-concept, self-esteem that is threatened and most significantly an internalised sense of the negative perceptions of HIV.

The study found that demographic factors such as location, and socio-economic status impacted the type of access that the participants had, access to employment, access to healthcare centres and proper education. The participants who resided in informal settlements were subjected to poor housing infrastructures and lacked access to basic sanitation such as running clean water. This limited access then implied that their health was often compromised. Those mostly impacted by these adverse conditions are the most vulnerable in society, the children, and this exposure posed a developmental risk to the participants as they risked missing school due to lack of finances, not meeting nutritional targets due to food scarcity and impaired immune system due to sanitary challenges. This study then sought to explore how the experiences of socio-economic status compound the already existing burden of living with HIV.

Due to these critical and sensitive periods of childhood, the ACE framework and related theories were reviewed to ascertain the varying levels of impact that exposure to ACEs has on child development. This study established that many research studies have indicated negative effects on neuro and psychosocial development later in life. A growing body of literature also demonstrated that this negative impact translates to externalised behaviours, impacting adaptive functioning and a child's social competence. A further review of the ACE model provided a contextualised understanding of the participants' experiences of ACEs. Through recognising systems that create and maintain inequality, particularly for previously disadvantaged communities, there is an understanding of why experiences of poverty, poor health care access and unemployment persist, even post-apartheid. Additionally, providing a framework for understanding how ACEs can disinhibit a child's brain development, and immune system and be moderators for adopting unhealthy lifestyles and harmful behaviours that would serve as detrimental to their health, with the risk of premature death.

However, these participants demonstrated resilience with exposure to all the adverse childhood experiences. With risk factors posing a threat to a successful transition to adulthood, the participants all had various factors that served as buffers in mitigating the effects of adversity. The study found that certain individual traits served as protective factors, such as a sense of meaning and purpose in life, commitment, and problem-solving. These traits allowed the participants to find meaning in life beyond the diagnosis.

Even more significant was the observation of how these phenomena as the capacity of an ecological system, can exist without even manifesting itself. An inherent difficulty of applying the concept of resilience was made easy through the exploration of lived experiences as they are more telling of their purpose. Through this theory three key understandings were prevalent, the experience of resilience, being adaptable and most importantly being transformable. A considerable amount of research evidenced several mitigating effects of individual, family and larger environmental resources and their place in fostering resilience attributes which lead to wellness.

Similarly, this research also noted experiences that challenge resilience in Youth living with HIV. Notably, was the transition from childhood to youth, and accessing health care applicable and relevant to their needs. Youth transitioning from childhood face emerging challenges, particularly black youth living with HIV in South Africa. Moreover, the use of Garmezy's theory of resilience demonstrated that black youth living with HIV maintain hope when faced with various adversities and often work to access support to mitigate negative outcomes. Through the review of various research, it also became clear that critical resources such as health care centres suitable for developing youth and social support are critical elements of development and resilience. Because the age of youth is a critical and delicate time of development, navigating social relationships, making critical decisions in life and existing in an unequal society, the focus on this group of young people for the study was critical.

6.2 Significance and Implications of Study

The scope of the impact of HIV on children is quite vast, spanning from health implications to developmental impacts such as learning and interpersonal growth. However, there has been limited research on the lived experiences of children living with HIV, and most importantly their traits or experience of resilience. Therefore, this research sought to contribute to a few aspects of contextual experiences of living with HIV. Firstly, it aimed to contribute to the effect of socio-economic conditions on the well-being of children living with HIV (Whiteside, 2005). By illustrating through the ACE theories and model the challenges encountered by those who live on the margins of inequality in South Africa while navigating a marred identity. Secondly by contributing to the literature on resilience and lived experiences of HIV-positive youth in marginalized communities (Harrison & Li, 2008). Adding more youth involvement in the research on resilience then provides an opportunity for more engagement with the younger population (Booyesen *et al.*, 2002). The researcher further sought to aid in the knowledge base informing intervention programs that are aimed at improving retention in HIV care, particularly in vulnerable communities (Brewer *et al.*, 2020), by highlighting stigmatising experiences, that potentially hinder healthcare attendance. In addition, the research also aimed at contributing to the knowledge expansion on social identity, particularly among HIV-positive youth. How the changes in identity experiences impact the status quo, and how they potentially navigate themselves in interpersonal relationships.

6.3 Limitations

6.3.1 Methodology:

IPA has become a preferred method in qualitative research due to its critical emphasis on detailed nuances while working with smaller sample sizes (Tuffov, 2017). However, this qualitative methodology also provided some limitations. Pringles (2021) shares that smaller sample sizes are a limitation as the data cannot be generalised to a larger population. However, Smith & Osbourn (2007) share that IPA is not interested in broad generalisations but rather fuller in-depth analysis that a bigger size could potentially hinder. Secondly, IPA has been questioned for the focus on experience, because experience is such a subjective experience this can allow for the researcher's bias to filter in (Eatough & Smith, 2017). Though

this is an inevitable part of IPA, reflexivity allows for the moderation of this effect. To this critique, is a critique of IPA's ability to accurately record the intended/ said experiences and their meanings and not just opinions (Eatough & Smith, 2017). The researcher worked to pay close attention to collecting valuable and in-depth information from her participants. Lastly, IPA's emphasis on perceptions has been deemed challenging and is restrictive to our understanding as it only provides an account of lived experiences but not an explanation for the occurrence of this (Eatough & Smith, 2017). By providing the context in which these experiences occur, the researcher worked to provide an account of why these experiences could be happening.

