Evaluation of a psychosocial support intervention on adherence and retention in care among adolescents on antiretroviral treatment in Ehlanzeni District Municipality, Mpumalanga, South Africa

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Declaration

I declare that the work contained in this thesis, *Evaluation of a psychosocial support intervention on adherence and retention in care among adolescents on antiretroviral treatment in Ehlanzeni District Municipality, Mpumalanga, South Africa*, is my original work. I declare that this work has not been submitted for any degree or examination at any other university, and that all sources I have used or quoted have been indicated and acknowledged using complete references.

Student: ______ _______

Date: ______14 October 2022___

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I give special thanks to the Almighty GOD, whom, in HIS infinite goodness and mercy, has given me the grace to complete this study in good health and sound mind.

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Finally, I would like to acknowledge my wife, Osaretin Christabel Okonji, and my children, Onyinye, Joshua, and Michael, whose prayers and support have kept me going throughout this doctoral research project.

Dedication

To my mother, Francisca K. Okonji,
and to my late father, Ogbueshi David M. Okonji, who passed away
a few months before I commenced this doctoral research project.

Acronyms

AHR	Adjusted Hazard Ratio
AOR	Adjusted Odds Ratio
ALHIV	Adolescents living with HIV
ART	Anti-retroviral treatment
ARV	Anti-retrovirus
CATS	Community adolescent treatment supporters
EAC	enhanced adherence counselling
FCD	Family Clinic Day
FGD	focus group discussion
HIV	Human Immunodeficiency-Virus
HIVDR	HIV drug resistance
KII	key informant interview
LMICs	low- and middle-income countries
MMD	multi-month dispensing
NGO	non-governmental organisation
NIMART	nurse-initiated management of anti-retroviral therapy
OLHIV	older adults living with HIV
PICOT	Population, Intervention, Comparison, Outcome and Time
PRISM	Preferred reporting items for systematic reviews and meta-analyses
PSS	Psychosocial support
RTC	Right to Care
TB	Tuberculosis
UNICEF	United Nations Children's Fund
WHO	World Health Organisation

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Abstract

In 2021, it was estimated that globally approximately 1.8 million adolescents (aged 10-19 years) were living with HIV, of whom over 90% resided in sub-Saharan Africa. While the global number of adolescents living with HIV fell by 57% from 2000 to 2020, the number of AIDS-related deaths amongst adolescents in eastern and southern Africa increased during the same period.

Adolescents living with HIV (ALHIV) face many challenges related to adherence to antiretroviral treatment (ART) and remaining engaged in care. Some of these challenges result from the physiological and psychosocial characteristics of their stage of development. It is hypothesized that providing psychosocial support may mitigate high levels of anxiety, fear of disclosing their HIV-positive status, low self-esteem, low self-efficacy, depressive disorders, and suicide reported amongst adolescents living with HIV. Improved wellbeing in these areas may, in turn, enable adolescents to attain higher rates of adherence to HIV treatment and engagement in care. Recent studies have shown that psychosocial interventions can improve adherence and retention in care amongst adults on ART. However, to date, few studies have investigated the effects of psychosocial support on adherence to ART and retention in care for ALHIV in sub-Saharan Africa.

Aim: This study aimed to assess the implementation, uptake and effects of the Right to Care (RTC) psychosocial support (PSS) intervention to boost the adherence to ART and retention in care of adolescents living with HIV in Ehlanzeni District in the Mpumalanga province of South Africa, six months after their enrolment in the programme.

Methodology: A sequential, multi-method study design was employed that involved: a scoping review of interventions designed to improve adherence and retention in care among adolescents living with HIV; a cross-sectional analysis of adherence and retention in care among ALHIV on ART in Ehlanzeni District; and a qualitative study of the implementation and uptake of the RTC psychosocial support intervention among programme implementers and adolescents involved in the programme in Ehlanzeni District, South Africa.

Findings: At baseline, the viral suppression rate (<1,000 copies/ml) among ALHIV in Ehlanzeni district was 74%; retention rates were 90.5%, 85.4%, 80.8%, and 76.2% at 6, 12, 18 and 24 months, respectively. The qualitative study found that the PSS program facilitated the full disclosure to adolescents of their HIV status; support for treatment adherence through health education, peers, family/caregiver, and healthcare provider- and client relations; and fast-tracked access to health service delivery. The ALHIV participating in the RTC PSS intervention reported positive experiences with the healthcare system: particularly, improved provider-client relations and fast-tracked access to health services. The PSS programme proved successful in keeping ALHIV engaged in ART care despite disruptions to the provision of health services that were encountered during the COVID-19 pandemic.

Conclusion: The Right to Care psychosocial support (PSS) intervention, in conjunction with the standard of care provided at the Ehlanzeni District clinics, improved ART adherence and retention in care among adolescents living with HIV (ALHIV) by addressing the complex biological, psychological and social issues that affect ALHIV. Further research is recommended to quantitatively assess viral suppression and retention rates among ALHIV twelve months after enrolment in the PSS programme.

Keywords:
Adolescent, HIV and AIDS, adherence, retention, antiretroviral treatment, peer group, community workers, treatment supporters, psychosocial support.

Chapter 1: Introduction

1.1 Overview of chapter

This chapter presents the context of this study, in terms of the HIV burden on adolescents (children in the age group 10 to 19 years) and barriers to their adherence to ART and retention in ART care. The literature on adherence and associated adherence and retention challenges, both globally and in South Africa, is reviewed and available evidence on interventions to improve the psychosocial well-being of adolescents living with HIV (ALHIV) is explored. The chapter presents the problem statement, aim and objectives of the research project and the contributions of the doctoral candidate to the published research emanating from this study. The chapter concludes with an overview of the structure of the thesis.

1.2 Background

1.2.1 Global burden of HIV among adolescents

Globally, about 2.8 million children and adolescents aged 0 to 19 years were living with HIV in 2021 (United Nations Children's Fund [UNICEF], 2021). The majority of these children and adolescents resided in sub-Saharan Africa (Inbarani et al., 2022). It is estimated that 1.85 million (confidence interval: 1.24 million - 2.33 million) HIV-positive children and adolescents lived in eastern and southern Africa; 28% of whom resides in South Africa (ibid). The number of adolescents (aged 10 to 19 years) living with HIV declined by 57% between 2000 and 2020, which has been attributed to the effectiveness of interventions for the prevention of mother-to-child transmissions (PMTCT) (UNICEF, 2021). Between 2012 and 2020, the rate of new infections fell by 36% among children aged 0 to 9 years and 34% among adolescents aged 10 to 19 years (ibid). While the global rate of AIDS-related death has fallen substantially among children (0 to 9 years) and adults (20 years and above), this rate has increased amongst adolescents (10 to 19 years) in the same period (Marija, Casale, Cluver, Toska & Moshabela, 2020). This has been attributed to poorer adherence to antiretroviral treatment (ART) amongst adolescents (Bernays, Paparini, Seeley, & Rhodes, 2017; Marija et al., 2020).

1.2.2 Adolescence and HIV and AIDS

The World Health Organisation (WHO) (2013) defines adolescence as the period of a person's life between 10 to 19 years of age. This is a period of transition from childhood to adulthood, and a time when a child moves from dependence towards greater independence. During adolescence, many physiological and emotional changes occur within the individual (Estripeaut et al., 2016). Children develop a greater sense of autonomy and a desire to establish their individual identity (UNICEF, 2016). Baker (2007) and Cluver et al. (2016) note that during this time a child develops knowledge and skills to manage emotions and relationships and acquires attributes and abilities that will be important for navigating the adolescent years and assuming adult roles.

Adolescents living with HIV (ALHIV) face complex challenges as they explore their sexual identity and form relationships (Bernays, Jarrett, & Kranzer, 2014). Among these challenges is the issue of disclosing their status to others (Pretorius, Gibbs, & Crankshaw, 2015) and coming to terms with the importance of adherence to anti-retroviral treatment (ART) (Mupambireyi et al., 2014). Adolescence is also characterized by participation in high-risk behaviours that can be detrimental to an individual's health and wellbeing (Hashmi, 2013). Despite the importance of protecting themselves and others from HIV infection and other reproductive health risks, due to their age adolescents may not have access to critical information and services, particularly in resource-constrained settings (Idele et al., 2014).

Mental health issues, including neurological side effects, cognitive deficits and depressive disorders, are common amongst ALHIV due to the efavirenz component of antiretroviral therapy, as well as the fear of disclosing their HIV-positive status due to stigma and discrimination (Haberer & Mellins, 2009; Lacob, Lacob & Jugulete, 2017). Research indicates a higher incidence of common mental health problems among HIV-positive adolescents, which can negatively impact their adherence to ART and retention in care (Skeen et al., 2017; Vreeman, McCoy & Lee, 2017; Woollett, Cluver, Bandeira, & Brahmbhatt, 2017). This is due, in particular, to the impact of their HIV status on their quality of life which, in turn, affects their adherence to ART and retention in care (UNICEF, 2016).

1.2.3 HIV treatment adherence

Adherence, in the context of ART, refers to the extent to which patients comply with the recommendations of health providers for their ART treatment (WHO, 2014). Adherence is an important factor determining the effectiveness of an ART (Heestermans, Browne, Aitken, Vervoort, & Klipstein-Grobusch, 2016). Evidence has shown that adherence to ART with a prescribed medication intake threshold equal to or more than 95% is associated with complete viral suppression (Estripeaut et al., 2016). Conversely, individuals who have lower levels of adherence are at greater risk for increased levels of morbidity, treatment failure, and the development of drug resistant forms of HIV (Bertagnolio et al., 2012; Curioso, Kepka, Cabello, Segura & Kurth, 2010); viral progression and opportunistic infections (Bangsberg, 2006); and transmission to sexual partners (Kalichman et al., 2011).

1.2.4 Retention in HIV care

Though there is no standard definition for retention in HIV care, the WHO (2011) describes it as "the continuous engagement from diagnosis in a package of prevention, treatment, support, and care services". Several factors are associated with improved retention in ART care among ALHIV, such as whether clinics providing care are stocked with medication; whether clinic staff dedicate time specifically to care for adolescents and behave in a kind manner; and whether adolescents are accompanied to the clinic and have the means to reach the clinic safely (Cluver et al., 2018).

1.2.5 Adolescents and HIV treatment adherence and retention in care

Adolescents are less likely to adhere to ART and remain in care compared to adults and younger children; this place them at greater risk of developing HIV drug resistance (HIVDR) (Marija, Casale, Cluver, Toska & Moshabela, 2020). A study conducted in the Eastern Cape province of South Africa reported lower rates of ART adherence (27-90%) amongst adolescents 10 to 19 years old compared to younger children and adults (Gittings et al., 2016). Similarly, a cohort study conducted in southern Africa found that adolescents were less adherent to ART, had lower rates of virological suppression and immunologic recovery, and had a higher rate of virological rebound after initial suppression, compared to adults (Nachega, Mills, & Schechter, 2010). Evidence shows that many children and adolescents on antiretroviral treatment do not know, or are not adequately informed, about HIV and the benefits of adherence, and this hinders their adherence to treatment and retention in health care (De Carvalho Mesquita Ayres et al., 2006).

Evidence has shown that among HIV-infected children and adolescents, symptoms of depression and anxiety were associated with lower rates of adherence to ART and higher rates of substance abuse and risky sexual behaviour (Vreeman et al., 2017). For example, a depressed state may decrease motivation to adhere to treatment (Sanchez-Sosa, 2002). Interventions aimed at establishing adherence behaviours have been found to achieve improvement in patients receiving chronic treatment for conditions including HIV and AIDS (Sanchez-Sosa, 2002). These interventions involved the design and implementation of behavioural strategies that influenced the cognitive, emotional and behavioural activities of the patients (ibid). Similarly, psychosocial support interventions designed to address the mental health of adolescents living with HIV showed improvements in their emotional and behavioural well-being, self-esteem, coping skills, and social wellbeing (Vreeman et al., 2017). This suggests that adolescents living with HIV with improved cognitive and emotional behaviours are more likely to adhere to ART and retain their participation in care.

1.3 Literature Review

This section reviews literature related to barriers to adherence and retention in ART as well as programme interventions to promote the psychosocial well-being of adolescents living with HIV.

1.3.1 Barriers to adherence and retention in ART

Despite achieving significant milestones in the scale-up of life-saving ART-programmes, uptake by adolescents living with HIV remains low; and drop-out along the continuum of care among those who do initially participate is high, thereby increasing their risk of morbidity and eventually mortality (Joint United Nations Programme on HIV/AIDS [UNAIDS], 2022). Several factors have been identified in previous studies as barriers to adherence and retention in ART care for the general HIV population; these include socio-economic, individual/patient-related, sociocultural, healthcare provision and medication/drug-related factors.

Socio-economic factors include limited access to medications owing to lack of transportation and financial constraints, economic problems in the household, and lack of nutritional support (Mphe, Mphe & Amberbir, 2009). Katz et al. (2013) found that patients stopped ART when food was unavailable. Two main reasons for stopping ART as a result of food insecurity have been documented: individuals may experience aggravated (gastrointestinal) side effects from the medication when they have not eaten; and taking ARTs may make an individual feel hungrier (Heestermans, Aitken, Vervoort, & Klipstein-Grobusch, 2016).

Individual patient-related factors are wide ranging. Some studies have identified forgetfulness, substance abuse, adverse effects of drugs, perceived social support, health literacy, and mental health issues such as depression and self-stigma as barriers to adherence and retention in ART (Curioso, Kepka, Cabello, Segura, & Kurth, 2010; Kagee, Nothling, & Coetzee, 2012; Salas, 2012). Another study noted advanced HIV status, substance abuse, and dropping out of school as factors (Kahana, Rohan, Allison, Frazier, & Drotar, 2013). Poor insight into disease and treatment and more frequent dosing have also been found to be factors that hinder individuals from adhering to ART (Naidoo, Munsami, & Archary, 2015). Other personal psychosocial risk factors that contribute to poor ART adherence include being orphan, mental health problems, changes of guardianship, and absence of parental and social support (Lowenthal, Bakeera-Kitaka, Marukutira, Chapman, 2014). Individuals' perceptions of ART also contribute to adherence (Wasti, Simkhada, Randall, Freeman, & van Teijlingen, 2012).

Although these factors apply to both adolescents and adults, adolescents face unique challenges to adhere to HIV treatment, such as reliance on adults. The ability of HIV-infected adolescents to successfully transition from reliance on adults to autonomy in taking responsibility for their illness, managing their adherence to treatment, and visiting clinics regularly for care is complicated during this stage of development by the display of behavioural patterns that deviate from expected or prescribed patterns (Mannheimer, 2015). While older adults fail to adhere for a variety of reasons that have been mentioned, ART adherence among children, adolescents and young adults living with HIV is highly dependent on the complex relationships between themselves and their families, society, and other treatment regimen-related factors (Hudelson & Cluver, 2015).

Many ALHIV have also expressed lack of support for making the decision regarding how, when, and with whom to disclose their HIV status (Kagee et al., 2012). This can lead to anxiety and depression (Kagee et al., 2012; Wasti, Simkhada, Randall, Freeman, & Van Teijlingen, 2012a). For members of young, key populations, the situation is even more difficult, as they often face discrimination on account of the behaviour that makes them vulnerable to HIV, such as sex between men, as well as their HIV-positive status (Kagee et al., 2012; Wasti, Simkhada, Randall, Freeman, & Van Teijlingen, 2012a).

Some *sociocultural factors*, such as disclosing HIV status and having a good relationship with a health care provider, have been found to facilitate ART adherence (Croome, Ahluwalia, Hughes & Abas, 2017). Social factors found to negatively impact adherence are living with others, or having a larger household (Wagner, 2004); attitudes and beliefs (Hudelson & Cluver, 2015); stigma and discrimination; lack of community support; use of traditional or herbal medicine (Heestermans et al., 2016) and religious and ritual beliefs (Wasti, Simkhada, Randall, Freeman, & Van Teijlingen, 2012b).

With regard to the role of *health systems*, public health facilities often present challenging treatment circumstances ranging from staff shortages, long waiting times, negative experiences with clinic staff and medication stock outs (Gittings et al., 2016; Kagee et al., 2012; Tuller et al., 2010). In addition, inadequate infrastructure or systems for communicating information pertaining to medications adherence among patients and distance to the health facility have been found to be barriers (Shubber et al., 2016). These factors often make returning to the healthcare facility for scheduled follow-up consultations and maintaining long-term adherence challenging for patients on ART. A situation analysis of 218 facilities in 23 sub-Saharan African countries found that a quarter of the facilities did not have a working definition of adolescence, and non-adherence was reported as the key challenge in service delivery to adolescents (Mark et al., 2017). Kagee et al. (2012) found that at some clinics with youth corners where HIV services are provided to adolescents, utilisation by adolescents was low because the facility staff were perceived to be unfriendly and judgmental; this discouraged adolescents from using these services. Adolescents may thus be underserved by HIV services due to an unfriendly institutional culture at health facilities, contributing to failure to attend medical appointments and thus continue care.

Drug or medication factors that present barriers to ART adherence and retention include pill burden – or 'treatment fatigue' – and side effects (Kahana et al., 2013; Nachega et al., 2010). While the single pill treatment (fixed dose) regimen has resulted in higher ART adherence and acceptability, and thus improvement in the quality of care for HIV-infected adults, this option is not yet available to children (Naidoo et al., 2015). Complying with the 'cocktail' of drugs that is still used to treat adolescents is burdensome; this, then, also presents a barrier to adherence to the ART regimen.

1.3.2 Interventions to promote the psychosocial well-being of adolescents living with HIV

The interventions that have been found to be effective in improving adolescents' adherence to ART and retention in care are limited (Ferrand et al., 2017; Reif et al., 2020). While the existing interventions have shown small to moderate improvements in adherence to ART, and improvement in mental wellbeing, none have showed significant improvements in retention in care (Laurenzi et al., 2021; Simms et al., 2022; Spaan, van Luenen, Garnefski, & Kraaij, 2020). These interventions fail to provide comprehensive and holistic psychosocial support care to address the psychosocial needs of adolescent living with, or affected by, HIV and AIDS (Gibb & Coles, 2005). Where counselling has been provided, the quality of such counselling has been questionable giving the limited capacity and dedicated time of frontline workers, or health facility staff, to provide such services alongside the other duties they must perform at the facility (De Carvalho Mesquita Ayres et al., 2006; MacPherson et al., 2015; Khan et., 2021;

Makhado et al., 2020).

However, Skeen et al. (2017), in their systematic review of studies that assessed the effectiveness of interventions designed to address the psychosocial well-being of adolescents – including those living with HIV – found some positive psychological changes: a reduction in internalizing and externalizing behaviours; a decrease in symptoms of depression, anger, and anxiety; higher rates of prosocial behaviour; and improved self-help abilities and communication. Positive social outcomes that were recorded included retention in school, better school attendance, and reduced rates of early marriage. Though the review showed at least one positive benefit to children’s psychosocial well-being, the findings were inconclusive because the studies identified differed so greatly and were thus not directly comparable. Furthermore, only eight of the studies assessed focused on children living with HIV or children who had carers who were HIV-positive.

A Cochrane Review identified only sixteen quality trials of psychological interventions for adults affected by HIV (Sherr, 2017). The evidence base for adolescents is even less robust (Sherr, 2017). Unfortunately, limited information exists on effective adherence-promoting interventions among adolescents living with HIV/AIDS in low- and middle-income countries (LMICs), with one systematic review yielding only three out of sixteen studies conducted in LMICs (Cluver et al., 2016). Mannheimer (2015), however, argues that interventions tailored to the individual’s psychosocial needs have the greatest probability of success.

1.4 Problem statement

As discussed in the previous section, ALHIV face unique physiological and psychosocial challenges. It is widely acknowledged that adherence to chronic medication regimens, such as ART, is a challenge amongst this age group (Salas, 2012). In addition, because of the high levels of anxiety, isolation, depression, and suicide reported amongst adolescents living with HIV, studies have recommended the provision of psychosocial support interventions to ALHIV to help them navigate their experience and maintain high adherence and retention rates in ART care (Greifinger & Dick, 2011; MacPherson et al., 2015; Sanchez-Sosa, 2002; Vreeman et al., 2017). However, the psychosocial factors contributing to sub-optimal adherence to ART among ALHIV in sub-Saharan Africa have not been adequately explored (Nachega et al., 2010; Laurenzi et al., 2021); in the South African context, in particular, to the researcher's knowledge there has been no previous research on the impact of psychosocial interventions on adherence to ART among ALHIV.

This doctoral research project posits that the provision of psychosocial support services (i.e., disclosure and stigma support, substance abuse support, emotional and psychological counselling, mental health support and social support) and ART defaulter tracking and tracing (through, for example, WhatsApp/SMS messaging and home visits) will positively influence the intentions of ALHIV to adhere to ART and remain in care and that this will, in turn, lead to improved adherence to ART and retention in care.

1.5 Aim and objectives of this study

The aim of this doctoral research project was to assess the implementation, uptake, and effects of the Right to Care (RTC) adolescent psychosocial support intervention programme on adherence to anti-retroviral treatment (ART) and retention in care amongst adolescents living with HIV in Ehlanzeni District, six months after their enrolment in the programme.

The objectives of the research project were as follows:

1. To review psychosocial support interventions to improve adherence to ART and retention in care among ALHIV, globally and in South Africa, described in the literature.
2. To describe baseline viral suppression (proxy for adherence) and retention in care rates among ALHIV prior to enrolment into the PSS intervention in Ehlanzeni District Municipality, Mpumalanga, South Africa.
3. To assess the contextual factors impacting the implementation of the psychological support (PSS) intervention in Ehlanzeni District Municipality, Mpumalanga, South Africa.

4. To assess the experiences of adolescents living with HIV six months post enrolment into the PSS intervention in Ehlanzeni District Municipality, Mpumalanga, South Africa.

The research was conducted in four phases, which yielded five research publications and one research paper that is currently under review.

- Phase 1: A scoping review of literature on psychosocial support interventions to improve adherence and retention in antiretroviral treatment among ALHIV was conducted. One publication resulted from this phase (https://doi.org/10.1186/s12889-020-09717-y).
- Phase 2: A baseline cross-sectional analysis of programme electronic data was conducted to describe viral suppression and retention rates among ALHIV in Ehlanzeni District. Two published papers resulted from this phase (https://doi.org/10.1186/s12981-021-00391-7; https://doi.org/10.1080/09540121.2022.2057409).
- Phase 3: A document review of implementation and policy documents was conducted to describe the components of the psychosocial support (PSS) intervention. This resulted in one publication (doi:10.11604/pamj.2022.41.166.31985).
- Phase 4: Two qualitative studies were conducted to describe the implementation of the PSS programme and the experiences of ALHIV attending the PSS programme. Two research papers resulted from this phase; one has been published (https://doi.org/10.1177/23259582221121094) and the other is under review.

1.6 Organisation of thesis

This thesis is presented through a set of publications aligned with each study objective.

Chapter 1: Introduction. This chapter has presented background information on the global burden of HIV among adolescents living with HIV, followed by a review of the literature on barriers to adherence and retention in care and interventions to improve the psychosocial well-being of adolescents living with HIV.

Chapter 2: Methodology. This chapter presents the conceptual framework of the study and describes the setting and design of the study and the methodology that was used. The chapter also addresses how ethical principles were upheld in the study.

Chapter 3: Results. Six papers (five published, and one under review) are presented. Each paper is introduced and its respective contribution to the thesis, as well as the PhD candidate's contribution to each paper, is stated. The papers are as follow:

- Paper 1: **Okonji, E.F.**, Mukumbang, F.C., Orth, Z., Vickerman-Delport, S.A., van Wyk, B. (2020). Psychosocial support interventions for improved adherence and retention in ART care for young people living with HIV (10-24 years): a scoping review. *BMC Public Health*, *20*(1). https://doi.org/10.1186/s12889-020-09717-y

- Paper 2: **Okonji, E.F.**, van Wyk B, Mukumbang FC, Hughes GD. (2021). Determinants of viral suppression among adolescents on antiretroviral treatment in Ehlanzeni district, South Africa: a cross-sectional analysis. *AIDS Research and Therapy*, *18*(66). https://doi.org/10.1186/s12981-021-00391-7

- Paper 3: **Okonji, E.F.**, van Wyk, B., & Mukumbang, F.C. (2022). Two-year retention in care for adolescents on antiretroviral therapy in Ehlanzeni district, South Africa: a baseline cohort analysis. *AIDS Care*. https://doi.org/10.1080/09540121.2022.2057409

- Paper 4: **Okonji, E.F.**, van Wyk, B., & Mukumbang, F.C. (2022). Applying the biopsychosocial model to unpack a psychosocial support intervention designed to improve antiretroviral treatment outcomes for adolescents in South Africa. *Pan African Medical Journal*, *41*(166). https://doi:10.11604/pamj.2022.41.166.31985

- Paper 5: **Okonji, E.F.**, van Wyk, B., Hughes, G.D., & Mukumbang, F.C. (2022). Implementation of a Psychosocial Support Intervention for Adolescents on Antiretroviral Treatment: Challenges and Experiences from Ehlanzeni district, South Africa. *J Int Assoc Provid AIDS Care*, *21*. https://doi: 10.1177/23259582221121094

- Paper 6: **Okonji, E.F.**, van Wyk, B., Hughes G.D., & Mukumbang F.C. Psychosocial support programme improves adherence and health systems experiences for adolescents on antiretroviral therapy in Mpumalanga province, South Africa (***Under Review***: *International Journal of Environmental Research and Public Health*)

Chapter 4: Discussion and conclusion. This chapter summarizes the contribution of the thesis to knowledge on psychosocial support programmes to improve adherence and retention in antiretroviral treatment among ALHIV. The chapter discusses the limitations of the thesis and concludes by making recommendations for programme practice, policy and future research.

Chapter 2: Methodology

2.1 Overview of chapter

This chapter presents an overview of the methods employed in this doctoral research project. To contextualise the research, the chapter begins by presenting the conceptual framework used to evaluate the psychosocial support intervention implemented to improve adherence and retention in ART care among ALHIV in Ehlanzeni District Municipality in Mpumalanga, South Africa. The chapter describes the Right to Care (RTC) psychosocial support (PSS) intervention and the setting of the research. The study design and methodology are discussed; these are described in more detail in the six papers presented in Chapter 3 (Findings). The chapter also discusses the steps taken to ensure rigour in the research and concludes with a discussion of the ethical considerations relevant to this doctoral research project.

