



Adolescents living with HIV in South Africa

COLLABORATORS



FUNDERS



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*We dedicate this report to all adolescents in South Africa who
are living with HIV.*

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FOREWORD

This report should be judged by its cover. Because the pictures and words convey the youthful vitality that lies at the heart of the paradoxes, problems, and ultimately promises of being an adolescent living with HIV (ALHIV). Within these pages are studies and stories of young people *living – with* HIV, but equally *within* families and communities, systems and structures, and most of all their age-aligned attitudes and behaviours.

The report benefits greatly from its collaborative ‘3-team’ approach, which distinctly addressed this challenging topic from using two data sources and a literature review. This noteworthy approach capitalises on rich datasets: the additional resources from this project supplemented the original large-scale studies to explore sub-analyses (in this case by age), thereby filling critical evidence gaps and triangulating complementary data sources. This initiative fills a gap that is particularly pronounced in research among adolescents – which is complex ethically, methodologically, and logistically – thus making this study’s attention to this ‘weak spot’ especially valuable. This trio of investigations into separate materials has been combined with collective consideration of their results, and the process has generated a fruitfully reinforcing range of findings and perspectives. As the first effort of its kind, we hope that it paves the way for similar collaborations among researchers and implementers, joining forces to capitalise on existing datasets, studies, and research to reveal ‘the bigger picture’. This rich combination of datasets and methodologies makes three key novel contributions. First, it provides the first nationally representative data on how ALHIV in South Africa are doing with regards to the 90-90-90 targets. Second, it elucidates the experiences of ALHIV as compared to their uninfected peers. Third, it highlights the glaring gaps in research and programming for adolescent boys and young men living with HIV.

What emerges with stark clarity is the core fact that ALHIV fare worse on many measures than any of their peer groups – both adults living with HIV and non-HIV infected adolescent age peers. This report most helpfully illuminates the reasons for this multiplicity of disadvantages:

- in the complexity of socio-economic factors shaping the microcosm of daily lives and the macrocosm of demographic determinants
- in the features and functioning – both structural and attitudinal – of health system provision
- in the interplay between actors and forces in the political, professional and personal spheres
- in the compounding of risks and vulnerabilities, and the interlinking identities which can at once enhance and inhibit, embrace and exclude these adolescents from their multiple communities of affiliation.

For ALHIV with disabilities, the disadvantages they face are even more extreme.

A key insight comes on page 44 and deserves quoting in full: ‘The system may be characterised as one of control – firstly of HIV disease, but secondly of the patient. In both cases, ART is the agent and the regular viral load tests are the markers of the level of compliance. Such regimes take the form of life under scrutiny and this conflicts with rebellious psychological states.’ This cogently encapsulates the way that ‘defaulting’ from the treatment regime becomes a ‘diagnosis’ in itself, replicating the stigma of the original diagnosis of HIV, and as with that initial label, this renewed stigmatising wreaks further damage on the teens, their caregivers and health workers, and the relationships between them.

This report thus reminds us of a key lesson learned from the initial responses to the emergence of HIV decades ago: stigma defeats and derails from generating healthier behaviours and outcomes. To achieve (belatedly) the 90-90-90 goal envisioned for 2020, we must avoid turning the clock back to earlier errors.

If this report shows us what does not work, it also guides us to what does:

- support that is effective in its range, reach and intensiveness
- support that is integrated into families, communities and health systems, yet tailored to the mindsets of adolescents
- support that is both parallel to that provided for patients in other demographics and also holistic, both in addressing all aspects of the lives of these adolescents and in attending to the whole of their life-course, in its transitions from childhood and forward to adolescents.

Such an intergenerational awareness sustains the full familial unit: the person living with HIV, those caring for them directly and indirectly, and their capacity to be well-functioning caregivers of their children in turn.

From cover to conclusion, this report evidences the specific needs of ALHIV using a unique combination of data sources, while showing that meeting these entails the same essentials as those which contribute to the self-esteem, dignity, and worth of any young person. The case studies of teen rebellion, assertion of independence, energy, and enthusiasm graphically portray ALHIV as adolescents living. An HIV diagnosis does not have to become a determinant of a downward life-course nor down-stream damage to their wider families and communities. The best models of treatment and support go beyond the labeling status of 'patient' and credit each individual's standing as a human being, as a 'Being ALHIV'.

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LIST OF ACRONYMS AND ABBREVIATIONS

AGYW	Adolescent Girls and Young Women
AIDS	Acquired Immunodeficiency Syndrome
ALHIV	Adolescents Living with Human Immunodeficiency Virus
ART	Antiretroviral Therapy
ARV/s	Antiretroviral drug/s
AUDIT	Alcohol Use Disorders Identification Test
DBE	Department of Basic Education
DBS	Dried Blood Spot
DSD	Department of Social Development
DREAMS	Determined, Resilient, AIDS-free, Mentored and Safe
FDC	Fixed-dose Combination
GBV	Gender-based Violence
HIV	Human Immunodeficiency Virus
HIVDR	HIV Drug Resistance
HSRC	Human Sciences Research Council
HSV2	Herpes Simplex Virus 2
IPV	Intimate Partner Violence
KP	Key Population
Lag	Limiting Antigen
LGBTQIA+	Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, Asexual/Ally +
MMC	Medical Male Circumcision
MSM	Men who have sex with men
MTCT	Mother to Child Transmission
NDOH	National Department of Health
NNRTI	Non-nucleoside reverse transcriptase inhibitor
NRTI	Nucleoside reverse transcriptase inhibitor

PLHIV	People Living with Human Immunodeficiency Virus
PMTCT	Prevention of Mother to Child Transmission
PTSD	Post-traumatic Stress Disorder
SABSSM	South African National HIV Prevalence, Incidence, Behaviour and Communication Survey
SADAG	South African Depression and Anxiety Group
SAMRC	The South African Medical Research Council
SANAC	South African National Aids Council
SBCC	Social and Behaviour Change Communication
SIB	Social Impact Bond
SRH	Sexual Reproductive Health
SSA	Sub-Saharan Africa
Stats SA	Statistics South Africa
STI	Sexually Transmitted Infection
TB	Tuberculosis
UCT	University of Cape Town
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNICEF	United Nations Children's Fund
US	United States
VLS	Viral load suppression
VMMC	Voluntary Male Medical Circumcision
WHO	World Health Organisation
WSW	Women who have sex with women

EXECUTIVE SUMMARY

As we approach the fourth decade of the HIV pandemic, there are still glaring gaps in the evidence base regarding the mode of transmission, health, behaviours, sexual practices and lived experiences of adolescents living with HIV (ALHIV) in South Africa. This project is a collaboration between the Human Sciences Research Council (HSRC) and the University of Cape Town's AIDS and Society Research Unit, in partnership with the South African Medical Research Council (SAMRC). It was implemented to further our understanding of the context and lived experiences of adolescents aged 10 – 19 years living with HIV in South Africa. It also informs the SAMRC's Social Impact Bond (SIB) programme that focuses on HIV interventions to support adolescent girls and young women in South Africa.

Methods

A mixed-methods approach consisted of analysing secondary data from two sources – the South African National HIV Prevalence, Incidence, Behaviour and Communication Surveys 2005 – 2017 and the South African Mzantsi Wakho study. Mzantsi Wakho is a longitudinal study on medicines-taking and sexual health among ALHIV. These findings were contextualised with a review of the literature on adolescents living with HIV in sub-Saharan Africa with an emphasis on South Africa. The literature review drew on research published in English in peer-reviewed journals or produced by international organisations, governments, universities, adolescent health study teams, and other researchers.

Aims and objectives

The overall aim of the study was to understand the context of ALHIV in South Africa in order to inform and strengthen ALHIV programmes.

Objectives include:

- describing characteristics and trends regarding ALHIV
- exploring HIV risks concerning ALHIV
- identifying concerns and gaps that are relevant to programmes for ALHIV.

Findings

SABSSM Surveys

The 2017 survey showed that 3.7% of all adolescents in South Africa are living with HIV of whom 2.7% were aged 10 – 14 years and 4.9% were aged 15 – 19 years. The highest prevalence was among adolescent girls aged 15 – 19 years. HIV prevalence among adolescent males increased between 2012 and 2017. A total of 62.3% of HIV-positive adolescents aged 10 – 19 years knew their status. Approximately two-thirds (65.4%) of ALHIV who knew their status were on antiretroviral treatment (ART). Among ALHIV on ART, 78.1% were virally suppressed.

An analysis of risky behaviours showed that compared to their HIV-negative peers, ALHIV had higher levels of risky sexual behaviours. A total of 56.7% of female ALHIV aged 15 – 19 years reported that they ever had sex compared to 34.5% who were not living with HIV. Furthermore, among female ALHIV aged 15 – 19 years, 82.1% reported that they had sex in the past year compared to 70.2% who were not living with HIV. Condom use at last sex was 48.2% among ALHIV females aged 15 – 19 years compared to 60.6% among those not living with HIV. In 2017, 21.3% of adolescent females aged 15 – 19 years

who were sexually active in the past year reported being pregnant in the past 24 months, of whom 41.5% were ALHIV. By comparison, only 18.9% of adolescents who were not living with HIV had been pregnant.

In 2017, knowledge about HIV transmission was higher among 15 – 19-year-olds (55.8%) compared to 12 – 14-year-olds (40.0%). A total of 77.6% of adolescent females aged 15 – 19 years said they had disclosed their HIV-positive status to a main sexual partner. Data on multiple sexual partners and age-disparate sexual relationships showed that these behaviours were more common among female ALHIV when compared to those not living with HIV.

The results showed an improvement in the self-rated health status among ALHIV. In 2012, 12.1% of ALHIV aged 15 – 19 years rated their general health as poor, compared to 6.8% in 2017. Our findings on psychological distress reveal high distress levels among ALHIV aged 15 – 19 years in 2012 compared to those not living with HIV.

A majority of adolescents aged 15 – 19 years were in school (86.7%). However, it was noted that a higher proportion of ALHIV were not attending school when compared to adolescents who are not living with HIV. A quarter of female ALHIV aged 15 – 19 (24.8%) were not attending school. Among them, 19.2% had not completed Grade 12 and 5.6% had completed Grade 12. Among adolescents out of school, all male ALHIV and nearly all female ALHIV (99.3%) were not employed. By comparison, 7.4% of males and 5.1% of females not living with HIV were employed.

Mzantsi Wakho

The *Mzantsi Wakho* findings focus on various aspects of accessing and sustaining HIV treatment and care from the perspectives of adolescents, healthcare providers, and family members. These rich qualitative findings show that many healthcare workers were deeply frustrated by non-adherence to ART by their adolescent patients. They understood adolescents' seeming inability or refusal to take HIV medicines correctly as a matter that was beyond a healthcare worker's control, but a circumstance for which they would bear the negative consequences, as a result of protracted patient burden.

Healthcare workers also offered more structural and environmental explanations for why adolescents might not honour scheduled clinic appointments or adhere to their medicines. Common explanations included limited access to health facilities due to the high cost of transport, and a lack of strong familial support. Many adolescents within the wider Mzantsi Wakho study were orphans, with 44% of HIV-positive adolescents being maternal orphans, 30% paternal orphans, and 16% double orphans. Elderly caregivers – often a grandmother or great aunt – struggled to monitor and control their movements and actions. Household incomes – principally constituted by social grants – made precious little provision for the costs of transport to a clinic, nor the opportunity costs of accompanying an adolescent to a clinic, which often entailed costly transport fees in addition to long waiting periods that exacted a toll on family members. Nurses recognised these costs and challenges, including the dangers of adolescents traveling without the physical presence of an adult caregiver.

Healthcare workers observed that adolescent patients who defaulted on their ART tended to abscond from healthcare services, only returning when an opportunistic infection – often tuberculosis (TB) – occurred due to viral resurgence and compromised immunity. Similarly, caregivers of HIV-positive adolescents who were not adhering to their medicines understood this as a form of defiance, associated with other reckless and insubordinate

behaviours. Expressions of both adult caregivers and healthcare workers oscillated between ‘determination and despair’ and ‘concern and hopelessness’ as they tried various tactics to implore or demand that adolescents adhere to their HIV medicines.

A review of adolescent clinic files from public healthcare facilities’ ARV units captured a similar variety of responses to adolescent non-adherence. Approaches ranged from attempting to ameliorate structural barriers to ART adherence, to individual-focused reprimands and punishments. Some healthcare workers, together with adult caregivers, sought to incentivise and promote ART adherence through praise and the promise of gifts. Similar to interviews with healthcare workers, exasperation and despair over participant non-adherence were evident, alongside hope, enthusiasm and pleasure when participants appeared to adhere better.

The study found that the terms ‘adherence’ and ‘defaulting’ were largely absent from the HIV treatment lexicon of ALHIV. Encouraging adolescents to speak about the challenges that they encountered, asking the same question in different ways, comparing ART uptake to other behaviours, and exploring wider challenges such as availability of transport or experiences of stigma, encouraging adolescents to acknowledge and to describe imperfect ART adherence.

When adolescents spoke about their non-adherence, they would oftentimes share how pill-taking reminded them that they are different from their families and peers. For many adolescent research participants, pill-taking was also framed within other priorities. That is, for some young people their non-adherence was not an isolated decision, but rather a by-product of other desires and priorities. One spoke about this in relation to feeling torn between health workers’ insistence that he take ART, and his desire to go out and party.

Fear of changes to the body and the impact of side effects were cited by the teens. Participants noted that some adolescents wanted to see if there would be changes in their bodies. Some experienced depression. Some worried about the impact of ART on their physical development, believing that it may interfere in or even prevent their physical maturation.

ALHIV recounted being coerced into adhering to their ART, with threats or punishments meted out in response to imperfect adherence. Threats included harsh words, which teenagers described as making them feel trapped and desiring a break from ART or medicine taking. Treatment fatigue is a challenge for achieving adherence in a participants’ words, adolescents living with HIV ‘do get tired of taking ART, because it dominates their lives, and they don’t want things to take away their choices, to intervene with their choices, to dominate their lives’. These results outline lived experiences of ALHIV and also highlight areas of focus for public health intervention.

Literature Review

The literature review explored diverse aspects of the contexts of adolescents living with HIV in sub-Saharan Africa and South Africa, highlighting complex underlying factors, programmatic responses and gaps. Themes explored included socioeconomic contexts and demographic factors; knowledge, attitudes and behaviour; HIV-related prevention, treatment and care; key populations (KPs); disclosure of HIV status; disability; stigma and discrimination; mental health; substance use; gender-based violence (GBV); interventions and programmes; ALHIV strategies and policies.

The review focused on providing insight into the context in which ALHIV live and also highlighted the conditions and challenges that adolescents have to address when making decisions around HIV and their health. Challenges identified include both developmental and contextual factors. Developmental challenges faced by most adolescents include navigating emerging independence, social and structural barriers while finding and negotiating their place within their families and societies. At a contextual level, adolescents live within communities with high levels of violence – particularly in the form of gender-based violence, substance use and abuse. At the level of service delivery, schools and healthcare services do not always meet the needs of adolescents, especially those who are living with HIV. Healthcare facilities particularly, are not orientated to the needs of adolescents (both females and males) and the transition from paediatric care is often not well planned and negotiated for adolescents. At the socio-economic level, many adolescents from poor communities face a lifetime of poverty, gross inequality marked by consistently high rates of unemployment and income inequality. All these factors are significant and render decision-making around adopting protective behaviour and health-seeking difficult.

The review also focused on points of entry for healthcare delivery and groups of adolescents that are missing in the national response. Healthcare for ALHIV needs to be expanded. At present, the focus is almost exclusively on the 90-90-90 cascade, with a limited range of prevention and contraception approaches. ALHIV need much broader services that includes mental health, social support, social security, education and training, and help with finding employment. Some care and treatment interventions have to be tailored to the needs of individuals and groups of ALHIV. In particular, adolescent girls and boys may need interventions to respond to their gendered needs and practices, allowing them to reflect on the particular identity issues attached to their gender. These circumstances must be accounted for for ALHIV who face additional circumstances, such as those who belong to the LGBTQI community, who are disabled, or are orphaned, as they may further obstruct access and adherence to ART. Another neglected group of ALHIV are young, pregnant women, who require additional care and support.

Among ALHIV, prevention of onward transmission of HIV includes condom use, initiation onto ART, and adherence to a successful regimen to achieve viral suppression. The needs of the adolescents are for a full and normal life, and the interface between healthcare monitoring and managing compliance to the continuum of care may be perceived by ALHIV as invasive and disempowering, or even infantilising. Interventions to support ALHIV, therefore, have to be delivered in a way that allows adolescents to maintain a sense of normality in other areas of their lives. A participatory or at least consultative approach to service provision and health research is needed.

In conclusion, this review has summarised the various needs of this group to provide optimum services for ALHIV. Interventions in schools were identified as one way of delivering care, coupled with the provision of correct HIV education. They can also be used for building and strengthening supportive environments to prevent stigmatisation of ALHIV. Such school-based interventions would enhance ALHIV's understanding of HIV, its transmission, and the efficacy of ART as both a means of treatment and prevention of onward transmission. Schools-based programmes could be supported by family and community interventions that incorporate family counselling, training in parenting skills, and stigma reduction interventions.

Recommendations

The study makes recommendations for improving policies, strategies, and programmes for ALHIV in South Africa. These include:

- Noting that new infections continue to occur, particularly in older adolescents. Hence the pool of ALHIV is not diminishing over time. Programmes focused on HIV prevention need to be intensified to the extent that they substantially impact HIV incidence, including setting reductions of the prevalence of ALHIV as a target.
- Recognising that knowledge about HIV transmission and engagement with HIV programmes are suboptimal. There is an opportunity to include social media interventions as a means of communication because many adolescents use this platform, along with improvements in retention of adolescents in schooling and healthcare services.
- Using the findings to highlight a need for multi-sectoral interventions to ensure that young people entering adolescence do complete school and then enter the workforce later, postponing sex and childbearing and preventing HIV infection.
- Implementing strategies and programmes to support ALHIV who are out-of-school, as this is a gap area.
- Recognising that pregnancy among adolescents occurs at a high level and is greater among ALHIV than those not living with HIV. There is a need for diverse support including for PMTCT, but also for sustaining ART among ALHIV mothers, as adherence to ART programmes is known to drop off in the post-natal period. Programmes for ALHIV mothers are necessary, and it is also clear that targeted programming regarding reproductive health, contraception, and safer sex, in general, is needed to moderate the high rates of pregnancy among this group.
- Observing that ALHIV are not adequately integrated into the HIV treatment cascade, and although it is anticipated that there have been improvements in the trajectory towards the 90-90-90 targets after 2017, it remains evident by those gaps that ALHIV are underserved. Specific targeting of ALHIV in relation to the treatment cascade is necessary, including extending support for achieving targets to include activities parallel to and complementary to health service delivery. Support needs related to the well-being of ALHIV include mental health, sexual reproductive health, psychosocial support, social security, education and training, and finding employment.
- Recognising that while treatment and support for VLS clearly require a multifaceted response, gaps in HIV testing of ALHIV also need to be addressed. This includes developing strategies for testing children and younger adolescents.
- Noting that the 90-90-90 strategies do not include adequate support to the disclosure of HIV status, and that this is an area of central concern for ALHIV who need both direction and support if they are to manage to live with HIV within and outside of their family structures. There is a need to support ALHIV through increasing the availability of community-based services, family-centred interventions, employment, and economic empowerment.
- Providing training for educators and others in the school system, given that school environments do not appear to be sensitive to the needs of ALHIV. Improving resources such as the provision of school health nurses, counsellors and providing family coaching and parenting training at schools, are relevant focal areas for programming.