6.3.2 Sample Size

Although IPA does not emphasize sample size, however, being able to locate one's sample within a much broader and much more encompassing data pool is essential for data adequacy (Vasileiou, Burnette & Young, 2018). O'Mullan (2016) further highlights that although participants in IPA are selected based on their ability to give insight into a selected experience, smaller sample sizes in this regard pose a challenge for generalising the data. The researcher has worked to make meaning of participants' experiences through their words to provide an in-depth and adequate analysis of the study. Furthermore, Vasileiou et al., (2018) highlight that the use of a smaller sample size can also limit the depth and comprehensiveness of the data, consequently impacting the quality of the research. However, the researcher worked closely with the data to draw various themes that encompass the participants' broad experiences and as such account for a richer experience.

6.4 Recommendations

6.4.1 Research Recommendations.

In as much as the research at hand provides an account of the lived experiences of South African youth living with HIV, the study recommends that further research be done on the youth populations. Further research in this area should include the experiences of male participants to ascertain possible experiences of masculinity to social identity formation as postulated by the social constructivism theory. Due to the close interaction of IPA research, it is recommended that interviews of this nature be only conducted in person, this is to build stronger rapport with participants and eliminate any hindrances from online platforms.

There is ample research on the individual aspects of resilience among children living with HIV, however, more research can be done on resilience outside of the individual, located in interpersonal and communal settings that can be key in encouraging individuals to adapt to more positive emotional experiences. A focus on how schools can actively act as mediators who bridge the gap between the home environment and the community can be integral in devising more relevant and applicable intervention plans. There is an acknowledgement, however, that to undertake such a study, a bigger sample size may be needed thus moving away from a qualitative to a more quantitative approach.

6.5 Conclusion

This research study explored the lived experiences of black South African youth living with HIV from disadvantaged communities and with various encounters of Adverse Childhood experiences. Although they presented with similar experiences of poor socio-economic conditions, stigmatised encounters and adverse experiences, their individual experiences provided unique outcomes of adversity and as such rendered their encounters crucial. The participants have demonstrated resilient traits that enabled them to navigate adverse situations and mitigate any adverse outcomes. It appears that various contextual systems played a role in fostering their resilience, and these included positive communication and support from families, as well as community structures that were empowering to them. Their resilience has enabled them to not just survive difficulties encountered in their childhood but to strive for excellence while successfully transitioning to adulthood. These vast experiences of resilience demonstrate that the adverse experiences did not leave them feeling incapable and hopeless but gave them a reason to live and do better for themselves and their families.

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Appendix A: Information Sheet for NGOs



PSYCHOLOGY
THE SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT (SHCD)



INFORMATION SHEET FOR NGOS

Greetings,

My name is Nozipho Sigola, and I am currently a Masters student enrolled at the University of Witwatersrand, and I am conducting a study on Adverse Childhood Experiences and Resilience among HIV-positive Youth. This research is required for the completion of my degree in Psychology.

I would kindly like to request your assistance in retrieving potential participants for my research project. My cohort should consist of young people between the ages of 18-26 who are HIV positive, are currently at tertiary or are working. Young people who contracted HIV at birth or when they were young.

Participation in this study is voluntary and none of the participants will be forced to participate against their will. Participants can also withdraw from the research at any point. Participation in this study will involve one in-depth interview where I will be asking the participants questions about their personal life stories and experiences. I am hoping to understand the experiences of HIV-positive youth in South Africa, the challenges that they encountered growing up and how they were resilient.

Ethical clearance has been approved and granted for this research which means that my project does not pose any harm to participants in any way. Willing participants who accept to partake in this study will be contacted at the end of the study to be given a summary of all

the findings and a full research report is available to participants upon request. I am available for questions and queries, and I can be reached telephonically on 073 030 7153 or via email on noexysigola@gmail.com

You are welcome to contact me directly or contact my supervisor using the details below.

Yours truly,

Nozipho Sigola

noexysigola@gmail.com

Research supervisor

Lecturer/Counselling Psychologist

Ruby Patel

0820450620

Ruby.Patel@wits.ac.za

Appendix B: Participation Information Sheet



PSYCHOLOGY
THE SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT (SHCD)



PARTICIPANT INFORMATION SHEET

Greetings,

My name is Nozipho Sigola, and I am currently a Masters student enrolled at the University of Witwatersrand, and I am conducting a study on Adverse Childhood Experiences and Resilience among HIV Positive Youth. This research is required for the completion of my degree in Psychology, and I would like to invite you to participate in this research study.