2.2 Conceptual framework of the doctoral research project

The conceptual framework of this doctoral research project is based on the premise that HIV has become a chronic illness, or disease, due to improvements in antiretroviral treatment that enable infected individuals to live with the illness. The biopsychosocial model (Engel, 1977) is thus appropriate for this research as it provides the conceptual tools to navigate the complex interacting factors associated with managing chronic illnesses or diseases. The biopsychosocial model views the management of chronic illness and diseases as a complex interaction between biological, psychological, and social factors; an understanding of these factors is key for programmes to design interventions that effectively improve health outcomes. Applying the biopsychosocial model allowed the researcher to reflect on the interactions between biological, psychological, and social factors at play in the implementation of the psychosocial support intervention designed to improve the health outcomes of adolescents living with HIV.

The management of care for adolescents living with HIV and receiving ART must be informed by a sound understanding of the complex interaction between the biological, psychological, and social factors involved. A deep understanding of these aspects supports programme implementers to be able to design interventions that are effective in improving the health outcomes of ALHIV.

The key propositions underpinning this biopsychosocial model are:

- **Biological factors.** The biomedical model assumes that disease occurs because of abnormalities in biological molecules inside the body, and minimises the significance of social, psychological, or behavioural or aspects of the illness (Syed & Bhardwaj, 2020).
- **Psychological factors.** Psychological wellbeing refers to the absence of negative emotions and states, such as depression, anxiety, anger, fear, and the presence of positive psychological conditions, such as healthy relationships, mastery of one´s environment, engagement, and self-actualization (Adler, Unanue, Osin, Ricard, Alkire & Seligman, 2017). There is evidence that the use of drugs or alcohol as a coping strategy is associated with non-adherence to ART among people living with HIV (Power et al., 2003).
- **Social support:** This refers to having positive relationships with parents/caregiver, peers and with the clinicians that provide HIV treatment, care and support for ALHIV. There is a plethora of evidence that ALHIV who received support from clinicians, parents, caregivers or relatives are more likely to develop self-efficacy (Naar-King et al., 2006), which in turn improves adherence and retention in ART care (Umar, Levy, Bailey, Donenberg, Hershow & Mackesy-Amiti, 2019; Hong et al., 2010; Callaghan & Morrisey, 1993).

2.3 Description of the Right to Care psychosocial support intervention

Right to Care (RTC) is a non-governmental organisation (NGO) in the vanguard of providing support and delivering prevention, care, and treatment services for HIV and associated diseases. RTC works with government and communities to pioneer solutions to build and strengthen public healthcare in two of South Africa's district municipalities: Ehlanzeni District

Municipality and Thabo-Mofutsanyane District Municipality.
RTC launched the psychosocial support (PSS) programme for adolescents in October 2019. The programme facilitates ‘full’ disclosure to adolescents and young adults (ages 10 to 24 years) who are unaware of their HIV positive status. Adolescents and young adults living with HIV are enrolled into adherence support groups.

The intervention utilizes peer supporters to support participants’ adherence to, and retention in, ART care. The peer supporters work together with the healthcare system, and obtain the names and addresses of adolescents and young adults who have tested positive for HIV from local healthcare facilities. With the assent of the adolescents and consent of their parents/caregivers, the peer supporters register them into the Right to Care psychosocial support (PSS) programme. As participants, the adolescents and young adults are guided and counselled on the importance of adherence and retention in care and are followed up regularly. In most cases, the peer supporters also fast track the collection of ARVs for the beneficiaries when they visit the health facilities.

The peer supporters are trained to use the psychosocial-oriented *Flipster* facilitation model developed by RTC to facilitate support group sessions with participants at selected ‘safe spaces’. Participants are organised into groups by age (10-13, 14-16 and 17-24 years). The aim of the support groups is to empower adolescents and young people living with HIV to become resilient, better informed and better able to make well-informed choices about the management of their HIV status.

Figure 1 illustrates the components of Right to Care’s psychosocial support intervention.

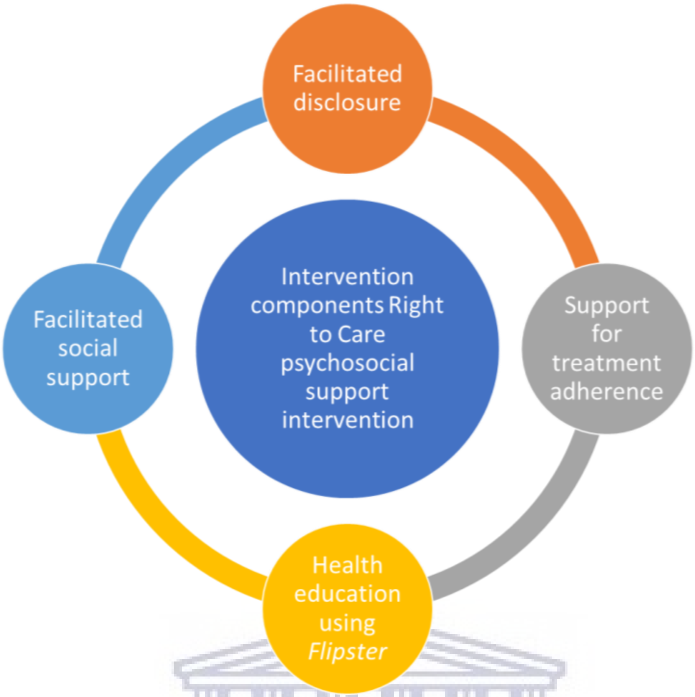


Figure 1. Intervention components of the Right To Care psychosocial support (PSS) intervention

2.4 Description of study setting

In 2017, the prevalence of HIV across all age groups in South Africa was estimated at 14%, representing an estimated 7.9 million people living with HIV (Simbayi et al., 2019). Adolescents and young children represented about 10.4% of those living with HIV, nationally (ibid).

The *South African National HIV Prevalence, Incidence, Behaviour and Communication Survey, 2017* reported that Ehlanzeni District Municipality, located in the province of Mpumalanga, had the second-highest prevalence of HIV of all district municipalities in South Africa, with an estimated prevalence rate of 17.3% (ibid). The intervention under study in this doctoral research project was implemented amongst adolescents living with HIV residing in Ehlanzeni District Municipality.

The Ehlanzeni District Municipality is situated in the north-eastern part of the province of Mpumalanga. It makes up just over a third of the province's geographical area. The district is comprised of four local municipalities: Bushbuckridge, Mbombela, Nkomazi and Thaba Chweu. Three border posts to neighbouring countries are found in Ehlanzeni: the Matsamo Border Post to eSwatini, and the Komatipoort and Mananga Border Posts to Mozambique. As a result of its geographical position between these neighbouring countries and Gauteng, commercial traffic has boosted the Ehlanzeni economy.

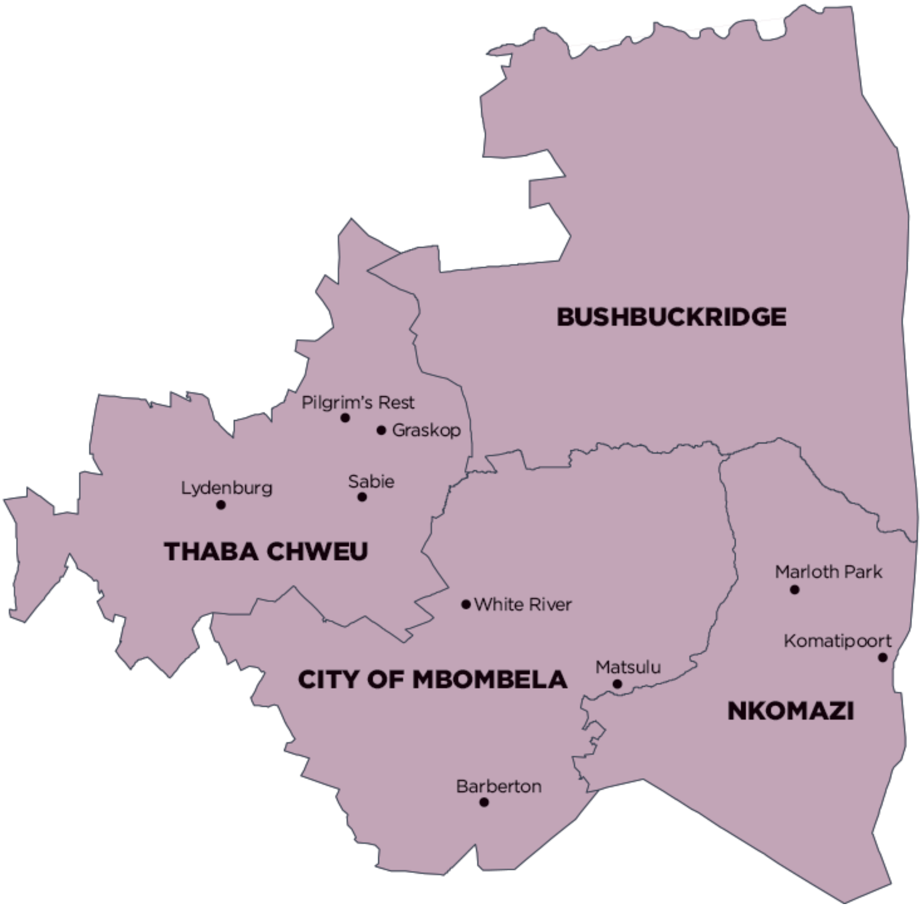


Figure 2. Map of Ehlanzeni District Municipality, Mpumalanga, South Africa
(Source: Municipalities of South Africa, 2022).

2.5 Study design

To address the objectives of the doctoral research project, the research was conducted using a multi-method design that involved six studies conducted over four research phases. Both quantitative and qualitative research methods were used. This section describes the phases of the research (Section 2.5.1), followed by a description of each study in terms of its aims and methodologies (Section 2.5.2). An overview of the doctoral research project is provided in Figure 3 at the end of Section 2.5.1.

2.5.1 Research phases

This doctoral research project was implemented in four phases. Six studies were conducted during these phases and six scholarly papers were produced (five of which have been published; one is under review by a publisher). The phases were designed as follows:

Phase 1 consisted of a scoping review. The study aimed to identify, classify, and assess the types and effects of psychosocial support interventions focused on improving adherence and retention in care among young people living with HIV on ART in the literature. This study was published in Paper 1 (introduced in Section 2.5.2 and presented in Chapter 3).

Phase 2 involved two retrospective studies utilising anonymized individual patient electronic medical records. First, a baseline quantitative cross-sectional analysis was conducted to assess the adherence rate of ALHIV. This study was published in Paper 2 (introduced in Section 2.5.2 and presented in Chapter 3). For the second study conducted in Phase 2, a baseline quantitative cohort analysis was conducted to assess the retention rates of ALHIV in care. This study was published in Paper 3 (introduced in Section 2.5.2 and presented in Chapter 3).

Phase 3 involved a content analysis of the implementation documents developed by Right to Care for the psychosocial support (PSS) intervention. The components of the intervention were analysed using the biopsychosocial model to understand how their design facilitated improve adherence and retention in care,. This study was published in Paper 4 (introduced in Section 2.5.2 and presented in Chapter 3).

Phase 4 involved two qualitative studies. Five key informant interviews (KII) were conducted; informants comprised a programme coordinator, two professional nurses, and two community systems technical officers, representing five different health centres. Their feedback on the implementation process and challenges were analysed inductively and reported in Paper 5 (introduced in Section 2.5.2 and presented in Chapter 3). The second study in Phase 4 involved conducting 24 focus group discussions (FGDs) involving 173 ALHIV participants from the PSS intervention. Their experiences participating in the PSS intervention and the challenges encountered were analysed inductively and reported. This study was written up in Paper 6, which is still under review by the publisher (introduced in Section 2.5.2 and presented in Chapter 3).

An overview of the doctoral research project is presented in Figure 3.

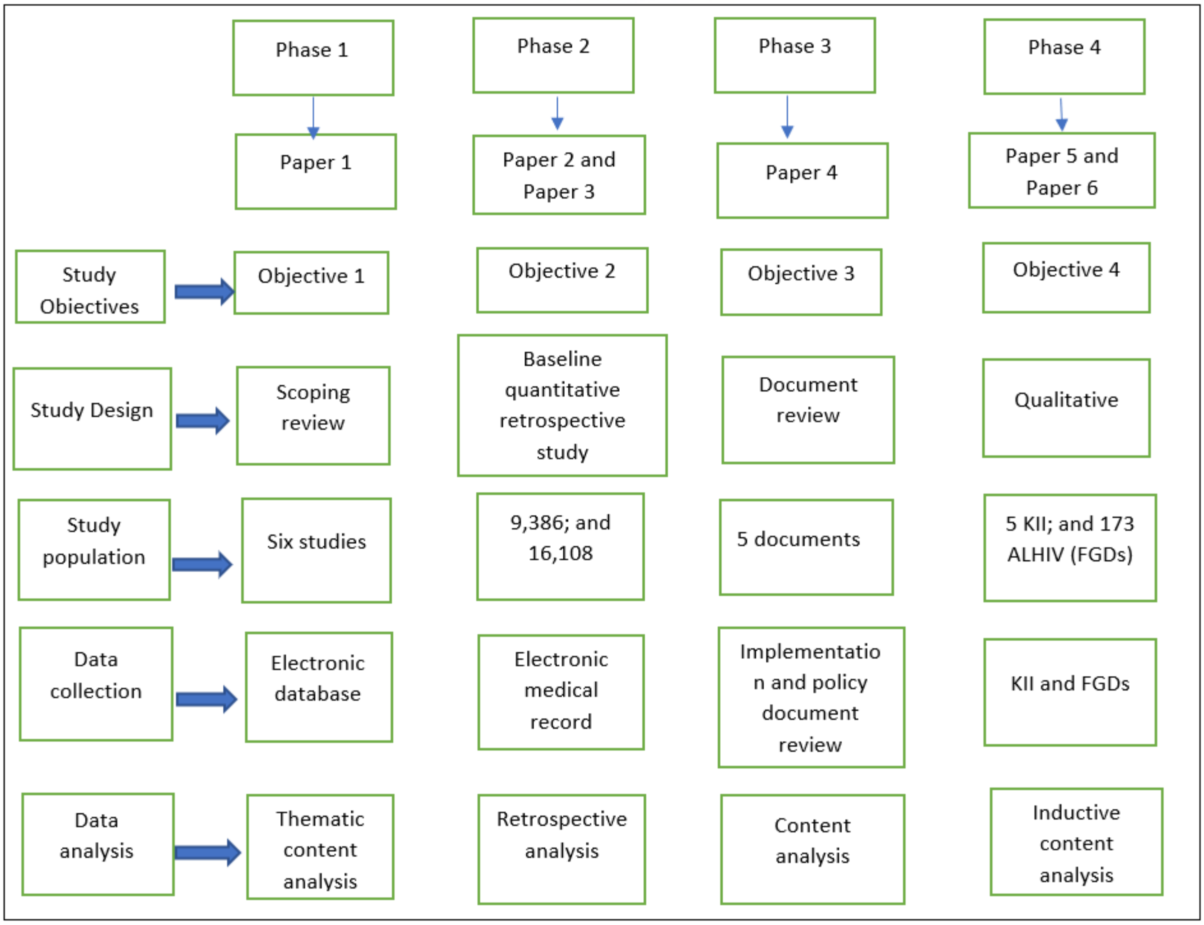


Figure 3. Overview of the research process

2.5.2 Studies conducted within the doctoral research project

This section provides a summary of each study, including its aim and methodologies.

Study 1: **Psychosocial support interventions for improved adherence and retention in ART care for young people living with HIV (10-24 years): a scoping review**

Aim: To identify, classify and assess the types and effects of psychosocial support interventions focused on improving adherence and retention in care among young people living with HIV on ART in the existing literature.

Study design: A scoping review.

Data search: Six electronic databases (Scopus, Pubmed and EBSCOHost, Academic Search Premier, CINAHL, Psycarticles and Medline) were searched, resulting in 5,243 records. After deduplication and screening of full text, six relevant articles published between 2011 and 2019 met our inclusion criteria. These reported on studies from the United States (2), Kenya (1), Uganda (1), South Africa (1), and Zimbabwe (1).

Data extraction. Data were extracted using a Microsoft Excel spreadsheet under the following headings: study setting, sample characteristics, intervention objectives, study design and methods, outcome measures, and results. Information relevant to the nature and outcomes of the reported interventions was documented using thematic content analysis informed by the Population, Intervention, Comparison, Outcome and Time (PICOT) framework.

Data synthesis. A thematic content analysis approach was employed to distil information from the selected articles. The extracted information was coded into two broad categories: intervention components and outcomes (measured against the study aim). The intervention components were coded and classified according to the following categories: (1) how the interventions were administered; (2) who delivered the intervention; (3) point of intervention delivery; and (4) components of the intervention. The outcomes were coded according to the reported primary and secondary outcomes of the study.

Study 2: Determinants of viral suppression among adolescents on antiretroviral treatment in Ehlanzeni district, South Africa: a cross-sectional analysis

Aim: To determine the predictors of viral load suppression among HIV-positive adolescents (ages 10 to 19) receiving ART in Ehlanzeni District Municipality, South Africa, between September 2002 and October 2019.

Study design: A retrospective cross-sectional analysis was conducted of routine data on ALHIV (ages 10 to 19) who were registered to receive ART from 136 clinics in Ehlanzeni District Municipality between September 2002 and October 2019.

Population/sample: We extracted 9,386 anonymised individual patients' data for ALHIV who had been on ART for at least six months. In addition, only individual patient data with documented viral load result were included in the analysis.

Data collection: We extracted 9,386 anonymized individual patients' electronic medical records, including clinical data and treatment outcomes (viral load result) for ALHIV who had been on ART for at least six months.

Analysis: STATA statistical software version 16.0 (STATA Corporation, College Station, Texas, USA) was used for analyses. Descriptive statistics were used to characterize the demographic and clinical variables (at baseline and/or six months after ART initiation). Furthermore, a multivariate logistic regression model was used to estimate factors associated with viral suppression and adjusted for potential confounders.

Study 3: Two-year retention in care for adolescents on antiretroviral therapy in Ehlanzeni District, South Africa: a baseline cohort analysis

Aim: To investigate retention in care rates and associated factors among adolescents (ages 10 to 19 years) receiving ART in Ehlanzeni District Municipality based on routine clinical electronic data.

Study design: A retrospective cohort analysis was conducted of ALHIV (ages 10 to 19 years) registered to receive ART from 136 clinics in Ehlanzeni District Municipality between September 2002 and October 2017.

Population/sample: A total of 16,108 adolescents met the inclusion criteria.

Data collection: Anonymised individual patient demographic (i.e., gender and age), clinical and treatment outcome (viral load results three months after ART initiation) data were extracted from electronic medical records (Tier.net).

Analysis: Data were imported to STATA statistical software version 16.0 (STATA Corporation, College Station, Texas, U.S.A.) for analyses. Descriptive statistics were used to characterise the demographic and clinical profile of adolescents at baseline and/or specific time points after ART initiation. Comparisons between retention in care at months 6, 12, 18 and 24 and clinical parameters among ALHIV were measured using chi-square tests for proportions (replaced by Fisher's exact test for sparse data), and Cox regression analysis adjusted for potential confounders and interactions.

Study 4: Applying the biopsychosocial model to unpack a psychosocial support intervention designed to improve antiretroviral treatment outcomes for adolescents in South Africa

Aim: To explain how the components of the RTC ALHIV intervention were designed to improve adherence to ART and retain ALHIV in ART to improve health outcomes.

Study design: Using the biopsychosocial model, hypotheses were formulated to explain how the components of the RTC ALHIV intervention were designed to improve adherence to ART and retain ALHIV in ART to improve health outcomes.

Population/sample: Data were obtained from five programme documents.

Data collection: Programme documents, comprising policies and guidelines on friendly spaces for adolescents and youth, the RTC PSS implementation plan and the Flipster training manual, were reviewed using content analysis.

Analysis: Thematic content analysis

Study 5: Implementation of a psychosocial support intervention for adolescents on antiretroviral 2 treatment: Challenges and experiences from Ehlanzeni District, South Africa

Aim: To report on the implementation of a psychosocial support intervention designed to improve adherence and retention of ALHIV on ART in Ehlanzeni District Municipality, Mpumalanga, South Africa.

Study design: A qualitative descriptive research design was applied between 1 and 30 November 2021.

Population/sample: The study was conducted at five public primary healthcare facilities: Buffelspruit Clinic, Kanyamazane Community Health Centre, Cunningmoore Clinic, Langloop Community Health Centre and Naas Community Health Centre. Five purposively selected key informants, comprising a programme coordinator, two professional nurses and two community system technical officers (CSTO) were interviewed for the study.

Data collection: Programme documents were reviewed, including policies and guidelines for adolescent and youth friendly spaces, the implementation plan and the Flipster training manual. Interviews with the key informants were conducted between 3 and 10 December 2021.

Analysis: Four programme objectives were identified from the document review; these were used as a framework to organize the key informant interview data. Data were analysed manually using inductive content analysis.

Study 6: Psychosocial support programme improves adherence and health systems experiences for adolescents on antiretroviral therapy in Mpumalanga, South Africa.

Aim: To qualitatively explore the experiences of a PSS intervention delivered to ALHIV in five primary healthcare facilities in Ehlanzeni District Municipality, Mpumalanga, South Africa, during the COVID-19 pandemic.

Study design: A qualitative descriptive research design was applied between 1 and 30 November 2021.

Population/sample: Twenty-four focus group discussions (FGD) were conducted with ALHIV (ages 10 to 19) on ART who participated in the PSS intervention at five public primary healthcare facilities in Ehlanzeni District Municipality.

Data collection: Twenty-four focus group discussions were conducted with adolescents living with HIV (ALHIV). Of the 173 participants, 91 were females and 82 were males. Of the females, 42 were 10 to 14 years old and 49 were 15 to 19 years old. Of the males, 33 were 10 to 14 years old and 49 were 15 to 19 years old.

Analysis: Data were captured in a Microsoft Excel table with five columns representing categories, themes, subthemes, codes and quotations or remarks. Codes were developed from the responses provided by the participants. The codes were later reviewed and organised into subthemes, themes, and categories (pattern coding).

2.6 Credibility and trustworthiness

To strengthen the credibility and dependability of the qualitative data, the following measures were taken. Prolonged engagement with, and persistent observation of, participants was used, as recommended by Shenton (2004), to assure the credibility of the data. To enable triangulation of the data, multiple data collection methods were used, a broad range of informants was included, and the data was verified through peer review. To strengthen dependability, the researcher (doctoral candidate) kept an audit trail, which involved detailed documentation of the research process (including methods and decisions) and field notes that were made after each interview that recorded the context of the interview, the dynamics between interviewer and interviewee(s) and any other impressions noted by the researcher.

Rigour, with respect to dependability, was achieved by outlining the decisions made throughout the research process to provide a rationale for the methodological and interpretative judgements of the researcher, as recommended by Shenton (2004). These explanations include a justification for the research design, study participant selection, data collection and data analysis methods. For dependability in the research, a detailed description of the methodology was made to enable replication of the study. Once again, an audit trail was kept to provide any observer with a step-by-step understanding of the research process, including decisions made and procedures followed.

As has been mentioned, to ensure confirmability, as recommended by Norris (1997) the doctoral candidate kept an audit trail detailing the process of data collection, data analysis, and interpretation of the data in order to ensure that the findings and results obtained from the study emerged from the data collected rather than from the researcher's own predispositions. An independent research assistant translated the questionnaires to ensure that meanings and intended outcomes in the questions were retained. That is after translations from English to Tsonga, another research assistant translated the questionnaire back to English from Tsonga (the local language in which interviews were conducted).

2.7 Validity and Reliability

Quantitative data were extracted from the Tier.Net medical electronic record into Microsoft Excel and imported to STATA statistical software version 16.0 (STATA Corporation, College Station, Texas, USA) for analyses. Information on clinical stationery was reviewed against information on Tier.net. Patient clinical records identified as incomplete or not correctly captured on Tier.net were retrieved and subsequently updated on Tier.Net.

2.8 Ethical considerations

Ethical clearance was obtained from the University of the Western Cape Biomedical Research Ethics Committee (BM19/1/8). Approval to use the Tier.Net medical electronic dataset was obtained from the National Health Research Ethics Committee (MP_202102_006). The study complied with the principles of the 1964 Declaration of Helsinki (World Medical Association, 2013), which states that research that involves human subjects must strive to protect the life, health, privacy and dignity of the research participants; must employ care to protect the participants from harm; and that the importance of the research objective must outweigh any possible risks and burdens to the research participants at the time of the study or in the future.

Ethical clearance was obtained from the Biomedical Research Ethics Committee of the University of Western Cape, as well as the Mpumalanga Provincial Department of Health Research Committee before commencing data collection. Participant information sheets were developed to solicit candidates to participate before recruiting them into the study. The information sheet described the purpose of the study, potential risks and how these risks would be mitigated so as not to cause harm to the participant. Furthermore, it stated that participation was completely voluntary, and no penalty or punishment would arise if the individual chose not to participate in the study. The details of a professional psychologist were provided in case the participants began to experience psychological trauma during the interview.

Informed consent was obtained from all respondents, who were assured of confidentiality. During group discussions, facilitators explained the purpose of the study and its methodology. Participants were assured that their participation was voluntary and that they could withdraw from the interview or discussion at any stage without consequence. Furthermore, electronic medical records obtained from Tier.net, such as viral load results, were de-identified so that patients' names could not be traced to their result.

Participants' HIV status was not disclosed to any person outside of the study. The names of participants in the focus group discussions were not recorded so that their identities remained unknown throughout the study.

All standard ethical procedures were adhered to throughout the study including treating patients' information with anonymity, and all data obtained were treated as confidential. This was important because the data included sensitive information such as HIV status, viral load status, field notes, taped recordings, and transcribed copies of the interviews. To ensure that confidentiality of the participants' information would be maintained, all field notes, recordings and transcriptions were locked in a safe drawer during the study and after completion of the study.

To maintain the anonymity and privacy of individuals, pseudonyms were used for participants in all notes taken by the researcher. For any recordings made, pseudonyms were used to identify participants after transcribing, ensuring names of participants were not used in documentation. The final research report did not contain any identifiable names of participants.

The consent and assent forms, on which participants' names were recorded, were stored together with the recorded interviews. All information recorded electronically was kept on a password-protected computer. Interview sessions were conducted in the boardrooms of the health centres to attempt to create a safe and comfortable environment for participants.

Lastly, because the study involved children, the process of seeking the assent of minors was followed in an age-sensitive and culturally- and developmentally-appropriate manner, following the specific regulations of the South African National Department of Health for written documentation, including name and signature. For study participants under the age of 18 (legal minors below the South African age of consent), the following steps were followed.