- Supporting healthcare workers to assess their knowledge, personal views, attitudes, and behaviours to improve their response to the needs of ALHIV. This needs to be aligned with community-based services that are relevant to their specific communities, including family interventions, coaching and programmes to support employment and socio-economic redress.
- Implementing holistic approaches for programming for all adolescents whilst considering gender-based issues. Acknowledging the numerous challenges faced by adolescents is important to create awareness of the internal dynamics that adolescents face.
- Addressing how young males and females are socialised in different contexts in South Africa and developing specific interventions for 10 – 14-year-olds to manage living with HIV if perinatally infected.
- Conducting further research on drug resistance among ALHIV on ART.
- Addressing stigma through programmes for families and caregivers. The need to intensify programming based on good existing models for intervention is particularly urgent for younger ALHIV aged 10 – 14 years.
- Developing programming for ALHIV who are Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, Asexual/Ally + (LGBTQI+), or other key populations (KPs) such as men who have sex with men (MSM), and sex workers. Strategies and programming for ALHIV who fall within KP categories require attention.
- Developing a social theory that can be used to develop interventions and services accurately and constructively for ALHIV.

Introduction

In 2019, there were 1.7-million adolescents aged 10-19 living with HIV globally, among whom 1.5 million (88%) were living in sub-Saharan Africa (SSA) and 360 000 were living in South Africa.¹ Adolescents living with HIV (ALHIV) include those who have acquired HIV perinatally or through sexual intercourse. While younger ALHIV aged 10-14 years include similar proportions of girls and boys, those who are aged 15-19 years are more likely to be female due to their heightened biological and structural vulnerabilities and susceptibility to HIV infection through sexual intercourse in comparison to males of the same age groups.²

ALHIV tend to experience higher levels of neurodevelopmental disorders, mental health and other health challenges in comparison to peers of the same age due to the burden of the disease.³ They are less likely to know their HIV status or to access antiretroviral therapy (ART) in comparison to adults living with HIV. They tend to be lost to ART follow-up, are less likely to sustain ART, and often need psychosocial support in comparison to adults.³ While deaths from HIV-related causes have declined among people living with HIV (PLHIV) in most age groups, this is not the case for ALHIV aged 15-19 whose HIV-related mortality levels remain high by comparison.⁴ This has been attributed to late ART initiation, poor adherence and retention in care. For example, a study in South Africa showed that ART uptake among children and adolescents aged 1-19 years increased over a period of 10 years from 2005-2016, it also found that less than half of ALHIV in the 15-19 year age group who had received health care did not start ART.⁵ Even for adolescents who do initiate ART, retention in care has been found to decline over time, thereby negatively impacting attaining and sustaining viral suppression (VLS).⁶

1.1 Vertical HIV infection

Pregnancy, labour, delivery and breastfeeding contribute to the risk of paediatric HIV infection (vertical transmission). These risks are reduced by assessing the HIV status of expectant mothers, providing ART during pregnancy, managing delivery, and sustaining HIV-positive mothers on ART.⁹ Post-natal HIV prevention for infants is achieved through ART prophylaxis, and through promoting optimal breastfeeding and other safer feeding practices.⁹ The HIV status of infants is typically determined by six months of age.⁷ HIV transmission to an infant is more likely if a mother does not receive ART during pregnancy, if she is infected with HIV after pregnancy or during the period of breastfeeding, or if ART is interrupted when she is pregnant or breastfeeding.⁸

In South Africa, vertical transmission rates have reduced to less than 3% nationally as a product of the ongoing Prevention of Mother-to-Child Transmission (PMTCT) programme. In 2010, the first South African national population-based survey of the effect of HIV transmission from mother to child reported an overall transmission rate of 3.5%. When repeated in 2011, the transmission rate was found to be 2.7%.^{9, 10} Furthermore, due to critical improvements in access to ART, children born with perinatal HIV infection are reaching adolescence in large numbers, especially in low- and middle-income countries.¹¹

Although treatment efficacy, ART rollout, and strategic plans to eliminate parent-to-child transmission in the adult population have improved and mortality has reduced over time,¹² research shows that the HIV epidemic amongst adolescents is not yet under control¹³ and that transmission rates are higher among 15-24 year old mothers living with HIV compared to older mothers.

1.2 Children, adolescents and ART

The global rollout of ART has provided access to life-saving therapy for millions. However, between 2005 and 2012, mortality among ALHIV globally rose by 50%.¹⁴ Once infants or children are determined to be HIV positive and are placed on ART, retention in care is vital for ensuring immediate and long-term health.

Barriers impeding the health of children and ALHIV include lack of knowledge of their HIV-status, the complexity of medication routines and paediatric dosing required for ART, drug side effects, difficulty accessing health facilities, the mental health of adolescents and caregivers, non-disclosure of HIV status, being an orphan, or holding particular religious beliefs.^{15, 16} Initiation of ART of a perinatally infected child later in childhood is associated with chronic comorbidities that compromise long-term health and quality of life.¹⁷ ALHIV have been found to have higher rates of virologic failure (failure of virus suppression) and AIDS-related mortality than adults or children. These health outcomes are largely related to non-adherence to ART and require further exploration.

1.3 The global context of ALHIV adherence to ART

The ART rollout highlights the challenges that HIV-positive adolescents face in initiating HIV treatment and remaining in care. It underscores the need to understand how HIV-positive adolescents take their medicines, or alternately, why they do not.^{18, 19} While the majority of studies on ART adherence have been located in well-resourced centres in the global north,^{20, 21} a growing body of clinical and social science research has investigated ART adherence among adolescents in Southern Africa.^{22, 23, 24, 25} Operational, clinical and experiential challenges that adolescents face in accessing and adhering to ART have been explored.^{26, 27, 28, 29} These studies demonstrate that even when ART may be accessible and available in healthcare facilities, there are social and structural circumstances that prevent ALHIV from adhering to HIV medicine routines and from attaining VLS. For example, accessing and adhering to ART is challenging in the context of physical, psychological and social changes for adolescents. Underlying factors that inhibit effective treatment for children and adolescents include stigma, poverty, lack of education, family factors, and limited health and social support systems.^{30, 31} Emotional and spiritual support, as well as support from caregivers, family members, peers, health care workers and social workers, also contributes to ART adherence and disclosure of HIV status.^{30, 31}

1.4 Supporting ALHIV in South Africa

South Africa has one of the largest populations of PLHIV globally – this includes children and adolescents. The South African Medical Research Council (SAMRC) has implemented a Social Impact Bond (SIB) intervention to address health and social challenges faced by adolescent girls and young women (AGYW) in South Africa.³²

SIB is designed to finance social programmes through non-governmental investments. Such financial responsibilities more typically fall to governments. The approach appeals to commercial philanthropic investors who are reimbursed if beneficiaries are determined to have achieved positive socio-economic and other outcomes that are clarified at the outset of an intervention, empirically evaluated, and independently verified.

The approach involves three elements: monetary investment by investors, a planned programme put in place for the intervention, and a government's or organisation's commitment to making re-payments for achieving the improved outcomes as envisaged by these socially motivated investors.³³

SIB has the potential to reduce risks while increasing positive health and social outcomes and saving public money by increasing the implementation of evidence-based programmes.³⁴

Through the SIB intervention, the SAMRC generates knowledge on the understanding of successful and unsuccessful programmes targeting South African AGYW. It focuses further on clarifying the underpinnings and implementation processes attached to such programmes. The focus for South African AGYW involves the implementation of comprehensive biomedical, socio-behavioural, and community-based interventions.

The ALHIV Study

The HSRC, Human and Social Capabilities Division, and the University of Cape Town's (UCT) AIDS and Society Research Unit partnered with the SAMRC to contribute to the SIB intervention by improving our understanding of ALHIV in South Africa. This involved compiling and analysing data from the following sources:

- The South African National HIV Prevalence, Incidence, Behaviour and Communication Survey (SABSSM) conducted since 2002, which includes the most recent survey conducted in 2017.
- The South African *Mzantsi Wakho* ('Your South Africa') study – a longitudinal study on medicines-taking and sexual health practices among ALHIV conducted since 2013 in the Eastern Cape. The study includes quantitative and qualitative data components. Interviews, focus groups, direct observations, and participatory research provided the primary source base for qualitative findings.
- Peer-reviewed research articles and reports on ALHIV, with an emphasis on sub-Saharan African settings and South Africa.

Combining quantitative and qualitative datasets from research studies offers a valuable opportunity for triangulating findings across settings and allows for the emergence of insights from research to support programming and implementation.

Although the HSRC and *Mzantsi Wakho* datasets differ considerably, their integration offers numerous benefits. Both datasets are located in South Africa, with the HSRC survey being a national survey, and the *Mzantsi Wakho* study being located in the Eastern Cape's Amathole District and the Buffalo City Metropolitan Municipality. The latter locations are representative of similarly resourced settings where ALHIV live in South Africa. In combination with the literature review, there is an opportunity for data triangulation towards well-grounded, new perspectives regarding the health and social support needs of ALHIV.

2.1 Aims and objectives

The overall aim of the study is to understand the context of ALHIV in South Africa to inform and strengthen ALHIV programmes.

Objectives include:

- Describing characteristics and trends regarding ALHIV;
- Exploring HIV risks in relation to ALHIV;
- Identifying concerns and gaps that are relevant to programmes for ALHIV.

2.2 Methods

This study is a secondary analysis that draws on quantitative and qualitative data and a literature review. The study focus is ALHIV who are 10 – 19 years old. Data collation and analysis were conducted by three separate teams of researchers who shared findings through bi-monthly workshops over the six month duration of the project. The methods for this research and analysis are described below. It begins with the SABSSM method, is followed by the *Mzantsi Wakho* methods, and is completed by the literature review methods.

2.2.1 SABSSM

The SABSSM is a nationally representative survey that has been conducted since 2002. It was one of the first population-based HIV surveys globally, and it provides diverse information on the distribution and underlying determinants of HIV in South Africa.

Datasets from four SABSSM surveys – 2005, 2008, 2012, 2017 – were collated and reviewed. The data from the 2002 survey were excluded because of the relatively small sample sizes, and because the HIV testing methods used in that survey were not directly comparable to subsequent surveys.

In line with the SIB objectives, attention was given to understanding the circumstances of AGYW aged 10 – 19 years old. Males and females were included in the analysis, as were ALHIV, and adolescents not living with HIV.

Predetermined focal areas were aligned with SIB indicators to determine analysis variables. Key indicators included HIV prevalence, HIV incidence, laboratory determined ART exposure, VLS as determined from blood samples, and demographic and behavioural variables.

Comparative analyses were conducted where sufficient data were available, and trend analysis was conducted using the data from the various relevant survey periods. Age group disaggregation included 10 – 14 years, 12 – 14 years and 15 – 19 years. Count limits were set to ensure validity and reliability for comparison.

Stata software version 15.0³⁵ was used for the analysis. All data were weighted and analysed using the 'svy' command to account for the complex survey design.

2.2.2 *Mzantsi Wakho*

Mzantsi Wakho is an in-depth research repository comprising the largest known mixed methods, community-traced, longitudinal study of medicines-taking and sexual health among ALHIV.

Within the *Mzantsi Wakho* research sites, adolescents aged 10 – 19 years who had tested HIV-positive within a public health facility in Amathole District and Buffalo City Metropolitan Municipality, were recruited into the wider study sample. The study sample combined qualitative and quantitative approaches. In addition to research with the adolescents themselves, data were also collected from caregivers and health workers to provide diverse perspectives on ART adherence and the health practices of ALHIV.

The analysis included in this report focuses on the issue of non-adherence to ART among ALHIV using qualitative data from the *Mzantsi Wakho* study. Inductive analysis of the data established themes on adherence among adolescents and included the meaning and implications of non-adherence to ART. Deductive analysis was used to identify instances of participant-reported or directly observed divergence between an adolescent's understanding of ART adherence, and the interpretations of healthcare workers and caregivers.

2.2.3 Literature review

The literature review drew on research published in English in peer-reviewed journals, or produced by international organisations, governments, universities, adolescent health study teams and other researchers.

Inclusion criteria were as follows:

- Studies conducted in, or pertaining to, South Africa over the past decade, with an emphasis on more recent literature.
- Studies conducted in, or pertaining to, SSA countries over the past decade, including reviews published by various organisations or research entities.

Literature was identified through online electronic searches conducted using Google Scholar and PubMed. Research reports were derived from websites and enquiries made to international organisations such as the World Health Organization (WHO) and the United Nations Programme on HIV and AIDS (UNAIDS), as well as the South African government and research entities including the National Department of Health (NDOH), the Department of Social Development (DSD), Statistics South Africa (Stats SA), and the South African National AIDS Council (SANAC). Themes explored included socioeconomic contexts and demographic factors; knowledge, attitudes and behaviours among ALHIV; HIV-related prevention, treatment and care; key populations (KPs); disclosure of HIV-status; disability; stigma and discrimination; mental health; substance use; gender-based violence (GBV); interventions and programmes; and ALHIV strategies and policies.

CHAPTER 3

SABSSM surveys

Findings are presented for adolescents aged 10 – 19 years drawing on SABSSM surveys from 2005 – 2017.

3.1 Demographic characteristics of ALHIV

Table 1 shows the distribution of ALHIV in South Africa who participated in the 2017 survey by residential locality, race, and marital status. An estimated 3.7% [95% CI: 3.2 – 4.3] of all adolescents are living with HIV – 2.7% [95% CI: 2.1 – 3.4] aged 10 – 14, and 4.9% [95% CI: 4.0 – 5.9] aged 15 – 19.

The 2017 estimate translates to 360 582 adolescents that are living with HIV [95% CI 302 021 – 419 144], among whom 136 913 are 10 – 14 years old and 223 669 are 15 – 19 years old. Among ALHIV aged 10 – 19 years, 202 923 are female and 157 659 are male.

Over half of ALHIV aged 10 – 19 years [53.2%, 95% CI: 44.8 – 61.4] live in urban areas in comparison to 42.5% [95% CI: 34.6 – 50.8] who live in rural informal areas and 4.3% who live on farms. Most ALHIV either live in KwaZulu-Natal [27.0%, 95% CI: 20.3 – 34.8] or Gauteng [18.5%, 95% CI: 11.9 – 27.6], with Northern Cape having the lowest proportion of ALHIV at 0.6% [95% CI: 0.3 – 1.5]. Nearly all ALHIV [95.4%, 95% CI: 89.3 – 98.1] are black African, while a small proportion are white [3.4%, 95% CI: 1.1 – 10.4] or coloured [1.2%, 95% CI: 0.5 – 2.8]. Only 3.6% [95% CI: 1.2 – 10.2] of ALHIV aged 15 – 19 are married.

Table 1: ALHIV aged 10 – 19 by age group, locality, race and marital status, South Africa, 2017

	Males 10 – 14 years		Females 10 – 14 years		Male 15 – 19 years		Females 15 – 19 years		Total 10 – 19 years	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Locality										
Urban	26	40.7	30	54.3	29	66.8	63	48.5	148	53.2
Rural informal (tribal areas)	41	54.6	44	42.1	46	28.7	79	47.1	210	42.5
Rural (farms)	8	4.8	9	3.6	11	4.5	21	4.4	49	4.3
Race*										
African	73	99.2	80	92	84	92.5	157	97.6	394	95.4
White	1	0.8	1	6.2	2	7.5	0	0	4	3.4
Coloured	1	0	2	1.8	0	0	6	2.4	9	1.2
Marital status										
Married	–	–	–	–	0	0	4	3.6	–	–
Not married	–	–	–	–	83	100	153	96.4	–	–

*There were no data for the Indian population group.

The majority of adolescents aged 15 – 19 years were in school (86.7%) (Table 2). However, a higher proportion of ALHIV were not attending school when compared to adolescents who are not living with HIV. A quarter of female ALHIV aged 15 – 19 years (24.8%) were not attending school. Among them, 19.2% had not completed Grade 12, and 5.6% had completed Grade 12. Among adolescents out of school, all male ALHIV and nearly all female ALHIV (99.3%) were not employed. By comparison, 7.4% of males and 5.1% of females not living with HIV were employed.

Table 2: Adolescents aged 15 – 19 by HIV status, schooling and employment, South Africa, 2017

	Male HIV– 15 – 19 years		Female HIV– 15 – 19 years		Male HIV+ 15 – 19 years		Female HIV+ 15 – 19 years		All 15 – 19 years	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Schooling										
In school	1 214	88.0	1 376	86.2	58	83.4	75	75.2	2 723	86.7
Not in school – did not complete Grade 12	120	7.9	136	7.9	7	13.9	18	19.2	281	8.3
Not in school – completed Grade 12	46	4.0	93	5.9	2	2.8	3	5.6	144	4.9
Employment among adolescents out of school										
Unemployed	194	92.6	278	94.9	12*	100	30	99.3	514	94.2
Employed	23	7.4	14	5.1	0	0	1	0.7	38	5.8

n<30

3.2 Disability

Only 1.0% [95% CI: 0.7 – 1.5] of all adolescents 15 – 19 years reported having a disability. Self-reported disability was higher at 0.9% [95% CI: 0.2 – 1.0] among females living with HIV compared to HIV-negative females of the same age at 0.5% [95% CI: 0.2 – 3.5].

Around half (55.9%) of adolescents who reported having a disability had a physical disability, and a third (32.6%) had a mental disability or psychiatric illness.

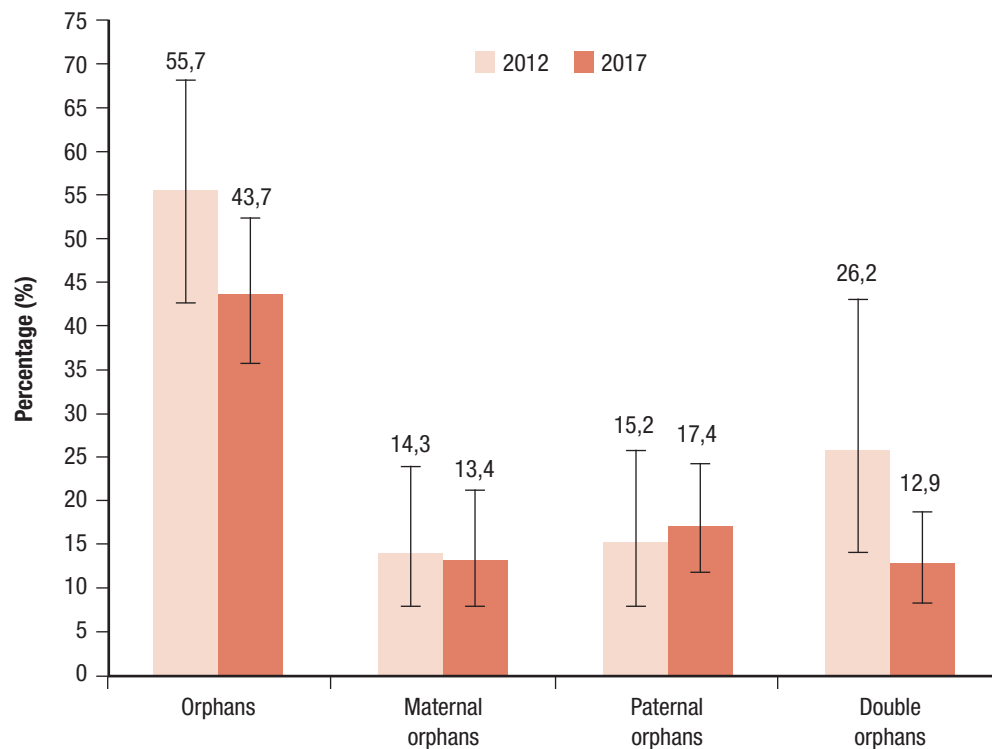
Table 3: Adolescents aged 15 – 19 by disability, South Africa, 2017

	Male HIV– 15 – 19 years		Female HIV– 15 – 19 years		Male HIV+ 15 – 19 years		Female HIV+ 15 – 19 years		All 15 – 19 years	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Self-reported disability	1 740	1.5	2 028	0.5	83	1.4	157	0.9	4 008	1.0

3.3 Orphanhood among ALHIV

Orphanhood – which is defined in South Africa as having lost one or both parents – has declined among ALHIV from 55.7% in 2012 to 43.7% in 2017 (Figure 1). The differences between each year are not statistically significant, however there are some apparent trends. Despite this overall decline, paternal orphanhood was slightly higher at 17.4% in 2017 in comparison to 15.2% in 2012. Maternal orphanhood declined slightly at 14.3% in 2012 compared to 13.4% in 2017. The main decline in orphanhood was among ALHIV who had lost both their parents (double orphans).