Participation in this study will involve one in-depth interview where I will be asking you questions about your personal life stories and experiences. I am hoping to understand your experiences in growing up with HIV. In taking part in this research, you will assist us in learning more about the challenges of growing up with HIV, and the role resilience in mitigating through the challenges.

Because it is of utmost importance that what you say to me, the researcher, is not misconstrued, I would like to request your permission to use a tape recorder during our interview to aid me when writing up my report. Your identity will be protected by using pseudonyms/fake names and only my supervisor and I will be permitted to listen to the audio-recordings. I may use direct speech in writing up my final report but even in those cases, fake names will be used. Confidentiality will be maintained at all times throughout the interview process and afterwards when data is being transcribed and reported on in the form of my research report. All recordings will be kept locked away in a save room on my computer which requires a password to gain access. After the recording have been transcribed verbatim, original recording will be destroyed. The transcripts will be kept until my degree has been

completed and safely stored on my personal laptop that requires a password which means this will not be accessible to the public.

The interview will be approximately 60-90 minutes and some discomfort may arise when answering particular questions. You have the right to withdraw from the study at any time without offering any reasons and/or you may refuse to answer any question that you are not comfortable discussing. Your participation in this study is voluntary and warmly welcomed. This study offers free of charge counselling services which can be obtained through available Mental health practitioners

Willing participants who accept to partake in this study will be contacted at the end of the study to be given a summary of all the findings and a full research report is available to participants upon request. I am available for questions and queries, and I can be reached telephonically on 073 030 7153 or via email on noexysigola@gmail.com

Your participation will be greatly appreciated. You are welcome to contact me directly or alternatively contact my supervisor using the details below.

Yours truly,

Nozipho Sigola.

noexysigola@gmail.com

Research supervisor

Lecturer/Counselling Psychologist

Ruby Patel

0820450620

Ruby.Patel@wits.ac.za

Appendix C: Consent Form



PSYCHOLOGY
THE SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT (SHCD)



I, _____, consent to being interviewed by Nozipho Sigola, for their study on exploring the lived experiences of HIV Positive Youth. **Please tick relevant boxes. I understand that:**

- Participation in this study is voluntary.
- I may refrain from answering any questions.
- I may withdraw my participation and/or my responses from the study at any time before the research report is examined.
- There are no risks or benefits associated with participation in this study.
- All information provided will remain confidential, although I may be quoted in the research report.
- If I am quoted, a pseudonym (Participant A, Respondent B etc.) will be used.
- None of my identifiable information will be included in the research report.
- I am aware that the results of the study will be communicated in the form of a research report or journal articles.
- The research may also be presented at a local/international conference and published in a journal and/or book chapter.

Signed: _____

Date: _____

Appendix D: Audio Recording Consent Form



PSYCHOLOGY
THE SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT (SHCD)



I, _____ give my consent for my interview with
Nozipho Sigola, to be audio recorded for their study.

Please tick the relevant boxes: I understand that:

- The audio-recordings and transcripts will not be seen or heard by anyone other than the researchers and/or their research assistants. ☐
- The audio-recordings and transcripts will be kept in a password protected computer. ☐
- No identifying information will be used in the transcripts or the research report. ☐
- Although direct quotes from my interview may be used in the research report, I will be referred to by a pseudonym. ☐

Signed: _____

Date: _____

Appendix E: Ethics Clearance

UNIVERSITY OF THE
WITWATERSRAND,
JOHANNESBURG



SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT ETHICS COMMITTEE CONSTITUTED UNDER THE UNIVERSITY HUMAN RESEARCH ETHICS COMMITTEE (NON-MEDICAL)

CLEARANCE CERTIFICATE:

PROTOCOL NUMBER: MACC/22/10

PROJECT TITLE:

Adverse Childhood Experiences and
Psychological Resilience among HIV positive
youth.

INVESTIGATOR

Sigola Nozipho (852195)

SCHOOL/DEPARTMENT OF INVESTIGATOR

SHCD/Psychology

DATE CONSIDERED

13 May 2022

DECISION OF THE COMMITTEE

Approved unconditionally

RISK LEVEL

Low Risk

EXPIRY DATE

31 December 2024

ISSUE DATE OF CERTIFICATE

23 May 2022

CHAIRPERSON



(Dr Vinita Jithoo)

Cc: Ms Ruby Patel (Supervisor)

DECLARATION OF INVESTIGATOR

To be completed in duplicate and **ONE COPY** returned to the Chairperson of the
School/Department ethics committee.

I fully understand the conditions under which I am authorized to carry out the abovementioned
research and I guarantee to ensure compliance with these conditions. Should any departure to be

contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee.



Signature

Date *12.08.2022*

**PLEASE QUOTE THE PROTOCOL NUMBER ON
ALL ENQUIRIES**