First, the researcher contacted the child's parent or legal guardian to request permission for contact with the child. Their consent was documented by means of a written informed consent form. If the child's parent or legal guardian was unavailable, no further attempt was made to include the prospective participant. If consent was obtained from the child's parent or legal guardian, the researcher then sought the assent of the child to participate in the research. If the minor agreed to participate in the study, they indicated their active agreement. Mere failure to object was not construed as assent. In accordance with regulations from the South African National Department of Health, this too was documented by means of an informed assent form, which was signed by children 10 to 17 years of age. A member of the research team indicated by signing the assent form that they had witnessed this active agreement.

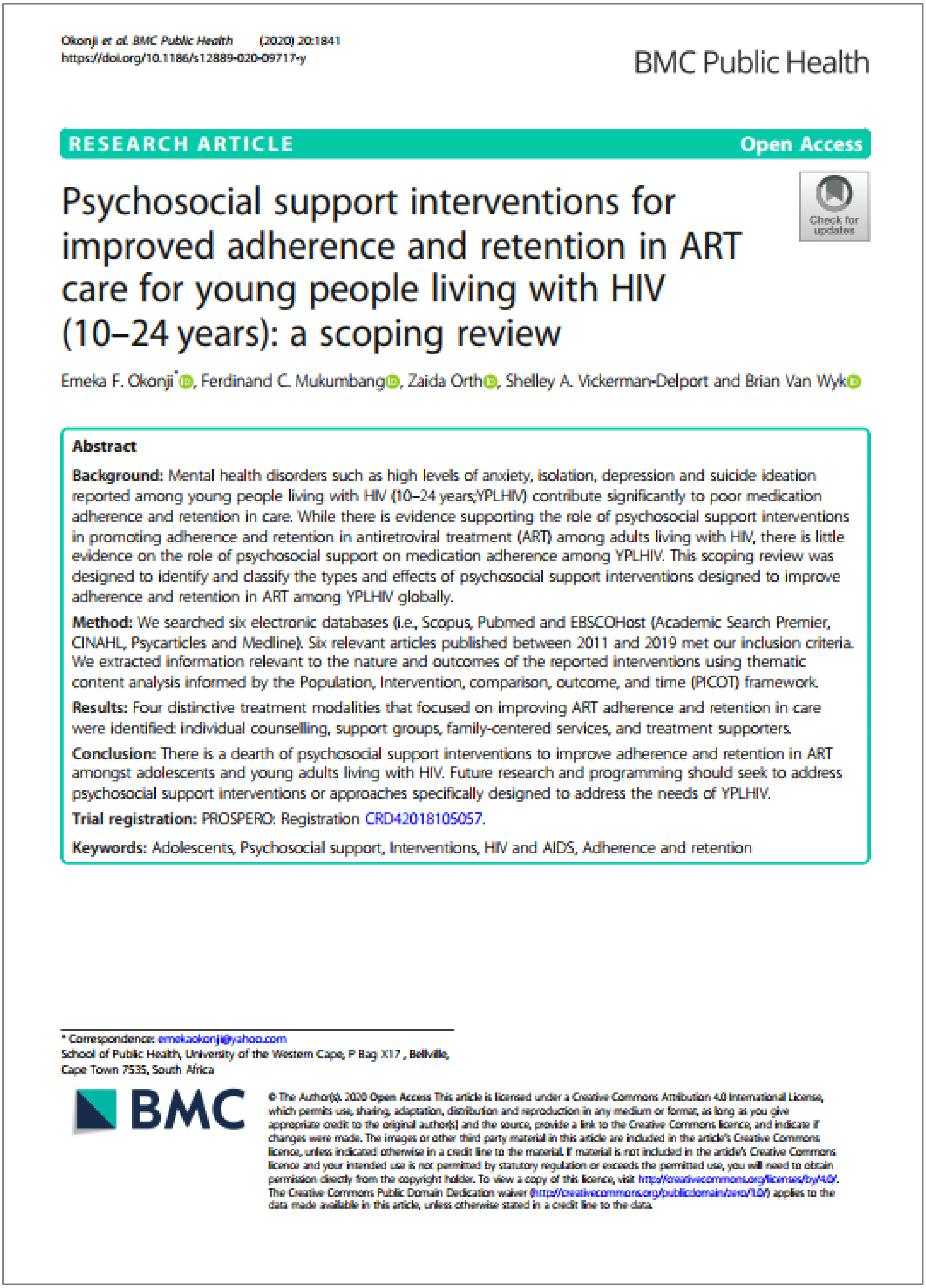
Chapter 3: Findings

Paper 1: Psychosocial support interventions for improved adherence and retention in ART care for young people living with HIV (10–24 years): a scoping review.

Citation: Okonji, E.F., Mukumbang, F.C., Orth, Z., Vickerman-Delport, S.A & van Wyk, B. (2020). Psychosocial support interventions for improved adherence and retention in ART care for young people living with HIV (10–24 years): a scoping review. *BMC Public Health, 20*, 1841. https://doi.org/10.1186/s12889-020-09717-y

Introduction: The scoping review identified six papers on psychosocial support intervention for improved adherence and retention in care among adolescents on ART, published between 2011 and 2019. Two of the studies were conducted in the United States of America and four were conducted in countries in southern and eastern Africa: Uganda, Kenya, South Africa, and Zimbabwe. The psychosocial support interventions included psychosocial education, group adherence counselling, individual counselling, peer-support groups, and peer counselling. Two of the studies evaluated the impact of a family-centred appointment intervention and health education on patient retention and adherence to monthly appointment scheduling. Three of the studies evaluated a youth-centred management model that combined psychosocial case management, treatment education, adherence support, and HIV risk reduction counselling to provide a client-centred intervention through which care was coordinated. Three of the studies evaluated interventions that included fast-track service deliveries to streamline medication pick-up. The review highlighted the dearth in published literature on psychosocial support interventions to improve adherence and retention in ART amongst adolescents and young adults living with HIV. The review recommended future research and programming to address psychosocial support interventions or approaches specifically designed to address the needs of young people living with HIV (YPLHIV).

Contribution of candidate: EO, FCM, and BvW designed the study and selected the search terms. EO, SV, and ZO screened titles and abstracts using the identified inclusion and exclusion criteria. The data were analysed by SV, ZO, EO, and FCM. EO, SV, and ZO drafted the first manuscript with editorial and content input from BvW and FCM.



Okonji *et al. BMC Public Health* (2020) 20:1841
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BMC Public Health

RESEARCH ARTICLE Open Access

Psychosocial support interventions for improved adherence and retention in ART care for young people living with HIV (10–24 years): a scoping review

Emeka F. Okonji*, Ferdinand C. Mukumbang, Zaida Orth, Shelley A. Vickerman-Delport and Brian Van Wyk

Abstract

Background: Mental health disorders such as high levels of anxiety, isolation, depression and suicide ideation reported among young people living with HIV (10–24 years;YPLHIV) contribute significantly to poor medication adherence and retention in care. While there is evidence supporting the role of psychosocial support interventions in promoting adherence and retention in antiretroviral treatment (ART) among adults living with HIV, there is little evidence on the role of psychosocial support on medication adherence among YPLHIV. This scoping review was designed to identify and classify the types and effects of psychosocial support interventions designed to improve adherence and retention in ART among YPLHIV globally.

Method: We searched six electronic databases (i.e., Scopus, Pubmed and EBSCOHost (Academic Search Premier, CINAHL, Psycarticles and Medline). Six relevant articles published between 2011 and 2019 met our inclusion criteria. We extracted information relevant to the nature and outcomes of the reported interventions using thematic content analysis informed by the Population, Intervention, comparison, outcome, and time (PICOT) framework.

Results: Four distinctive treatment modalities that focused on improving ART adherence and retention in care were identified: individual counselling, support groups, family-centered services, and treatment supporters.

Conclusion: There is a dearth of psychosocial support interventions to improve adherence and retention in ART amongst adolescents and young adults living with HIV. Future research and programming should seek to address psychosocial support interventions or approaches specifically designed to address the needs of YPLHIV.

Trial registration: PROSPERO: Registration CRD42018105057.

Keywords: Adolescents, Psychosocial support, Interventions, HIV and AIDS, Adherence and retention

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Psychosocial Support Interventions for Improved Adherence and Retention in ART care for Young People Living with HIV (10-24 years): A Scoping Review

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Abstract

Background: Mental health disorders such as high levels of anxiety, isolation, depression and suicide ideation reported among young people living with HIV (10-24 years; YPLWH) contribute significantly to poor medication adherence and retention in care. While there is evidence supporting the role of psychosocial support interventions in promoting adherence and retention in antiretroviral treatment (ART) among adults living with HIV, there is little evidence on the role of psychosocial support on medication adherence among YPLWH. This scoping review was designed to identify and classify the types and effects of psychosocial support interventions designed to improve adherence and retention in ART among adolescents and young people living with HIV globally.

Method: We searched six electronic databases (i.e., Scopus, Pubmed and EBSCOHost (Academic Search Premier, CINAHL, Psycarticles and Medline). Six relevant articles published between 2011 and 2019 met our inclusion criteria. We extracted information relevant to the nature and outcomes of the reported interventions using thematic content analysis informed by the Population, Intervention, comparison, outcome, and time (PICOT) framework.

Results: Four distinctive treatment modalities that focused on improving ART adherence and retention in care were identified: individual counselling, support groups, family-centered services, and treatment supporters.

Conclusion: There is a dearth of psychosocial support interventions to improve adherence and retention in ART amongst adolescents and young adults living with HIV. Future research and programming should seek to address psychosocial support interventions or approaches specifically designed to address the needs of adolescents and young adults living with HIV.

PROSPERO: Registration CRD42018105057

Keywords: Adolescents, psychosocial support, interventions, HIV and AIDS, adherence and retention.

Background

Since the introduction of antiretroviral therapy (ART), significant gains have been made in mitigating the impact of the HIV/AIDS pandemic [1]. The increasing effectiveness of and access to ART, along with increasing innovations in ART service delivery have redefined the HIV epidemic from a deadly infectious disease to a chronic, manageable disease [1–3]. However, poor adherence to treatment and suboptimal retention in care continue to present significant challenges to ending AIDS by 2030 [4].

In 2018, UNAIDS estimated that 1.6 million young people aged 10–24 years were living with HIV [5, 6]. Therefore, young people living with HIV (YPLHIV) constitute a growing and key sub-population of people living with HIV globally. The increasing availability and effectiveness of ART worldwide, has resulted in more children and adolescents living longer with HIV [7, 8]. However, it is well-documented that adolescents struggle to initiate, remain engaged, and consistently adhere to ART [9, 10]. While most of the individual, social and health systems barriers associated with ART adherence and retention in care affecting the general population also apply to YPLWH, the latter face greater risks of mental and behavioural health problems, which constitute additional barriers [7, 11, 12]. Psychological risk factors such as depressive disorders result from the chronicity of HIV infection, being orphaned, changes of guardianship, and the nature of parental and other adult support [11, 13, 14].

Due to the high levels of anxiety, isolation, depression and suicide reported among YPLWH, studies have recommended psychosocial support for YPLWH in addition to standard ART services to help them adapt and cope with the chronicity and stigma associated with HIV [3, 11, 12, 15–17]. Psychosocial support interventions are interpersonal or informational activities, strategies or techniques that can target biological, behavioural, cognitive, emotional, interpersonal, social or environmental factors with the aim of improving an individual’s health functioning and mental well-being [18]. To promote ART adherence and retention in care among YPLWH, a comprehensive psychosocial intervention is needed. Such psychosocial support interventions should promote HIV disclosure and communication, support adherence to medication, address feelings of isolation and other emotional-related distress, and the needs associated with emerging sexuality [19, 20].

Interventions such as counselling, cognitive behavioural therapy, and peer support have been applied to improve the mental health and overall well-being of people living with HIV over 18 years with success [21], supporting the role of psychosocial support interventions in promoting adherence and retention in ART care among adults living with HIV [22]. Nevertheless, there is little evidence on the nature and role of psychosocial support for YPLHIV [23]. To this end, in this review, we sought to identify, classify and assess the types and effects of psychosocial support interventions focused on improving adherence and retention in care among YPLHIV on ART in the current existing literature.

Method

Our scoping review was conducted in line with the guidelines proposed by Khan et al. [24] i.e. (1) Framing the question; (2) Identifying relevant publications; (3) Assessing study quality; (4) Summarising the evidence; and (5) Interpreting the findings.

Based on the literature, we developed Boolean phrases that were tested using PubMed. The first literature search was conducted between March and October 2018. Due to unforeseen delays, an updated search using the same Boolean phrases and databases was conducted between October 2019 to March 2020. We searched multiple electronic databases – Scopus, PubMed and EBSCOHost (Academic Search Premier, CINAHL, Psycarticles and Medline) using a standard Boolean combination: "((adolescen* OR teenage* OR young people OR youth) [AND] (psychosocial intervention) [AND] (adherence in antiretroviral therapy OR retention in care))". In addition, we hand-searched grey literature on mental health among YPLWH and transitioning YPLWH from paediatric to adult care. All titles and abstracts (including conference abstracts) were independently screened by SAV and ZO using the PICOT (Participants, Interventions, Comparisons, Outcomes and Time) mnemonics criteria described in Table 1. Discrepancies were resolved via discussions with a third researcher (FCM). Full texts of potentially relevant articles were retrieved and independently examined by the authors. The reference lists of considered relevant articles were also hand searched to identify further potentially relevant studies. Summaries of the interventions described in each article were retrieved using a standardized form, and key information such as study purpose, nature of intervention described, outcome of intervention and conclusions of each study were extracted.

The acronym PICOT informed the eligibility criteria for inclusion in the scoping review: the population (participants) of focus, types of interventions (and comparisons), and the outcomes of interest. The time relates to the period within which the studies were published [see Table 1 below].

Table 1 PICOT based inclusion criteria

Patient population	**Adolescents or young adults (10-24 years) living with HIV**
Intervention of Interest	Psychosocial support
Comparison interventions	None
Outcomes	
Primary outcomes	(1) Adherence to antiretroviral treatment (viral load); (2) Retention in care
Secondary outcomes	(1) Quality of life and wellbeing; (2) Stigma and discrimination; (3) Disclosure
Time	2005–2020
Other considerations	
Language	English

Studies were considered eligible for inclusion in this scoping review if they met the following criteria: (i) Evaluated the effects of or associations between psychosocial support intervention and adherence ART or retention in care or related biomedical outcomes e.g., viral suppression (primary outcomes). (ii) Reported quantitative measures of the primary outcomes. (iii) Targeted or included samples of adolescents (10–19 years) and/or youth (15–24 years) living with HIV in a mixed sample. (iv) Was published between January 1, 2005 and March 31, 2020. Only articles published in English were considered. There was no restriction by geographical location.

Studies were excluded if they met the following criteria: (i) Adopted a qualitative research design (ii) Were a study protocol, or any form of review or conference abstracts not developed into full manuscripts. (iii) The population deviated from the age range specified. (iv) The intervention did not target the psychosocial needs of the study population. (v) The intervention focused on HIV prevention.

The quality of the included articles was rated as either “poor”, “fair” or “good” by three independent researchers (EO, SAV and ZO), and EO made the final adjudication in cases of non-agreement. The rating of the articles was based on the criteria provided by the NIH-NHLBI Quality Assessment of Systematic Reviews and Meta-Analyses assessment tool [25].

Data Extraction

The data were extracted using an excel spreadsheet under the following headings: study setting, sample characteristics, intervention objectives, study design and methods, outcome measures and results [Additional file 1].

Data Analysis

We employed a thematic content analysis approach to distil information from the selected articles [26]. The extracted information was coded into two broad categories: Intervention components and outcomes measured as informed by the study aim. The intervention components were coded/classified along the following categories: (1) How the interventions were administered; (2) who delivered the intervention; (3) Point of intervention delivery; and (4) components of the intervention. The outcomes were coded according to the reported primary and secondary outcomes of the study.

Results

Figure 1 shows the PRISMA diagram illustrating the selection process of the included studies. The literature search resulted in 5,244 citations [**Figure 1**], which were imported into a reference manager. Electronic (31) and manual (28) deduplication identified 59 duplicates. After screening for potentially relevant titles and abstracts 5,162 articles were excluded. After screening full-texts, 17 papers were further excluded because they did not report on the effects of a psychosocial support intervention on adherence and retention in ART for YPLWH. Subsequently, six papers were included in the review of having good quantitative standards. Five studies were considered to be of good methodological quality [27–31] and one of a fair quality [32].

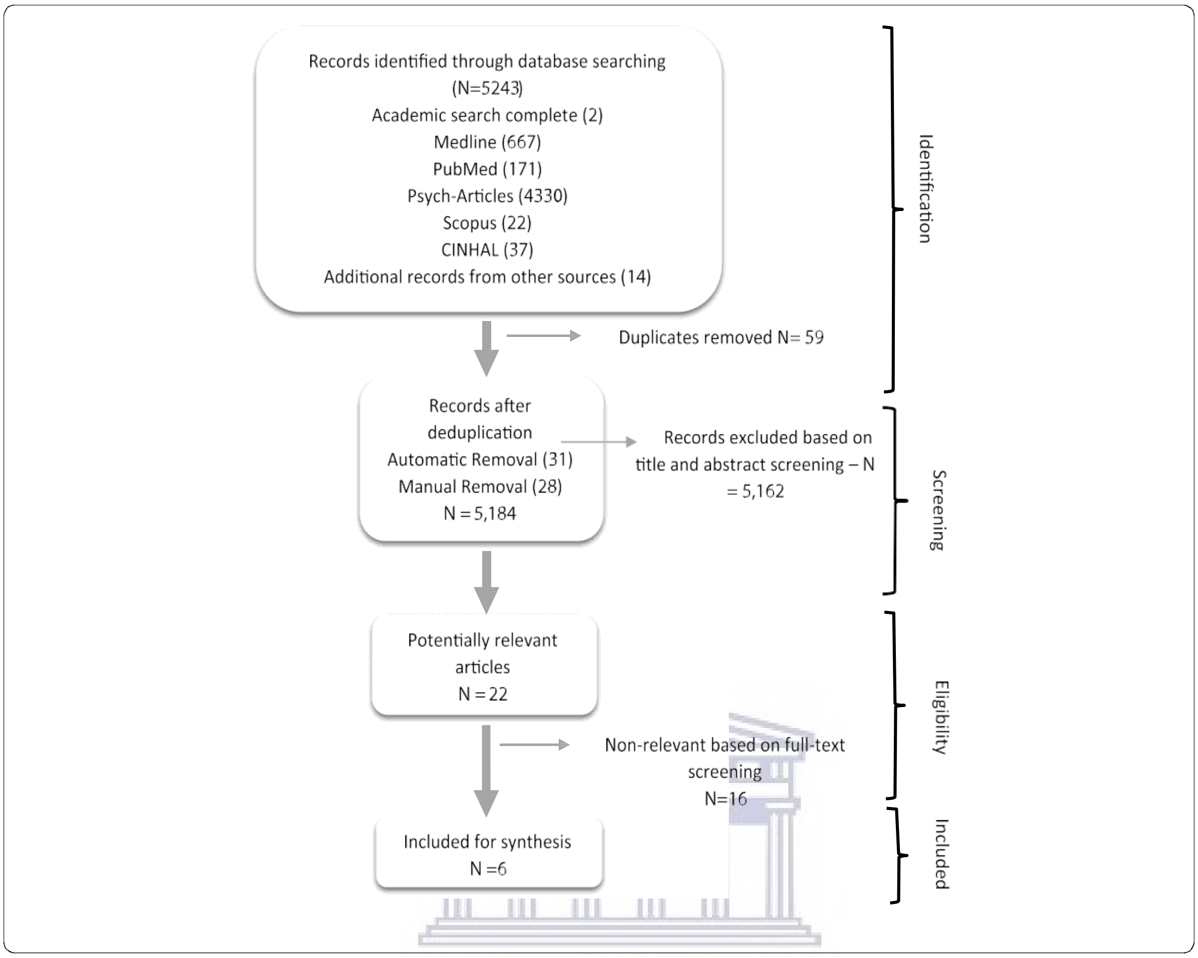

Figure 1. The PRISMA flow protocol for studies selection

Characteristics of included studies

The characteristics of the studies included in the review are summarised in Table 2.

Table 2 Characteristics of Included Studies (N=6)

Characteristics	Count	References
Year of Publication		
2011 – 2015	3	[27] [28] [30]
2016 – 2020	3	[29][31][32]
Country		
United States of America	2	[28][30]
Kenya	1	[29]
Uganda	1	[32]
South Africa	1	[27]
Zimbabwe	1	[31]
Study design (sample size)		
Pre and post intervention studies (61; 952)	2	[29][30]
Randomized controlled trial (4,504; 66; 94)	3	[27][31][32]
Retrospective cohort (174)	1	[28]

The six papers were disseminated between 2011 and 2019. Two of the studies were conducted in United States of America [28, 30] and four in Southern and Eastern Africa (Uganda, Kenya, South Africa and Zimbabwe) [27, 29, 31, 32]. Two of the papers were pre- and post-intervention studies (n=1,113) [29, 30], three randomized control trials (RCT) [27, 31, 32] (n=4,664), and one retrospective cohort study (n=174) [28].

Intervention duration

The duration of study was between 3 months and 10 years [Table 3].

Table 3 Intervention/study location and duration of intervention

Article	Country (location)	Duration of intervention
Wohl et al. [30]	USA (Los Angeles)	2 years
Davila et al. [28]	USA (Texas)	Decentralised era: 2 years Centralised area: 3 years Enhanced youth services: 10 years
Ruria et al. [29]	Kenya (Homa Bay)	6 months
Graves et al. [32]	Uganda	6 months
Bhana et al. [27]	South Africa (KwaZulu-Natal)	3 months
Willis et al. [31]	Zimbabwe (Gokwe south district)	12 months

Six studies evaluated psychosocial support interventions, namely: psychosocial education, group adherence counselling, individual counselling and peer-support groups and peer counselling. Two studies evaluated the impact of a family-centred appointment scheduling and health education on patient retention and adherence to monthly appointment scheduling [27, 32]. Three studies evaluated a youth centred management model that combined psychosocial case management, treatment education/adherence support and HIV risk reduction counselling to provide a client-centred intervention through which care was coordinated [28, 30, 31]. Three studies [29, 30, 32] evaluated interventions that included fast-track service deliveries to streamline medication pick-up. Table 4 illustrates the nature and characteristics of the interventions identified.

Health and psychosocial education delivered in the form of educational activities and workshops to provide information on HIV and other relevant topics formed an integral part of all six interventions [27–32]. Health education was delivered using posters and cartoons in a structured manner that provided participants with real life situations on navigating through being orphaned by AIDS; moving in with relatives; learning about own HIV diagnosis and treatment needs, while coping with family loss, stigma, peer relationships, identity, and family functioning [27–32]. Furthermore, trained staff who were equipped with the tools to care for and skilled in treating adolescents were employed in six of the interventions e.g. adolescent care providers, youth-focused social workers and psychologist [27–32].

Table 4 The nature and characteristics of the interventions

Type of intervention	**N**	**References**
Psychosocial education		
Teaching/education	6	[27][28][29][30][31][32]
Educational workshops	3	[28][29][32]
Adherence counselling		
Group cou nselling/ support groups	5	[27][28][29][31][32]
Individual counselling	5	[27][29[30]][31][32]
Family-centred		
Family based psychosocial intervention	2	[27][32]
Fast track/fast lane services		
Priority clinic scheduling	3	[29][30][32]
Use of reminder cards/sms		
Reminder cards/sms	1	[32]
Intervention agent		
Social worker	2	[30][28]
Adolescent care provider	3	[29][31][32]
Clinical psychologist/Bachelor-level counsellor	2	[27][30]
General practitioner/Nurse	3	[27][29][32]
Peer counsellor	4	[28][29][31][32]
Lay counsellor/CHW	2	[27][32]
Point of intervention delivery		
Facility-based	6	[27][28][29][30][31][32]
Community-based	2	[28][31]
School-based	1	[29]
Components of intervention		
Knowledge/education on HIV/AIDS	6	[27][28][29][30][31][32]
Adherence to treatment and retention in care	6	[27][28][29][30][31][32]
Family-focused programme	2	[27][32]
Scheduled visits	3	[29][30] [32]
Emotional/Affective support	4	[27][30][31][32]
Structural support (youth clinic)	4	[28][29][31][32]
Sexual and reproductive health	5	[27][28][29][30][31]
Disclosure, stigma and discrimination	5	[27][28][29][31][32]
Health promotion	1	[32]
AIDS related loss and bereavement care	1	[27]

Six studies evaluated interventions that involved individual and peer counselling as part of the interventions [27–32]. The counselling sessions were facilitated by trained community adolescent treatment supporters (CATS), social workers, lay health workers, trained health professionals, or research teams, and aimed to increase HIV knowledge and address adherence and retention barriers [27-32]. These individual counselling methods used a client-centred approach [27, 30–32], or motivational interviewing [28] or peer counselling [29]. Group counselling or support groups were found in five articles as a means of psychosocial support [27-29, 31, 32]. Youth specific support groups addressed issues such as emotional needs; developing self-management skills; capacity building; sexual health; and the stigma related to HIV [28, 31, 32].

One study implemented a school-based programme to create a supportive environment for adherence for YPLWH [29]. The programme offered counselling at schools on sexual and reproductive health and encouraged adolescents to establish health clubs among themselves [29]. In addition, the intervention provided HIV medication on the school premises to enhance adherence and linkage to care, as well supporting participating learners in disclosure [29].

Two of the interventions had family-centred services [27, 32]; with one intervention 3implementing a family clinic day (FCD) [32]. FCD applied to paediatric and adolescents living with HIV and their immediate family who received priority HIV-care and counselling on a day allocated specifically to them [32]. Another component of FCD was the use of reminder cards and calendars for scheduling appointments. Health education workshops were held, which were led by peers equipped in leading discussions around HIV, sexual and reproductive health, adherence, disclosure, puberty and life skills [27-29, 32]. In addition, the VUKA family programme [27] another family-centred intervention conducted 10 health education workshop sessions that covered subject areas addressing mental and depressive disorders experienced by adolescents living with HIV. These sessions included AIDS-related loss and bereavement, HIV transmission and treatment knowledge; disclosure of HIV status to others; youth identity, acceptance, and coping with HIV; adherence to medical treatment; stigma and discrimination; caregiver child communication, particularly on sensitive topics such as puberty and HIV. The VUKA family programme also identified and developed strategies to keep children safe in high-risk situations where sexual behaviour and drug use are common [27]. Furthermore, integrated group sessions were held that were comprised of HIV-infected youth and their caregiver/s, as well as separate group activities for caregivers and preadolescents.