Figure 1: ALHIV aged 15 – 19 by orphanhood type, South Africa, 2012 and 2017



Among orphaned ALHIV aged 10 – 19 years in 2017, 43.2% were male and 56.8% were female. Among males, 32.1% were maternal orphans, 36.3% were paternal orphans, and 31.6% were double orphans. By comparison, 29.6% of females were maternal orphans, 42.6% were paternal orphans, and 27.9% were double orphans.

A higher proportion of older ALHIV was orphaned compared to younger ALHIV. Among ALHIV aged 10 – 14 years, 40.3% [95% CI: 28.7 – 53.1] were orphans in comparison to 45.9% [95% CI: 35.5 – 56.7] for ALHIV aged 15 – 19 years.

Table 4: ALHIV aged 10 – 19 by orphanhood type and sex, South Africa, 2017

	Male ALHIV 10 – 19 years			Female ALHIV 10 – 19 years			All ALHIV 10 – 19 years		
	<i>n</i>	%	95% CI	<i>n</i>	%	95% CI	<i>n</i>	%	95% CI
Orphan	51	43.2	31.6 – 55.7	87	56.8	44.3 – 68.4	138	43.7	35.7 – 52.1
Orphan type									
Maternal	18	32.1	15.3 – 55.2	19	29.6	16.7 – 46.7	37	30.7	19.7 – 44.4
Paternal	19	36.3	20.2 – 56.1	37	42.6	28.6 – 57.8	56	39.9	28.5 – 52.5
Double orphan	14	31.6	16.5 – 52.0	31	27.9	16.8 – 42.5	45	29.5	19.9 – 41.3

n<30

3.4 HIV prevalence trends among adolescents

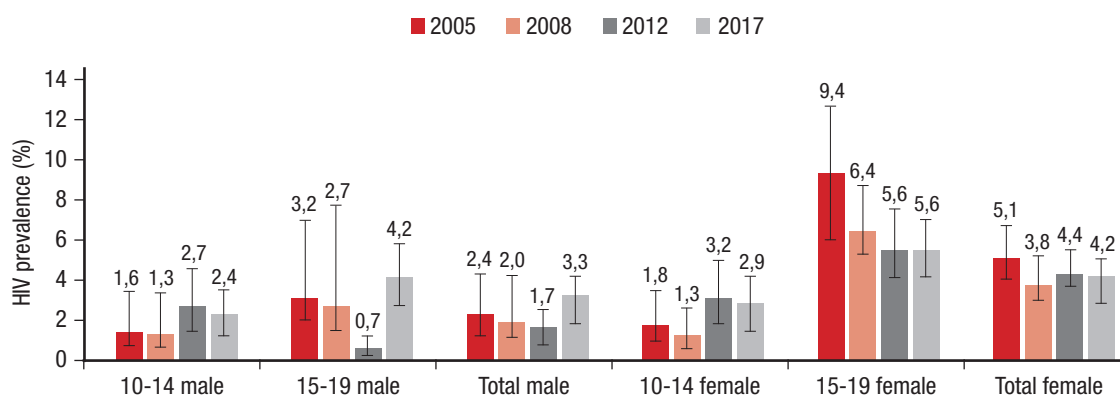
Table 5 and Figure 2 show the trend in HIV prevalence among females and males aged 10 – 14, 15 – 19 and 10 – 19 years from 2005 to 2017. In all years, females aged 15 – 19 years had the highest HIV prevalence in comparison to other age groups. Among this group, HIV prevalence declined from 9.4 % in 2005 to 5.6% in 2017. The opposite trend was found for females aged 10 – 14 years, with an increase in HIV prevalence from 1.8% to 2.9% across the survey years.

In 2012, HIV prevalence among female adolescents aged 15 – 19 years was eight times higher than males in the same age group – a significant difference at 5.6% vs 0.7%. In 2017, HIV prevalence among female adolescents aged 15 – 19 years remained at 5.6% whilst for males of the same age group, HIV prevalence increased from 0.7% to 4.2%. Generally HIV prevalence was lower – but not significantly lower – for males aged 10 – 14 years in comparison to females. For the 10 – 19 years age group as a whole, HIV prevalence declined from 3.6% in 2005 to 3.0% in 2012, then increased to 3.7% in 2017.

Table 5: Adolescent HIV prevalence trends by sex and age group, South Africa, 2005 – 2017

Age group	2005			2008			2012			2017		
	<i>n</i>	%	95% CI	<i>n</i>	%	95% CI	<i>n</i>	%	95% CI	<i>n</i>	%	95% CI
All												
10 – 14	1 745	1.7	1.0 – 2.8	1 505	1.3	0.7 – 2.3	2 793	2.9	2.1 – 4.1	4 524	2.7	2.1 – 3.4
15 – 19	2 154	5.9	4.3 – 8.0	1 928	4.5	3.1 – 6.7	3 117	3.2	2.4 – 4.1	4 238	4.9	4.0 – 5.9
10 – 19	3 899	3.6	2.8 – 4.7	3 433	2.9	2.1 – 4.0	5 910	3.0	2.5 – 3.7	8 762	3.7	3.2 – 4.3
Females												
10 – 14	936	1.8	0.9 – 3.5	792	1.3	0.6 – 2.6	1 346	3.2	2.0 – 4.9	2 356	2.9	2.1 – 4.2
15 – 19	1 153	9.4	7.1 – 12.4	987	6.4	4.7 – 8.6	1 606	5.6	4.2 – 7.5	2 303	5.6	4.5 – 6.9
10 – 19	2 089	5.1	3.9 – 6.7	1 779	3.8	2.9 – 5.1	2 952	4.4	3.5 – 5.5	4 659	4.2	3.5 – 5.0
Males												
10 – 14	809	1.6	0.8 – 3.4	713	1.3	0.5 – 3.3	1 447	2.7	1.6 – 4.6	2 168	2.4	1.8 – 3.3
15 – 19	1 001	3.2	1.4 – 7.1	941	2.7	0.9 – 7.7	1 511	0.7	0.4 – 1.2	1 935	4.2	3.0 – 5.8
10 – 19	1 810	2.4	1.3 – 4.3	1 654	2	0.9 – 4.3	2 958	1.7	1.1 – 2.6	4 103	3.3	2.6 – 4.1

Figure 2: Adolescent HIV prevalence trends, South Africa, 2005 – 2017



3.5 HIV incidence among adolescents

The Limiting Antigen (LAG) Avidity EIA (LAG-Avidity EIA, Portland, USA) was used as part of a multi-assay algorithm that considered ARV treatment and HIV viral load to estimate HIV incidence. Although the data available to estimate HIV incidence in this age range were limited and should be interpreted with caution, new infections in this population are well-demonstrated, as are changes in incidence over time. The incidence data were insufficient for reliable estimates by sex and for younger adolescents aged 10 – 14 years.

The annual HIV incidence rate among adolescents aged 10 – 19 years was 0.50% [95% CI: 0.44 – 0.56] in 2012, declining to 0.39% [95% CI: 0.35 – 0.43] in 2017. The HIV incidence rate in older adolescents, aged 15 – 19 years was 0.87% [95% CI: 0.82 – 0.92] in 2012 and remained largely unchanged at 0.82% [95% CI: 0.74 – 0.90] in 2017.

3.6 Sexually transmitted infections prevalence among adolescents and ALHIV

Approximately 32% (N=16) of male ALHIV and 4% (N=60) of female ALHIV aged 15 – 19 years who said they had ever had sex, self-reported having an ulcer or sore on or near their genitals, which are symptoms associated with sexually transmitted infections (STIs). By comparison, the proportion of self-reported symptoms of STIs among HIV negative adolescents aged 15 – 19 years who had ever had sex was 5% for males (N=430) and 11% for females (N=457).

3.7 HIV testing and disclosure among ALHIV

Adolescents aged 15 – 19 years were asked whether or not they had tested for HIV in the past 12 months, and whether they were aware of their HIV status. Among ALHIV, 37.9% [95% CI: 29.2 – 47.4] had done so. A higher proportion of female ALHIV knew their status, 51.5% [95% CI: 40.2 – 62.7] in comparison to males, 17.8% [95% CI: 9.0 – 32.3] (Table 6). Proportions of females disclosing their HIV status to a main sexual partner were markedly higher in comparison to males (77.6% vs 11.5%).

Table 6: ALHIV aged 15 – 19 who tested in the past year, know their HIV status and have disclosed their status to their main partner by sex, South Africa, 2017

Sex	ALHIV who tested in the past year and know HIV status			Of those aware of HIV status, disclosed to a main sexual partner		
	n	%	95% CI	n	%	95% CI
All	234	37.9	29.2 – 47.4	52	60.5	40.4 – 77.6
Male	79	17.8	9.0 – 32.3	9	11.5	2.4 – 40.8
Female	155	51.5	40.2 – 62.7	43	77.6	58.6 – 89.4

3.8 Progress towards UNAIDS 90-90-90 targets

In 2013, the UNAIDS Programme Coordinating Board called on UNAIDS to lead new targets for the scale-up of HIV treatment. The targets aim to contain the AIDS epidemic by 2030 and include the following for 2020: 90% of persons living with HIV (PLHIV) know their HIV status, 90% of those diagnosed with HIV receive ART, and 90% of all people receiving ART have achieved viral suppression.³⁶ A person who sustains viral suppression cannot transmit HIV to others.³⁷ The 90-90-90 formula sets out to achieve a level of 73% VLS among all PLHIV.

In the SABSSM studies, HIV treatment status was determined by laboratory testing for the presence of ARVs in HIV-positive dried blood spot (DBS) samples. VLS was determined through viral load testing on all confirmed HIV-positive DBS samples.

Figure three illustrates the achievements to target by 2017. The gap in attaining VLS was 43% for male ALHIV and 40% for female ALHIV.

Figure 3: ALHIV progress and gaps in reaching 90-90-90 targets, South Africa, 2017

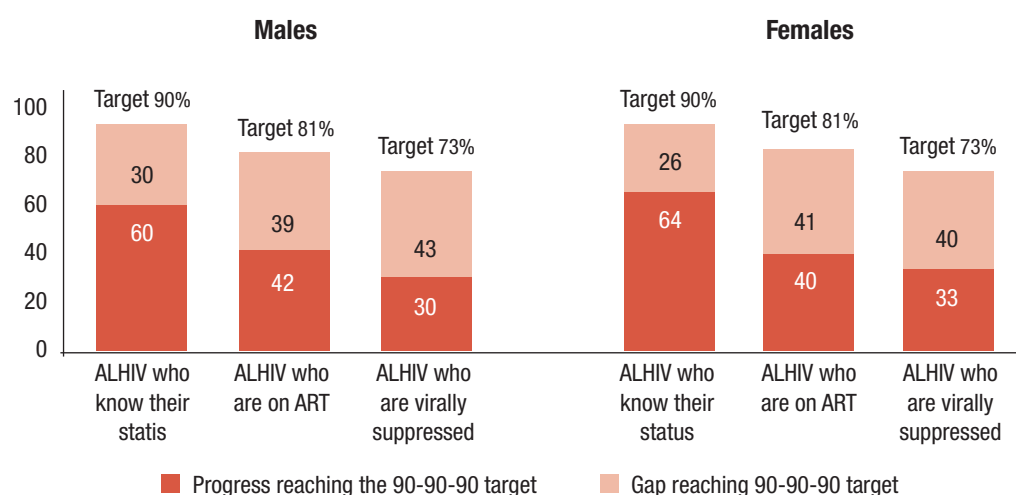


Table 7 shows 62.3% of HIV positive adolescents aged 10 – 19 years knew their HIV status. Knowledge of HIV status was significantly lower for ALHIV aged 10 – 14 at 44.5% [95% CI: 33.1 – 56.5] in comparison to 73.1% for those aged 15 – 19 years [95% CI: 64.2 – 80.5] ($p<0.001$).

Around two-thirds (65.4%) of ALHIV who knew their HIV status were on ART. Among ALHIV who knew their status, being on ART was significantly higher among those aged 10 – 14 years at 89.9% [95% CI: 72.9 – 96.7] in comparison to 57.9% [95% CI: 45.6 – 69.3] for 15 – 19 year olds ($p=0.001$). Among ALHIV on treatment, 75.2% [95% CI: 55.2 – 88.1] of 10 – 14 years were VLS, as were a similar proportion of 15 – 19 year olds at 79.5% [95% CI: 68.5 – 87.4].

Table 7: ALHIV aged 10 – 19 and the 90-90-90 targets by age group, South Africa, 2017

	10 – 14 years			15 – 19 years			All 10 – 19 years		
	<i>n</i>	%	95% CI	<i>n</i>	%	95% CI	<i>n</i>	%	95% CI
All ALHIV	4 513	2.7	2.1 – 3.4	4 228	4.9	4.0 – 5.9	8 741	3.7	3.2 – 4.3
Know HIV status	158	44.5	33.1 – 56.5	249	73.1	64.2 – 80.5	407	62.3	54.7 – 69.2
Of ALHIV who know status, on ART	54	89.9	72.9 – 96.7	157	57.9	45.6 – 69.3	211	65.4	54.3 – 75.0
Of ALHIV on ART who are VLS	48	75.2	55.2 – 88.1	105	79.5	68.5 – 87.4	153	78.1	69.0 – 85.1

Table 8 shows ALHIV in relation to the 90-90-90 targets by sex. Similar proportions of ALHIV aged 10 – 19 years knew their HIV status – 60.1% of males and 63.9% of females, although ART uptake was lower among females at 62.1% [95% CI: 50.1 – 72.8] in comparison to 70.5% for males [95% CI: 50.7 – 84.7]. However, among ALHIV on ART, more females achieved VLS at 82.8% [95% CI: 71.3 – 90.3] in comparison to males at 71.7% [95% CI: 55.4 – 83.9] although these differences were not significant.

Table 8: ALHIV aged 10 – 19 and the 90-90-90 targets by sex, South Africa, 2017

	Male 10 – 19 years			Female 10 – 19 years			All 10 – 19 years		
	<i>n</i>	%	95% CI	<i>n</i>	%	95% CI	<i>n</i>	%	95% CI
All ALHIV	4 093	3.3	2.6 – 4.1	4 648	4.2	3.5 – 5.0	8 741	3.7	3.2 – 4.3
Know HIV status	161	60.1	49.6 – 69.7	246	63.9	53.4 – 73.3	407	62.3	54.7 – 69.2
Of ALHIV who know status, on ART	73	70.5	50.7 – 84.7	138	62.1	50.1 – 72.8	211	65.4	54.3 – 75.0
Of ALHIV on ART who are VLS	57	71.7	55.4 – 83.9	96	82.8	71.3 – 90.3	153	78.1	69.0 – 85.1

Self-reported ART and the presence of ARVs in blood samples were compared for the ALHIV ($n=63$) who reported that they had been tested for HIV and that they were aware of their status. Table 9 describes the discordance in agreement between self-reported ART versus ART detected in the blood. The Kappa coefficient is 0.212, indicating fair agreement between self-report and blood sample-based ART.

Among all ALHIV, 84.8% reported that they were on ART while 73.4% had ARVs present in their blood samples (Table 9). All the ALHIV who had ARVs detected in their blood also self-reported being on ART ($n=51$). However, among ALHIV for whom ARVs were not detected in their blood, 12.7% (8/63) reported that they were taking ART. This result demonstrated a significant discordance between self-reported ART and the presence of ARVs in the blood (McNemars' Chi (1) =12.0, $p<0.001$).

When disaggregating by sex and age group, significant discordance was found among females ($p=0.008$) and 15 – 19 year olds ($p=0.004$). A higher proportion of female ALHIV (96.4%) self-reported being on ART than male ALHIV (71.0%) ($p=0.017$). All the 10 – 14 year old ALHIV reported being on ART compared to 72.7% of 15 – 19 year old ALHIV. Similarly, a lower proportion of 15 – 19 year olds (56.1%) had ARVs detected in their blood samples than 10 – 14 year olds (95.2%) ($p<0.001$).

Table 9: ALHIV who know their HIV status and are on ART, blood test and self-report, by sex and age group, South Africa, 2017

Of ALHIV who were tested and were aware of HIV status ¹								
	On ART (blood test)			On ART (self-reported)			Test of discordance	
	<i>n</i>	%	95% CI	<i>n</i>	%	95% CI	<i>n</i>	McNemar's test <i>p</i> -value
Total	51	73.4	52.6 – 87.3	59	84.8	60.3 – 95.3	63	<0.001
Sex								
Male	18	67.4	33.4 – 89.5	20	71	34.5 – 91.9	22 ²	0.125
Female	33	78.4	55.6 – 91.3	39	96.4	82.8 – 99.3	41	0.008
Age group								
10 to 14	25	95.2	84.5 – 98.7	28	100		28 ²	0.250
15 to 19	26	56.1	31.3 – 78.1	31	72.7	41.2 – 91.0	35	0.004

1. Of ALHIV who were tested, aware of their status, and disclosed their positive status in the survey

2. $n<30$

3.9 Viral load suppression

VLS is defined as having a viral load of <1 000 copies HIV RNA/ml. HIV viral load results were available for 398 ALHIV aged 10 – 19 years. Among this group, 48.9% [95% CI: 41.5 – 56.3] had VLS. A higher proportion of ALHIV aged 10 – 14 years, 54% [95% CI: 41.9 – 65.7] had VLS compared to their older counterparts, but these differences were not significant.

Table 10: ALHIV with VLS, by sex and age group, South Africa, 2017

	10 to 14 years			15 to 19 years			All 10 – 19 years
	<i>n</i>	%	95% CI	<i>n</i>	%	95% CI	<i>n</i>
All	95	54.0	41.9 – 65.7	121	45.7	36.5 – 55.3	216
Male	49	67.5	51.9 – 79.9	32	37.4	23.7 – 53.6	81
Female	46	42.8	27.6 – 59.5	89	51.9	41.1 – 62.6	135

3.10 HIV drug resistance

Out of a total of 398 ALHIV aged 10 – 19 years with VLS data, 51.1% [95% CI: 43.7 – 58.5] were not virally suppressed (VL >1 000 copies/ml). Among these, 46 samples – 31 females and 15 males – were successfully amplified and sequenced for HIV drug resistance (HIVDR). HIVDR was detected in the samples of 10 female ALHIV. Among these, 7 had non-nucleoside reverse transcriptase inhibitor (NNRTI) mono resistance, while the remainder had dual NNRTI and nucleoside reverse transcriptase inhibitor (NRTI) resistance.

3.11 Pregnancy in the past 24 months

Adolescent females aged 15 – 19 years who were sexually active in the past year were asked if they had been pregnant in the past 24 months. In 2017, 21.3% [95% CI: 17.0 – 26.4] reported having been pregnant, among whom 41.5% [95% CI: 26.7 – 58.0] were ALHIV. These estimates translate to 107 859 females aged 15 – 19 years reporting that they were pregnant, among whom 22 705 were HIV positive. By comparison, 18.9% [95% CI: 14.8 – 23.8] females who were not living with HIV reported being pregnant.

Among female ALHIV aged 15 – 19 years living in urban areas, 36.1% were pregnant in the past 24 months in comparison to 16.2% among those not living with HIV. Among ALHIV living in rural areas, having been pregnant in the past 24 months was also higher at 46.3% in comparison to 23.3% for those not living with HIV.

Among adolescent females in school who were pregnant in the past 24 months, levels of pregnancy among ALHIV were nearly three times higher at 37.7% ($p=0.349$) in comparison to adolescents not living with HIV at 12.7% ($p=0.019$). Among ALHIV who were orphans, 44.4% had been pregnant in the past 24 months in comparison to 20.5% of orphans who were adolescents not living with HIV.