In the case of the Red-Carpet Intervention, adolescents were given VIP express cards- a card offering adolescents fast-track counselling and HIV treatment [29]. One of the interventions also offered adolescents the opportunity to schedule their appointments [32]. Moreover, adolescent waiting areas were implemented to create an adolescent-friendly environment aimed at improving retention to ART services at facilities [28, 32]. Although referral systems were used in two of the programmes, the programmes lacked the services needed by participants, like individual counselling [27]; and support groups for substance abusers; and housing or nutrition services.

Reminders cards and sms were used in one of the studies [32]. Participants were scheduled to attend their next appointment visit using reminder cards and reminded to take their medications by sending SMS messages at regular intervals.

Outcomes measured

The primary outcomes of interest were adherence to ART and retention in care. The measures of psychosocial support outcomes reported were: (i) self-management (self-efficacy and self-esteem), which is associated with improved self-concept and future orientation [27, 28, 31, 32]; (ii) reduction of stigma and discrimination [27, 31]; (iii) disclosure and communication [27, 31, 32]; and (iv) perceived support in the form of social support, instrumental support, family and/or peer support and informational support [28-32]. Our findings showed that five of the studies [28-32] reported on both the primary and secondary intended outcomes [Table 5].

Table 5 Reporting of primary and secondary intervention outcomes

	Studies					
Outcomes	[30]	[32]	[28]	[29]	[27]	[31]
Retention in care	✓	✗	✓	✗		✓
Adherence to medication		✓	✗	✗	✓	✓
Self-management					✓	✓
Disclosure/Communication		✓			✓	✓
Social support					✓	
Instrumental support	✓			✗		
Family and/or peer support		✓		✗		✓
Information				✗	✓	✓
Confidence, self-esteem, self-worth						✓

✓ : Reported statistical significance

✗ : No statistical significance

Reference 28 only reported outcomes of retention in care and adherence to medication and no other psychosocial outcome. Nevertheless, the reference was included because its intervention included educational activities and support groups offered by social services staff trained in the use of motivational interviewing.

Retention in care was investigated in five of the six studies [28-32]. Three studies found retention in care at 24 months [28], 12 months [31], and 6 months [30] to be significantly higher following exposure to the psychosocial interventions. Wohl et al. [30], found that participants' HIV clinic visits significantly increased between baseline and at six months following the youth case management intervention ($p < 0.0001$). Davila et al. [28] found that the centralisation of youth services, which was composed of multifaceted psychosocial intervention components, improved the retention in care of YPLWH ($p < 0.01$) at 12 months. However, there were no significant differences observed in baseline viral load by service era ($p = 0.91$) [28].

Similarly, Ruria et al. [29] conducted a pre- and post-intervention to measure retention of YPLWH in ART care. The findings indicated that after one month, 90% of patients were linked to care in the pre-intervention cohort compared to 85.7% in the post-intervention cohort. The high rate of linkage to care in the pre-intervention phase was attributed to the national policy on Adolescent Reproductive Health and development [29]. However, the results show that following the implementation of the peer counselling and psychosocial support intervention, a significant increase from 66% to 90%; and 54.4% to 98.6% were observed at three months and six months respectively. While there is a high rate of YPLWH linking to care within the first month of ART initiation, these numbers drop with time, and that the intervention is more successful in linking YPLWH to ART over time.

Results from the Family Clinic Day (FCD) intervention showed a significant increase in patient adherence to clinic appointment schedules, that is 65% ($p < 0.01$) of adolescent participants were adherent to their appointment schedules compared to 53% participants in the control facilities). However, no effect on retention in care between the control group and the intervention group ($p = 0.94$) was observed [39].

Adherence to medication was reported as a significant outcome in three studies [27, 31, 32]. According to Bhana et al. [27], a self-reported scale on how often medication was missed over the past six months by participants in the VUKA intervention reported significantly greater adherence to treatment than those in the control group ($p < 0.05$) [27]. Willis et al. [31] found that the intervention group were 3.9 times more likely to adhere to treatment compared to the control group.

Four of the studies reported on secondary outcomes [27, 30-32]. The study conducted by Wohl et al. [30], showed that personalised case management interventions provided instrumental support for participants (tangible help provided by others). For example, support in the form of referrals for housing, mental health services, risk reduction education and transportation assistance within the first six months post the intervention [30]. Similarly, qualitative findings from the FCD intervention conducted by Graves et al., suggests that the family groups component of the intervention provided participants with increased instrumental, family, peer, and informational support [32]. The findings from the VUKA pilot programme reported significant increases in individual self-concept and future orientation, improved parent-child communication, improved social support and informational support [27]. Furthermore, caregivers reported improved family support, and a decrease in the experience of stigma [27]. One study investigated the effects of community adolescent treatment supporters on psychosocial wellbeing [31]. Willis et al. [31] found a statistical significant increase in confidence, self-esteem and self-worth ($p < 0.001$). In addition, the intervention group reported a statistically significant improvement in the quality of life, while the control group reported a significant decline in the quality of life ($p = 0.028$) [31].

Discussion

Our review revealed that individual and peer counselling was a distinctive treatment modality when focusing on improving ART adherence, linkage to care and/or retention in care [27-32]. While in two instances, individual counselling was carried out using client-centred theory [30] and motivational interviewing [28], one study employed trained community adolescent treatment supporters (CATS) to provide peer to peer support to YPLWH [31]. These techniques have proved to improve adherence and retention in care among YPLWH [22, 31] . Motivational interviewing is confirmed to help people adopt better health behaviours such as helping young people to use condoms more often, and also to reduce viral load [34]. Individual counselling interventions have also been identified as resource-intensive approaches [16] as they are applied at an individual level. Although it may be challenging to implement in low and middle-income countries (LMICs), however equipping low cadre health care workers such as peer lay counsellors or CATS with the necessary skills could prove effective in providing ART care and support tailored to adolescent's particular needs [35].

Support groups were used in five of the interventions [27-29, 31, 32] that created a space for participants to share knowledge, build social capital and expand their support systems. This method of delivering psychosocial support has been found to improve adherence, linkage to care and quality of life, while being a viable treatment option in LMIC where healthcare staff and resources are limited [28]. Peer support has been reported as a major source of social support and information among adolescents in relation to living with HIV [29, 31]. Furthermore, centralising health services for youth have the propensity to reduce barriers to retention and adherence to ART care by providing medical and social services at one central location and reducing the need for navigating complex healthcare systems and improving coordination of services. The enhanced centralised youth service programme attempted to reduce negative health beliefs and misinformation about HIV by supporting patient's emotional needs and providing youth friendly HIV education to address misconceptions about living with HIV [28, 30, 31]. Youth specific support groups and educational activities offer opportunities for youth to develop support systems, knowledge, and self-management skills.

Family/household-centred services were found in two articles [27, 32], which enhanced family cohesion and communication in both cases. The family/household-centred care approach argues that the family shares the responsibility of caring for the YPLWH [38]. A recent review conducted to explore the availability and effectiveness of family/household-focused interventions to improve ART adherence and retention in care found that some of the HIV-related interventions with a household focus were focused on YPLWH, and incorporated aspects of information sharing on HIV; improving communication; stimulating social support and promoting mental health [39]. Furthermore, studies have shown that integrating paediatric and adult services has positive outcomes in adherence and retention in care [40]. Additionally, the VUKA family programme addressed sensitive topics relating to HIV by using a culturally tailored cartoon [27]; such interactive modes of delivering interventions have been found to enable parent-child communication [41].

Appointment cards were used in one of the interventions where calendars and reminder cards helped schedule eligible patients to attend their next appointment on a family clinic day [32]. There are growing evidence from published literature that mHealth as a means of active client follow-up could improve the retention of patients in care through sending of SMS reminders of their appointment dates [33, 42]. The World Health Organization recommend utilising mobile phone reminders to improve adherence, bearing in mind that the process should be carefully monitored when aimed at adolescents for effective implementation [43]. In addition, it has been argued that adherence interventions adopting a single approach, such as phone call reminders, are less effective compared to multicomponent interventions that mobilise several support strategies and delivery modalities [44], specifically due to lower cell phone network coverage in rural and remote areas in LMICs [45].

Our scoping review identified six studies that reported on the effects of psychosocial interventions on adolescent adherence to ART and retention in care. Despite the growing recognition of the burden of HIV and psychosocial challenges faced by YPLWH, this review indicates that there is a dearth of evidence on psychosocial support interventions aimed at YPLWH. Other authors have shared the same sentiments [46, 47]. Strasser et al. [46] state that evidence-based psychosocial support services for children are currently under-developed and under-resourced, and argue that the current state of affairs need to be addressed and improved. Petersen et al. [47] also identified the need for targeted efficacy-based mental health promotion interventions for children and adolescent HIV populations in South Africa.

Five studies in this review reported increased retention and adherence to ART among adolescents and young people following the administration of an intervention with psychosocial components [27, 28, 30-32]. A study evaluating the effects of a psychosocial intervention among PLHIV attending clinical care in Estonia reported that the intervention increased the proportion of patients that were optimally adherent [48]. Similarly, a study conducted by Tominari et al. [49] reported that the implementation of mental health services demonstrated a significant increase in retention in care among PLHIV.

Evidence suggests that ART adherence interventions need to adopt long-term and flexible approaches to effectively support adherence behaviour [44]. The study conducted by Wohl et al. [30] reported that a significant dose response trend was observed between retention in care and increasing number of hours in the intervention and increasing number of intervention appointments.

Furthermore, Wohl et al. [30] found that a time-intensive intervention delivered by a non-judgemental and culturally competent peer is effective in engaging participant in consistent ART care. These findings are supported by previous studies, which suggest that intensive interventions are required to produce effective adherence outcomes, while one-time interventions without ongoing educational support may prove inefficient [50]. According to Edwards and Barker [51], developing frameworks for understanding and describing contexts, which incorporate an adaptive approach for intervention implementation and scale-up are necessary to advance HIV/AIDS implementation research and to ensure the effectiveness of an intervention.

We learnt from the scoping review that psychosocial support interventions for YPLWH are feasible and acceptable to participants and healthcare workers. However, more empirical evidence is needed to understand the mechanisms which allow these interventions to work, to improve the availability of services and care for YPLWH. Limited information exists regarding the effectiveness of adherence interventions for YPLWH in LMICs [1]. The findings from the CATS and VUKA programme indicate that psychosocial interventions may be successfully implemented to improve YPLWH adherence to ART in resource limited settings. These findings are supported in a recent study reporting on the effectiveness of teen adherence clubs in Zimbabwe and South Africa [52].

Limitations and strengths of the review

A strength of this scoping review is our extensive and comprehensive database search that encompasses global peer reviewed papers with a narrative reporting approach. All questions related to inclusion/exclusion of a study were discussed with the investigating team. We observed significant heterogeneity in measurements and definition of optimal adherence and inclusion criteria for participants in the different studies.

The limitation of this scoping review and inference of results is limited by the quality of the individual papers underlying the process. For example, many of the papers included had small sample size. Further limitation to this scoping review is the exclusion of interventions that may have been evaluated using qualitative methods such as those conducted by Dorothy et al. [53], Donenberg et al. [54] and Mahvu et al. [55]. In addition, we only focused on English publications and those published before 2005 introducing the potential to have excluded studies that might have otherwise met these inclusion criteria. Our focus in the last 15 years was meant to capture the most recent evidence because so much has changed in the HIV/AIDS treatment and care protocol since its inception. Capturing the last 15 years would provide more relevant evidence regarding the most recent treatment care protocols. Furthermore, self-reported measures are fraught with bias compared to more objective measures of adherence such as viral load, antiretroviral drug levels and pill counts. Lastly, in this review we did not differentiate the impact of behavioural patterns as a result of the intervention offered. For example, exploring the behavioural patterns between newly acquired HIV vs perinatal HIV. As well as, the different age groups 10-19 years and 20-24 years as these age groups' psychosocial needs are different.

Conclusion

Individual and group counselling including family-centered group counselling and the use of adolescent peer support were distinctive treatment modalities when focusing on improving ART adherence, linkage to care and/or retention in care. However, this review found only six studies that evaluated psychosocial support interventions suggesting that there is dearth of evidence on psychosocial support interventions to improve adherence and retention in ART care amongst young people living with HIV. Where studies exist; methodological quality, target population, and sample size are limited. Future research and programming should seek to address psychosocial support interventions or approaches specifically designed to address the needs of adolescents and young adults living with HIV.

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Paper 2: Determinants of viral suppression among adolescents on antiretroviral treatment in Ehlanzeni district, South Africa: a cross-sectional analysis

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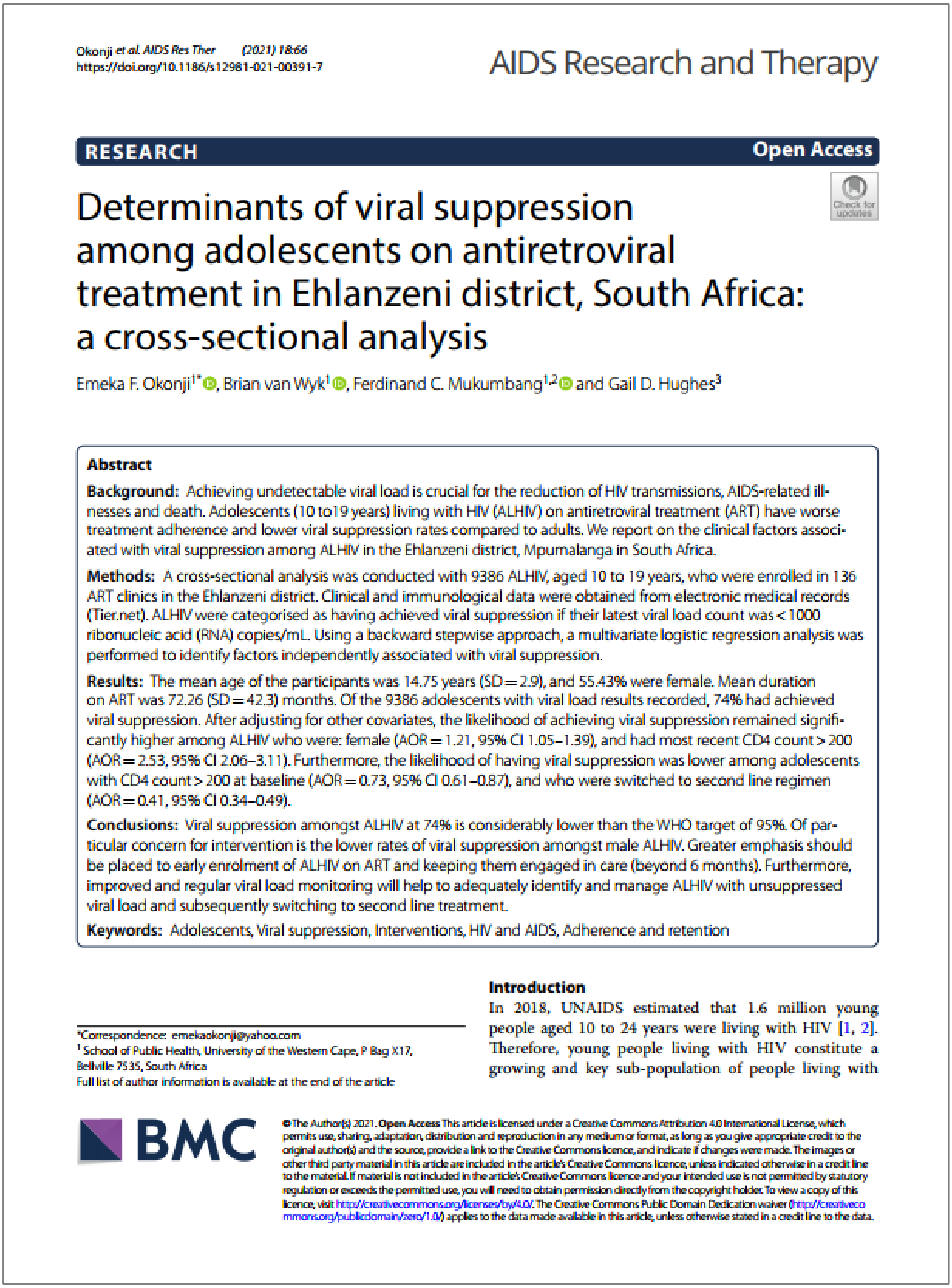
Introduction: The cross-sectional quantitative analysis of anonymized patients' electronic medical records (Tier.net) describes the viral suppression rate (i.e., <1000 RNA copies) among ALHIV on ART. The study found that adherence rate (viral suppression) among ALHIV was 74%, which fails to meet the UNAIDS 90 90 90 target by 2020. Furthermore, viral suppression was significantly higher among female adolescents compared to males, and adolescents with most recent CD4 count >200. On the other hand, achieving viral suppression was lower for adolescents with CD4 count >200 at baseline who were switched to second line regimen. It was found that a longer duration (18 to 24 months) on ART was a risk factor for viral non-suppression. Adolescents on second-line treatment were less likely to attain viral suppression. It is possible that those on second line regimen could have a history of poor adherence behaviour that continues despite being on the 'rescue' regimen. There is also evidence that having a history of treatment failure is a risk factor for viral suppression.

The paper highlights the importance of regular viral load monitoring to adequately identify and manage ALHIV with unsuppressed viral load and subsequent timely switching to second line treatment.

Contribution of candidate: EFO and BvW designed the study. EFO analysed the data and developed the manuscript with editorial and content input from BvW, FCM, and GDH.



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AIDS Research and Therapy

RESEARCH **Open Access**

Determinants of viral suppression among adolescents on antiretroviral treatment in Ehlanzeni district, South Africa: a cross-sectional analysis

Emeka F. Okonji[1*], Brian van Wyk[1], Ferdinand C. Mukumbang[1,2] and Gail D. Hughes[3]

Abstract

Background: Achieving undetectable viral load is crucial for the reduction of HIV transmissions, AIDS-related illnesses and death. Adolescents (10 to19 years) living with HIV (ALHIV) on antiretroviral treatment (ART) have worse treatment adherence and lower viral suppression rates compared to adults. We report on the clinical factors associated with viral suppression among ALHIV in the Ehlanzeni district, Mpumalanga in South Africa.

Methods: A cross-sectional analysis was conducted with 9386 ALHIV, aged 10 to 19 years, who were enrolled in 136 ART clinics in the Ehlanzeni district. Clinical and immunological data were obtained from electronic medical records (Tier.net). ALHIV were categorised as having achieved viral suppression if their latest viral load count was < 1000 ribonucleic acid (RNA) copies/mL. Using a backward stepwise approach, a multivariate logistic regression analysis was performed to identify factors independently associated with viral suppression.

Results: The mean age of the participants was 14.75 years (SD = 2.9), and 55.43% were female. Mean duration on ART was 72.26 (SD = 42.3) months. Of the 9386 adolescents with viral load results recorded, 74% had achieved viral suppression. After adjusting for other covariates, the likelihood of achieving viral suppression remained significantly higher among ALHIV who were: female (AOR = 1.21, 95% CI 1.05–1.39), and had most recent CD4 count > 200 (AOR = 2.53, 95% CI 2.06–3.11). Furthermore, the likelihood of having viral suppression was lower among adolescents with CD4 count > 200 at baseline (AOR = 0.73, 95% CI 0.61–0.87), and who were switched to second line regimen (AOR = 0.41, 95% CI 0.34–0.49).

Conclusions: Viral suppression amongst ALHIV at 74% is considerably lower than the WHO target of 95%. Of particular concern for intervention is the lower rates of viral suppression amongst male ALHIV. Greater emphasis should be placed to early enrolment of ALHIV on ART and keeping them engaged in care (beyond 6 months). Furthermore, improved and regular viral load monitoring will help to adequately identify and manage ALHIV with unsuppressed viral load and subsequently switching to second line treatment.

Keywords: Adolescents, Viral suppression, Interventions, HIV and AIDS, Adherence and retention

Introduction

In 2018, UNAIDS estimated that 1.6 million young people aged 10 to 24 years were living with HIV [1, 2]. Therefore, young people living with HIV constitute a growing and key sub-population of people living with

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Determinants of viral suppression among adolescents on antiretroviral therapy in Ehlanzeni district, South Africa: a cross-sectional study

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Abstract

Background

Achieving undetectable viral loads is crucial for the reduction of HIV transmissions, AIDS related illnesses and death. Adolescents (10-19) living with HIV (ALHIV) on antiretroviral therapy (ART) have worse treatment adherence and lower viral suppression rates compared to adults. We report on the clinical factors associated with viral suppression among ALHIV in the Ehlanzeni district, Mpumalanga in South Africa.

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A cross-sectional study was conducted with 9,386 ALHIV, aged 10–19 years, who were enrolled in 136 ART clinics in the Ehlanzeni district. Clinical and immunological data were obtained from electronic medical records (Tier.net). ALHIV were categorized as having achieved viral suppression if their latest viral load count was < 1000 ribonucleic acid (RNA) copies/mL. Using a backward stepwise approach, a multivariate logistic regression analysis was performed to identify factors independently associated with viral suppression.

Results

The mean age of the participants was 14.75 years (SD = 2.9), and 55.43% were female. Mean duration on ART was 72.26 (SD = 42.3) months. Of the 9,386 adolescents with viral load results recorded, 74% had achieved viral suppression. After adjusting for other covariates, the likelihood of achieving viral suppression remained significantly higher among ALHIV who were: female (AOR = 1.21, 95% CI 1.05–1.39), and had CD4 count >200 at last visit (AOR = 2.53, 95% CI 2.06–3.11. Furthermore, the likelihood of having viral suppression was lower among adolescents with CD4 count >200 at baseline (AOR = 0.73, 95% CI 0.61–0.87), and who were switched to second line regimen (AOR = 0.41, 95% CI 0.34–0.49).

Conclusions

Viral suppression amongst ALHIV at 74% is considerably lower than the WHO target of 95%. Of particular concern for intervention is the lower rates of viral suppression amongst male ALHIV. Greater emphasis should be placed to early enrolment of ALHIV on ART and keeping them engaged in care (beyond 6 months). Furthermore, improved and regular viral load

monitoring will help to adequately identify and manage ALHIV with unsuppressed viral load and subsequently switching to second line treatment.

Keywords: Adolescents, viral suppression, interventions, HIV and AIDS, adherence and retention.

Introduction

In 2018, UNAIDS estimated that 1.6 million young people aged 10–24 years were living with HIV [1,2]. Therefore, young people living with HIV (YPLHIV) constitute a growing and key sub-population of people living with HIV globally. The increase in HIV prevalence amongst adolescents (10-19 years) is the result of the generation of children infected with HIV perinatally who are surviving into adolescence because of improved access to antiretroviral therapy (ART), and increased HIV incidence as a result of risky (sexual) behaviour in this age group [3,4]. Despite tremendous gains in the reduction of over-all AIDS-related deaths to the tune of 43%, AIDS-related deaths amongst adolescents in Eastern and Southern Africa have increased in the last decade [5]. This is mainly because adolescents struggle to initiate and remain engaged on antiretroviral treatment (ART) [6].

Monitoring the level of detectable viral load and achieving undetectable viral loads are crucial in the reduction of HIV transmission, earlier detection of treatment failure, and timely switching to second-line ART [7–10]. The aim of ART is to suppress the replication of the HIV thereby protecting people living with HIV from AIDS-related illnesses and death and preventing further transmission to others [3,11]. Conversely, adolescents who have poor ART adherence are at greater risk of morbidity, mortality, treatment failure, the development of drug resistant forms of HIV, viral progression, opportunistic infections, and transmission to babies and sexual partners [8,12–16].

Compared to adult populations living with HIV, adolescents living with HIV (ALHIV) have a higher likelihood of suboptimal adherence, viral load progression, lost to follow-up, morbidity and mortality [11,17,18]. This is because adolescence is accompanied by rapid physical, psychological and physiological changes, which influence health-related behaviour [19]. Therefore, monitoring the treatment outcomes for ALHIV is crucial as they become aware of their HIV status and have to navigate health care facilities and self-manage their medication adherence and retention in ART care [20]. Regrettably, there is limited information on viral outcomes of adolescents in sub-Saharan Africa where the biggest burden of deaths is experienced, because these results are masked by routine reporting for children under 14 years and adults from 15 years up only [17,19].

The aim of this study is to investigate the predictors of viral load suppression among HIV-positive adolescents (10–19 years) receiving ART in the Ehlanzeni district of South Africa. Improved reporting of virological outcomes from a wider range of settings is required to support efforts to improve HIV care and treatment for adolescents [19].

Setting

Ehlanzeni District Municipality is in Mpumalanga province, located in the Northern Eastern part covering the whole Southern part of the Kruger National Park. The district is surrounded by Mozambique in the East and Swaziland in the South. The district comprises of four sub-districts namely: Bushbuckridge, City of Mbombela, Nkomazi, and Thaba Chweu.

According to the 2017 South African National HIV prevalence, incidence, behaviour and communication survey, among people living with HIV in South Africa, Mpumalanga province has the second highest HIV prevalence with an estimated prevalence rate of 17.3%, and the lowest in viral load suppression (82.9%) [21,22]. Furthermore, the Ehlanzeni district compared to other districts has high rate of people living with HIV who know their HIV status (1st 95), 90.6%. On the contrary, ART coverage (2nd 95) remains low at 67.2%, and lowest rate of viral load suppression at 65.3% [21].

Methods

Study design and participants

A cross-sectional study involving ALHIV, aged 10–19 years, who were registered to receive ART from 136 health centres in the Ehlanzeni district between September 2002 and October 2019. On October 31, 2019, we extracted individual patient data (sociodemographic variables), clinical data and treatment outcomes (viral load result) of ALHIV who have been on ART for at least 6 months from electronic medical records (TIER.net) as part of a larger study assessing the effects of psychosocial support on adherence, treatment outcomes (viral suppression) and retention in care amongst adolescents on ART. The electronic medical records (Tier.net) only records the last viral load test done; CD4 count at baseline and last ART visit - i.e. most recent CD4 count).

ALHIV who have been on ART for less than 6 months, without viral load done, who have died, lost to follow up, and transferred/moved out were excluded from the analysis. Only ALHIV with viral load done after 6 months of ART initiation were included in the analysis (see appendix 1 for inclusion and exclusion criteria).

The primary outcome, viral suppression, was defined according to the South African National Department of Health as patients achieving a viral load < 1000 RNA copies/mL [23]. In South Africa, the first viral load test is done six months after initiation on ART. The predictor variables such as age, gender, method of entry into ART programme at the health facility, pregnant on ART, age at ART initiation, duration on ART, initiated on Isoniazid Preventive Therapy (IPT), TB history, ART regimen, CD4 count at baseline and last ART visit (most recent CD4 count), WHO stage at initiation, and initiated on ART same day as HIV diagnosis were employed in a bivariate and multivariate analysis to determine factors influencing viral suppression.