Table 11: Proportion of adolescent pregnancy in past 24 months among females 15 – 19 by HIV status, locality, schooling and orphanhood, South Africa, 2017

	Pregnant			Not pregnant			Total
	<i>n</i>	%	95% CI	<i>n</i>	%	95% CI	<i>n</i>
Total	151	21.3	17.0 – 26.4	362	78.7	73.6 – 83.0	513
HIV status							
HIV+	25*	41.5	26.7 – 58.0	34	58.5	42.0 – 73.3	59
HIV–	126	18.9	14.8 – 23.8	328	81.1	76.2 – 85.2	454
Locality							
Urban, HIV+	7*	36.1	15.2 – 64.1	12*	63.9	35.9 – 84.8	19*
Urban, HIV–	53	16.2	11.1 – 23.1	169	83.8	76.9 – 88.9	222
Rural, HIV+	18*	46.3	28.6 – 64.9	22*	53.7	35.1 – 71.4	40
Rural, HIV–	73	23.3	17.6 – 30.2	159	76.7	69.8 – 82.4	232
Current school attendance							
In school, HIV+	5*	37.7	14.1 – 69.0	10*	62.3	31.0 – 85.9	15*
In school, HIV–	37	12.7	8.2 – 19.1	145	87.3	80.9 – 91.8	182
Orphanhood status							
Orphan, HIV+	8*	44.4	20.2 – 71.5	11*	55.6	28.5 – 79.8	19*
Orphan, HIV–	46	20.5	12.9 – 31.1	108	79.5	68.9 – 87.1	154

3.12 Knowledge and misconceptions about HIV

Table 12 shows the proportion of ALHIV aged 12 – 19 years who had correct knowledge about HIV. This was measured by correctly answering either two questions on HIV prevention, or who correctly addressed three misconceptions about the disease, or who correctly answered both sets of questions to achieve a composite correct score. The two questions on HIV prevention were: ‘Can a person reduce the risk of getting HIV using a condom every time you have sex?’, and ‘Can a person reduce the risk of HIV by having fewer sexual partners?’ The three questions about misconceptions were, ‘Can AIDS be cured?’, ‘Can a healthy-looking person have HIV?’, and ‘Can a person get HIV by sharing food with someone who is infected?’

A higher proportion of ALHIV aged 15 – 19 years correctly answered the HIV prevention questions in comparison to 12 – 14 year olds – 55.8% versus 40.0%. A higher proportion of males in both age groups and those ALHIV residing in rural areas answered the HIV prevention questions correctly in comparison to females.

More ALHIV aged 15 – 19 years correctly addressed the misconceptions in comparison to 12 – 14 year olds – 56.9% versus 36.4%.

Regarding the composite scores, older ALHIV scored correctly in comparison to younger ALHIV (31.6% vs 22.4%) while younger males aged 12 – 14 years scored lower in

comparison to females (8.3% vs 30.7%), and ALHIV living in urban locales scored lower in comparison to ALHIV living in rural locales (26.0% vs 32.2%).

Table 12: ALHIV aged 12 – 19 years by correct knowledge of HIV transmission and rejection of misconceptions, by age group, sex and locality, South Africa, 2017

	Accurate knowledge about HIV transmission			Rejection of misconceptions			Composite score		
	<i>n</i>	%	95% CI	<i>n</i>	%	95% CI	<i>n</i>	%	95% CI
Age									
12 – 14	88	40.0	25.2 – 56.8	88	36.4	22.6 – 52.9	88	22.4	11.3 – 39.7
15 – 19	240	55.8	46.5 – 64.6	240	56.9	47.6 – 65.7	240	31.6	24.5 – 39.6
Sex									
Males,									
12 – 14	38	41.2	23.0 – 62.1	38	36.7	19.7 – 57.9	38	8.3	2.6 – 23.4
Females,									
12 – 14	50	39.3	19.9 – 62.7	50	36.2	18.2 – 59.1	50	30.7	14.1 – 54.4
Males,									
15 – 19	83	61.5	45.2 – 75.5	83	51.1	36.2 – 65.8	83	31.0	19.8 – 45.0
Females,									
15 – 19	157	51.7	40.1 – 63.0	157	61.1	50.3 – 70.8	157	32.0	22.6 – 43.1
Locality									
Urban	118	48.8	36.3 – 61.4	118	47.9	35.0 – 61.0	118	26.0	17.3 – 37.2
Rural	210	53.9	44.0 – 63.4	210	54.4	45.5 – 63.0	210	32.2	24.2 – 41.5

3.13 HIV related stigma

Several questions were asked to measure perceived stigma including willingness to discuss HIV status with a family member. Responses to three of these questions are presented here. They include perceptions of others living with HIV and openness regarding discussions about HIV in the family.

In Table 13, the results for ALHIV and adolescents not living with HIV are presented by age group, showing neither marked nor significant differences for 12 – 14 and 15 – 19 year olds on any of the questions by age group, although a higher proportion of the younger age group held stigmatising views about PLHIV who are teachers or shopkeepers.

Among ALHIV, 82.2% of males aged 12 – 14 years agreed an HIV-positive teacher should be allowed to continue teaching in comparison to 64.0% of females. Among ALHIV aged 15 – 19 years, females were more accepting in comparison to males. 93.2% of females agreed that an HIV-positive teacher should be allowed to continue to teach, in comparison to 77% of males. The influence of HIV information and awareness programmes, and of the harms of HIV-related stigma, seem to be influencing the opinions and ideas of young men and women in different ways in interpretations of these survey questions. Responses among urban and rural youth aged 12 – 19 years were similar.

Table 13: Adolescents aged 12 – 19 years and stigma perceptions, by HIV status, age group, sex and locality, South Africa, 2017

	If a teacher has HIV but is not sick, he or she should be allowed to continue to teach?			If you knew that a shopkeeper or food seller had HIV, would you buy food from them?			Are you comfortable talking to at least one member of your family about HIV and AIDS?		
	n	%	95% CI	n	%	95% CI	n	%	95% CI
12 – 14, HIV–	1 758	69.3	66.3 – 72.2	1 439	58.2	55.1 – 61.2	1 584	64.5	61.5 – 67.4
12 – 14, HIV+	71	70.7	50.8 – 85.0	57	55.1	38.0 – 71.1	62	64.7	46.2 – 79.7
15 – 19, HIV–	3 310	87.2	85.5 – 88.7	3 043	80.2	78.0 – 82.2	3 079	80.3	78.1 – 82.4
15 – 19, HIV+	214	86.8	77.8 – 92.5	205	87.0	79.9 – 91.9	193	75.1	66.2 – 82.3
Sex (ALHIV)									
Males, 12 – 14	32	82.2	58.1 – 93.9	25	59.0	37.0 – 77.9	25	67.0	45.2 – 83.3
Females, 12 – 14	39	64.0	37.4 – 84.1	32	52.9	30.4 – 74.2	37	63.4	37.1 – 83.6
Males, 15 – 19	71	77.7	59.3 – 89.2	70	89.4	77.3 – 95.4	61	70.1	54.3 – 82.3
Females, 15 – 19	143	93.2	87.3 – 96.5	135	85.3	75.1 – 91.8	132	78.6	67.5 – 86.7
Locality (ALHIV)									
Urban, 12 – 19	104	80.7	64.2 – 90.7	98	81.0	66.8 – 90.0	90	69.8	55.9 – 80.8
Rural, 12 – 19	181	83.7	76.2 – 89.2	164	73.7	63.1 – 82.1	165	74.7	65.5 – 82.1

3.14 Alcohol use

Adolescents aged 15 – 19 years were asked if they drank alcohol and, if yes, the quantity that they consumed in the past 12 months. In the 2012 and 2017 surveys, the majority of adolescents – 80% of those not living with HIV and 84.4% of ALHIV – reportedly did not drink alcohol. Using the Alcohol Use Disorders Identification Test (AUDIT) scale,³⁸ it was determined that among those who did drink alcohol, most were low-risk drinkers, although a small proportion of adolescents aged 15 – 19 years fell into the risky and high-risk categories. As shown in Table 14, a higher proportion of female ALHIV and those living in rural locales were non-drinkers.

3.15 Trends in sexual behaviours and relationship practices among female adolescents

Several risk behaviours and relationship practices have been established through research to increase the risk of HIV acquisition or transmission among adolescents. These include early sexual debut (at younger than 15 years of age), having a most recent sexual partner who is five or more years older than oneself, having two or more partners in the past year, and using a condom during sex (measured as 'condom use at last sex'). For HIV negative adolescents, these risks of HIV acquisition are elevated for females in comparison to males. For ALHIV, they pose elevated risks for onward transmission of HIV to sexual partners and potentially to their children.

Figure 4 on page 24 describes the findings for these risk factors from the 2005, 2008, 2012 and 2017 surveys. While the differences between each year are not statistically significant, there are some apparent trends. Reporting ever having had sex (sexual debut) has declined from 65.8% in 2005 to 56.7% in 2017; having first sex when younger than 15 years of age increased from 12.7% to 14.4%; using a condom at last sex decreased from 54.2% to 48.2%; having a most recent sexual partner who is five or more years older than oneself increased from 39.2% to 47.5%; and having two or more sexual partners increased from 8.1% to 16.2%.

Table 14: Adolescents aged 15 – 19 years by alcohol use (abstainers, hazardous or harmful alcohol users) and by HIV status, sex and locality, South Africa, 2017

	Do not drink			Low risk (1 – 7)			Risky/hazardous (8 – 15)			High risk/harmful (>=16)		
	<i>n</i>	%	95% CI	<i>n</i>	%	95% CI	<i>n</i>	%	95% CI	<i>n</i>	%	95% CI
HIV status												
HIV–	2 955	80.0	77.6 – 82.2	391	14.2	12.4 – 16.3	116	4.4	3.4 – 5.7	34	1.4	0.8 – 2.2
HIV+	207	84.4	74.2 – 91.0	14	8.0	4.1 – 14.9	6	4.2	1.0 – 16.8	2	3.4	0.9 – 12.3
Sex (ALHIV)												
Males												
15 – 19	72	76.1	56.7 – 88.6	4	7.9	2.5 – 22.2	1	7.7	1.1 – 38.2	2	8.3	2.2 – 26.5
Females												
15 – 19	135	90.2	81.3 – 95.1	10	8.0	3.6 – 16.9	5	1.8	0.5 – 6.3	0	0.0	
Locality (ALHIV)												
Urban	69	75.0	59.4 – 86.0	11	12.9	6.3 – 24.7	2	6.0	0.9 – 29.8	2	6.1	1.6 – 20.6
Rural	138	96.2	89.9 – 98.6	3	1.8	0.4 – 6.8	4	2.0	0.4 – 8.5	0	0.0	

Table 15 compares the findings for adolescents aged 15 – 19 years who drank alcohol at least twice a month.

Table 15: Adolescents aged 15 – 19 years who drink alcohol at least twice a month by HIV status, sex and locality, South Africa, 2012 and 2017

	2012			2017		
	Drank alcohol at least twice a month			Drank alcohol at least twice a month		
	<i>n</i>	%	95% CI	<i>n</i>	%	95% CI
HIV–	234	7.5	6.0 – 9.3	186	6.8	5.5 – 8.4
HIV+	4*	3.4	0.9 – 12.4	7*	4.1	1.5 – 10.5
Sex (ALHIV)						
Males 15 – 19	1*	5.6	0.7 – 33.4	2*	5.7	1.3 – 21.0
Females 15 – 19	3*	3.1	0.6 – 14.4	5*	2.9	0.8 – 10.2
Locality (ALHIV)						
Urban	4*	8.0	2.0 – 27.1	4*	6.4	2.1 – 17.9
Rural	0*	0.0	–	3*	1.1	0.2 – 4.8

* *n*<30

Figure 4: HIV risk behaviours among female adolescents aged 15 – 19, South Africa, 2005 – 2017

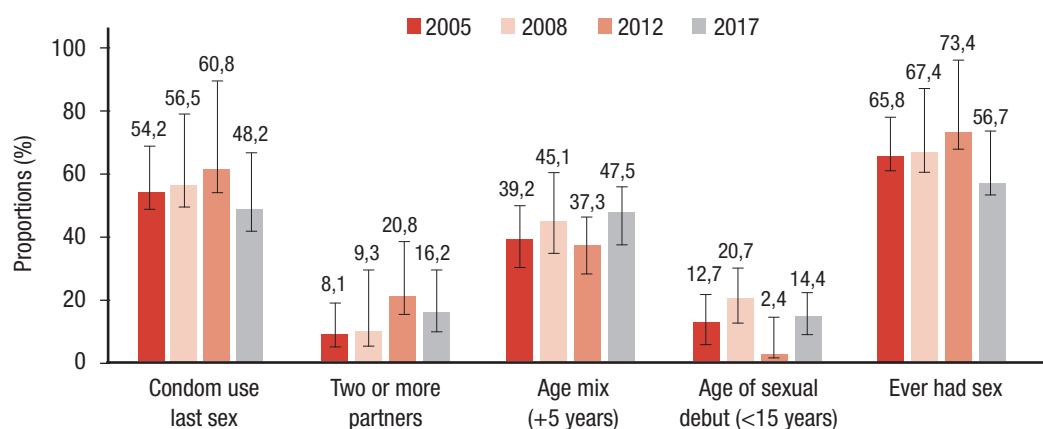


Table 16 shows the sexual behaviours and relationship practices among female adolescents aged 15 – 19 years. More female ALHIV reported that they had ever had sex (56.7%) in comparison to female adolescents who were not living with HIV (34.5%). Among female adolescents aged 15 – 19 years who reported ever having had sex, more ALHIV (82.1%) reported having had sex in the past year in comparison to those who were not living with HIV (70.2%). Having had first sex before the age of 15 was similar for both categories at 14.4% for ALHIV and 12.5% for those who were not living years with HIV.

The proportion of female ALHIV who used a condom at last sex was lower than for female adolescents not living with HIV – 48.2% vs 60.6%. In comparison to female adolescents not living with HIV, female ALHIV more commonly reported having had two or more sexual partners in the past year (16.3% vs 12.4%) and having a most recent sexual partner who was five or more years older than they were (47.2% vs 32.6%).

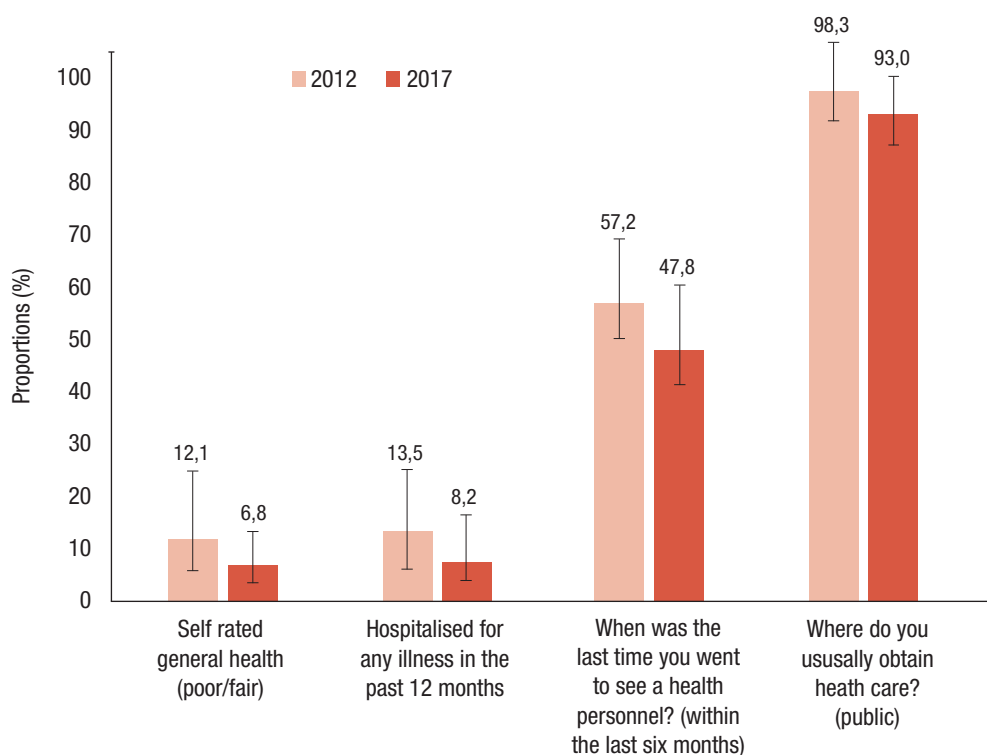
Table 16: Female adolescents aged 15 – 19 by HIV status, sexual behaviours and relationship practices, South Africa, 2017

	Female, HIV– 15 – 19 years			Female, HIV+ 15 – 19 years			All 15 – 19 years		
	<i>n</i>	%	95% CI	<i>n</i>	%	95% CI	<i>n</i>	%	95% CI
Ever had sex	1 991	34.5	31.0 – 38.2	155	56.7	45.5 – 67.3	2 146	35.8	32.4 – 39.4
Among those who said they ever had sex									
Had sex in the past year	611	70.2	63.6 – 76.0	71	82.1	66.0 – 91.6	682	71.3	65.2 – 76.7
Sexual debut at <15 years	618	12.5	9.2 – 16.9	73	14.4	6.8 – 27.9	691	12.7	9.5 – 16.8
Among those who said they had sex in the past year									
Used a condom at last sex	451	60.6	54.0 – 66.8	58	48.2	31.6 – 65.3	509	59.2	53.0 – 65.2
Two or more partners in the past year	449	12.4	8.4 – 18.0	57	16.3	6.4 – 35.4	506	12.8	9.0 – 18.0
Most recent partner 5 years older	452	32.6	26.6 – 39.3	58	47.2	31.5 – 63.4	510	34.2	28.5 – 40.4

3.16 Self-rated health and utilisation of health care among female ALHIV 15 – 19 years in 2012 and 2017

Figure 5 shows self-rated health and health care utilisation among female ALHIV 15 – 19 years in 2012 and 2017. In 2012, 12.1% of female ALHIV aged 15 – 19 years rated their general health as poor, compared to 6.8% in 2017. In 2012, 13.5% were hospitalised for any illness in the past 12 months, and this decreased to 8.2% in 2017. Visiting a health care worker in the past 6-months declined from 57.2% in 2012 to 47.8% in 2017. The vast majority of ALHIV usually accessed health care from a government facility in both periods, with a slight decline from 98.3% to 93.0% in 2017.

Figure 5: Self-rated health and healthcare utilisation among female ALHIV aged 15 – 19 years, South Africa, 2012, 2017



3.17 Psychological distress

Psychological distress was measured through a matrix of questions regarding experiences of anxiety and depressive disorders in the past 30 days. Responses were organised into two categories: low distress, scoring <20, and high distress, scoring ≥ 20 .

As shown in Table 17, in 2012, almost a third (31.2%) of HIV-positive adolescents experienced psychological distress. This was significantly higher than for adolescents not living with HIV (16.1%) ($p=0.008$). In 2017, however, low and high distress levels for ALHIV as well as adolescents not living with HIV were similar, illustrating commonality in at least some of the stressors that young people face – regardless of HIV-positive status.

Among ALHIV, more males reported low distress levels in comparison to females in 2012 (94.3% vs 65.8%), whereas, in 2017, levels of low distress were similar (82.6% vs 85.4%).

In 2012, the prevalence of high distress was significantly higher for ALHIV living in urban areas (48.0%) compared to those in rural areas (19.5%) ($p=0.032$). In 2017, levels of distress were similar by locality.

Table 17: Adolescents aged 15 – 19 and prevalence of psychological distress by sex and locality, South Africa, 2012, 2017

	2012			2017			2017					
	n	%	95% CI	n	%	95% CI	n	%	95% CI			
HIV status												
HIV-	2 481	83.9	81.3 – 86.3	445	16.1	13.7 – 18.8	3 219	84.2	82.2 – 85.9	535	15.9	14.1 – 17.8
HIV+	65	68.8	54.2 – 80.5	25	31.2	19.5 – 45.8	197	84.2	76.4 – 89.8	42	15.8	10.2 – 23.6
Sex (ALHIV)												
Males 15 – 19*	15*	94.3	70.6 – 99.1	2*	5.7	0.9 – 29.4	69	82.6	66.0 – 92.1	14*	17.4	7.9 – 34.1
Females 15 – 19	50	65.8	50.1 – 78.6	23*	34.2	21.4 – 49.9	128	85.4	75.8 – 91.6	28*	14.6	8.4 – 24.2
Locality (ALHIV)												
Urban	26*	52.1	30.7 – 72.7	15*	48.0	27.3 – 69.3	73	85.6	72.3 – 93.1	14*	14.4	6.9 – 27.7
Rural	39	80.6	63.1 – 90.9	10*	19.5	9.1 – 36.9	124	82.5	72.6 – 89.3	28*	17.5	10.7 – 27.5

* n<30

3.18 Intimate partner violence

Among all adolescents aged 15 – 19 years in 2017 and who had a sexual partner in the past 12 months, the proportion who reported being pushed, shaken or having had an object thrown at them by their partner was 16.3%, having been slapped by a partner was reported by 18.3%, being punched, 7.6% and being forced to have unwanted sex, 2.4%.

Table 18: Adolescents aged 15 – 19 years and partner violence in the past 12 months, South Africa, 2017

	Pushed, shaken or object thrown (n=199)			Slapped (n=199)			Punched (n=198)			Physically forced to have sex, unwanted (n=198)		
	n	%	95% CI	n	%	95% CI	n	%	95% CI	n	%	95% CI
All												
15 – 19 years	24*	16.3	8.4 – 29.3	29*	18.3	10.1 – 30.7	8*	7.6	2.1 – 23.8	5*	2.4	0.9 – 5.9

**n<30

This concludes the analyses of the SABSSM datasets and leads to the next section on findings from the *Mzantsi Wakho* study, focusing on ART adherence.

Mzantsi Wakho

4.1 Adherence to ART among ALHIV

This study component explored adherence to ART among ALHIV including:

- How adolescents, adult caregivers, and healthcare workers understand, prescribe and practice medicines-taking.
- How adolescents and their adult caregivers regard and report adherence.
- How ALHIV, adult caregivers and healthcare workers understand adolescents' deviations from their medical prescriptions, and their defaulting from ART.

4.2 Profiling ART adherence among ALHIV

Non-adherence to ART has traditionally been determined via three measures: self-report, pill counts by healthcare workers, or biomarker data based on blood samples that demonstrate a decline in CD4 count and an increase in viral load. Some of these measurements have flaws and limitations.²⁴ Within the *Mzantsi Wakho* study, researchers reviewed patient files housed within ART and paediatric wards, and data capturing offices at healthcare facilities.

In the *Mzantsi Wakho* study, 'collateral reports' – in which caregivers described adolescents' treatment-taking – were another means by which healthcare workers monitored and captured ART adherence in the absence of the patient's presentation at the healthcare facility.³⁹ In many cases – particularly among younger ALHIV – adult caregivers served as proxy patients attending clinic visits, fetching medications, and providing health updates on behalf of adolescents. Consequently, cases of non-adherence were typically reported to healthcare workers by adult caregivers. Strategies were then explored directly with adolescent patients to seek to improve their adherence to ART.

Within the study, open-ended questions and various forms of participatory research engagements were used to explore healthcare behaviours such as non-adherence to ART, having sex with multiple partners, or not using condoms. These diverse approaches, and their combination, aimed to confront and curtail the social desirability bias that often tempers accounts of stigmatised or 'irresponsible' behaviours: including not taking medicines as prescribed, not abstaining from sex, or not using contraception.

Years of ongoing engagement with adolescents in conjunction with participatory research strategies allowed for authentic and spontaneous accounts of the challenges of adhering to medicines. Furthermore, observations in participant's homes and accompaniment on clinic visits gave a more detailed picture of the many ways in which adolescents practice ART adherence beyond the instructions or proscriptions of healthcare workers or caregivers.⁴⁰

4.3 Measuring adherence

Adherence to ART is crucial to the effectiveness of HIV treatment. However, there is considerable dispute over how to measure and track adherence. Adherence measurements, such as self-reporting, rely on a patient's ability to understand, recollect and recount pill-taking. 'Collateral report', which refers to the descriptions of caregivers of adolescents' treatment-taking, includes the perspectives of others in assessing a patient's adherence. In the case of many adolescents, the accounts of their adult caregivers or healthcare

providers offer insights into how consistently they are taking their medicines. Applying more objective measures of adherence, including pharmacy records and bioassay, are other means of assessing a patient's adherence. Yet resource constraints, such as limits on healthcare workers' time for data collection, or indeed a lack of motivation or interest in populating, storing and retrieving patient files, mean that these documents and the diagnostics they are supposed to capture are often disorganised or inaccessible to ALHIV at the healthcare facilities in which they are treated.⁴¹

Within interviews and observations with adult caregivers and healthcare workers, terms for non-adherence were used widely. ALHIV who were not taking medicines at the right times and in the correct doses were described as having 'poor compliance', being 'non-compliant' or 'non-adherent', or as 'defaulting'. In most cases, the term 'defaulting' or 'defaulter' was reserved for patients with the worst adherence outcomes and the weakest retention in care, and for those who had disengaged entirely from the health sector or were 'lost-to-follow-up'.

4.4 Healthcare workers' perspectives on ART non-adherence

Many healthcare workers were deeply frustrated by non-adherence to ART among their ALHIV patients. They understood adolescents' seeming inability or refusal to adhere to HIV medicines as instructed as a matter beyond their control, but for which they would bear the negative consequences in the form of a protracted patient burden and a heavier workload. Some healthcare workers observed that patients who defaulted on their ART would abscond from healthcare services, only to return months or even years later with an opportunistic infection (often tuberculosis) resulting from the viral rebound. But beyond the additional labour of treating adolescent defaulters, healthcare workers were frustrated and saddened by the seeming recalcitrance of their young patients, and by their perceived inability or refusal to take ART as prescribed, leading to damaging or lethal consequences.

The healthcare workers in this study, many of whom had careers that spanned the entirety of South Africa's rollout of ART, understood defaulting as a waste of their time and precious public resources. Those who had worked in public facilities before the rollout had hoped that access to medicines would ensure a total transformation in the health of their HIV-positive patients. Many could not fathom why patients refused or failed to take their ART despite its public accessibility.

Sexually active adolescents, and particularly those who were pregnant, provoked particular censure from healthcare workers who feared that they would transmit HIV to their sexual partners or their children, driving HIV incidence and thwarting the government's objectives – and indeed those of UNAIDS – of 'ending AIDS' by 2030.

For healthcare workers, the emotional toll exacted by ART non-adherence was especially prominent in relation to ALHIV patients in comparison to adults, given that they were on the cusp of adulthood or even parenthood, with a potentially long and healthy future ahead. They expressed their bewilderment and frustration with defaulting ALHIV, explaining that ALHIV:

Present a challenge: *'These teenagers, they are a big problem. They are in a big mess.'* (Nurse, Eastern Cape Hospital, 25 October 2013).

Had unfathomable rationale: *'We don't know why they default while they default.'* (Nurse, Eastern Cape Day Hospital, 20 June 2014).

Exacerbated their workload: *'We don't know how to stop this defaulting business. We sit with piles and piles and piles of cards of patients who have defaulted.'* (Nurse, Eastern Cape Clinic, 17 June 2014).

For many healthcare workers, ART defaulting by ALHIV seemed inevitable. When asked about why ALHIV default, the nurse-in-charge of an ART clinic at a hospital exclaimed: *'Teens will be teens!'*

Healthcare workers were also cognisant of the structural and environmental factors for ALHIV not adhering to ART. Common explanations included limited access to health facilities due to the high cost of transport and a lack of strong familial support. Many adolescents within the wider *Mzantsi Wakho* study were orphans, with 59% being paternal orphans and 49% maternal orphans.⁴²

Elderly caregivers – often a grandmother or great aunt – struggled to monitor and control the movements and actions of ALHIV. Household incomes, principally constituted by social grants, made little provision for the costs of clinic transport, and the costs of accompanying an adolescent to a clinic, often entailing long waiting periods. Nurses recognised these costs and challenges for ALHIV, including the dangers of young people traveling without the physical presence of an adult caregiver: *'The road is too dangerous. She cannot come alone.'* (Nurse, Eastern Cape Hospital, 18 February 2014).

Healthcare workers noted that mobility was a challenge to adherence. Throughout the *Mzantsi Wakho* study, many ALHIV migrated to urban hubs in Gauteng and the Western Cape in search of work, and as an assertion of their greater autonomy and independence. Healthcare workers believed that once beyond the purview of their families, ART adherence and its monitoring by caregivers would waver:

'The teens who are at school are adhering very well. They want to look good. They want to be seen out of that illness. They are adhering very well, more especially when they are at school and their supporters are living with them. So, there is no way that they can default because they are staying at home. Once they start to move around, there is more defaulting.' (Nurse, Eastern Cape Hospital, 18 February 2014).

Patients who were especially rebellious and non-compliant were labelled as 'chronic defaulters', described by healthcare workers as being 'stubborn' and 'boring'. These labels captured healthcare workers' sentiments of their powerlessness and their frustration when confronted with the seeming intractability of youthful disobedience.

4.4.1 Addressing non-adherence

Healthcare workers sought to address non-adherence in various ways – depending on their diagnosis of its causes. They recommended referrals to external sources of motivation and support including social services, education and counselling. They also used more direct and emotive techniques such as shouting at patients (both privately in consultation rooms, and publicly in front of other patients and clinic staff in waiting rooms). At times, they threatened to contact family members or even the police to report a patient's poor adherence.

A review of adolescent clinic files from public healthcare facilities' treatment units captured similar responses to adolescent non-adherence within their patient folders. Healthcare workers documented their approaches within patient's files, including their attempts to ameliorate structural barriers to ART adherence, through linking patients to social support services through which they might access government grants. Some healthcare workers, together with adult caregivers, sought to incentivise and promote ART adherence through praise and the promise of gifts. Similar to interviews with healthcare workers, exasperation and despair over participant non-adherence were evident, alongside hope, enthusiasm, and pleasure when participants appeared to adhere better.

Patient files housed at healthcare facilities documented the struggles of healthcare workers to improve ART adherence among ALHIV. In the following example, a 'sister in charge' of a paediatric ART unit documented her attempts to improve ART adherence:

Case study 1: Vuyo

Vuyo* (name changed to protect identity), a twelve-year-old male was initiated onto ART in 2011. His 'non-compliant' and 'defaulting' behaviour was met with a variety of strategies by the healthcare worker to support better ART adherence. These included giving him a pillbox and promising him 'another chance to prove himself'. Excerpts from this clinic file are included below, demonstrating the frustrations of the healthcare worker, alongside her strategies to get him to adhere:

- *'Don't know what to do. Social worker to intervene.'* (December 2011).
- *'We spoke to (Vuyo) and he says he wants another chance to prove himself. He wants ARVs. I am going to give him another chance, if brother says he is doing better and (Vuyo) says he is ready, then restart.'* (10 January 2012).
- *'Counselled. Will try. If VL <400 in 6/12, (Vuyo) will get present.'* (14 February 2012).
- *'Calendar pillbox given!'* (14 February 2012).
- *'1 month late, educated (Vuyo) once again.'* (21 May 2014).

On one page of his file, Vuyo's ART adherence as monitored by this healthcare facility is tracked closely over four months. During this time, the nurse relies on the recollections of Vuyo's family member to help ascertain his challenges to adherence:

'Brother says child refuses to take his meds at time...'; 'He is still messing around and doesn't come home. He plays till 22h00...' (January 2011).

By December 2012, almost two years later, Vuyo was described in his patient folder as a 'chronic defaulter'.

In April 2013, Vuyo's patient folder stated that he was 'stunted' and that the dietitian was *'worried about nutrition'*. Surprisingly, this entry also notes that Vuyo is 'well and happy', perhaps a record of Vuyo's own perceived good health, or of his unwillingness or inability to complain about illness.

A year later, in May 2014, Vuyo's patient file again documents another missed appointment and inconsistent adherence: *'1 month late... educated... once again.'*

This case study illustrates one healthcare worker's mounting frustration with an adolescent's non-adherence to ART. It documents her engagement with his physical and social environments, and her pursuit of multiple tactics to fortify and improve medicines-taking. Her strategies included seeking external support from social workers, offering motivation, providing incentives including the promise of gifts, engaging with family members, and providing counselling on the importance of ART adherence.

4.4.2 The challenge of 'disobedience'

Caregivers of HIV-positive adolescents understood non-adherence as a form of deviance that was similar to other insubordinate behaviours. Such behaviours included rudeness towards older relatives, walking around after dark, absconding over weekends, and spending time at taverns and nightclubs. Below are excerpts of interviews with the caregivers of ALHIV, sharing perspectives on disobedience, non-compliance with medicines, and other mischievous behaviours. As adult caregivers described:

- *'He doesn't listen. He wants to be reminded all the time... He will come back at night and realise that he forgot to take his pills. He should take them at seven. Seven to seven, but the doctor said he must take them after a meal. He is meant to take them after breakfast and at night. He forgets a lot, but it's better now. Now he is forced [to adhere] after he defaulted.'* (Mother of 14-year-old adolescent, 2014)
- *'I have to be honest. She likes the street. If she has gone out, she comes back after we have long gone to sleep... I shout at her all the time. Even when her friends come here, I tell her all the time that she should not be sleeping out or at parties... She does have an element of being naughty... She does not want to be corrected.'* (Grandmother of 15-year-old adolescent, 2014)

As with healthcare workers' narratives, interviews with the caregivers of ALHIV demonstrated the perception of their non-adherence as delinquency. Both adult caregivers and healthcare workers vacillated between determination and despair or concern and capitulation as they tried various tactics to implore that ALHIV adhere to their HIV medicines. Such efforts often combined iterations of reprimand, surveillance, instruction, information giving, and attempts to improve the social, structural, and individual circumstances that they understood to underlie an adolescent's ART defaulting.

4.4.3 Adolescents: Agency and the 'free zone'

The term 'adherence' was rarely used by ALHIV in this qualitative study, and the term 'defaulting' was only used by a single participant, although these terms were used frequently by caregivers and healthcare workers (as demonstrated above). By encouraging adolescents to speak about the challenges that they encountered, asking the same question in different ways, comparing pill-taking to other health practices, or exploring wider challenges such as transport or stigma, it was possible to draw out adolescent perspectives on non-adherence.

ALHIV often gave inconsistent or even contradictory accounts of their treatment practices over the course of a series of interviews, or even in single interviews. When they spoke about non-adherence, they often described how pill-taking reminded them that they were different from their families and friends. For example, Nkweza* (18) said he took his pills 'occasionally' because when he doesn't take them, he 'becomes normal just like any other person'.

For many ALHIV participants, adherence was understood as contrasting with pleasure and fun. X-man (22), for example, spoke about the conflict between the advice and his desire for independence: ‘When they [healthcare workers] talk to me, I hear them, but on the other side the happiness in the street is calling me.’

Case study 2: Hlehle

Hlehle* was 14-years old in 2013 and was interviewed numerous times over the course of the *Mzantsi Wakho* study, from 2013 – 2018. She was perinatally infected and initiated onto ART at the age of 10. Although she reported perfect adherence in all seven qualitative interviews, her clinic file noted that she struggled with adherence, and there were times when she didn’t take her pills. Hlehle did not raise these concerns herself.

She explained that her best friend was also on ART, noting that her friend was: ‘sick and tired of taking pills’. Then, reflecting on her adherence, and her desire for the fixed-dose combination (FDC), she said that taking so many tablets (three daily) made her feel that her skin had started to ‘stink like medicine’. She worried about her body’s capacity to dissolve so many medicines and feared that ART made her body offensive to others, as it was shameful to herself. She felt as though her body would be better able to ‘process’ ART if her pill burden was reduced.

Case study 3: Sandra

Sandra* was 17-years old in 2014 and was interviewed from 2014 to 2018. Having acquired HIV perinatally, Sandra felt that her adult caregivers (a maternal uncle and his partner) were over-protective of her, treating her differently from her cousins who were HIV-negative. Sandra had survived several severe opportunistic infections as a younger child.

Over weekends, she spent most of her time at a house that belonged to an older boy in her friendship circle. She described this place as a ‘free zone’ where her friends could do what they wanted without adult surveillance.

Over a series of interviews and focus group discussions, Sandra* explained that she had, at times, gotten ‘carried away’ during afternoons, evenings and weekends spent in the free zone. As a result, she had defaulted from ART, missing evening and weekend doses in particular. Sandra developed viral resistance and was switched to another, more complicated regimen, which required that she take five pills a day. During one appointment, the doctor had shouted at Sandra and threatened that she would die if she didn’t take her ARVs as prescribed. In a later interview, she explained that she was ‘sick and tired’ of ART.

Case study 4: Dineo

Dineo* was 15 years old in 2014. She was interviewed four times between 2014 and 2016, three times in her home, and once in the paediatric ART ward of the district hospital. Dineo died of AIDS in 2018.

Dineo was extremely reticent to speak about medicine-taking and what she understood about her ART adherence is largely based on her clinic file and interviews with her grandmother, Ezzy. Ezzy recounted that, in earlier years, Dineo had taken ARVs with ease, even enjoying the attention that she was given when reminded to take her pills. However, around the age of 11, her behaviour changed. She seemed less willing to obey her elders and started coming home later. In anger over her refusal to follow her grandmother's instructions, and to deter her from becoming sexually active, Dineo's uncle told her that she was HIV-positive. While she had been taking ART for almost half a decade, Dineo had never been told that these medicines were to treat HIV. Once she learned she was HIV-positive and following an angry and humiliating encounter with her uncle, Dineo began to default.

The third of the four interviews with Dineo was conducted, on her request, together with her best friend and neighbour, Alicia. In recent weeks, according to Ezzy, Dineo and Alicia had stolen her social grant card, drawn money that was intended for the family's subsistence, and disappeared for the weekend. According to Ezzy, they had spent the money on alcohol and had slept over at men's houses. Neither Dineo nor Alicia spoke about this particular weekend during the interview (although at the time, a passing neighbour shouted at the pair, telling the interviewer that the girls were 'out of control').

In all interviews besides the one in which her friend was present, Dineo spoke little and seemed fearful of getting into trouble. Her accounts of adherence were inconsistent. Within single interviews, she would explain that she never missed doses but would then go on to state that she had. When prompted carefully about her beliefs about ART side effects, Dineo explained that she feared ARVs were preventing her breasts and hips from growing – in essence, delaying physical maturity. She was tired of taking ARVs and viewed treatment breaks as a kind of 'luxury', similar to eating ice cream while on a diet (as the interviewer noted).

ALHIV are frequently told that their lives depend on adherence to ART. Faced with full waiting rooms, and limited resources, healthcare workers often distil adherence counselling to a single message: 'comply or die'. But ALHIV, many of whom have been on ART for years, question the biomechanics of treatment, and experiment with missing doses – either purposefully, because they want to see what happens to their bodies – or mistakenly because they find themselves away from home or a familiar healthcare facility. For many ALHIV in this study, ART adherence was understood, in part, as a practice of deference to the authority of elders, including family members and healthcare workers. Non-adherence was seen by these older authorities as a form of recklessness and irresponsibility, warranting greater surveillance or punishment or, if persistent and intractable, abdication. Comprehensive empowering ART literacy, and HIV treatment retention programmes which include psychosocial support and which validate the aspirations of ALHIV for healthy, pleasurable lives and futures, are urgently needed.

The next section describes the findings of the literature review on ALHIV.