Analysis

Data were extracted from Tier.Net in Excel, and imported to STATA statistical software version 16.0 (STATA Corporation, College Station, Texas, USA) for analyses. Information on clinical stationery was reviewed against information on Tier.net. Patient clinical records identified as incomplete or not correctly captured on Tier.net was retrieved and subsequently updated on Tier.net.

Descriptive statistics were used to characterize the demographic and clinical variables (at baseline and/or three months after ART initiation). Comparisons between viral suppression and clinical parameters among adolescent living with HIV were achieved using chi-square tests for proportions (replaced by Fisher's exact test for sparse data), and bivariate logistics regression analysis to examine associations.

Furthermore, a multivariate logistic regression model was used to estimate factors associated with viral suppression adjusting for potential confounders using the following variables: age, gender, age at ART initiation, duration on ART, CD4 cell count at baseline and last visit, WHO stage at initiation, and initiated on ART same day as HIV diagnosis. The multivariate logistic regression model employed a backward stepwise analysis. In the backward selection model, we included all candidate variables in the model with $p<0.15$ in selecting the final model [24]. At each step, the variable that is the least significant is removed. This process continued until no non-significant variables remained. The significance level was set at 95% at which variables can be removed from the model. Analyses were conducted among all patients with viral load test done after 6 months of ART initiation.

Ethics approval

Ethics clearance was obtained from the University of the Western Cape Biomedical Research Ethics committee (BM19/1/8) and informed consent to use the electronic medical dataset (Tier.net) was obtained from the National Health Research Ethics committee. We adhered to the 1964 declaration of Helsinki guidelines. According to the declaration, research that involves human subjects amongst others must keep with the following (1) strive to protect life, health, privacy, and the dignity of the research participants, (2) employ greater care to protect the participants from harm and (3) conduct the research because the importance of the research purpose, outweighs the risk that might be attributed to the study either at present or in the future (18th WMA General Assembly, Helsinki, 2001).

Data extraction excluded adolescent's unique identifiers such as name, surname, patient folder number and identity number.

Results

Table 1 shows the demographic characteristics of ALHIV enrolled in the ART programme in 136 facilities in Ehlanzeni district South Africa. This study included 9,386 adolescents (aged 10 to 19 years) with mean age 14.75 years (SD=2.9); of whom 55.43% were female. Of the 9,386 ALHIV with viral load results recorded, 74.31% had achieved viral suppression. Compared to ALHIV in the age group (15 to 19 years), ALHIV (10 to 14 years) are more likely to have viral load below 1000 RNA copies/mL (p <0.001).

In terms of gender comparison, females are more likely to have viral load below 1000 RNA copies/mL (p =0.000). Most (67.88%) of the ALHIV attended the ART programme in the clinic they were initiated as new patients as opposed to transferred in from another clinic. Amongst the female ALHIV, 8.35% were reported pregnant at the time of enrolling into ART.

Table 1 Viral load suppression by demographic and clinical characteristics of adolescents 10-19 years living with HIV in Ehlanzeni district, South Africa (N = 9,386)

	Total	**Viral load**		
	9386	**Yes** **n (%)** **6975 (74.31)**	**No** **n (%)** **2411 (25.69)**	***p*-value**
Current age (in years)				0.000
10 to 14	4506 (48.01)	3455 (76.41)	1063 (23.59)	
15 to 19	4880 (51.99)	3603 (72.38)	1348 (27.62)	
Gender				0.000
Female	5158 (54.95)	3946 (76.50)	1212 (23.50)	
Male	4253 (44.57)	3029 (71.64)	1199 (28.36)	
Pregnant at ART start (N =5160)				0.001
No	4729 (91.65)	3590 (75.91)	1139 (24.09)	
Yes	431 (8.35)	357 (82.83)	74 (17.17)	
Age at ART start (in years)				0.000
0 to 9	5512 (58.73)	4116 (74.67)	1396 (25.33)	
10 to 14	2548 (27.15)	1786 (70.09)	762 (29.91)	
15 to 19	1326 (14.13)	1073 (80.92)	253 (19.08)	
Duration on ART (in months)				0.002
6 to 11 months	459 (4.89)	364 (79.30)	95 (20.70)	
12 to 17 months	450 (4.79)	332 (73.78)	118 (26.22)	
18 to 24 months	458 (4.88)	366 (79.91)	92 (20.09)	
25 months +	8019 (85.44)	5913 (73.74)	2106 (26.26)	
Initiated on Isoniazid Preventative Therapy (IPT)				0.002
Yes	2111 (22.49)	1623 (76.88)	488 (23.12)	
No	7,275 (77.51)	5352 (73.57)	1923 (26.43)	
History of TB				0.009
Yes	78 (0.87%)	48 (61.54%)	30 (38.46%)	
No	8934 (99.13%)	6659 (74.54%)	2275 (25.46%)	
CD4 count at last ART visit (n =7999)				
<200	1071 (13.39%)	608 (56.77%)	463 (43.23%)	0.000
>200	6928 (86.61%)	5284 (76.27%)	1644 (23.73%)	
CD4 count at baseline				0.006
CD4<200	1676 (28.16%)	1200 (71.60%)	476 (28.40%)	
CD4>200	4276 (71.84%)	3210 (75.07%)	1066 (24.93%)	
WHO stage at initiation				0.000
1	4067 (52.72%)	3106 (76.37%)	961 (23.63%)	
2	1873 (24.28%)	1363 (72.77%)	510 (27.23%)	
3	1527 (19.79%)	1088 (71.24%)	439 (28.75%)	
4	248 (3.21%)	176 (70.97%)	72 (29.03%)	
Initiated same day				0.145
Yes	808 (61.59%)	631 (78.09%)	177 (21.91%)	
No	504 (38.41%)	376 (74.60%)	128 (25.40%)	
Initiated on second line ART				
Yes	1550 (16.51%)	888 (57.29%)	662 (42.71%)	0.000
No	7836 (83.49%)	6087 (77.68%)	1749 (22.32%)	

Demographic and clinical history

Table 1 shows the clinical history of ALHIV enrolled in the ART programme in Ehlanzeni district South Africa. The mean age at which the adolescents started ART was 8.7 years (SD=4.8); and 85.44% were on ART for more than 25 months. ALHIV on ART for six to eleven months were more likely to attain viral suppression compared to adolescents on ART for 12 to 17 months and 25 months and above ($p=0.002$).

Only 22.49% (n=2,111) were started on Isoniazid preventative therapy (IPT) after ART initiation. Only 2.6% completed TB preventive therapy. A very small proportion (0.87%) developed TB after initiation on TB preventive therapy. ALHIV who were started on IPT after ART initiation were more likely to attain viral suppression compared to those who did not ($p=0.002$).

Regarding history of TB, 0.87 % had TB and HIV comorbidly. ALHIV with a history of TB were less likely to have viral load <1000 RNA copies/mL ($p=0.009$).

Compared to ALHIV with CD4 count >200, ALHIV with CD4 count <200 were less likely to have viral load <1000 RNA copies/mL ($p<0.001$). This is true for CD4 count at baseline and CD4 count at last visit or most recent CD4 count.

Slightly more than half (52.72%) of the ALHIV were initiated on ART at WHO stage 1. Compared to ALHIV with WHO stage 1, 2, and 3 at ART initiation, ALHIV with WHO stage 4 were less likely to have viral load <1000 RNA copies/mL ($p<0.001$).

Most (61.59%) of the ALHIV were initiated on ART on the same day of HIV diagnosis. However, there was no association between ALHIV's time of ART initiation with viral load suppression ($p=0.145$).

Only 16.51% (n=1,550) of ALHIV were switched to second line ART regimen. However, ALHIV who were switched to second line regimen were less likely to attain viral suppression ($p<0.001$).

Factors associated with suppression of viral load among adolescent living with HIV (N=9,386)

Table 2 shows the factors associated with viral suppression in a multivariate logistic regression model. After controlling for the effect of other covariates, the likelihood of attaining viral suppression remained significantly higher among female adolescents (AOR = 1.21, 95% CI 1.05–1.39), had most recent CD4 count > 200 (AOR = 2.53, 95% CI 2.06-3.11). ALHIV on second line treatment were less likely to attain viral suppression compared to their reference group (AOR = 0.41, 95% CI 0.34-0.49), followed by ALHIV who had been on ART for 18 to 24 months (AOR = 0.37, 95% CI 0.15–0.93), and ALHIV with CD4 count >200 at baseline (AOR = 0.73, 95% CI 0.61-0.87).

Table 2 Multivariate logistic regression analysis of factors associated with viral suppression among adolescents living with HIV in Ehlanzeni district South Africa (N=9,386)

	Crude OR	95% CI	Adjusted OR	95% CI
Age				
10 to 14	1*	0.74–0.89	1	
15 to 19	0.81		0.92	0.78–1.09
Gender				
Male	1*	1.17–1.41	1*	
Female	1.29		1.21	1.05–1.39
Method into ART at facility				
Transferred in from another facility	1			
New ART patient	0.94	0.85–1.04		
Started IPT				
No	1*		1	
Yes	1.19	1.01–1.25	1.04	0.89–1.23
History of TB				
No	1*		1	
Yes	0.55	0.35–0.86	0.73	0.37–1.26
WHO stage				
Stage 1	1*		1	
Stage 2	0.83	0.73–0.94	0.88	0.75–1.04
Stage 3	0.77	0.67–0.91	0.86	0.72–1.03
Stage 4	0.76	0.57–1.00	0.85	0.57–1.26
ART initiation on same day				
No	1			
Yes	1.21	0.93–1.57		
Duration on ART				
6 to 11 months	1*		1*	
12 to 17 months	0.73	0.54–0.99	0.62	0.25–1.55
18 to 24 months	1.04	0.75–1.43	0.37	0.15–0.93
25 months +	0.73	0.58-0.92	0.60	0.22–1.28
Age at art start				
0 to 9 years	1*		1	
10 to 14 years	0.79	0.72–0.87	0.88	0.74–1.04
15 to 19 years	1.44	1.24–1.67	1.30	0.97–1.75
Pregnant during ART start				
No	1*			
Yes	1.53	1.18–1.98		
CD4 count at last visit				
CD4<200	1*		1*	
CD4>200	2.45	2.14–2.79	2.53	2.06–3.11
CD4 count at baseline				
CD4<200	1*		1*	
CD4>200	1.19	1.05–1.36	0.73	0.61–0.87
Second line				
No	1*		1*	
Yes	0.38	0.34–0.43	0.41	0.34–0.49

* p-value statistically significant at 5%

Discussion

In this study, we set out to investigate the predictors of viral load suppression among ALHIV receiving ART in the Ehlanzeni district of South Africa. The proportion of ALHIV with viral suppression after six months of ART initiation was relatively high at 74.31% compared to another study conducted in South Africa [20], but falls short of the global target of 95%. Furthermore, our study revealed that being female, and having most recent CD4 count level >200 were associated with viral suppression. On the other hand, being on ART for more than six months, as well as being on second line treatment are enhancing factors for viral non-suppression.

Evidence on the relationship between gender and viral load suppression is mixed. While one study showed that males were more likely to achieve viral load suppression compared to females [20], another study found that males are more likely to achieve viral non suppression [25]. However, we found that females were more likely to attain viral suppression compared to males. Adherence among males ALHIV is poor compared to females; males have poor treatment seeking behaviours [25] and as such to get males to test for HIV, link and retain them to ART care remains a challenge [26]. The poor treatment outcome reported among males have been attributed to strong gender norms and practices specifically the perception of masculinity inherent within societies in South Africa. In addition, lack of male-friendly services inhibits males from seeking health care services [26–28].

The literature indicates that older age group or adults can achieve viral suppression because they are able to successfully take their ART medication regularly without supervision i.e. possess self-efficacy and self-competency on ART adherence [9]. Interestingly, our study did not show any significant difference between viral suppression among adolescents in the age group 10-14 years and 15-19 years. This is likely because if no support is provided, adolescents (10-19 years) are faced with psychosocial challenges, lack self-efficacy and self-esteem, and are unable to self-manage themselves with regard to medication adherence [29]. However, a retrospective study conducted among adolescents registered in the Cape Metropole ART clinic in South Africa found younger adolescents (10-14 years) were more likely to achieve viral suppression compared to older adolescents (15-19 years). It was reported that the older adolescents face adherence challenges as a result of transitioning from adolescence to adulthood in which they are expected to self-manage themselves with regard to medication adherence [20].

We also found that longer duration (18 to 24 months) on ART was a risk factor for viral non-suppression. This is contrary with evidence that patients on ART for shorter period are more likely to experience virological failure [9]. Our study findings is interesting given that patients who have been on treatment longer have more experience in managing their treatment [9]. Similar findings were reported in a study, which reported that adolescents who had been on ART between 6 and 12 months were more likely to have viral non-suppression (viral load > 400 RNA copies/mL) compared with those who had been on treatment for longer [9].

Immunological treatment failure refers to a CD4 cell count of <100 cells/μL after 6 months of therapy [9]. According to the WHO guidelines, a decreasing CD4 cell count is considered a proxy marker for treatment failure when viral load monitoring is not available, and should trigger a switch in ART, particularly if the CD4 cell count is <200 cells/μL [9]. Although the relationship between viral non-suppression and immunological responses, is not always consistent [9], our study found that adolescents with CD4 cell count >200 cells/μL at last ART visit were more likely to achieve virological suppression. However, the ability of CD4 counts to predict virologic failure is poor [11].

Studies have shown that delayed detection of treatment failure may increase drug toxicity, which in turn lead to the accumulation of drug resistance-associated mutations, hence may result in increased morbidity and mortality [30]. On the contrary, a timely switching to second-line ART after virological failure along with enhanced adherence counselling is a protective factor against viral progression and mortality [10]. However, we included ALHIV who were already initiated on second line ART to determine whether second-line ART would be a successful ‘rescue’ for viral suppression. Our findings showed that adolescents on second-line treatment were less likely to attain viral suppression. It is possible that those on second line regimen could have a history of poor adherence behaviour that continues in spite of being on the ‘rescue’ regimen. There is also evidence that having a history of treatment failure is a risk factor for viral suppression [17]. Furthermore, second-line regimens are more complex than first-line regimens, are often twice daily regimens and have more adverse side effect than first-line regimens hence impacting negatively on adherence. Unfortunately, assessing HIV resistance among HIV naïve patients is challenged by cost and volume of HIV positive patients in South Africa.

Findings implications

Several implications arise from our findings. First, to achieve the 95% global target by 2030, there is a need to design an intervention (i.e. psychosocial support) aimed at ALHIV to improve self-efficacy and self-competency so that they are able to adhere to their ART medication. Adopting a combination of multiple approaches including psychosocial support intervention may be necessary to improve adherence. For instance, providing social support and focusing on psychosocial needs of adolescents to bolster their self-esteem and self-efficacy will in turn improve their self-management regarding medication adherence and subsequently improve their treatment outcomes.

Timely and accurate identification of virological failure is crucial to avoid misclassification of non-suppression leading to switching to a second-line or third-line which are costly and can lead to viral non suppression. It is recommended that second line regimens especially for ALHIV are simplified and changed to once daily, and less toxic regimens which could improve adherence and in turn lead to viral load suppression. Furthermore, providing enhanced adherence counselling for ALHIV who are males, on second line regimen and being on ART for more than 18 months is very crucial.

Study limitations

This study has several limitations, which should be taken into account when interpreting the findings. Firstly, adolescents who are eligible for viral load assessment but failed to have it done because they were lost to follow-up, died or transferred out, were not included, which could have resulted in overestimating the rate of viral load suppression. Secondly, as is the case for all cross-sectional studies, it is subject to other risk or confounding factors that may be present but were not measured. For example, household income status, head of household, type of social support and psychosocial well-being. Thirdly, as is the case for routine programme data which is exposed to data quality issues. We were not able to delineate which clients had low CD4 because they were early in treatment and been allowed to have a drop in CD4 before initiation, and those that had been doing well and now had a drop in CD4. Similarly, the type of ART regimen used for first- and second-line treatment were excluded from analysis due to poor data capturing. Lastly, the electronic medical record (Tier.net) only captures the last viral load test done, as a result, we are not able to measure two consecutive viral load test three months apart for those with VL>50 cp/ml making it impossible to explain what is going on for those who are not undetectable as recommended by World Health Organisation.

Conclusion

Viral suppression amongst adolescents at 74% is considerably lower than the WHO target of 95%. Of particular concern for intervention is the lower rates of viral suppression amongst male adolescents. Greater emphasis should be placed to enrol adolescents on ART earlier and keeping them engaged in care (beyond 6 months). Furthermore, improved and regular viral load monitoring will help to adequately identify and manage ALHIV with unsuppressed viral load and subsequently switching to second line treatment.

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Paper 3: Two-year retention in care for adolescents on antiretroviral therapy in Ehlanzeni District, South Africa: a baseline cohort analysis

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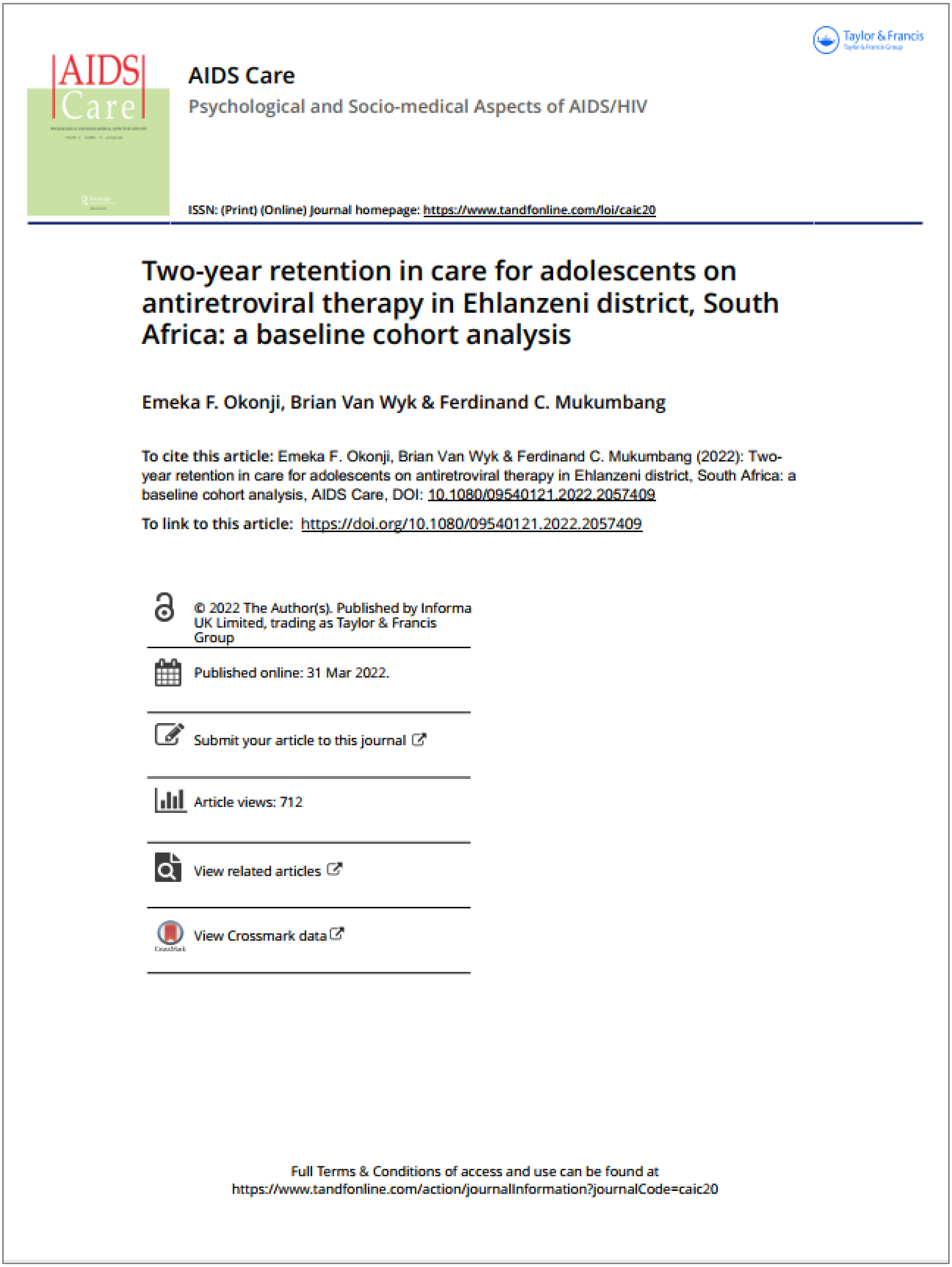
Introduction: Using individual anonymised electronic medical records, the cohort analysis describes the retention in care rate over a two-year period and its associated factors among ALHIV on ART. Retention in care rates among ALHIV were 90.5%, 85.4%, 80.8% and 76.2% at 6, 12, 18 and 24 months respectively. Although ALHIV in Ehlanzeni achieved the UNAIDS' 90-90-90 target for 2020, their retention in care declined sharply from 90% at 6 months to 85% at 12 months. Furthermore, the findings show that the risk of dying or lost to follow-up increased for female adolescents compared to males, females who began ART during adolescence (10 to 19 years of age) or pregnancy or who had a history of tuberculosis. In addition, the risk of ALHIV dying or becoming lost to follow-up increased for adolescents newly initiated on ART compared to those previously initiated on ART. Similarly, ALHIV who were diagnosed with TB were more likely to die or become lost-to-follow-up compared to ALHIV without TB disease.

The paper highlights that family or caregivers and peer support groups centred interventions designed to promote early initiation and retention in care through early case identification are needed.

Contribution of candidate: EFO and BvW designed the study. EFO analysed the data and developed the manuscript with editorial and content input from BvW and FCM.



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Two-year retention in care for adolescents on antiretroviral therapy in Ehlanzeni district, South Africa: a baseline cohort analysis

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Abstract

Adolescents living with HIV (ALHIV) struggle to remain engaged in and adhere to antiretroviral treatment (ART) due to a myriad of physical, psychological and cognitive-developmental challenges. We report on the profile of ALHIV aged 10-19 years on ART and the clinical factors associated with retention in care.

A retrospective cohort analysis was conducted with 16,108 ALHIV, aged 10–19 years, who were enrolled in 136 ART clinics in the Ehlanzeni district. Anonymised data were obtained from electronic medical records (Tier.net). Trends in retention in care among adolescents on ART was described using Kaplan-Meier survival estimates. Cox proportional analysis was performed to identify factors associated with retention in care over 2 years.

More than half (53%) were females, and median duration on ART was 8 months. Retention in care among adolescents at months 6, 12, 18 and 24 was 90.5%, 85.4%, 80.8% and 76.2%, respectively. After controlling for confounders, risk of dying or lost to follow up increased for female adolescents (aHR=1.28, 95% CI 1.10-1.49); being initiated on ART while pregnant (aHR=2.72, 95% CI 1.99-3.69); history of TB infection (aHR=1.71, 95% CI 1.10-2.65); and started ART at age 10-14 years (aHR=2.45, 95% CI 1.96-3.05), and 15-19 years (aHR=9.67, 95% CI 7.25-12.89).

Retention in care among adolescents on ART over two-year period was considerably lower than the UNAIDS 2030 target of 95%. Of particular concern for intervention is the lower rates of retention in care among females and pregnant adolescents and starting ART between the ages of 10 and 19 years. Family or caregivers and peer support groups centred interventions designed to promote early initiation and retention in care through early case identification, quality clinical and psychosocial support, as they transition from adolescent to adult ART care.

Keywords: Adolescents, interventions, HIV and AIDS, adherence and retention.

Introduction

In 2018, an estimated 1.8 million adolescents (aged 10 to 19 years) were living with HIV (ALHIV) globally (Enane et al., 2018; MacPherson et al., 2015; Mark et al., 2017), of which 61.1% reside in Eastern and Southern Africa (Enane et al., 2018). Adolescents are the fastest growing age group of people living with HIV (PLHIV) (Naidoo, Munsami, & Archary, 2015), representing about 90% of those living with HIV in sub-Saharan Africa (Gittings et al., 2016). While the incidence of HIV amongst adults and children younger than 10 years has declined in the last decade, the HIV incidence amongst adolescents between the ages of 10 and 19 years has increased within the same period (Enane et al., 2018; Slogrove, Mahy, Armstrong, & Davies, 2017). The increase in HIV amongst adolescents is attributed to a generation of children infected with HIV prenatally who are surviving into adolescence, and increased incidence resulting from risky (sexual) behaviour (Enane et al., 2018).

To combat the increasing incidence of HIV and reduce AIDS-related mortality, UNAIDS in 2014 set an ambitious 95-95-95 target. The aim of the 95-95-95 target is end the AIDS epidemic by 2030 by achieving 95% of all PLHIV know their status; 95% of all diagnosed HIV positive on antiretroviral therapy (ART); and 95% of all those on treatment virally suppressed (UNAIDS, 2014). In August 2017, the South African National Department of Health (NDoH) rolled out the universal test and treat (UTT) campaign that aimed to make ART available to all PLHIV, regardless of their CD4 count, and with an emphasis on providing same-day initiation (SDI) subject to clinical and psychological readiness (Lilian, Rees, Mcintyre, Struthers, & Petersid, 2020). Despite tremendous gains made by the South African government in the implementation of UTT, adherence and retention in care among adolescents (10 to 19 years) remain poor (Kusemererwa et al., 2021). Therefore, AIDS-related deaths among ALHIV have increased compared to decreases among adults and children under 10 years (Ajayi, Otukpa, Mwoka, Kabiru, & Ushie, 2021; Enane et al., 2018; Gittings et al., 2016; Nachega, Mills, & Schechter, 2010). Adolescents experience a myriad of physical, psychological and cognitive developmental changes at this stage in life, which challenge adherence to ART and remaining engaged in care. (Busza, Dauya, Bandason, Mujuru, & Ferrand, 2014; Hudelson & Cluver, 2015; Shroufi et al., 2013).

The World Health Organization (WHO) describes "retention in HIV care" as the continuous engagement from diagnosis in a package of prevention, treatment, support and care services (World Health Organization, 2011). Several studies reported on retention in care rates at 6 and 12 months among young adults (15-24 years) (World Health Organization, 2011), but there is a dearth of information on retention among adolescents (10-19 years) due to the challenges of accessing data and inherent ethical concerns among this age group (Murray et al., 2017). The current paper reports on the retention in care rate and the factors associated among adolescents (10–19 years) receiving ART in the Ehlanzeni district of South Africa based on routine clinical electronic data.

Methods

Study design and participants

We conducted a retrospective cohort analysis of ALHIV (10–19 years) registered to receive ART from 136 clinics in the Ehlanzeni district between September 2002 and October 2017. A total of 16,108 adolescents met our inclusion criteria. Anonymised individual patient demographic (i.e. gender and age), clinical and treatment outcome (viral load results after 3 months of ART initiation) data were extracted from electronic medical records (Tier.net). The current analysis provide a baseline to the larger study that aims to assess the effects of psychosocial support on adherence, treatment outcomes (viral suppression) and retention in care over 2 years for adolescents on ART.