Literature review

5.1 Adolescence and ALHIV

Adolescence is the developmental phase linking childhood and adulthood. In psychological terms, the 'development of a capacity for independence' is the dominant process for adolescents. This means that breaks must be made with past support systems as independence is forged. Socially, adolescents are likely to begin to separate from their family, spend more time away from home, and affiliate with their peers during this time. Social relationships change from being primarily family-based, towards the inclusion of a wider network of peers and other individuals in the community, and contacts established through social media.⁴³

As adolescents transition to adulthood, they explore their sexuality and navigate their sexual and reproductive health.⁴⁴ Adolescents' moodiness and emotional outbursts may include anxiety, shame, embarrassment, guilt, shyness, depression and anger.⁴⁵

Susceptibility to peer influence is affected by age, personality, socialisation, history and perceptions of peers.⁴⁶ The social competencies of adolescents, such as initiating interaction, self-disclosure and support, develop throughout adolescence and are related to the quality of their friendships. In later adolescence, decisions are less influenced by peers, with a preference for individual relationships. With sexual maturation, adolescents are likely to engage in friendships with the opposite sex and romantic relationships.⁴⁷

If family relationships are strong, the increasingly important role of peer relationships may occur alongside continued supportive relationships and emotional attachment to family members. For example, adolescents may demonstrate independence when making decisions about friends but may want their parents' support and understanding in difficult or serious situations.⁴⁸ Further, family support has been found to reduce the practice of risk behaviours such as multiple sexual relationships amongst HIV-positive adolescents.⁴⁹ This process of separation can generate conflict within the household if caregivers are not sensitive and aware of the issues that adolescents are facing.

As they become older, adolescents develop personal beliefs, values, and standards and may question religious and political views held by caregivers. Since they are in the process of developing their self-concept, they may describe themselves in contradictory ways, for example, shy with friends but outgoing at home, and their self-concept may also differ across contexts.⁵⁰

Decisions about morality may be driven by social approval and conformity. Adolescents may want to obey instructions from healthcare workers or parents so that they may be thought of as being 'good' but conversely want to appear 'normal' to their peers and thus rebellious.⁵¹ This reasoning may change in the later stages of adolescence where moral reasoning moves beyond the need for individual approval.

ALHIV who know their status may be particularly emotionally vulnerable because of their HIV status.⁵² For example, ALHIV experience a sense of isolation and rejection because they perceive themselves to be different from others, with depression and suicidal ideation being manifestations of a sense of grief and loss due to their life circumstances.⁵³ Behavioural and emotional problems, including psychiatric disorders among ALHIV, typically exceed those of the general population.⁵⁴ Besides having to grow up, ALHIV live with a stigmatised and transmittable disease. They also face challenges such as parental ill health or death. For orphaned adolescents living in poor economic situations, the risk of emotional and physical abuse and transactional sexual exploitation is substantially increased.⁵⁵ Other general challenges include illness and hospitalisation and other stressors that may compound decisions related to HIV disclosure and affect friendships, sexuality, and increase the risk of HIV transmission to others.^{56, 57} When considering all these factors during adolescent development, there are specific influences that ALHIV experience that impacts decisions regarding sexual risk-taking behaviours.^{58, 59}

5.1.1 Vertically infected ALHIV

HIV infection includes a risk of mortality for infants and young children. Such risks are moderated by early detection of HIV infection and initiation of ART and other treatment and care regimes. Not all cases of infant HIV are detected and some children living with HIV are not diagnosed until the point when illness manifests.⁶⁰ HIV testing of children is not routine, and children with HIV are not typically diagnosed if asymptomatic. Even during adolescence, the rationale for testing would mainly be determined by exposure to potential sexual transmission.

A study in the Western Cape explored the psychological vulnerabilities of ALHIV.⁶¹ It found that perinatally infected ALHIV were significantly more likely to be ART adherent, retained in health care, or to receive good treatment from health care staff in comparison to ALHIV who acquired HIV through sexual transmission. Horizontally infected ALHIV were more likely to be depressed, anxious, experience internal stigma or suicidal ideation, or be engaged in substance abuse.

5.1.2 Disclosure of HIV status

Disclosure of HIV status to children and adolescents is of direct medical benefit, and children who know their HIV positive status are likely to accept medical care including treatment because it is linked to a known health condition.⁶²

Adolescents who are aware of their status are also more likely to practice safer sex such as condom use. However, there may be a reluctance to disclose their HIV status because of concerns related to anxiety, depression and social exclusion.^{63, 64}

Parents and guardians often do not tell children that they are living with HIV because they fear that the child may face stigma and discrimination – not only for the child but for the family as well.⁶⁵ A study in South Africa found that parents delayed disclosing their children's HIV-positive status because the information might be spread through their communities. This would then lead to the family being stigmatised and isolated.⁶⁶ Mothers may be concerned about their children knowing that they, themselves, have a life-threatening disease, and may lack skills to facilitate disclosure.⁶⁷

Processes of disclosure for adolescents differ from those of adults because of psychological factors that may be more likely to detrimentally impact the mental health of ALHIV,⁶⁸ and specific and tailored support is therefore necessary.⁶⁹ A study in Eastern Africa found that around half of ALHIV had not disclosed their HIV status except to health care providers, and only 18% had disclosed their status to a friend, peer or relationship partner. Disclosure to peers was related to being older, having lost a father, being involved in family income generation, accessing HIV care, and having greater levels of support from peers. Safe environments were necessary for practicing disclosure skills and other support to disclosure is also needed.⁷⁰

5.1.3 ALHIV and the family

ALHIV who have acquired HIV perinatally may have lost one or both parents and possibly siblings to AIDS. This creates a scenario of loss and grief in the household and the need for alternative care arrangements, which may not be adequately be met. In some instances, ALHIV may be stigmatised if they transition to new households.⁷¹

The United Nations Children's Fund (UNICEF) estimates that there are 3.9 million orphans in South Africa, at least half of whom have been orphaned because of AIDS.⁷² Orphans themselves are more likely to be HIV positive.⁷³

Social vulnerabilities including poverty, poor access to education, homelessness, neglect and abuse may result in orphans experiencing substantial barriers to accessing healthcare, leading to poorer treatment and compromised developmental outcomes.^{74, 75, 76, 77, 78, 79} Orphans living with HIV are at increased risk of delayed access to HIV care and poor ART adherence.^{80, 81, 82} Orphans may enter care later than non-orphaned adolescents. Although a study in Johannesburg found that they were less likely than non-orphans to experience attrition in care at 12 months, orphans were more likely to have detectable viral loads.⁸³ Lower attrition among orphans may be due to their being in institutional or foster care, which contributes to ensuring timeous access to health care. Higher rates of non-suppression may result from a lack of psychosocial support or stigma resulting in struggles to adhere to ART.

5.1.4 ALHIV and disability

UNAIDS describes persons with disabilities as: 'those who have long-term physical, mental, intellectual or sensory impairments, which in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others'.⁸⁴ People with disabilities are largely overlooked by HIV and AIDS programmes, yet their risk of HIV infection is often exacerbated by their disability – and disability poses additional challenges when living with HIV.⁸⁵ This latter aspect includes disabilities emanating from HIV infection including opportunistic infections. For example, some drug regimens may lead to visual impairment, while others pose a risk for hearing loss or physical disability. Social functioning may also be impaired for children and ALHIV, and this is also a consequence of disability.⁸⁶

Adolescents with disabilities are less likely to be the recipients of information on HIV or sexuality and reproductive health. They also have challenges in discussing matters to do with sexuality with their parents and caregivers, some of whom may associate disability with being disinterested in sex.⁸⁷

5.1.5 Adolescent key and vulnerable populations

UNAIDS defines KPs as population sub-groups that have specific higher risk behaviours irrespective of epidemic type or local context.⁸⁸ KPs are often additionally marginalised due to punitive laws, discriminatory policies, constrained access to health and social services, and stigmatising cultural beliefs and discrimination at the community level. Defined in relation to the high risk of HIV acquisition, KPs include gay men and other men who have sex with men, sex workers, transgender persons, people who inject drugs, and prisoners.

UNAIDS views vulnerable populations as a broader category than KPs, applying to categories of people who are made vulnerable by HIV, or whose economic, social and other circumstances increase their risk of HIV infection.

KPs and vulnerable populations intersect in various ways. For example, lesbian, gay, bisexual, transgender, queer, intersex (LGBTQI), other sexual identities such as agender, asexual and ally (A+), are all vulnerable to HIV infection, with some overlaps in higher risk sexual behaviours. While risk-behaviour categories such as men who have sex with men (MSM), women who have sex with women (WSW), and bisexual men and women, are included in HIV-related studies, LGBTQIA+ identities and HIV vulnerabilities are less well studied, as are ALHIV who are LGBTQIA+.

Adolescents in KPs face barriers to HIV service access, are generally neglected by HIV programmes, and are overlooked in relation to HIV strategies and policies.⁸⁹ A study in South Africa found that lesbian, gay, and bisexual youth are at a greater risk of having more sexual partners and engaging in transactional sex than heterosexual youth.⁹⁰ The challenges of living with HIV for LGBTQI adolescents may be exacerbated by social isolation, stigma, and oppression associated with sexual orientation.⁹¹ LGBTQI adolescents experience a lack of support from family members, peers, and teachers who do not accept and support them as they develop their gay or bisexual identity, and may even perpetuate verbal and physical acts of violence against them.⁹²

In South Africa, the extent to which acts of prejudice and discrimination affect LGBTQIA+ living with HIV is under-researched. HIV stigma is linked to specific psychological challenges for ALHIV including, for example, depression, anxiety and decreased self-esteem.⁹³ Such psychological distress, in turn, has been associated with sexual risks and substance use risk behaviours, as well as decreased adherence to ART and medical appointments among ALHIV.^{94, 95, 96}

5.1.6 Pregnancy and motherhood

In 2017, nearly 100 000 girls aged 15-19 years gave birth in South Africa.⁹⁷ An assessment of the 2017 Antenatal Sentinel Survey in South Africa found that 61% of pregnant women living with HIV were aware of their HIV-positive status before falling pregnant, and 91.1% had started ART before pregnancy.⁹⁸ In the 15 – 19 year age group, only 38.9% were aware of their HIV-positive status before their first antenatal clinic visit, and 86.7% of ALHIV in this age group, initiated ART before pregnancy.

In a study conducted in KwaZulu-Natal, it was found that most pregnant ALHIV find out about their positive status during their first antenatal visit. Compared to adult mothers, adolescent mothers had three times lower PMTCT uptake and had an increased risk of MTCT.⁹⁹ This pattern has been found in other studies.¹⁰⁰

ALHIV who are pregnant or who are new or young mothers face multiple challenges related to integrating HIV treatment and care into pregnancy and motherhood, and health services are less oriented toward adolescent support.¹⁰¹ Multiple factors influence why young PLHIV who are pregnant or who are mothers, default from ART. These include lack of motivation, not feeling ill, feeling hopeless, being challenged by poverty, being overwhelmed by daily life, and being stigmatised.¹⁰²

5.2 ALHIV and the 90-90-90 treatment cascade

Most countries have adopted the 'treat all' approach which focuses on early initiation of treatment following diagnosis, and then sustaining ART to achieve VLS.^{103, 104}

ALHIV, in comparison with other PLHIV age categories, tends to have worse outcomes than others in care.¹⁰⁵ A higher risk of HIV acquisition among adolescents is, in the first instance, influenced by biological and physiological factors in combination with an early sexual debut, sex with older partners, and gender disempowerment, among other factors.^{106, 107} ALHIV who acquire HIV before adolescence have typically been infected perinatally as a result of MTCT. Some may, however, have acquired HIV through rape and sexual abuse, and this exposure may go undetected.¹⁰⁸ Identifying ALHIV and getting them into treatment remains a priority.¹⁰⁹

ALHIV who have positive relationships with family members, healthcare providers, or peers, are more likely to be retained in care, whereas ALHIV who lack support as a result of orphanhood, poverty, illness of caregivers, conflict in the family, and poor relationships with healthcare providers, are more likely to disengage from care.¹¹⁰

HIV is managed as a chronic condition and self-management is an important component of care.¹¹¹ Self-management is a patient-centered approach to care, and empirical evidence shows that the health outcomes of individuals and families who engage in self-management are ultimately better.¹¹² ALHIV whose status is known are typically supported by parents or caregivers, although this varies with age. Self-management of medication may be challenging for ALHIV. For example, they may be reluctant to manage ART outside their homes and private spaces as families tend to manage HIV treatment privately. Skills required for consistent adherence may be complex, and the motivation of ALHIV to take ART may be inconsistent.¹¹³

Transitioning from paediatric to adolescent care presents a challenge for ALHIV who have acquired HIV before adolescence. Even though the South African national guidelines on ART management include protocols for shifting from paediatric to adult ART regimens, to date, no official guidelines for transitioning from paediatric to adolescent care exist, nor for adolescent to adult care.^{114, 115}

With the rollout of FDC and dolutegravir, adherence to ART may be less complex. However, this only addresses one aspect of treatment.¹¹⁶ Friendly and approachable healthcare services are also a vital component,¹¹⁷ and particular skills are needed for supporting ALHIV on ART in a healthcare setting.¹¹⁸ ALHIV may, for example, not be well accustomed to being pressured to comply with instructions and adhere consistently.

Drawing on the social stage of development, the construct of adherence to ART and compliance with clinic regimes conflicts with the adolescent tendency towards independence.¹¹⁹ Negative provider experiences inhibit long-term adherence whereas the use of community-based services, backed up by economic empowerment projects and home-based support has worked well for improving retention in care.¹²⁰ The system may be characterised as one of control – firstly of HIV disease, but secondly of the patient. In both cases, ART is the agent and the regular viral load tests are the markers of the level of compliance. Such regimes take the form of life under scrutiny and this conflicts with rebellious psychological states.

Maintaining submissiveness reduces the space to question and understand their disease and treatment.¹²¹ Lack of confidentiality in some clinics raises the continual fear of stigma. To provide services to large numbers of HIV-positive patients, some clinics establish directed services and documentation for this group that makes those with HIV readily identifiable.¹²²

According to Kim et al.,¹²³ the use of alcohol and exposure to violence are barriers to adherence among ALHIV. Non-adherence is also associated with forgetting, which in one study accounted for more than 90% of instances of non-adherence, followed by having to travel from home (14%), and being busy doing other things (11%). Not having confidence in managing treatment is a contributing factor.

In the efforts to reduce non-adherence, Cluver et al.,¹²⁴ found that ‘social protection provisions’ through providing meals at least two times a day, having access to HIV-support groups, and effective parental monitoring, may facilitate ART adherence among ALHIV. By combining the monetary care provisions and social protections, reductions in non-adherence were 54% with none of these social protections, and 18% with all three.

5.3 Sexual risks

5.3.1 Knowledge and awareness

Research on countries with generalised epidemics has shown that less than half of adolescents, aged 15 – 19 years, have a basic understanding of HIV.¹²⁵ In South Africa, HIV-related knowledge among adolescents is low and declining over time.¹²⁶ A study of adolescent girls accessing maternal health services in South Africa found that only 43% of respondents could correctly answer more than half of a series of questions on pregnancy, sexual and reproductive health.¹²⁷ Another study on knowledge among adolescents in South Africa found that 45% had never heard of STIs, even though most had been exposed to school-based programmes.¹²⁸

5.3.2 Sexually transmitted infections

The risks of acquiring STIs are considered to be high among adolescents (including ALHIV) as a product of early sexual debut, unprotected sex, lack of access to condoms, misassessment of personal risk, having multiple sexual partners, substance use, and having substantially older sexual partners. A study of ALHIV in Uganda found that 16% engaged in high-risk sexual behaviours that involved a high likelihood of STI acquisition. A study in South Africa found that adolescent girls have a high susceptibility to genital tract infections and nearly half of the study participants had at least one STI.¹²⁹ Another South African study conducted in a rural area identified chlamydia prevalence at 11.7%, herpes simplex virus 2 (HSV2) at 28.7%, and bacterial vaginosis at 41.1%.¹³⁰

5.3.3 Sexual abuse

Sexual abuse has a severe and detrimental long-term effect that influences the health and psychological wellbeing of adolescents, including negative impacts that run into adulthood.¹³¹ Cluver et al., 2011,¹³² found that sexual abuse at an early age could increase the likelihood of later exposure to intimate partner violence (IPV) and HIV infection. Sexual abuse is widespread in South Africa.¹³³ A detailed study and review noted that around one in three children experienced violence during their childhood, and one in five young people reported having experienced some form of sexual abuse in their lifetimes – which is the case for both boys and girls.¹³⁴

5.3.4 Transactional sex

Transactional sex is a driver of HIV infection among young people in SSA. It can also influence exposure to risks such as IPV, sexual coercion, increased alcohol consumption, and risky sexual practices.¹³⁵ A higher prevalence of transactional sex has been found among adolescent girls living with HIV who have had older partners and unprotected sex.¹³⁶

5.3.5 Age disparate relationships

Studies in SSA have found that age disparity between sexual partners is associated with prevalent HIV infection.¹³⁷ The vulnerability of young girls and women to HIV can be linked to the risky behaviours of their male partners.¹³⁸ Findings in South Africa demonstrate a higher prevalence of HIV among adolescents whose partners are five or more years older than themselves.¹³⁹

5.3.6 Mental health among adolescents

The WHO defines good mental health as ‘when an individual can cope with the normal stresses of everyday life and, in doing so, can work and contribute productively and fruitfully’.¹⁴⁰ According to the South African Depression and Anxiety Group (SADAG), there is a mental health crisis among youth. Nearly a third (31.5%) of adolescent suicide attempts require medical treatment, 17.6% of adolescents have considered attempting suicide, one in four university students were diagnosed with depression, and more than one in five 18-year-olds have had one or more suicide attempts.¹⁴¹ Researchers have noted that the transition from childhood to adulthood is characterised by major changes (physical, social and psychological) that increase the risk of developing mental health problems. This is even more pronounced among ALHIV, due to the biological impact of the disease and its treatment and the psychosocial burdens of living with HIV and HIV-related social and environmental stressors.

High prevalence of depression (41%), anxiety (16%) and post-traumatic stress disorder (PTSD) (21%) have been found among school-attendees aged 14 – 15 years in Cape Town.¹⁴² A study of youth aged 15 – 19 years in Johannesburg found the highest exposure to violence and, in turn, the highest levels of depression in comparison to four other country settings.¹⁴³ Being economically disadvantaged and experiencing violence were factors that negatively affected mental health. ALHIV orphaned by AIDS are more likely to report symptoms of depression, and post-traumatic stress when compared to HIV-negative adolescents or non-orphaned children.¹⁴⁴

These studies suggest an urgent need for mental health and psychosocial interventions. However, a recent study focusing on the effectiveness of psychosocial interventions in the promotion of positive mental health and prevention of mental health conditions in pregnant and parenting adolescents found limited evidence for the effectiveness of psychosocial interventions on common mental health disorders such as depression, anxiety, substance use including risky sexual and reproductive health behaviours, adherence to antenatal and postnatal care, and parenting skills. The review also did not find data on self-harm and suicide, aggressive, disruptive and oppositional behaviours, or exposure to intimate partner violence, which suggests a vacuum in knowledge in this area.

5.3.7 Substance abuse

The National Youth Risk Behaviour Survey in 2011 found that the prevalence of any substance use among learners was 17.6% for smoking, 25.1% for binge drinking was, 9.2% for current cannabis use, and 20.6% for having ever used any drugs. The national prevalence of binge drinking and ever using drugs was 25.1% and 20.6% respectively.¹⁴⁵ Methamphetamine has been reportedly more common in Cape Town, with 25% of treatment centre patients younger than 19 reporting methamphetamine as their primary substance of abuse. Methamphetamine use is significantly associated with aggressive behaviours among high school learners.¹⁴⁶ The use of cocaine has remained fairly stable over the years, except for Gauteng where the prevalence was 19%.¹⁴⁷

A study on substance use, risk behaviour and mental health among South African Grade 8 – 10 learners found that 41.4% of the learners were classified as being at ‘medium risk’ and 14.9% at ‘high risk’ for mental health problems, with female learners (18.5%) being more likely than male learners (10.1%) to be classified as ‘high risk’ for mental health problems.¹⁴⁸ There is consequently a need for adolescent-oriented mental health promotion and intervention.