Data source

The electronic ART database (Tier.net) developed by the University of Cape Town's Centre for Infectious Disease Epidemiology and Research, is used by the South African health facilities to store patients' routine clinical records electronically, and specifically for monitoring and management of ART patients.

Data collection

Anonymised patient data from 136 healthcare facilities were extracted from Tier.net in an excel format and subsequently imported into STATA statistical software. We searched for the relevant information from the Tier.net platform. Where information was missing, we accessed the patient's folder to confirm the availability of the required information**.** The intensive data collection approach employed enabled the extraction of participants' records from all included facilities where they may have received care, including undocumented silent transfers to a new facility.

The primary outcome was "retention in ART" at months 6, 12, 18 and 24 post HIV diagnosis and receiving a package of treatment, care and support services. The predictor variables were age, gender, method of entry into ART programme at the health facility, being on ART during pregnancy, age at ART initiation, duration on ART, initiated on Isoniazid Preventive Therapy (IPT), TB history, ART regimen, CD4 count at baseline and last ART visit, WHO stage at initiation, and same day ART initiation.

Analysis

Data were imported to STATA statistical software version 16.0 (STATA Corporation, College Station, Texas, USA) for analyses. Descriptive statistics were used to characterise the demographic and clinical profile of adolescents at baseline and/or specific time points after ART initiation. Comparisons between retention in care at months 6, 12, 18 and 24 and clinical parameters among ALHIV were measured using chi-square tests for proportions (replaced by Fisher's exact test for sparse data), and Cox regression analysis adjusted for potential confounders and interactions. The Cox proportional hazard model employed a backward stepwise analysis, where we included all candidate variables in the initial model. At each step, the variable that is the least significant was removed; until no non-significant variables remained. The significance level was set at 95% at which variables can be removed from the model.

Survival analysis was assessed with ‘died’ and ‘lost to follow-up’ (LTFU) as the outcomes of interest, transferred out patients were treated as intention to treat (censored). We did a comparative survival analysis for the age and sex of the study participants using Kaplan-Meier survival descriptor. We reported the hazard ratios and p-values. An ALHIV was considered LTFU if no contact with healthcare provider was registered 90 days after their last facility ART visit. The patient record is then updated on Tier.net as LTFU and the date record was updated given as LTFU date. Therefore, by using the intention-to-treat population in this study, the retention in care definition was the proportion of HIV-infected adolescents alive and on ART at months 6, 12, 18, and 24 in the study sample. Using bivariate and multivariate analyses, we determined factors influencing retention in care at months 6, 12, 18, and 24.

Results

Table 1 shows the demographic characteristics and clinical history of 16,108 ALHIV enrolled in the ART programme in 136 facilities in Ehlanzeni district South Africa between October 2022 and October 2017. The median duration on ART was eight months (median was reported because the variable is not normally distributed). Retention in care rates at 6, 12, 18, and 24 months were 90.5%, 85.4%, 80.8% and 76.2%, respectively.

Table 1 Retention in Care at 6, 12, 18 and 24 months by demographic characteristics and clinical outcomes of 16,108 adolescents on ART in Ehlanzeni district, South Africa, 2019

		Retained in care			
Month	Total	6	12	18	24
Overall	16,108 (%)	14,567 (90.48)	13,746 (85.38)	13,011 (80.81)	12,274 (76.24)
Age (current)*					
10–14 years	7,745 (48.11)	7,092 (91.57)	6,729 (86.88)	6,401 (82.65)	6,050 (78.11)
15–19 years	8,355 (51.89)	7,475 (89.47)	7,017 (83.99)	6,610 (79.11)	6,224 (74.49)
Gender*					
Female	8,542 (53.06)	7,605 (89.03)	7,153 (83.74)	6,276 (83.04)	6,320 (73.99)
Male	7,558 (46.94)	6,962 (92.11)	6,593 (87.23)	6,735 (78.85)	5,954 (78.78)
Method into ART*					
New	11,295 (70.19)	9,809 (86.84)	9,037 (80.01)	8,380 (74.19)	7,740 (68.53)
Previously on ART	4,796 (29.81)	4,752 (99.08)	4,703 (98.06)	4,625 (96.43)	4,529 (94.43)
Initiated on ART during pregnancy*					
No	7,762 (93.54)	7,047 (90.79)	6,699 (86.31)	6,339 (81.67)	5,994 (77.22)
Yes	536 (6.46)	348 (64.93)	273 (50.93)	236 (44.03)	190 (35.45)
Age at ART start (in years)*					
0–9	10,798 (67.07)	10,024 (92.83)	9,559 (88.53)	9,120 (84.46)	8,711 (80.67)
10–14	3,900 (24.23)	3,523 (90.33)	3,332 (85.44)	3,143 (80.59)	2,942 (75.44)
15–19	1,401 (8.70)	1,019 (72.73)	854 (60.96)	747 (53.32)	620 (44.25)
Initiated on Isoniazid Preventative Therapy (IPT)					
No	13,954 (86.67)	12,628 (90.50)	11,905 (85.32)	11,261 (80.70)	10,613 (69.23)
Yes	2,146 (13.33)	1,939 (90.35)	1,841 (85.79)	1,750 (81.55)	1,661 (37.01)
History of TB*					
No	12,296 (98.09)	11,513 (93.63)	11,108 (90.34)	10,746 (87.39)	10,333 (84.04)
Yes	239 (1.91)	160 (66.95)	144 (60.25)	131 (54.81)	118 (49.37)
CD4 count at baseline*					
CD4 below 200	3,264 (32.57)	2,881 (88.27)	2,702 (82.78)	2,515 (77.05)	2,328 (71.32)
CD4 above 200	6,759 (67.43)	6,194 (91.64)	5,810 (85.96)	5,496 (81.31)	5,211 (77.10)
CD4 count at last visit*					
CD4 below 200	2,226 (17.43)	1,871 (84.05)	1,734 (77.90)	1,609 (72.28)	1,486 (66.76)
CD4 above 200	10,546 (82.57)	10,016 (94.97)	9,583 (90.87)	9,158 (86.82)	8,722 (82.70)
WHO Stage at initiation*					
1	5,471 (45.66)	4,916 (89.86)	4,655 (85.08)	4,444 (81.23)	4,176 (76.33)
2	3,113 (25.98)	2,878 (92.45)	2,745 (88.18)	2,608 (83.78)	2,473 (79.44)
3	2,872 (23.97)	2,574 (89.62)	2,444 (85.10)	2,324 (80.92)	2,218 (77.23)
4	525 (4.38)	465 (88.57)	438 (83.43)	425 (80.95)	402 (76.57)
Initiated same day					
No	15,907 (99.03)	14,400 (90.53)	13,589 (85.43)	12,866 (80.88)	12,149 (76.38)
Yes	156 (0.97)	136 (87.18)	128 (82.05)	117 (75.00)	102 (65.38)
Second line regimen*					
No	14,113 (87.66)	12,598 (89.27)	11,790 (83.54)	11,068 (78.42)	10,362 (58.40)
Yes	1,987 (12.34)	1,969 (99.09)	1,956 (98.44)	1,943 (97.79)	1,912 (92.06)
Viral suppression (<1000)*					
No	4,113 (30.85)	3,919 (95.28)	3,774 (91.76)	3,610 (87.77)	3,432 (83.44)
Yes	9,220 (69.15)	9,167 (99.43)	8,897 (96.50)	8,561 (92.85)	8,172 (88.63)

Figure 1 shows the Kaplan-Meier survival estimate for retention in care among adolescents living with HIV in Ehlanzeni district Mpumalanga.

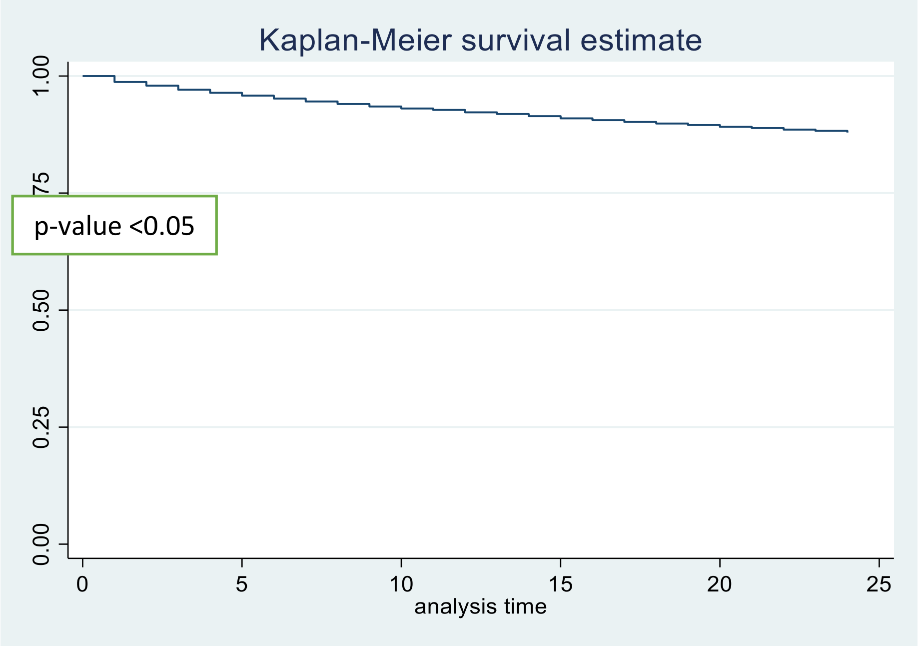


Figure 1 Kaplan-Meier survival estimates for retention among adolescent over 2 years period

Compared to older adolescents (15-19 years), younger adolescents (10-14 years) were more likely to be retained in care at 6 months (91.6% vs 89.5%), 12 months (86.9% vs 83.9%), 18 months (82.6% vs 79.1%), and 24 months (78.1% vs 74.5%). Figure 2 shows the Kaplan-Meier survival estimates for retention among younger adolescent (10-14 years) compared to older adolescents (15-19 years) over 2 years' period.

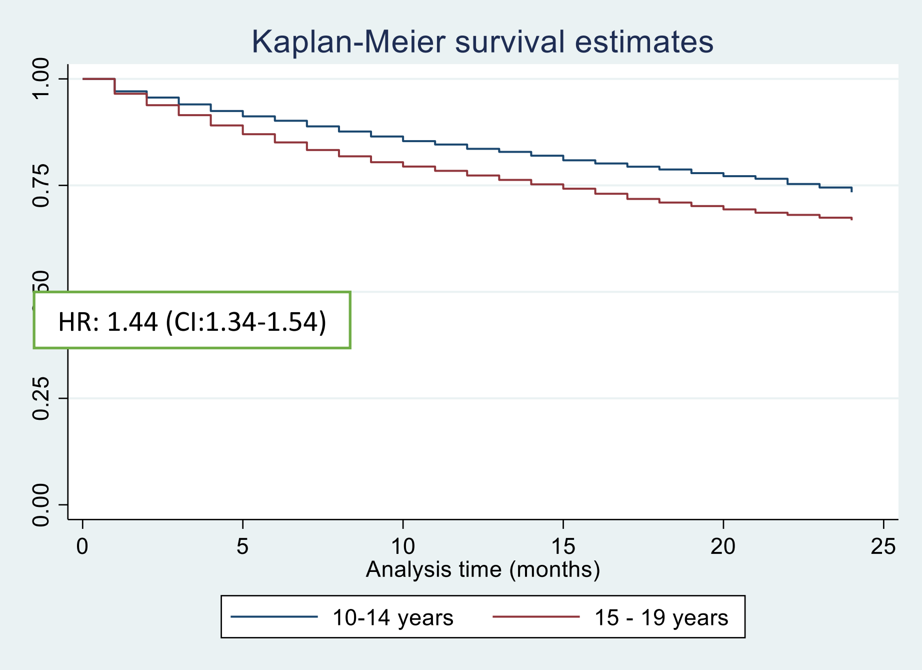


Figure 2 Kaplan-Meier survival estimates for retention among younger adolescent (10-14 years) compared to older adolescents (15-19 years) over 2 years period

In terms of gender comparison males were more likely to be retained in care compared to females at 6 months (92.1% vs 89.0%), 12 months (87.2% vs 83.7%), 18 months (83.0% vs 78.9%), and 24 months (78.8% vs 73.9%). Figure 3 shows the Kaplan-Meier survival estimate for retention in care among adolescent males compared to females over 2-years' period.

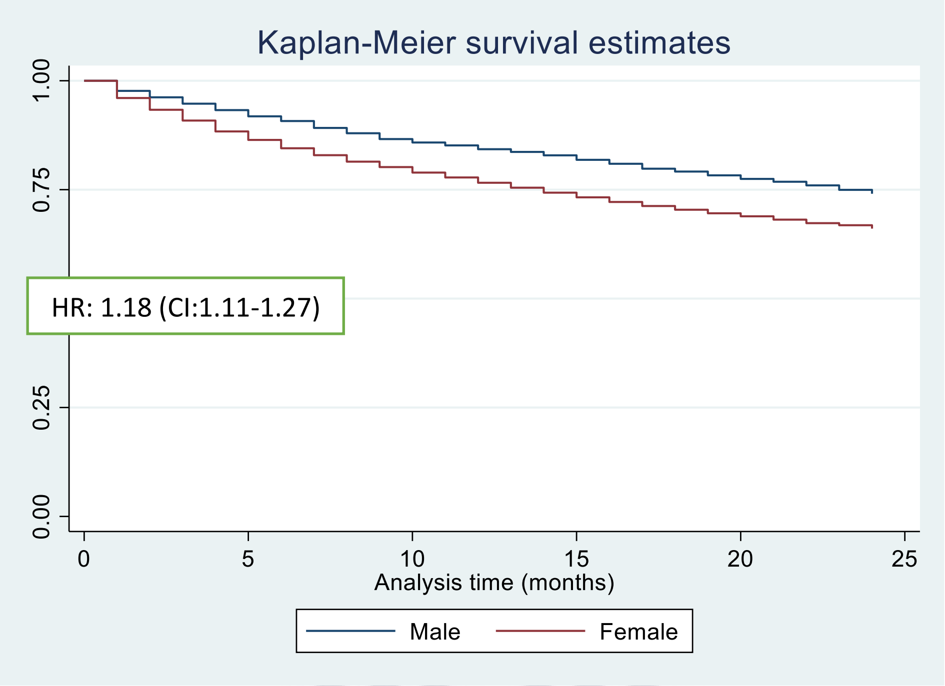


Figure 3 Kaplan-Meier survival estimates for retention among adolescent males compared to females over a 2-year period

Most (70.2%) of the adolescents attended the ART programme in the clinic they were initiated as new patients as opposed to transferred in from another clinic. Adolescents with previous ART experience were more likely to remain in care compared to ART naïve adolescents at 6 months (99.1% vs 86.4%), 12 months (98.1% vs 80.0%), 18 months (96.4% vs 74.2%), and 24 months (94.4% vs 68.5%; *p*=0.000).

Amongst the female adolescents, 6.5% were reported pregnant at the time of enrolling into ART. Compared to pregnant adolescent girls, non-pregnant adolescents are more likely to remain in care at 6 months (90.8% vs 64.9%), 12 months (86.3% vs 50.9%), 18 months (81.7% vs 44.0%), and 24 months (77.2% vs 35.5%; *p*=0.000).

Most (67.1%) of the adolescents were initiated on ART between 0-9 years. Compared to adolescents who initiated on ART at 10-14 years and 15 to 19 years, adolescents who initiated on ART at age 0-9 years are more likely to be retained in care at 6 months (92.8% vs 90.3% vs 72.7%), 12 months (88.5% vs 85.4% vs 60.9%), 18 months (84.5% vs 80.6% vs 53.3%), and 24 months (80.7% vs 75.4% vs 44.3%; *p*=0.000).

Adolescents with a history of TB were less likely to be retained in care at 6 months (66.9% vs 93.6%), 12 months (60.3% vs 90.3%), 18 months (54.8% vs 87.4%), and 24 months (49.4% vs 84.0%; *p*=0.000).

Compared to adolescents with CD4 count >200 at baseline, adolescents with CD4 count <200 at baseline were less likely to remain in care at 6 months (88.3% vs 91.6%); 12 months (82.8% vs 85.9%); 18 months (77.1% vs 81.3%); and 24 months (71.3% vs 77.1%; *p*=0.000). Similarly, adolescents with CD4 count >200 at last visit were more likely to remain in care at 6 months (94.9% vs 84.1%); 12 months (90.9% vs 77.9%); 18 months (86.8% vs 72.3%); and 24 months (77.1% vs 71.3%; *p*=0.000).

Nearly half (45.7%) of the adolescents were initiated on ART at WHO stage 1. Compared to adolescents with WHO stage 2, 3, and 4, adolescents with WHO stage 1 were less likely to retain in care at 6, 12, 18 and 24 months (*p*=0.000). Similarly, adolescents with WHO stage 4 were more likely to remain in care at 18 and 24 months (*p*=0.000).

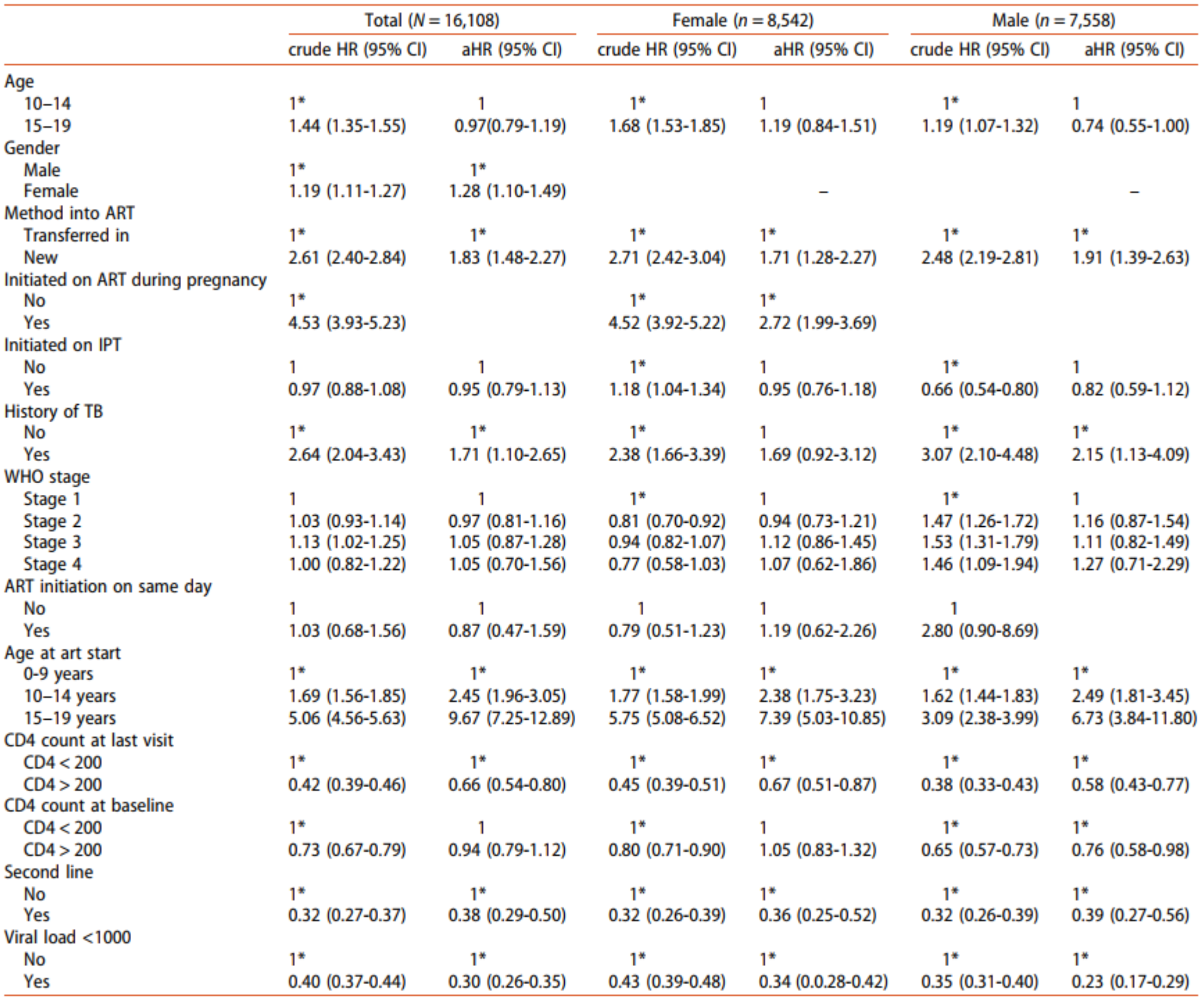
Only 12.3% of the adolescents were on second line regimen. Adolescents on second-line regimen were more likely to be retained in ART care at 6 months (99.1% vs 89.3%); 12 months (98.4% vs 83.5%); 18 months (97.8% vs 78.4%); and 24 months (92.1% vs 58.4%).

More than two-third (69.2%) of the adolescents achieved a viral suppression of <1000 RNA copies/mL. Adolescents with viral load <1000 RNA copies/mL were more likely to remain in care at 6 months (99.4% vs 95.3%); 12 months (96.5% vs 91.8%); 18 months (92.9% vs 87.8%); and 24 months (88.6% vs 83.4%).

Factors associated with retention in care among adolescent living with HIV

Table 2 shows the Cox proportional hazard analysis to understand risk factors for retention in care. After controlling for the effect of cofounders, the risk of dropping out of ART care increased for female adolescents (aHR=1.28, 95% CI 1.10-1.49); new naive ART adolescents (aHR=1.83, 95% CI 1.48-2.27); initiated on ART during pregnancy (aHR=2.72, 95% CI 1.99-3.69); had a history of TB (aHR=1.71, 95% CI 1.10-2.65); age at ART start 10-14 years (aHR=2.45, 95% CI 1.96-3.05), and 15-19 years (aHR=9.67, 95% CI 7.25-12.89).

Table 2 Cox Proportional Hazard analysis of factors associated with retention in care over 24 months among adolescents on ART in Ehlanzeni district, South Africa (N=16,108)



	Total (*N* = 16,108)		Female (*n* = 8,542)		Male (*n* = 7,558)	
	crude HR (95% CI)	aHR (95% CI)	crude HR (95% CI)	aHR (95% CI)	crude HR (95% CI)	aHR (95% CI)
Age						
10–14	1*	1	1*	1	1*	1
15–19	1.44 (1.35-1.55)	0.97(0.79-1.19)	1.68 (1.53-1.85)	1.19 (0.84-1.51)	1.19 (1.07-1.32)	0.74 (0.55-1.00)
Gender						
Male	1*	1*				
Female	1.19 (1.11-1.27)	1.28 (1.10-1.49)		–		–
Method into ART						
Transferred in	1*	1*	1*	1*	1*	1*
New	2.61 (2.40-2.84)	1.83 (1.48-2.27)	2.71 (2.42-3.04)	1.71 (1.28-2.27)	2.48 (2.19-2.81)	1.91 (1.39-2.63)
Initiated on ART during pregnancy						
No	1*		1*	1*		
Yes	4.53 (3.93-5.23)		4.52 (3.92-5.22)	2.72 (1.99-3.69)		
Initiated on IPT						
No	1	1	1*	1	1*	1
Yes	0.97 (0.88-1.08)	0.95 (0.79-1.13)	1.18 (1.04-1.34)	0.95 (0.76-1.18)	0.66 (0.54-0.80)	0.82 (0.59-1.12)
History of TB						
No	1*	1*	1*	1	1*	1*
Yes	2.64 (2.04-3.43)	1.71 (1.10-2.65)	2.38 (1.66-3.39)	1.69 (0.92-3.12)	3.07 (2.10-4.48)	2.15 (1.13-4.09)
WHO stage						
Stage 1	1	1	1*	1	1*	1
Stage 2	1.03 (0.93-1.14)	0.97 (0.81-1.16)	0.81 (0.70-0.92)	0.94 (0.73-1.21)	1.47 (1.26-1.72)	1.16 (0.87-1.54)
Stage 3	1.13 (1.02-1.25)	1.05 (0.87-1.28)	0.94 (0.82-1.07)	1.12 (0.86-1.45)	1.53 (1.31-1.79)	1.11 (0.82-1.49)
Stage 4	1.00 (0.82-1.22)	1.05 (0.70-1.56)	0.77 (0.58-1.03)	1.07 (0.62-1.86)	1.46 (1.09-1.94)	1.27 (0.71-2.29)
ART initiation on same day						
No	1	1	1	1	1	
Yes	1.03 (0.68-1.56)	0.87 (0.47-1.59)	0.79 (0.51-1.23)	1.19 (0.62-2.26)	2.80 (0.90-8.69)	
Age at art start						
0-9 years	1*	1*	1*	1*	1*	1*
10–14 years	1.69 (1.56-1.85)	2.45 (1.96-3.05)	1.77 (1.58-1.99)	2.38 (1.75-3.23)	1.62 (1.44-1.83)	2.49 (1.81-3.45)
15–19 years	5.06 (4.56-5.63)	9.67 (7.25-12.89)	5.75 (5.08-6.52)	7.39 (5.03-10.85)	3.09 (2.38-3.99)	6.73 (3.84-11.80)
CD4 count at last visit						
CD4 < 200	1*	1*	1*	1*	1*	1*
CD4 > 200	0.42 (0.39-0.46)	0.66 (0.54-0.80)	0.45 (0.39-0.51)	0.67 (0.51-0.87)	0.38 (0.33-0.43)	0.58 (0.43-0.77)
CD4 count at baseline						
CD4 < 200	1*	1	1*	1	1*	1*
CD4 > 200	0.73 (0.67-0.79)	0.94 (0.79-1.12)	0.80 (0.71-0.90)	1.05 (0.83-1.32)	0.65 (0.57-0.73)	0.76 (0.58-0.98)
Second line						
No	1*	1*	1*	1*	1*	1*
Yes	0.32 (0.27-0.37)	0.38 (0.29-0.50)	0.32 (0.26-0.39)	0.36 (0.25-0.52)	0.32 (0.26-0.39)	0.39 (0.27-0.56)
Viral load <1000						
No	1*	1*	1*	1*	1*	1*
Yes	0.40 (0.37-0.44)	0.30 (0.26-0.35)	0.43 (0.39-0.48)	0.34 (0.0.28-0.42)	0.35 (0.31-0.40)	0.23 (0.17-0.29)

Conversely, the risk of ALHIV dropping out of ART care decreased for adolescents with CD4 count >200 at baseline (aHR=0.94, 95% CI 0.79-1.12) and CD4 count >200 at last visit (aHR=0.66, 95% CI 0.54-0.80); on second-line regimen (aHR=0.38, 95% CI 0.29-0.50); and being virally suppressed (viral load <1000 RNA copies/mL) (aHR=0.30, 95% CI 0.26-0.35) respectively. There was no significant retention in care and age; initiating on IPT; and same-day ART initiation.

Discussion

In this paper we report on the retention in care rate over a two-year period and its associated factors among ALHIV (10–19 years) receiving ART in the Ehlanzeni district of South Africa. Although the retention in care of ALHIV reported in this study over a two-year period falls short of the USAID 95-95-95 for 2030 target, there is hope that this retention in care rates can improve if urgent interventions and resources are directed to this vulnerable age group. In our study, the median duration on ART was 8 months. ALHIV in Ehlanzeni achieved the UNAIDS' 90-90-90 target for 2020. However, the retention in care at 6 months declined sharply when observed at 12 months from 90% to 85%. Another study conducted in the Cape Metropole, South Africa found even lower retention in care at 4, 12 and 24 months as 68.6%, 50.5% and 36.4%, respectively (Van Wyk et al., 2020). A study on mental health of ALHIV (13-19 years) accessing treatment and care in Johannesburg health facilities found that being HIV is a predisposing factor to developing mental health challenges, which in turn negatively impacts on retention in care (Woollett, Cluver, Bandeira, & Brahmbhatt, 2017). Therefore, interventions that improve the mental health of ALHIV should be integrated in the HIV care and treatment programmes (Okonji et al., 2020). Furthermore, a recent qualitative study found that ALHIV drop out of care when they do not understand the reason for daily medication intake as a result of not being disclosed to (Lanyon et al., 2020).

Our findings show that male ALHIV were more likely to be retained in ART care compared to females. Associations between gender and retention in care among adolescents are conflicting. While some studies report that attrition rates among males are higher compared to females (Kusemererwa et al., 2021; Mutasa-Apollo et al., 2014), the opposite association were observed in a study in the Cape Metropole in South Africa (Van Wyk et al., 2020), which is consistent with our study findings. There is growing qualitative evidence suggesting that men's disinclination to engage in HIV care is linked to masculinity - set of local beliefs and practices that capture what it means in a particular context to be a man (Chikovore et al., 2016;

Mukumbang, 2021; Nyamhanga, Muhondwa, & Shayo, 2013; Skovdal et al., 2011). In the Cape Metropole study nearly half of the female adolescents initiated on ART were pregnant, which may account for higher dropout among females compared to males. It is well documented in the literature that adolescent pregnant women are more likely to be lost-to-follow-up from ART care after giving birth (Matyanga et al., 2016; Nuwagaba-Biribonwoha et al., 2018). The syndemic of early motherhood and HIV increases the vulnerability of these adolescent mothers to disengaging from HIV care (Toska, Laurenzi, Roberts, Cluver, & Sherr, 2020).

To address pre-ART lost to follow-up, the NDoH implemented same-day initiation (SDI) - ART initiation on the same day of HIV diagnosis. While there is evidence suggesting that same-day ART initiation improves clinical outcomes including viral load suppression and retention in care at 12 months after ART initiation (Ford et al., 2017), a recent systematic review showed that same-day ART initiation is a risk factor for retention in care (Knettel et al., 2018). In this study, we found no significant relationship in retention in care among adolescents initiated on ART on the same day of HIV diagnosis compared to those who did not initiate on the same-day of receiving their HIV diagnosis. Same day initiation is influenced by the acceptability by adolescents (Lilian et al., 2020); and the absence of clinical symptoms of TB and meningitis (Ford et al., 2018; Lilian et al., 2020). Structural factors (e.g. overcrowded clinics), social factors (e.g. perceived stigma) and psychological factors (e.g. poor ART readiness) have been found to increase the risk of poor retention in care among people initiating ART on the same day (Pry et al., 2020). Adolescent and youth staff training and implementation of adolescent and youth-friendly services have been shown to facilitate engagement in care among adolescent and youth populations (Okonji et al., 2020; Ruria et al., 2017).

Our study found higher retention in care among adolescents with a CD4 count >200 at baseline and at last visit. Our finding is consistent with another study that found higher risk to lost to follow-up among adolescents with low CD4 count (Matyanga et al., 2016). Our findings revealed that adolescents with suppressed viral load were less likely to drop out of care compared to those who did not achieve viral load suppression. This finding is consistent with a study that found direct correlation between perceived improved health outcomes with retention in care (Van Wyk et al., 2020). These adolescents are likely to remain in care because they are motivated by their health status and by the association between treatment and health outcomes (Bernays, Paparini, Seeley, & Rhodes, 2017; Van Wyk et al., 2020).

Complex medications i.e. increased dosing (twice daily) and medications with adverse side effects are risk factors for adherence and subsequently retention in care (Holtzman, Brady & Yehia, 2015). Our study found higher retention in care among adolescents on second-line regimen compared to those on first line regimen. Greater emphasis on monitoring and follow up of patients who have been switched to second-line treatment requires greater attention and follow-up to remain in care.

Our study also found that the risk of dying or being lost-to-follow-up increased among adolescents who started ART between the ages of 10 and 19 years compared to 0 and 9 years. This is because older adolescents initiate on ART at a stage of advanced immunodeficiency (Enane et al., 2018; Shroufi et al., 2013). This finding is consistent with that of another study that found that older adolescents (15-19 years) were more likely to initiate late (Maskew et al., 2019). In addition, evidence suggest that significant amount of older adolescents drop out of care as they transition from adolescent ART care to adult ART care (Meloni et al., 2020).

Similarly, the risk of ALHIV dying or becoming lost to follow-up increased for adolescents newly initiated on ART compared to those previously initiated on ART. Another study showed that patients newly initiated on ART were more likely to require additional retention in care support compared to patients previously initiated on ART (Brown et al., 2016). The retention of adolescents newly diagnosed with HIV on ART care requires that the adolescent is mentally and clinically prepared and are ready to initiate on ART (Ford et al., 2018; Lilian et al., 2020).

Although TB manifestations among HIV positive children are more severe and progression to death is more rapid than in HIV-negative children (Jacobs et al., 2020; Palme, Gudetta, Bruchfeld, Muhe, & Giesecke, 2002), early detection of TB infection and disease significantly reduces mortality in children and ALHIV (Vonasek et al., 2021). We found that ALHIV who were diagnosed with TB were more likely to die or become lost-to-follow-up compared to

ALHIV without TB disease. This result is consistent with a systematic review that observed a higher case fatality rate among children with HIV receiving treatment for TB compared to those without HIV (Jenkins et al., 2017).

Study limitations

This study has a number of limitations. Firstly, as is the case for all retrospective cohort studies, it is subject to other risk or confounding factors that may be present but were not measured such as household income status, head of household, type of social support and psychosocial wellbeing. Secondly, adolescents described as lost-to-follow up in Tier.net may be under-reported due to unrecorded mortality and silent transfers. Silent transfers were treated as still in care as they do not have outcome date and ART outcome as died or lost to follow-up.

Conclusion

Retention in care among adolescents on ART over two-year period was considerably lower than the UNAIDS 2030 target of 95%. Of particular concern for intervention is the lower rates of retention in care among females and pregnant adolescents and starting ART between the ages of 10 and 19 years. Family or caregivers and peer support groups centred interventions designed to promote early initiation and retention in care through early case identification, quality clinical and psychosocial support, as they transition from adolescent to adult ART care.

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Paper 4: Applying the biopsychosocial model to unpack a psychosocial support intervention designed to improve antiretroviral treatment outcomes for adolescents in South Africa

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Introduction: This paper uses the biopsychosocial model to describe how the components of the Right to Care (RTC) psychosocial support (PSS) intervention was designed to improve adherence to ART and retention in care to improve health outcomes. The interactions between the components embedded in the PSS intervention (psychological wellbeing, coping strategies, social support, treatment literacy (self-efficacy), and disclosure) are discussed. The paper highlights that the management of ALHIV for improved ART adherence and retention requires recognising and addressing the complex biological, psychological, and social issues peculiar to this age group.

Contribution of candidate: EFO, BvW and FCM designed the study. EFO reviewed Flipster documents and developed the manuscript with editorial and content input from BvW, FCM.

Article

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Commentary

Applying the biopsychosocial model to unpack a psychosocial support intervention designed to improve antiretroviral treatment outcomes for adolescents in South Africa

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Applying the biopsychosocial model to unpack a psychosocial support intervention designed to improve antiretroviral treatment outcomes for adolescents in South Africa

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Applying the biopsychosocial model to unpack a psychosocial support intervention designed to improve antiretroviral treatment outcomes for adolescents in South Africa

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Abstract

Adolescents (10 to 19 years) living with HIV (ALHIV) experience disproportionately poor adherence to antiretroviral treatment (ART) compared to other age groups. Several barriers, including psychosocial challenges, contribute to this observation. Psychosocial support (PSS) interventions show promising results as a strategy to deal with the biological and psychosocial challenges faced by ALHIV. However, there is dearth of information on how psychosocial support interventions designed to improve treatment adherence and retention in care among ALHIV are effective. In this commentary, we used the biopsychosocial model to formulate hypotheses on how the components of a PSS intervention could improve adherence and retention in ART care. Psychological wellbeing, coping strategies, social support, self-efficacy, and disclosure are key components in the intervention designed to improve ART adherence and retention in care. The management of ALHIV for improved ART adherence and retention requires recognising and addressing the complex biological, psychological and social issues peculiar to them.

Keywords: ALHIV, Adherence, Retention, Psychosocial support intervention, Biopsychosocial model.

Introduction

In 2017, there were approximately 2.1 million adolescents (aged 10 to 19 years) living with HIV globally [1,2], of which more than 90% resided in sub-Saharan Africa [3]. While the overall incidence of HIV amongst adults and children younger than 10 years has declined, HIV incidence amongst adolescents between the ages of 10 and 19 years has increased within this same period [4]. The increase in HIV among adolescents is attributed to the generation of children infected with HIV perinatally, who are surviving into adolescence due to advancements in antiretroviral treatment (ART), and increasing risky (sexual) behaviour exposing adolescents to contracting HIV.

Taking 95% or more of prescribed ART is associated with complete viral suppression [5]. Individuals who have lower levels of adherence are at greater risk of morbidity, treatment failure, and developing of drug resistant forms of HIV [6,7], viral progression, and opportunistic infections [8], and further transmission to sexual partners [9].

Several factors have been identified as barriers to ART adherence and retention in care in the general HIV population. Among these barriers are limited access to medications owing to lack of transportation and financial constraints [10].. Food insecurity is associated with non-adherence through two mechanisms: stopping ART when food was unavailable to avoid aggravated (gastrointestinal) side effects, or because taking ART when insufficient food is available increased hunger [11]. Forgetfulness, substance abuse, drug adverse effect, perceived lack of social support, health illiteracy, mental health issues such as depression, self-stigma [7,12,13], and advanced HIV status [14] constitute barriers to ART adherence. Other psychosocial risk factors for poor ART adherence, include being orphaned, changes of guardianship [15], and perception about ART [16].

ART adherence across all populations is highly dependent on complex relationships between the individuals, their families, society and other treatment factors [17]. In addition to the factors affecting ART adherence across all populations, adolescents face additional challenges to adhere to HIV treatment, such as reliance on adults. The ability of ALHIV to successfully transition from reliance on adults to self-managing adherence to medication and attending regular clinic visit clinics is complicated. [18]. Many ALHIV have also expressed lack of support regarding how, when and with whom to disclose their HIV status, which can lead to anxiety and depression. Adolescents often face discrimination relating to their risky sexual behaviours and HIV-positive status [12,16]. At the health systems level, issues such as staff shortages, long waiting times, negative experiences with clinic staff and medication stock outs inhibits regular clinic visits and adherence to ART [12,19,20]. Additional health systems barriers include inadequate counselling on medications adherence due to limited clinician patient interaction time and distance to health facility [21].

Furthermore, the transition of HIV from an acute, deadly disease to a manageable chronic disease has enormous implications for the neurocognitive and psychosocial development of children [22]. Studies show that psychosocial disorder impacts negatively on immunological health outcomes [23].

Psychosocial support (PSS) interventions can help ALHIV overcome barriers to adherence and retention in ART care thereby improving immunological health outcomes [24]. However, there are currently limited understanding on how psychosocial support interventions improve adolescents' ART adherence, retention in care and immunological health outcomes [25]. A recent scoping review showed that individual and group counselling including family-centred group counselling and the use of adolescent treatment supporters were commonly used intervention to improve ART adherence, linkage to care and/or retention in care among adolescents living with HIV [25].

Using the biopsychosocial model [26], we formulated hypotheses to explain how the components of the RTC ALHIV intervention is designed to improve adherence to ART and retain ALHIV in ART to improve health outcomes. Right to Care (RTC) is a South African non-governmental organisation that provides treatment care and support for people living with HIV. This is done through the identification of HIV positive clients, initiating and retaining them on ART care. In this paper, we describe how the adolescent psychosocial support intervention implemented by RTC works to improve adherence and retention in ART care among adolescents living with HIV in Ehlanzeni and Thabo Mofutsanye districts, South Africa, by applying the biopsychosocial model.

Description of PSS intervention

RTC developed an adolescent PSS intervention that provides adolescent and youth friendly services (AYFS). A description of the documents that informed the design of the intervention is shown in Appendix 1[1]. The intervention employs trained treatment supporters to support adolescents in the age group 10 to 24 years living with HIV (beneficiaries) in adherence and retention in ART care. This is achieved through the use of psychosocial oriented training material known as Flipster to facilitate support club session at selected safe spaces with adolescents and young people (i.e. youth clubs, teen clubs, support groups) organized by age (10-13, 14-16, and 17-24-years age groups). The aim of the support club is to produce resilient and empowered adolescents and young people living with HIV who are better informed and better able to make well-informed choices about medication adherence and retention in care.

The treatment supporters work with the health facility structures, as they are assisted with the names and addresses of adolescents who have tested for HIV and known to be positive. These treatment supporters with consent from these ALHIV and their caregivers registers them into the RTC adolescents programme where they are guided and counselled on the importance of medication adherence and then regularly followed up. The treatment supporters pre-pack antiretroviral medications for the beneficiaries when they visit the health facility.

The Flipster topics addresses age specific and sensitive issues that focuses on knowledge about HIV and treatment adherence. Key topics that the intervention seeks to address in order to improve treatment adherence and retention in care are identified and discussed including (1) biological factors (2) psychological factors, and (3) social factors. The duration of sessions for each age group varies: 10-13 years - 45 minutes; 14-16 years - approximately 60 minutes; and 17 years and above - approximately 75 minutes.

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[1] A description of the documents that were reviewed is not included in this thesis, but is available upon request.

Biopsychosocial Model for Management of HIV among ALHIV

The biopsychosocial model was originally developed by Engel (1977) who posited that understanding chronic illness and disease as a complex interaction between biological, psychological, and social factors will enable the designing of interventions to improve health outcomes [26]. The biopsychosocial model helps explain the association between the biomedical factors, psychological factors, and social factors at play in the treatment and management of HIV. Therefore, to understand the effectiveness of the RTC's psychosocial intervention, the bidirectional link between the biological, psychological, social factors and health outcome need to be explored (Figure 1). We choose the biopsychosocial model because we believe that the HIV infection goes beyond biomedical management of HIV to psychological and social management of the impact of the disease to achieve favourable health outcomes.

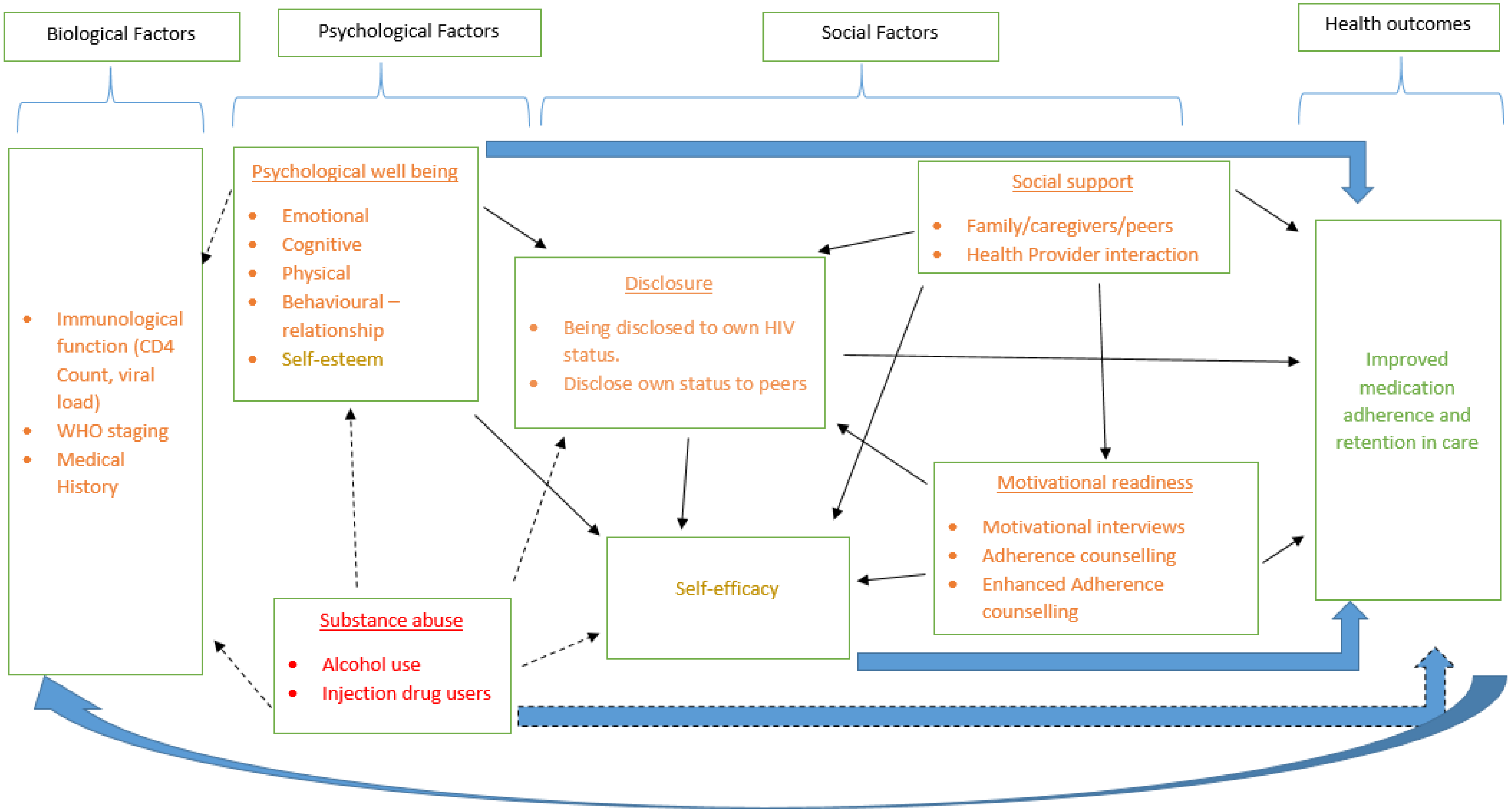

Figure 1 Biopsychosocial model explaining the psychosocial support intervention for ALHIV

In the following section we describe the biopsychosocial model of illness (i.e. the relationship between the biological, psychological, and social factors) among ALHIV that the PSS intervention addresses towards improving adherence to and retention in ART.

Biological Factors

The biomedical model assume that disease occurrence is as a result of abnormality of biological molecules inside the body, and excluded the significance of social, psychological and behavioural or social factors of the illness [27]. As such, biological factors relate to elements such as laboratory results (e.g. CD4 count and viral load), symptoms of the illness, and medical history of the patient to determine treatment. It is also noted that several factors such as drug toxicity, being too ill affects medication adherence and retention in care. Similarly, patients with psychological disorder are more likely to experience immunological compromise compared to individuals with no psychological distress. The PSS intervention ensures that ALHIV are screened for TB, as well as weight for age biometrics are taking in order to prescribe a suitable antiretroviral treatment. Furthermore, the PSS intervention improve access to medication access for ALHIV through medication pre-packs and tracking of adolescents who have missed their support group sections. In addition, regular (every six months) viral load monitoring is conducted, and ALHIV who are found to have high viral load are given enhanced adherence counselling section to help them improve their adherence.

Psychological Factors

Psychological wellbeing refers to the absence of depression, anxiety, anger, fear and the presence of positive emotions, meaning, healthy relationships, mastery of one’s environment, engagement, and self-actualization [28]. The intervention addresses stressors that trigger the emotional, cognitive, physical and behavioural aspects of the ALHIV psychological wellbeing through sessions that help them identify situations that can trigger stress and depressive symptoms and teaching them how to deal with such stressors when they arise. ALHIV face a myriad of emotional, behavioural and mental health challenges such as psychological distress, suicide, and risky sexual behaviours [24]. Similarly, children who experience difficulties in their peer relations have been found to be associated with loneliness [29], which in turn leads to depression and self-perceived stigma and subsequently suicidal particularly for ALHIV.

Substance abuse

Coping strategies among ALHIV play a role in whether or not patients adhere to their prescribed ART treatments. To cope with stressors, individuals often develop or adopt different coping strategies to help moderate the stressors [30]. Coping strategies can be emotional (e.g. crying, excessive eating, confrontation), avoidance-based (e.g. isolation, mental disengagement, behavioural disengagement, alcohol and other psychoactive drug use, suppression of competing activities) or adaptive strategies (e.g. seeking social support, problem-solving, positive re-appraisal, acceptance, humour, journaling and spirituality) [30].

Evidence suggest that patients who coped by using problem-solving and behaviour-modifying approaches were more likely to be adherent to ART medication compared to those who used emotional or avoidance-based strategies [31]. Drug and alcohol use as a means of coping strategy is associated with non-adherence to ART among people living with HIV (PLHIV) [31]. The PSS intervention seeks to empower ALHIV with problem-solving skills to deal with their HIV status through identifying and dealing with factors that could trigger risky behaviours, as well as to understand the implication of alcohol and drug use along with ART intake. ALHIV were screened for alcohol and drug use, and those found to be using drug or alcohol were provided with enhanced counselling and additional support to help combat alcohol and drug use.

Self-esteem and self-efficacy

Several sessions that educate on psychological wellbeing, substance abuse, motivational readiness, disclosure, and social support are posited to have direct impacts on self-esteem and self-efficacy. Furthermore, the intervention provides ALHIV with the skill to alter negative responses as well as understand the benefits of sharing positive feedback with peers. For example, ALHIV are skilled to recognise the concept of feelings and learning to speak about feelings.

Self-efficacy is widely documented as an important correlate of medication adherence in the treatment of HIV [32,33]**.** However**,** positive health care provider interactions may foster greater adherence self-efficacy, which is associated with better adherence to medications [34]. Furthermore, self-efficacy and reduced psychological distress were significantly correlated with adherence [35]. The sessions in the "flipster" support group utilises an approach that enables ALHIV to understand their emotions and underlying patterns of behaviour. By talking through these emotions and behaviours with a social worker, ALHIV come to know themselves better and make better decisions for themselves.

Disclosure

The intervention provides disclosure training at two level. Firstly, clinicians guide parents or caregivers to disclose HIV status to the adolescents. Secondly, uses role plays in dyads to help ALHIV understand the importance of disclosing their own HIV status as well as guiding them through the process of disclosure and overcoming challenges relating to disclosure. Having disclosed to peers was significantly related to regular visits to the HIV clinic, and greater social support through peers. ALHIV need safe environments to practice disclosure skills [36]. Interventions should enable them to make optimal use of available psychosocial resources even under constraining conditions such as disruptive family structures [36], including ALHIV who and orphans and their caregivers [37]. Another study that investigated path analysis of disclosure revealed that disclosure to family members had significant indirect effects on adherence via social support and self-efficacy [38].

Social support

The intervention utilises peers and dedicated clinicians to provide HIV treatment care and support for ALHIV there by strengthening the relationship between treatment supporters/clinicians and ALHIV. In addition, parents/ caregivers of ALHIV are provided with training on how to support the ALHIV in their treatment journey. Therefore, the network of support provided to ALHIV is designed to improve their adherence and retention in ART care. Studies have suggested that ALHIV who receive support from clinicians, peers, and/or caregivers improve their psychosocial wellbeing, which in turn improves adherence and retention in ART [33,39,40]. Another study found social support specific to taking medications was correlated with self-efficacy [35]**.** Engagement with health care providers (HCP) includes access to HCP as needed, information sharing, involvement of client in decision making and self-care activities, respect and support of the HCP for the client's choices, and management of client concerns. Promoting engagement with the HCP is necessary to facilitate skills that help PLHIV manage their HIV [41]. Improving the

HIV treatment-related knowledge and self-efficacy of caregivers may help to improve the clinical outcomes of HIV-infected children [42].

Motivational readiness

Motivational interviewing (MI) addresses patient ambivalence about a desired goal in a directed, patient-centered manner. MI intervention is established as a therapeutic tool within the pediatric population with positive outcomes for obesity, asthma, medication adherence and HIV management. MI is especially promising within the adolescent population where increasing independence tends to contribute to poorer health outcomes [43]. MI may be a promising intervention for AYAs with chronic illness in addressing non-adherence and potentially improving quality of life [44]. MI appears to be a promising intervention to improve HAART adherence in HIV-positive individuals [45], reductions in viral load (in the short term) and unprotected sexual acts, and a reduction in alcohol use was identified only in one of two studies that reported on this outcome. Retention rates were not affected by the intervention [46]. The intervention utilises this approach to initiate ALHIV into the ART programme as well as, provide enhanced adherence counselling to ALHIV with virologically failure to enable them adhere to ART.

Conclusion

The management of ALHIV in relation to ART adherence and retention requires identifying the complex developmental issues peculiar to this particular age and addressing the various components that inhibits optimal adherence to ART and retention in care. The psychosocial support club provides a compendium of topics that addresses the various developmental issues in this particular age group.