Alcohol and/or drug abuse has been linked to increased sex without a condom, as well as poor adherence to ART.^{149, 150, 151, 152} There is thus a need for regular screening of adolescents for substance use in HIV care settings in order to improve access to and delivery of appropriate substance use prevention and treatment services for ALHIV.¹⁵³ Social support for avoiding substance use in young peoples’ lives may also reduce the burden of substance use problems in this high-risk group.^{154, 155}

A systematic review of harm reduction interventions for adolescents who use substances has shown efficacy in delaying drug use by about one year.¹⁵⁶ Drug education programmes should include emotional competence (being empowered to say ‘no’) and stress management components, to improve the individual’s ability to cope effectively in difficult situations.¹⁵⁷ Prevention programmes seem more successful when they maintain intervention activities over several years.

5.4 Structural factors influencing risk

Within the South African context, several structural factors including physical, economic, cultural, and social realities, directly impact adolescent agency. These include the following:

5.4.1 Poverty

While South Africa is a middle-income country, there is an unbalanced distribution of income and widespread poverty. Government corruption has perpetuated this circumstance and many ALHIV fall within marginalised populations.¹⁵⁸ The impact of poverty is felt and mediated through multiple channels including limited access to resources, limited access to and capacity to use and apply education, inadequate access to food (especially healthy food), and limited access to clothing and shelter – among other omissions.

Poverty and food insecurity impact negatively on ART adherence.^{159, 160} Conversely, food assistance has been found to improve ART adherence.¹⁶¹ Poverty and food shortages contribute to other negative circumstances, for example, increasing transactional sex amongst adolescent girls living with HIV.¹⁶²

While most ALHIV are still in school, they face a future where they will have to compete for jobs in a context where unemployment rates are high. Psychosocial support programmes may be necessary to address vulnerabilities related to job seeking and unemployment.¹⁶³

5.4.2 Housing and the underdevelopment of communities

Housing remains a problem in South Africa, and 7.9% of adolescents live in informal housing.¹⁶⁴ Even in township settings, formal housing is crowded and includes living arrangements with multiple family – which limits privacy. Many township households include additional shacks on the property. This undermines the privacy and space that adolescents may require, sometimes pushing them out into the street where they may be exposed to negative peer influences, gangs or violence.^{165, 166, 167}

5.4.3 Politics, corruption and abuse of power

Political interference had a negative impact on the HIV response in the early 2000s in South Africa – specifically former President Thabo Mbeki's support for AIDS denialism. Many present-day ALHIV contracted HIV through MTCT during this period, some of whom have also been orphaned.^{168, 169}

Corruption, which is defined as the abuse of power conferred by the citizenry for private gain, impacts directly on ALHIV by reducing state capacity to deliver social services and directly undermines health services. Adolescents, including ALHIV, miss out on skills training and infrastructural development necessary for accessing employment, improving education, and accessing healthcare because of resource depletion by corrupt interests.^{170, 171, 172} Other manifestations include the private health system absorbing multiple shocks, shortages of professional staff in public health, poor leadership, and a lack of resources for the health system in general – all against a backdrop of diseases including HIV, TB, non-communicable diseases, as well as high rates of violence.^{173, 174}

5.4.4 Gender and patriarchy

HIV prevalence and incidence in South Africa are gendered as a product of a range of historical and circumstantial factors embedded in an overarching patriarchal culture. Far from being a homogenous and defenceless group, young women experience a *'multiplicity of hopes and desires and circumstances of emotional and relational fulfilment'* as both victims of patriarchy, as well as finding ways to resist and promote a new gender order.¹⁷⁵ The struggle for a new gender order is ongoing.¹⁷⁶ Young women's agency varies situationally and by relationship stage.

Boys and men also experience pressure to conform to hegemonic masculine norms in contexts of marginalisation, poverty and HIV.^{177, 178, 179, 180} This pressure generates uncertainties and vulnerabilities among adolescent boys and young men. Skewed distribution of income and power leads to abusive situations such as age-disparate relationships, multiple partner relationships, and sex in exchange for goods or money.¹⁸¹

Adolescence is an opportune time to influence the development of health, gender values and norms, and sexual behaviours. Gender transformative approaches have been defined as those that alter harmful gender practices, beliefs and ideas in favour of fostering gender equity.¹⁸² Gender transformative work with boys and men can shift harmful gender norms and practices that might put them and their partners at greater risk of contracting HIV and having poor HIV-related health outcomes.¹⁸³ Despite a few promising interventions such as Stepping Stones¹⁸⁴ and the work of Sonke Gender Justice, Grassroots Soccer and the iALARM project, research and interventions focusing on HIV services and needs of adolescent boys and young men are largely absent in South Africa.

Voluntary medical male circumcision (VMMC) service provision is one of the few intervention areas for which there is substantial funding and attention given to adolescent boys and young men within the HIV response. Makusha, 2019¹⁸⁵, suggests that this *'neglect in focus on adolescent boys and young men means that we have failed to understand how gender affects and drives the burden of ill health for adolescent boys and young men'. He goes on to observe: 'It is therefore necessary to accelerate HIV service delivery and uptake for adolescent boys and young men, and to develop male-centered, age-specific interventions that acknowledge that they are not a homogenous group, differing in terms of identity, age, experience and circumstances, mode of transmission and context.'*

5.4.5 Sexual debut

Sexual debut before the age of 15 years is considered a high-risk behaviour, particularly when sexual partners are significantly older.¹⁸⁶ Power dynamics are also skewed as a product of psychological immaturity and this circumstance is exacerbated in the case where there are gender, age and other power disparities between adolescents and their sexual partners.

Among adolescent girls aged 15 – 19 years in SSA, a higher percentage of girls (13%) than boys (9%) have had sex before the age of 15. In West and Central Africa, 16% of girls have had sex before the age of 15 years when compared to 7% of boys. In most low- and middle-income countries, an early sexual debut is common – almost 30% of adolescent girls aged 15 – 19 years in the Central African Republic and adolescent boys in Malawi and Lesotho reported having their first sexual encounter before they were 15 years old.¹⁸⁷

5.4.6 Violence and HIV risk

Violence has both direct and indirect links to HIV risk and treatment. Sexual violence can lead directly to HIV infection. Previous exposure to violence – including gender-based violence – can lead to post-traumatic stress disorder, which influences risk assessment in relation to sexual behaviour and substance use, which in turn, pose their own risks.^{188, 189}

Exposure to violence at home, school, and clinics significantly and cumulatively increase the risks for ALHIV and ART non-adherence, and non-adherence increases with additional victimisation.¹⁹⁰ The negative impact of exposure to violence on adherence has also been shown in other contexts, including Malawi and the United States (US).^{191, 192} Even witnessing domestic violence was found to have a negative impact on adherence and health generally.^{193, 194}

5.4.7 Gender-based violence

A meta-analysis of IPV amongst HIV-positive adult women (primarily in US-based studies) found associations with lower ART use. This is also indicated in South African studies^{195, 196} and in studies of adult women in SSA.^{197, 198}

A study of HIV-positive adolescents and young women in South Africa found associations between IPV and reduced medication adherence.¹⁹⁹ In a large cohort study of orphans – originally located in Cape Town – sexual abuse and violence increased the likelihood of transactional sex amongst HIV-positive adolescent girls.²⁰⁰

Karim et al., 2016²⁰¹ argue that young women aged between 15 – 24 years have the least power in society, and that adolescents bear heavy burdens of both IPV and HIV.

In South Africa, IPV is associated with increased sexual risk behaviours and HIV infections.²⁰² At a population level, interventions that address the underpinning societal gender norms that perpetuate IPV against women and girls are essential.²⁰³

South Africa has a high incidence of violence, and the South African Police report for 2019 shows increases in physical violence, sexual violence and murder perpetrated against children.²⁰⁴ The country has adopted the 16 Days of Activism, which is a worldwide awareness-raising campaign that promotes no violence against women and children. The campaign runs between 25 November and 10 December and overlaps with World AIDS Day on 1 December.²⁰⁵

5.5 Programmes for ALHIV

Numerous programmes target adolescents in South Africa – most with a focus on HIV prevention. Several such programmes emphasise AGYW such as the Determined, Resilient, AIDS-free, Mentored and Safe (DREAMS) initiative and the ‘She conquers’ campaign. DREAMS was launched in 2014 to synergistically address social, economic, behavioural, and biological risk factors that place young women at heightened risk of infection.^{206, 207} ‘She conquers’ is a three-year national campaign that targets AGYW aged 15 – 24 years as well as males aged 15 – 35 years.²⁰⁸

A key aspect of supporting children and ALHIV is a focus on families – in particular, family strengthening in contexts of widespread poverty.²⁰⁹ Such developmental support includes improving access to health services, schooling, and securing a basic income. Strengthening families enhances the capacity to support children and adolescents living with and impacted by HIV, while also enabling care and love in a context where severe distress emanating from the pressures of poverty is moderated.

Distinctions between perinatally and horizontally infected ALHIV are vital for programming, given the longer duration of awareness of infection that is more likely among ALHIV, engagement with HIV in the period preceding adolescence, and the likelihood that the negative impacts of HIV on the family are more severe as a product of parents being PLHIV themselves, or ALHIV being orphaned as a potential result of AIDS mortality.²¹⁰

A common finding regarding ART adherence and disclosure among ALHIV is that support is almost exclusively provided within families without the involvement of schools, churches, or other community groups. Nonetheless, group support provides an additional avenue of support and aids in the development of self-management skills for taking medication and disclosure, thereby complementing and strengthening families.^{211, 212} Self-management skills are noted to be an important area for focused support.²¹³

Resilience among ALHIV is positively associated with a sense of family belonging and family strengthening. It is, therefore, beneficial, given that underlying family circumstances typically include parents who may themselves be PLHIV, as well as absent parents, intergenerational family dynamics, foster care arrangements, and orphaning.^{214, 215, 216} A study in Eswatini found that a sense of family belonging was one of the most strongly desired aspects of support expressed by ALHIV,²¹⁷ while a study of ALHIV in Uganda emphasised a combination of family and peer support, given that family instability was a common circumstance, and even stable families were not necessarily able to provide sufficient emotional support.²¹⁸

A systematic review on the wellbeing of young people living with HIV in SSA found that acceptance and belonging enhanced wellbeing, and these aspects were framed by addressing stigma and providing social support.²¹⁹ More direct support included improving coping skills and addressing economic circumstances. Well-being was enhanced by self-acceptance, a sense of belonging, improved autonomy, healthy relationships with others, managing one's environmental circumstances, and having a sense of life purpose. A study in South Africa found that wellbeing was enhanced through strengthening social integration of young people – for example through family functioning programmes, clinic-based HIV support groups, and community programmes addressing stigma, crime or violence reduction.²²⁰ Health and wellbeing are also enhanced when linkages to services are supported – for example, as provided by community-based treatment supporters, which includes adolescent-focused peer support.^{221, 222}

General programmes delivered through government departments include social protection, youth unemployment and poverty alleviation programmes, and HIV prevention programming focused on ALHIV ('positive prevention').

5.5.1 Social protection interventions

Various grants and schemes are also available. These include the social grants or apprenticeship schemes for 18 – 24 year olds as a continuation of the Child Support Grant, and grants through the DSD such as social grants that focus on youth to reduce risky behaviours, that may reduce HIV transmission among adolescents that live in poverty-stricken areas.^{223, 224} There are also programmes implemented through the DOH, the Department of Basic Education (DBE), and the DSD that offers a range of services such as feeding schemes.^{225, 226, 227}

5.5.2 Positive prevention

This includes support through the DOH and DSD for the implementation of evidence-based parenting and caregiver programmes with demonstrated effects on adolescent health risk and protective behaviours. Examples include Families Matter and Sinovuyo Teen, as well as specific programmes to promote mental health and positive prevention for HIV-positive adolescents such as CHAMP+ and VUKA family programmes.^{228, 229}

5.5.3 Integrated School Health Policy

The Integrated School Health Policy involves revised school-based programmes to actively promote health through evidence-based programming.²³⁰ This includes coverage of topics including HIV and AIDS, TB, mental health, sexual and reproductive health, nutrition and healthy weight, substance abuse, and violence prevention. The approach includes interactive and participatory approaches that are non-judgemental and non-moralising.

5.5.4 Youth-friendly services

This includes a package of services for adolescents and youth, as well as strategies to render the same across all levels of the health sector starting with primary health care facilities and extending through to hospitals.²³¹ Healthcare workers are provided with training to support adolescent-friendly health services.

5.5.5 Utilisation of information technology and digital platforms

The DOH includes scaled-up information technology platforms to engage adolescents and youth for health care that includes information and support. The approach includes health monitoring tools and patient feedback mechanisms.

The next section presents the discussion and conclusions of the study.

Discussion and conclusions

The three components of this project provide an opportunity to integrate a range of data employing diverse methodologies to add a unique perspective to what is known about ALHIV in South Africa. The literature review contextualises the two data-driven components of this study.

Adolescence is a psycho-socially complex transitional period that is embedded within structural systems such as schooling and social protection programmes, which provide some support to vulnerable adolescents in general. However, these are still not up to the task of addressing the special needs of ALHIV as a whole, and for those aged 10 – 14 years and 15 – 19 years as distinct groups.

It is clear from the SABSSM surveys that ALHIV in South Africa are predominantly black Africans who live in rural and urban localities, and programmes must take these considerations into account.

6.1 HIV prevalence

HIV prevalence among adolescents aged 10 – 19 years decreased somewhat from 2005 to 2012, then increased slightly to 3.7% in 2017. When analysed by adolescent age group, and when comparing 2005 and 2017 study years, there have been increases in prevalence among 10 – 14 year old females (1.8% to 2.9%) and males (1.6% to 2.4%); declines in prevalence among 15 – 19 year old females (9.4% to 5.6%) and increases among 15 – 19 year old males (3.2% to 4.2%). These findings are attributed to increased access to ART and a decline in mortality, in combination with varying patterns of new HIV infections. It is thus not possible to draw definitive conclusions from the prevalence data alone. When interpreted in conjunction with HIV incidence data, it appears that the incidence rate has remained relatively stable. This finding illustrates that ART programmes are working, but that there is an urgent need to reduce the annual rate of new infections.

Factors underpinning HIV prevalence variations should be considered. PMTCT programmes and child-focused ART initiatives support a reduction in mortality among infants and children, thereby increasing the proportion of children living with HIV who transition into adolescence, and increasing the overall HIV prevalence among adolescents aged 10 – 14 and 10 – 19 years as a whole. While this might be anticipated to follow a uniform pattern for both sexes, the anomalous reduction in HIV prevalence among females aged 15 – 19 years is potentially related to the increase in ART uptake and VLS among their sexual partners who tend to be older than themselves (i.e., not adolescents).

Our finding that ART uptake was lower for females than males is consistent with other findings in South Africa.²³² Among adults, the reasons for this could be related to partner support or control over their ART use.²³³ Although there is limited data on gender differences for initiation of ART in sub-Saharan Africa, Mori et al., 2015,²³⁴ reported significantly more male than female children were initiated on ART.

Another potential influence may be the predominance of AGYW-focused programmes that might have reduced the extent of new infections among females in comparison to males. Nonetheless, HIV incidence among adolescents aged 15 – 19 years did not decline from 2012 to 2017, and this further reinforces the need for programming for adolescents that seeks to prevent new infections among females and males.

The proportion of ALHIV aged 15 – 19 years who reported testing for HIV in the past year was 37.9%, which is unacceptably low if the UNAIDS 90-90-90 targets for HIV testing are the goal. Responses to questions about HIV testing rates among young people bear further analysis. For example, there are a proportion of children who survive into adolescence without knowing their HIV status, and those who are not sexually active would not ordinarily consider being tested for HIV. In addition, those who were made aware of their HIV status in childhood, would also not require a recent test for HIV. Neither of these considerations, however, contributes markedly to changing the overall low prevalence of the previous testing for HIV among adolescents aged 15 – 19 years. Thus HIV testing shortfalls need to be addressed.

When responses are broken down by sex, males are far less likely to have been tested for HIV than females – 17.8% vs 51.5%. The reasons for this are partly explained by the higher likelihood of HIV infection being detected when pregnant through accessing antenatal care, or as a product of the greater emphasis of HIV programming being placed on AGYW, or that healthcare service provision is less focused on males.^{235, 236} According to Gray, 2009,²³⁷ both adolescents and guardians need to be included in routine provider-initiated testing and counselling, and guardians need to be assisted in the disclosure process to improve early diagnosis and adherence to ART. Community-based engagement coupled with addressing aspects of service provision for men has been advanced as ways to improve male access to care, including HIV testing.²³⁸ This would go considerably beyond the notion of narrow entry points to care for adolescent males such as VMMC programmes, which are not necessarily impactful.²³⁹

The data on HIV testing also shows that a much higher proportion of female ALHIV disclose their HIV status to their main sexual partner when compared to males (77.6% vs 11.5%). Fear of rejection, self-blame, and lack of social support, are among the factors that contribute to disinclination to disclose,²⁴⁰ and the findings suggest that females are more able to overcome reticence to disclose in comparison to males.

6.2 90-90-90 targets

The 90-90-90 targets for ALHIV that have been adopted by South Africa as part of the global goal of ending AIDS by 2030 were far from being achieved in 2017. While this situation has subsequently improved, it remains unclear what achievements have been attained for ALHIV relative to other PLHIV. For example, by 2018, modelling estimates suggested that 90% of PLHIV know their status, 68% were on ART, and 87% were VLS.²⁴¹ Lower levels of entry into care can be anticipated to be sustained among adolescents unless knowledge of HIV status increases dramatically, especially among younger ALHIV aged 10 – 14 years whose knowledge of their HIV status was 44.5% in comparison to 73.1% among ALHIV aged 15 – 19 years.

6.3 Contextual vulnerabilities of ALHIV

Apart from general programmes that provide support to adolescents and families, there is a dearth of programmes that provide more direct support to ALHIV tailored for the different needs of 10 – 14 years and 15 – 19 year old age groups. These include adolescent-related gender issues.

Living with HIV was previously associated with poor school attendance (aOR=1.7, 95% CI: 1.1–2.6) and educational delay (aOR1.7, 95% CI: 1.3–2.2). If these challenges are not addressed, ALHIV will continue dropping out of school or having poorer educational outcomes at higher rates than adolescents who are not living with HIV.²⁴² In the current study, we observed that fewer female ALHIV aged 15 – 19 years were in school when compared to male ALHIV, and that fewer ALHIV were in school when compared to adolescents not living with HIV. This finding contrasts with a previous study that found no differences in school enrolments between ALHIV and adolescents who are negative.²⁴³ Our results suggest a gap in specialised programmes aimed at retaining girls in school, even though this is typically a component of AGYW focused HIV prevention and other support programmes. This observation is supported by Toska and colleagues²⁴⁴ who argue for the use of schools to identify and also reach ALHIV that are left behind and link them into care, with a special focus on adolescents with poor attendance, frequent sickness, low mood and slow learning.

Our study also found that ALHIV who are no longer in school are less likely to be employed in comparison to adolescents who are not living with HIV, and there does not appear to be programmes that consider ALHIV as a specific group requiring additional support in relation to work-seeking. Similar findings have been reported among adolescent orphans and vulnerable children.²⁴⁵

The study also found that in line with global trends,²⁴⁶ orphaning among ALHIV has decreased over time – especially among younger ALHIV. This could likely be due to the increasing availability of ART to parents living with HIV, as well as PMTCT programmes that provide support to pregnant women and mothers through antenatal and post-natal care and support. However, many families of ALHIV are fragmented by challenging circumstances including: 1) parents or caregivers who are themselves PLHIV; 2) death of a parent or caregiver due to AIDS; 3) ambivalence or fracturing of families due to other aspects of HIV infection. Orphans need particular care, yet there are gaps in research regarding support programmes for vulnerable and orphaned ALHIV in the ART era when compared to the earlier phases of the epidemic, when concerns regarding orphaned and vulnerable children were strongly emphasised.

6.4 Challenges of ART adherence

The Mzantsi Wakho findings highlight the complexities of ART adherence among perinatally infected and horizontally infected ALHIV, while the literature review highlights the inadequate attention given to the circumstances and support needs of perinatally infected ALHIV. The proportion of perinatally infected ALHIV cannot be determined directly from the SABSSM survey data. To gain insight into the magnitude of possible perinatal transmission, we previously analysed mother-child pairs in the 2017 SABSSM survey for children under 10 years old. This analysis found that 6.4% (95% CI: 4.7 – 8.7, n=607) of HIV-positive mothers had an HIV-positive child younger than 10 years old.²⁴⁷ In addition, there were eight cases with an HIV-positive child and HIV-negative mother, suggesting non-perinatal routes of transmission among these children.

Perinatally infected ALHIV require specialised and different support when compared to horizontally infected ALHIV. Understanding the extent of vertical HIV infection among various age groups is fundamental to strategic programming and policy. This might include differentiating between infants and children under 5 years, children aged 5 – 9 years, early adolescents aged 10 – 14 years, and late adolescents aged 15 – 19 years.

There are heterogeneities among vertically infected ALHIV that need to be understood – for example, the timing of and processes of disclosure of a child’s HIV status to the child, rationale for ART adherence, support for mental health, and support for disclosure – among many other individual requirements. Although parents and caregivers may themselves know the HIV-positive status of a child, they may choose not to share this information to protect their families from the stigma and shame that still surround HIV. There also does not appear to be clear strategies for diagnosing HIV infection among children and young ALHIV who may unknowingly be living with HIV, including those who may have acquired HIV through rape and sexual abuse during childhood or long-term “slow progressors”. The findings suggest a need to implement interventions that promote disclosure to adolescents, and these can be facilitated by healthcare workers and caregivers. A study implemented in Namibia to assist healthcare workers and caregivers with HIV disclosure to children found that among children who reported incorrect knowledge of why they take ARVs, 83% showed improved knowledge after the intervention. At enrolment, only 11% knew their status and this increased to 38% full disclosure post the intervention. In addition, the intervention was found to help improve adherence to ART which improved viral suppression.²⁴⁸

Disclosure by children and ALHIV to others in their peer, social, and community networks is under-researched and insight into support strategies is therefore lacking. Improvements in this aspect of response could be achieved through adjusting general survey sampling strategies and methods to improve child and ALHIV case detection, or conducting smaller research studies from which findings may be extrapolated. The incidence estimates suggest that, for 10 – 19 year olds, most new infections occur among 15 – 19 year olds as a result of horizontal transmission. There is thus a need to intensify prevention programmes from early adolescence to mitigate the risk for acquisition for HIV transmission in older adolescence.

As with the SABSSM findings, the literature review illustrates challenges in drawing ALHIV into the 90-90-90 fast-track concept. ALHIV who have been infected perinatally do not appear to readily be transitioned into the treatment system, and the vast majority of ALHIV occupy social and economic strata where poverty, orphanhood, family conflict, and other factors all play into undermining adequate integration into the treatment cascade. ALHIV

cannot easily self-manage treatment initiation and adherence, and their motivations for health seeking are inconsistent over time. This is also highlighted in the *Mzansi Wakho* findings, as support for ART and other care are not feasibly addressed by healthcare workers alone.

There are gaps in support services for adolescents. Considerably better use could be made of schools as sites for intervention. For adolescents to achieve positive sexual health outcomes, there is an urgent need to scale up adolescent-friendly sexual and reproductive health (SRH) services and support.²⁴⁹

Most ALHIV view themselves as having good health, and this has improved over time, suggesting that ART programming might have contributed to an overall perception of good health. The *Mzantsi Wakho* analysis highlights and problematises labelling of behaviours around ART, clarifying that the way these are constructed may diverge among ALHIV, adult caregivers, and healthcare workers. The negative labels also affect how psychosocially vulnerable ALHIV engage with health care and how healthcare workers provide care and support. Negative or deterministic terms such as ‘defaulting’ or being ‘lost to follow-up’ do not capture the manifold nuance that contextualises the challenges of ART adherence among adolescents over time.

Negative labelling immediately positions the lines of power and authority as a top-down process in which rigid compliance is the preferred outcome. While some healthcare workers shout and cajole, others are sensitive to the complexities underpinning ART uptake for ALHIV – including healthcare workers themselves expressing worry, offering material incentives, and developing and implementing motivational strategies. However, the extent of support required by ALHIV around ART extends far beyond what can be achieved through a healthcare service interface alone. The health care workers’ notes on patient files and interviews highlight that the systems of implementation and support to ALHIV are deficient as a product of being narrowly focused on biomedical aspects of ART provision and adherence in comparison to a holistic approach. This includes the lack of support to parents, caregivers, and families as a backdrop to accessing clinical care. Specifically, biomedical approaches engage with ALHIV on an individual basis, and this removes the possibility of a range of group-based support systems, which includes support groups of ALHIV, family support groups and networks, and linkages to other social services. These could be coupled with support groups for healthcare workers who grapple on their own with the challenges of providing ART to ALHIV, yet do not have easy pathways to discuss or pursue problem-solving approaches in a systematic way with colleagues. If ART for ALHIV was positioned differently – as a complex process requiring multifaceted support, including language and protocols that are framed more appropriately – ALHIV would be better equipped for their journey towards sustained ART.

As much as healthcare workers deliver ART in the absence of adequate parallel support, adolescents themselves appear to have very little other support. This includes comprehending possible death because of their self-care practices. ALHIV are clearly not comfortable in their peer environments, do not have adequate networks of support within their families, and virtually none outside of the family environment. Adolescents offer insights into their frustrations and expose their logic about why they are inconsistent with ART, yet it is clear that they have no viable options or pathways for guidance and support. And while some appear to have supportive families or caregivers, fractured families are inevitably unsupportive to the extent that serious consequences follow regarding the mental and physical health of ALHIV.

Although data on drug resistance in the survey are limited, our findings suggest some level of pre-treatment HIV drug resistance in adolescents as well as acquired resistance. These findings are consistent with the challenges of retaining adolescents in care, and the higher rates of new HIV infections in youth aged 15 – 24 years. Further research is necessary, given that the data suggests that vulnerability among young women is exacerbated with age.

6.5 Sexual and other risks

Early pregnancy is well understood as a significant risk and does not appear to be adequately emphasised as having immediate and long-term deleterious effects on children, adolescents and families. The SABSSM data show that female ALHIV are significantly more likely to have been pregnant in the past 24 months when compared to female adolescents not living with HIV. Recent estimates show that 16% of young women aged 15 – 19 years had begun having children, and teenage pregnancies were mostly found in the lowest wealth quintiles.²⁵⁰ As is highlighted in the literature review, many pregnant ALHIV only find out about their positive status during their first antenatal visit,²⁵¹ and further, that diverse underlying factors diminish the capacity of ALHIV who are pregnant or mothers to sustain their adherence to ART. Interventions focusing on safer or delayed sexual relationships and contraception are relevant for female ALHIV, as are ALHIV-specific programmes for supporting PMTCT and treatment, care and support for young mothers.

Knowledge levels and rejection of myths were measured using very basic questions. Overall, less than one-third of ALHIV achieved a correct composite score. Basic awareness interventions in schools delivered through communication and other programmes are not adequately focused on the fundamentals of HIV. Declining levels of knowledge have been observed over time, and this appears to be linked to the decline of HIV awareness campaigns in South Africa.²⁵²

More profound aspects of understanding HIV are also not sufficiently appreciated. For example, around a third of younger ALHIV aged 10 – 14 years hold stigmatising attitudes toward PLHIV, and this may include an aspect of self-stigma among those who know or come to learn of their own HIV positive status. A similar proportion is also not comfortable talking with a family member about HIV and AIDS, which has a bearing on how disclosure and other aspects of HIV care might unfold. Addressing stigma remains a priority as it has been shown to have an impact on the wellbeing of ALHIV, and can have negative psychosocial effects if not addressed.²⁵³

In a review of social media use for global HIV care, Garrett and colleagues²⁵⁴ found a lack of studies using social media for HIV interventions among HIV positive groups, particularly for youth. In South Africa, approximately 45% of young women and 55% of young men aged 15 – 19 years did not make use of radio, television, newspapers/magazines, or community health workers for family planning messages.²⁵⁵ Furthermore, approximately 70% of AGYW and 56% of their male counterparts had heard about school-delivered family planning messages whilst attending school. This suggests that school-based interventions could reach a proportion of young people who do not access other communication routes.

There have been some positive changes in risk behaviours and relationship practices among ALHIV aged 15 – 19 years, but there is a need to consciously address risk reduction through programmes that involve ALHIV who know their HIV status. It is also relevant to differentiate between perinatally infected ALHIV and those who have acquired HIV through sex, as their perspectives on sex and sexuality are nuanced by their relation to HIV acquisition as well as other factors related to family and other underlying circumstances. Family-focused programmes are relevant for addressing sexuality, sexual risk, and relationship practices.²⁵⁶

Sexual risks among ALHIV may result in onward transmission, and higher risk sexual behaviours and relationship practices prevail for many. The literature review expands on underlying risk factors including impacts on mental health resultant from or exacerbated by diverse underlying challenges including structural factors, and poor systems of support in general. Factors such as corruption in South Africa have drawn immense resources away from support systems that could have fundamentally improved the lives and prospects of ALHIV and adolescents in general. Violence, especially IPV, has not been adequately addressed to date, nor has the perpetration of rape and sexual abuse of minors.

When it comes to relationships, adolescents of both sexes aged 15 – 19 years face partner violence at unacceptably high levels. This highlights the limited success in addressing violence in relationships among adolescents. Several programmes have focused on strengthening community capacities to address gender-based violence.

It is promising to see that levels of psychological distress among ALHIV were similar to adolescents not living with HIV. This finding is based on the 2017 SABSSM results, given that this was less evident in 2012. Around 16% of adolescents were noted to have ‘high distress’ levels. There is thus a critical need for programmes to focus on mental health. A comprehensive examination of the effect that HIV has on the mental health outcomes in adolescents is needed. Deficiencies regarding mental health are likely to affect HIV care and treatment, impacting the resulting adult burden of disease and secondary transmission.²⁵⁷

While alcohol abuse does not appear to be a significant problem, it remains that programmes should include addressing alcohol abuse among the minority of adolescents including ALHIV in the 15 – 19 year age group who do drink alcohol.

The prevalence of self-reported disability was low, but this proportion is likely to under-represent the general population of ALHIV who have a disability, because the literature does highlight higher prevalence levels of ALHIV with disabilities. Nonetheless, there is a dearth of information on strategies and programmes that provide support to ALHIV who have disabilities.

There are legitimate concerns that South Africa as a country is failing to adequately respond to the needs of adolescents. This is shown in the ongoing problems of poverty, the lack of development to provide adequate and safe work, the ongoing problems in the education system, the underdevelopment of communities, the consistently high levels of crime – especially violence which disproportionately affects adolescence, the massive inequities in income and access to resources, and the ongoing problems of corruption and abuse of power that puts a limit on the possibility of change. One of the immediate indicators of this failure is that adolescents remain a high-risk group for infection with

HIV, demonstrating that interventions that focus on prevention have not been sufficiently effective. Programmes targeting adolescent girls are well resourced when compared to those targeting boys, and few programmes specifically address ALHIV.

Gendered power relationships and gender-based violence have not been consistently or effectively addressed in national health or social interventions. The forces supporting gender power differentials need to be addressed. These include economic factors such as wage differential, cultural values, religious norms, and social norms. Gender-based violence is the extension of these gender norms. Gender violence is extremely high in South Africa, and includes sexual abuse of both male and female children, domestic violence, rape and sexual assaults, attacks, and discrimination against members of the LGBTQIA+ community that includes rape and active restrictions and restrictions on movement. LGBTQI are also under-represented in research studies in general, and ALHIV who are LGBTQI even more so, which limits the development of appropriate programming.

6.6 Study strengths and limitations

This study has provided the opportunity for secondary data analysis in combination with a review of the literature to draw together a comprehensive understanding of ALHIV in South Africa and implications for strategic programming. The data presented for 10 – 14 year olds and 15 – 19 year olds provides nuanced insights into the epidemic within and between these two adolescent age bands.

While the SABSSM datasets provide an opportunity to understand ALHIV trends, the studies were not specifically designed for in-depth analysis of ALHIV concerns. There are thus gaps regarding the questions that were asked and several instances where numbers of cases are insufficient to support definitive conclusions. In many instances, confidence intervals overlap substantially, although in others it is possible to discern clear and statistically valid and reliable patterns. There are limitations to the timeframe of the studies, as certain programmatic interventions – for example, the expanded roll-out of ART or prevention programming for adolescents that have occurred after 2017 – are not picked up in the dataset.

Mzantsi Wakho focuses specifically on the Eastern Cape, and the findings are not entirely generalisable to all settings in South Africa. Nonetheless, the nature of the qualitative data and findings presented here are relevant in many contexts. That said, it was also not feasible to analyse other aspects of this rich dataset within this project – and this is a limitation.

The literature review spanned a diverse range of research on ALHIV, and while it is comprehensive in many respects, certain themes require in-depth study. This includes accessing further literature, which was beyond the scope of the present study.

Recommendations

The following recommendations are made:

- Given their higher vulnerability and prevalence, emphasis in this study has been placed on female ALHIV. However, findings point to gaps in the response for ALHIV in general and highlight a dearth of male-focused programming. It is recommended that holistic approaches be followed for programming to obtain synergistic benefits for ALHIV, whilst considering adolescent gender-based issues.
- Our analyses for 10 – 14 year ALHIV and 15 – 19 year ALHIV as separate cohorts suggest that vulnerability among young women gains momentum from an early age. There is a need for focussed work to identify and address how young males and females are socialised in different contexts in South Africa, including specific interventions for 10 – 14 year olds to reduce their risk of being infected in late adolescence, and to manage to live with HIV if perinatally infected.
- School environments do not appear to be sensitive to ALHIV, so specific training and programming are necessary for educators and others within the school system. This includes creating linkages and support networks for families of ALHIV. There is also a need to identify children and young ALHIV who are unaware of their status, and for schools to potentially provide a context for exploring how this might be achieved. Improving resources at schools such as the provision of school health nurses, counsellors and providing family coaching and parenting training, are important focal areas for programming. In cases where a child or adolescent is diagnosed as HIV-positive, parents or guardians should be assisted in disclosing their child's HIV status to them. This may significantly improve early diagnosis and adherence to ART. Improving the understanding of the advantages of delayed sexual debut, as well as improving knowledge of safer sex and contraception, must be prioritised in schools – as should expanded understandings of living with HIV for children, adolescents and adults.
- Most adolescents out of school do not obtain employment when they fall within the 19 years or younger age range, and according to the SABSSM analysis, ALHIV are less likely to find employment. Strategies and programmes supporting ALHIV out of school need to be pursued.
- New infections continue to occur, particularly in older adolescents. The pool of ALHIV is not diminishing over time. Programmes focused on HIV prevention need to be intensified to the extent that they substantially impact HIV incidence, including setting reductions of the prevalence of ALHIV as a target. Knowledge and engagement with HIV are suboptimal. There is an opportunity to include social media interventions as a means of communication – as many adolescents use this platform – along with improvements in schooling and healthcare. The findings highlight a need for multi-sectoral interventions to ensure that young people entering adolescence are likely to spend more time in school and enter the workforce later, postponing sex and childbearing, and preventing HIV infection.
- Pregnancy among adolescents occurs at a high level and is greater among ALHIV. There is a need for diverse support including for PMTCT, but also for sustaining ART among ALHIV mothers, because adherence is known to drop off in the post-natal period. Programmes for ALHIV mothers are necessary, and it is also clear that targeted programming regarding reproductive health, contraception, and safer sex, in general, is needed to moderate the high rates of pregnancy in this group.

- ALHIV are not adequately integrated into the HIV treatment cascade, and although it is anticipated that there have been improvements in the trajectory towards the 90-90-90 targets after 2017, ALHIV remain underserved. Specific targeting of ALHIV in relation to the treatment cascade is necessary. This includes extending support for achieving targets to include activities parallel to and complementary to health service delivery. While treatment and support for VLS require a multifaceted response, gaps in HIV testing of ALHIV also need to be addressed. This includes developing strategies for testing children and younger adolescents. The 90-90-90 strategies do not include adequate support to disclosure, and this is an area of central concern for ALHIV who need both direction and support if they need to manage living with HIV within and outside of their family structures. There is a need to support ALHIV through increasing the availability to access community-based services, family-centered interventions, and employment and economic empowerment.
- Social theory is needed to build interventions and services accurately and constructively, again considering the context in which these interventions and services are provided. The construct of what constitutes healthcare needs to be widened. At present, the focus rests almost exclusively on the 90-90-90 cascade, with a limited range of prevention and contraception approaches. ALHIV need much broader services, which include mental health support, social support, social security, education and training, and employment. It is necessary to develop enhanced protocols and new language around support to ALHIV in relation to their access to care and treatment. There is a need to include a wider set of support services and referral networks to ensure increased uptake of ART, and to support sustained treatment through the critical adolescent phase. ART programmes should be framed in a way that supports adolescents' sense of futurity and promotes messages of empowerment and wellbeing, rather than disability, disease and death. Supporting healthcare workers to assess their knowledge, personal views, attitudes, and behaviours may be a strategy to shift their attitudes.
- There is a strong need to develop directed service approaches for ALHIV that acknowledge their needs and that are relevant and responsive to local contexts. This needs to be backed up with community-based services that are relevant to their specific communities, family interventions and coaching, and economic empowerment. Optimised strategies focussing on adolescent psychosocial support, mental health, and sexual reproductive health, are needed.
- Drug resistance among ALHIV requires further investigation, including the predominance of drug resistance among female ALHIV. This is a common finding in females and is generally associated with prior ART exposure – possibly during pregnancy. Multicentre studies, which test for drug-resistant mutations, are recommended. We need to track HIV drug resistance in children infected from birth to monitor the acquisition of resistant mutations associated with ART over time.
- Programmes addressing stigma do not appear to be implemented or effective when implemented, nor does there appear to be adequate levels of openness regarding discussing HIV within the family. The need for programming in this area is particularly required for younger ALHIV aged 10 – 14 years.

- Knowing the complex development challenges faced by adolescents is important to make parents, teachers and healthcare workers aware of the internal dynamics that adolescents face. This may reduce some of the dismissive attitudes and patronising approaches often replete within clinics and schools. Further work is needed on the mechanisms and processes by which these impacts are felt by ALHIV. Interventions are required that recognise the contextual factors that challenge the health and wellbeing of ALHIV, and that interrupt the pathways between developmental, socio-economic and structural risk factors and poor health outcomes.
- There is a need to better understand the different modes of transmission for ALHIV so that services can be differentiated. Specific programmes are needed for perinatally infected ALHIV, and there is the possibility to extend programmes such as CHAMP+ and VUKA that have worked well with children and families. Family interventions could include family counselling, and training in parenting skills especially in the context of HIV. Community interventions to reduce stigma and encourage acceptance must be implemented and sustained. Family members need to access information and support to undertake, guide and assist the process of HIV status disclosure, ART adherence, and retention in care for ALHIV.
- ALHIV who are LGBTQI+ do not appear to have been given attention, and there is also a dearth of ALHIV programming for other KPs such as MSM and sex workers. Strategies and programming for ALHIV who fall within KP categories require attention.
- While levels of alcohol abuse among ALHIV are somewhat low, they are based on self-reports. Hence this is not an area for complacency. Levels of drug abuse are high in some communities, and it is unclear to what extent drug abuse impacts directly on ALHIV. Further research is necessary to assess risks for substance abuse among ALHIV and determine response strategies accordingly.

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Mzantsi Wakho

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