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Paper 5: Implementation of a psychosocial support intervention for adolescents on antiretroviral treatment: Challenges and experiences from Ehlanzeni District, South Africa

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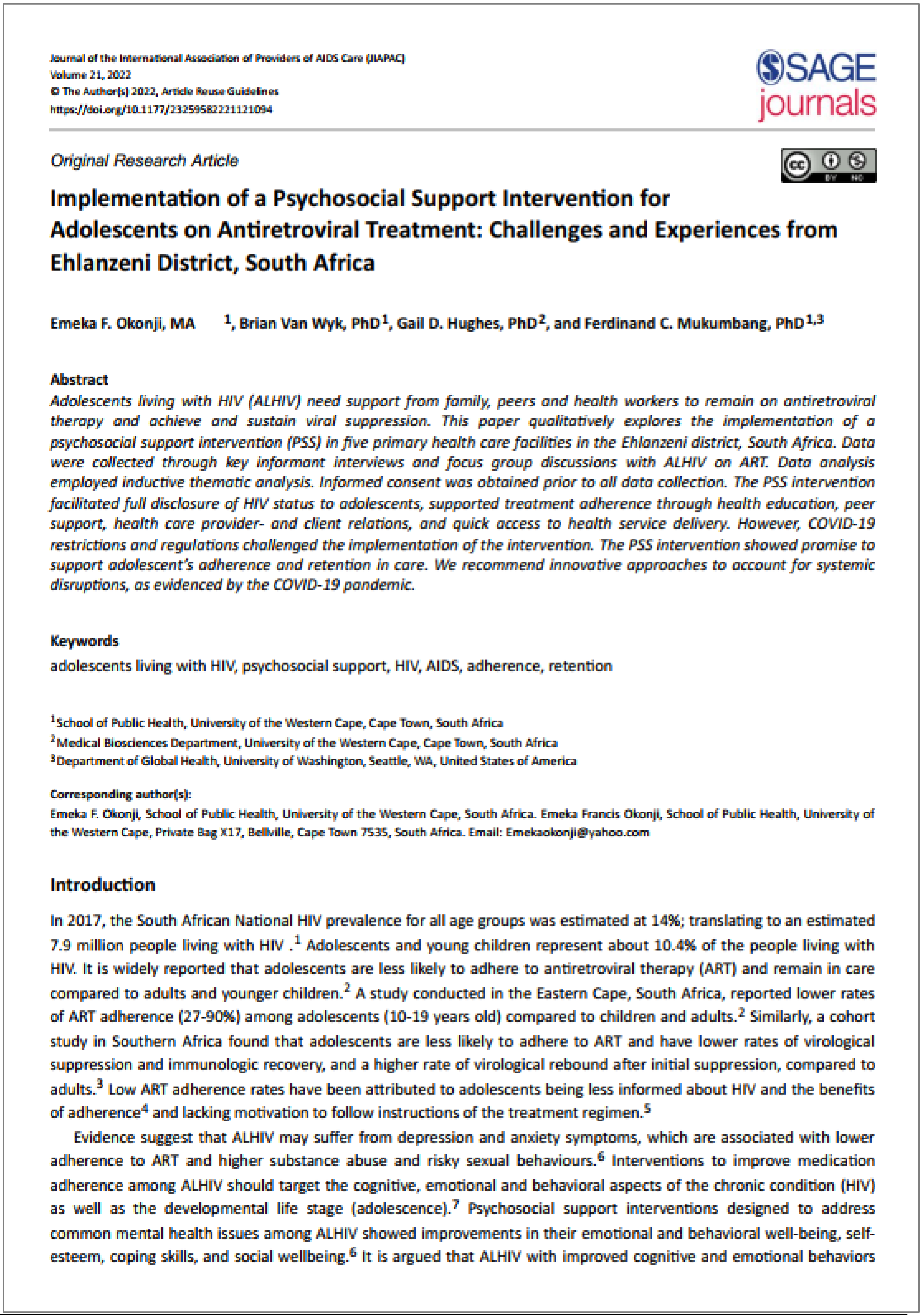
Introduction: This paper explores the implementation of the Right to Care (RTC) psychosocial support (PSS) intervention for adolescents on antiretroviral treatment using a qualitative approach. The experiences of the implementing agents and challenges encountered are discussed. The study specifically explores the mechanisms employed for implementation to improve adherence and retention in care among ALHIV on ART. These mechanisms include facilitated full disclosure of HIV status to adolescents, supported treatment adherence through health education, peer support, health care provider- and client relations, and quick access to health service delivery. During the period of the study, COVID-19 restrictions and regulations challenged the implementation of the intervention. The PSS intervention showed promise to support adolescents' adherence to ART and retention in care. The paper highlights the importance of employing innovative approaches to account for systemic disruptions, such as the COVID-19 pandemic. The importance of regular growth monitoring of ALHIV to regularly adjust their regimen (dosage) according to their growth is also highlighted.

Contribution of candidate: EFO and BvW designed the study. EFO analysed the data and developed the manuscript with editorial and content input from BvW, FCM, and GDH.



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Original Research Article

Implementation of a Psychosocial Support Intervention for Adolescents on Antiretroviral Treatment: Challenges and Experiences from Ehlanzeni District, South Africa

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Abstract

Adolescents living with HIV (ALHIV) need support from family, peers and health workers to remain on antiretroviral therapy and achieve and sustain viral suppression. This paper qualitatively explores the implementation of a psychosocial support intervention (PSS) in five primary health care facilities in the Ehlanzeni district, South Africa. Data were collected through key informant interviews and focus group discussions with ALHIV on ART. Data analysis employed inductive thematic analysis. Informed consent was obtained prior to all data collection. The PSS intervention facilitated full disclosure of HIV status to adolescents, supported treatment adherence through health education, peer support, health care provider- and client relations, and quick access to health service delivery. However, COVID-19 restrictions and regulations challenged the implementation of the intervention. The PSS intervention showed promise to support adolescent's adherence and retention in care. We recommend innovative approaches to account for systemic disruptions, as evidenced by the COVID-19 pandemic.

Keywords

adolescents living with HIV, psychosocial support, HIV, AIDS, adherence, retention

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Introduction

In 2017, the South African National HIV prevalence for all age groups was estimated at 14%; translating to an estimated 7.9 million people living with HIV .[1] Adolescents and young children represent about 10.4% of the people living with HIV. It is widely reported that adolescents are less likely to adhere to antiretroviral therapy (ART) and remain in care compared to adults and younger children.[2] A study conducted in the Eastern Cape, South Africa, reported lower rates of ART adherence (27-90%) among adolescents (10-19 years old) compared to children and adults.[2] Similarly, a cohort study in Southern Africa found that adolescents are less likely to adhere to ART and have lower rates of virological suppression and immunologic recovery, and a higher rate of virological rebound after initial suppression, compared to adults.[3] Low ART adherence rates have been attributed to adolescents being less informed about HIV and the benefits of adherence[4] and lacking motivation to follow instructions of the treatment regimen.[5]

Evidence suggest that ALHIV may suffer from depression and anxiety symptoms, which are associated with lower adherence to ART and higher substance abuse and risky sexual behaviours.[6] Interventions to improve medication adherence among ALHIV should target the cognitive, emotional and behavioral aspects of the chronic condition (HIV) as well as the developmental life stage (adolescence).[7] Psychosocial support interventions designed to address common mental health issues among ALHIV showed improvements in their emotional and behavioral well-being, self-esteem, coping skills, and social wellbeing.[6] It is argued that ALHIV with improved cognitive and emotional behaviors

Implementation of a psychosocial support intervention for adolescents on antiretroviral treatment: Challenges and experiences from Ehlanzeni District, South Africa

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The PSS intervention facilitated full disclosure of HIV status to adolescents, supported treatment adherence through health education, peer support, health care provider- and client relations, and quick access to health service delivery. However, COVID-19 restrictions and regulations challenged the implementation of the intervention. The PSS intervention showed promise to support adolescent's adherence and retention in care. We recommend innovative approaches to account for systemic disruptions, as evidenced by the COVID-19 pandemic.

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There is a burgeoning call for psychosocial support intervention to improve adherence and retention in care among ALHIV.[9–11] While psychosocial interventions for HIV-affected adults have shown high impact to adherence and retention in care,[10] fewer studies have reported little to moderate impact of psychosocial intervention on adherence and retention in care among ALHIV. The implementation process of psychosocial interventions among ALHIV are even less reported.[9] The aim of this paper is to report on the implementation of a psychosocial support intervention designed to improve adherence and retention of ALHIV on ART in Ehlanzeni District in Mpumalanga province, South Africa.

Methods and Materials

Study setting

According to the 2017 National HIV prevalence, incidence, behavior and communication survey, the Ehlanzeni District has the second highest HIV prevalence in South Africa with an estimated prevalence rate of 17.3%. The Ehlanzeni District Municipality is in the north-east of the Mpumalanga Province. The study was conducted in five public primary health care facilities, namely Buffelspruit clinic, Kanyamazane CHC, Cunningmore clinic, Langloop CHC and Naas CHC. Our baseline study in the Ehlanzeni district found a 74% viral suppression rate (confidence interval: 73.1%-74.8%) among ALHIV on antiretroviral treatment in 2019,[12] and retention in care rates at 6, 12, 18 and 24 months of 90.5%, 85.4%, 80.8% and 76.2%, respectively[13] – which fail to meet the UNAIDS target of 95%, 95%, 95% by 2030.

Overview of the Right to Care psychosocial support intervention

Right to Care (RTC) is a registered South African Non-Governmental organization (NGO) that provides quality health care services including prevention, treatment care and support services for people living with HIV. RTC developed a PSS intervention consisting of adolescent and youth-friendly services that aim to improve adherence and retention to ART care among ALHIV. The comprehensive PSS intervention package consists of services to address disclosure, treatment adherence, social support and HIV treatment literacy[8] as illustrated in Figure 1.

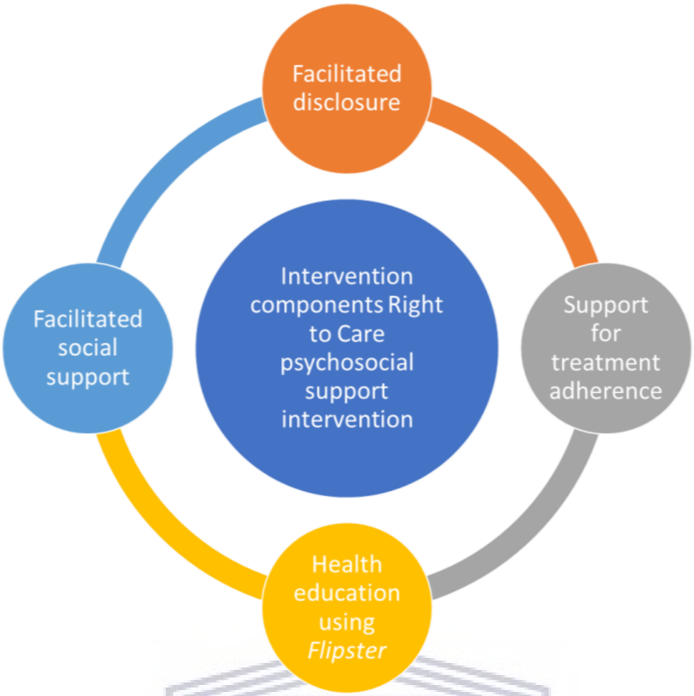


Figure 1 Intervention components of the Right-to-care psychosocial support intervention

Research design, sample size and sampling

We applied a qualitative descriptive research design. Five purposively selected key informants comprising a program coordinator, two professional nurses and two community system technical officers (CSTO) were interviewed for the study. Twenty-four focus group discussions were conducted with 173 ALHIV (10–19 years old) on ART who received the psychosocial support group intervention in five public primary health care facilities in Ehlanzeni District.

Data collection procedure

We reviewed program documents including adolescents and youth friendly space policies and guidelines, implementation plan and the *Flipster* training manual.[8] The focus group discussions were conducted between 1 and 30 November 2021, and the key informant interviews were conducted between 3 and 10 December 2021. Before starting the key informant interviews, the program coordinator and implementers were briefed on the purpose of the interviews and interview dates were scheduled with the potential key informants.

Through the support of clinic professional nurses, parents/caregivers of ALHIV were contacted and briefed on the focus group discussions. Consent was also sought from the parents/caregivers of the ALHIV and assent from ALHIV who were under 18 years old. The key informant interviews were conducted virtually (through Microsoft Teams meetings) in English and voice recorded. The focus group discussions were conducted in person and in the local language (Tsonga). Recorded data were translated verbatim in English and prepared for analysis.

Data analysis

From the program documents, we identified the four program objectives, and use these (program objectives) as a framework to organize the data. Data within this framework were analyzed manually using inductive content analysis. The inductive content analysis technique is suitable for analyzing qualitative data collected without the guidance of a theoretical framework, but deriving purely from emergent data and formulating themes.[14] A fifth category (Other challenges) was formed to capture the themes that did not fit into the program objectives framework, but captured "Other challenges" encountered in the implementation of the intervention. Data were captured in an Excel table with five columns to depict categories, themes, subthemes, codes and direct quotations. We developed codes from the responses provided by the participants. Data codes were reviewed by the authors and later organized into subthemes, themes, and categories (pattern coding). We further read and cross-checked the transcribed data to confirm the developed pattern coding. A final matrix containing columns for categories, themes, subthemes, and codes was developed using Microsoft Excel 2016.

Rigor and Trustworthiness

The rigor and trustworthiness of the study findings were ascertained by doing the following. (1) We conducted a pilot of the interview guide, which helped us assess the type of information that we asked were likely to produce. (2) We applied the processes of information triangulation, which entailed using more than one stakeholder group - key implementers and adolescent beneficiaries. (3) We conducted iterative questioning in data collection dialogues with the study participants. Conducting a document review provided us with relevant concepts and theories to engage with the study participants. (4) Trustworthiness was enforced by actively searching for disconfirming evidence through negative case analysis[15] or deviant case analysis,[16] and keeping an audit trail. Finally, we followed the relevant aspects of the Criteria for Reporting Qualitative Research (COREQ) outlined by Tong et al.[17,18]

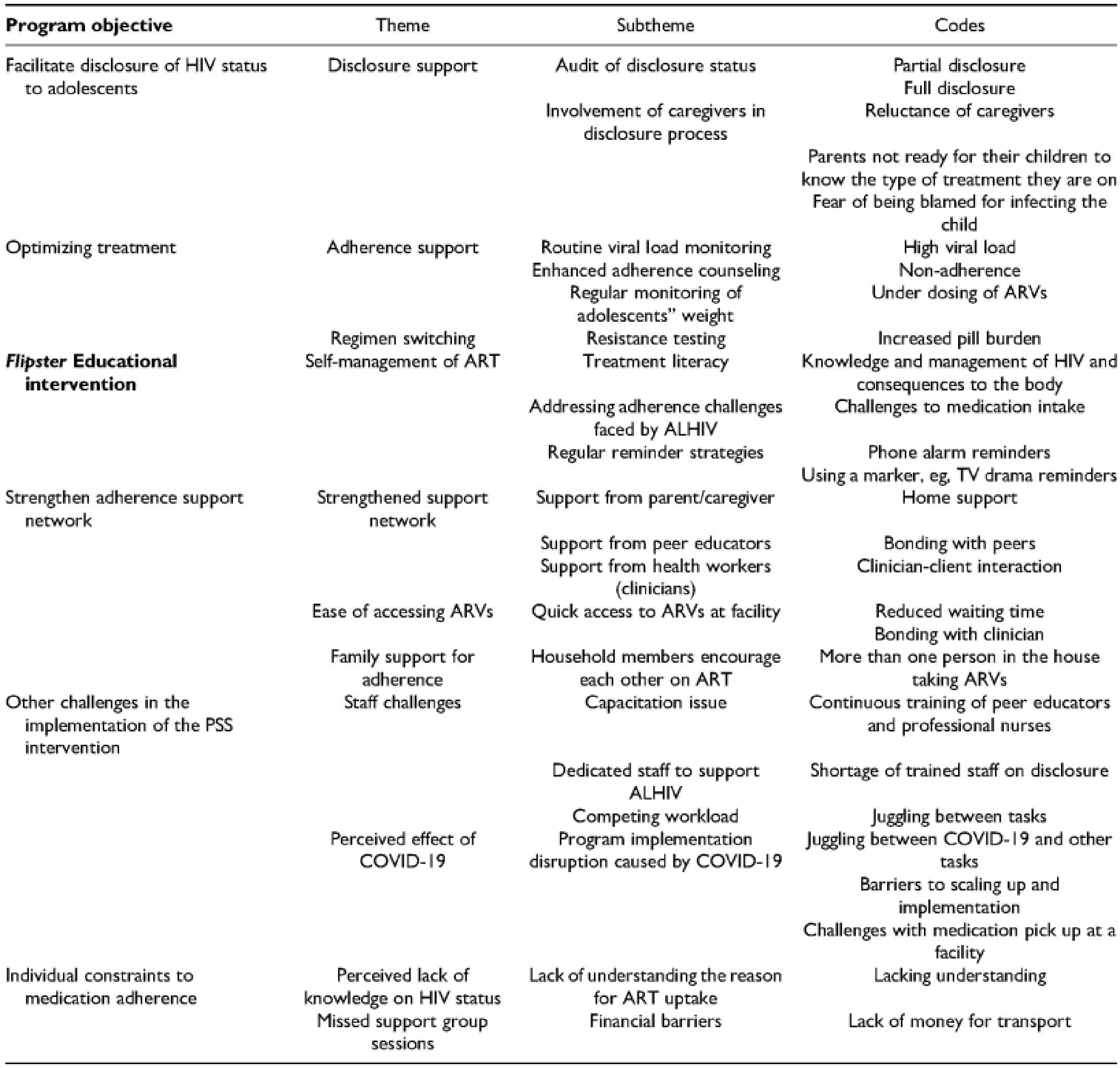
Ethical Approval and Informed Consent

Ethics clearance was obtained from the University of the Western Cape Biomedical Research Ethics committee (BM19/1/8) and the National Health Research Ethics committee (MP_202102_006). We adhered to the 1964 declaration of Helsinki guidelines. The researchers sought verbal and written consent from all study participants, including parents/caregivers. Pseudonyms were also used to identify study participants during key informant interviews (KII's) and focus group discussions (FGD's). In addition, participants consented to publishing of their responses if they were kept anonymous.

Results

The objectives of the PSS program were to facilitate and support disclosure, optimizing treatment effectiveness, and providing health education and social support to improve adherence and retention in ART among ALHIV. The themes, subthemes and codes derived as aligned with each of these program objectives are illustrated in Table 1.

Table 1 Themes, subthemes and codes derived as aligned with the program objectives



Program objective	Theme	Subtheme	Codes
Facilitate disclosure of HIV status to adolescents	Disclosure support	Audit of disclosure status	Partial disclosure Full disclosure
		Involvement of caregivers in disclosure process	Reluctance of caregivers
			Parents not ready for their children to know the type of treatment they are on Fear of being blamed for infecting the child
Optimizing treatment	Adherence support	Routine viral load monitoring	High viral load
		Enhanced adherence counseling	Non-adherence
		Regular monitoring of adolescents" weight	Under dosing of ARVs
	Regimen switching	Resistance testing	Increased pill burden
***Flipster* Educational intervention**	Self-management of ART	Treatment literacy	Knowledge and management of HIV and consequences to the body
		Addressing adherence challenges faced by ALHIV	Challenges to medication intake
		Regular reminder strategies	Phone alarm reminders Using a marker, eg, TV drama reminders
Strengthen adherence support network	Strengthened support network	Support from parent/caregiver	Home support
		Support from peer educators	Bonding with peers
		Support from health workers (clinicians)	Clinician-client interaction
	Ease of accessing ARVs	Quick access to ARVs at facility	Reduced waiting time Bonding with clinician
	Family support for adherence	Household members encourage each other on ART	More than one person in the house taking ARVs
Other challenges in the implementation of the PSS intervention	Staff challenges	Capacitation issue	Continuous training of peer educators and professional nurses
		Dedicated staff to support ALHIV	Shortage of trained staff on disclosure
		Competing workload	Juggling between tasks
	Perceived effect of COVID-19	Program implementation disruption caused by COVID-19	Juggling between COVID-19 and other tasks Barriers to scaling up and implementation Challenges with medication pick up at a facility
Individual constraints to medication adherence	Perceived lack of knowledge on HIV status	Lack of understanding the reason for ART uptake	Lacking understanding
	Missed support group sessions	Financial barriers	Lack of money for transport

Disclosure support

One of the primary objectives of the PSS intervention was to facilitate and support “full” disclosure of HIV status to adolescents on ART safely and healthily. According to the 2016 South African National Department of Health disclosure guidelines for children, “full” disclosure should be conducted gradually regarding the cognitive development and maturity of the child and adolescent. The intervention disclosure process started with auditing the files of ALHIV on ART to determine whether they have received “full” disclosure.

Partial disclosure

The PSS intervention through trained health care workers provide a gradual disclosure process starting from partial disclosure (where the adolescents are taught about gems) to full disclosure (the adolescents are taught about HIV and consequences of non-adherence to ART). The intervention implements partial disclosure between ages 4 and 9 years old, where the ALHIV are told that they have germs in their body and will need medication to fight the germs. This information is given because at this age, the child can comprehend germs as opposed to HIV as a virus. The knowledge of germs in the body provides the child with a reason to continue to take ARV drugs daily.

> It [disclosure] was not easy at first, because they did not understand why they should take the treatment every day. Because most of them even were not told the truth about the treatment. They knew that they were taking medicine. [but] they did not really understand why they should take the treatment every day - Professional nurse, Kanyamazane CHC

Full disclosure

After the partial disclosure, “full” disclosure is provided to the adolescent when they reach 10 years of age. At this age, the adolescents are considered to be mature enough to take their medication on their own (i.e., learn self-management of their chronic condition). In this session, they are told about the virus, its consequences to the body, and how to manage their chronic illness. Full disclosure of HIV status is done with the support of a parent or guardian.

> So, from ten years upward we expect that the child should know that they have got a virus. But we need to do that through the parents, the parents of the kids must give their consent” – Community system technical officer, Langloop CHC

The second step in the intervention process is to contact parents or caregivers and invite them to the clinic to facilitate “full” disclosure to the adolescent.

> I make sure that after doing the audits, I call the parents [of ALHIV] and inform them [parents] I have got this child that is not disclosed. So how about you come to the

> facility, so we start with the child's disclosure*?* – Community system technical officers, Kanyamazane CHC

Reluctance of caregivers to disclose to their children

It was reported by program implementers that some of the parents/caregivers are reluctant to participate in the disclosure process because they are not comfortable for their children to know their HIV status, for fear that they may be blamed for infecting their child.

> One parent said she was not ready for the child to know what kind of treatment he was taking. That came from a place of her fearing that the child would blame her. And I think because she blames herself; …she feared that the child was also going to blame her for infecting him with HIV - Community system technical officers, Kanyamazane CHC

In the focus group discussions, the adolescents expressed that the intervention helped provide clarity on the reason for their continuous medication intake helped them come to terms with their HIV status and subsequently adhere to taking their medication.

> When they told me I was not shocked, but I became aware when they told me. I was first told that the treatment was for flu, but I wondered why I have flu this long and not getting better. But then they eventually told me it was for HIV - 14-year-old male, Kanyamazane CHC

> Now I am happy because I know my status unlike not knowing that I am HIV positive. I feel free now because I know my status- 18-year-old female, Kanyamazane CHC

Adolescents who were perinatally infected with HIV lacked understanding of continuous medication intake. Full disclosure is a key component of the PSS program to provide clarity on the need for adherence, and a criterion for recruiting the ALHIV into adolescent support groups. The disclosure component of the intervention was implemented as planned, and it provided clarity for the ALHIV on their continuous ART intake, enhanced their ability to take responsibility for their medication intake; and subsequently improved medication adherence.

Optimizing treatment

The PSS intervention provides treatment adherence support for ALHIV through four mechanisms, namely: routine viral load monitoring, enhanced adherence counseling (EAC), regular monitoring of adolescents' weight, and resistance testing leading to switching to a second-line regimen.

Routine viral load monitoring

The intervention enables the routine monitoring of viral load of ALHIV every six months and once a year if the ALHIV on ART have achieved two successive viral load suppressions to ensure adherence to ART. However, for adolescents with a history of non-adherence or missing clinic appointments, blood is drawn every two months to ensure adherence before reverting to the routine of six months, and once a year.

> We collect the viral load when the patient is due for blood, and when I notice that the viral load is high, then counsel them [ALHIV]…after two months I will collect blood again to see if the viral load is going down. If the viral load is not going down, we then switch to second line - Professional nurse, Langloop CHC

Enhanced adherence counselling

Through the intervention, enhanced adherence counselling (EAC) is provided to ALHIV who defaulted on clinic appointments and have a viral load >1000 copies/ml. The main goal of the counseling is to help the adolescents overcome the barriers to adherence and regular clinic visits, and to re-engage with treatment regime.

> When I noticed that the viral load is high, I will seat with the patient [adolescent] and talk to them to understand the problem for not adhering. If the patient [adolescent] is

> not adhering I will ask them why they are not adhering [provide EAC] - Professional nurse, Kanyamazane CHC

Regular monitoring of adolescent's body weight

The PSS intervention provides regular monitoring of adolescents' body weight. Regular monitoring of body weight gains/losses is vital to maintaining appropriate antiretroviral (ARV) dosage for the ALHIV. The 2019 adherence guideline for HIV, Tuberculosis (TB), and non-communicable diseases (NCDs) recommended a specific regimen for a specific weight in ALHIV.[19] Under-dosing of ARVs due to adolescents' rapid growth was commonly observed as a reason for unsuppressed viral load among ALHIV.

> Most of them their viral load was very high, but when I check their file, most of them were under dosed. Because they are kids, they grow every now and then. What I noticed is that the nurses will not update their treatment according to the weight of the child, so I correct it - Professional nurse, Kanyamazane CHC

Resistance testing

ALHIV whose viral load remain unsuppressed after receiving counselling were switched to a second-line regimen if the unsuppressed viral load persisted. In the focus group discussions, the adolescents expressed that blood was taken for testing to monitor whether they (ALHIV) were adhering to their treatment.

> They do blood check to see if we are taking our ART when at home. It [regular blood checks] assisted us to collect our ART regularly -14-year-old female, Langloop CHC

The adolescents also recounted how the counselling they received for not adhering to their treatment helped them to re-engage with their treatment.

> I would get sick, and they found out that I was not taking my pills and they admonished me for not doing that and I was told these pills will help me live and I continued taking them. They also said I should always eat my food so by the time I

> take my pills I have something in my stomach and that I should drink a lot of water. So, I took that and continued up until now – 13-year-old male, Kanyamazane CHC

Through regular monitoring of their viral load and weight and providing enhanced adherence counselling to these adolescents, those on ART were supported in their treatment journey to attain viral suppression.

Health Education

The intervention provided health education to ALHIV using the *Flipster* training manual. The *Flipster* training manual consists of discussion topics covering HIV knowledge and treatment literacy, treatment adherence, disclosure, stress and mental health management, self-esteem, nutrition and substance abuse. Additionally, the tool consists of two sides-on one side of the tool (seen by participants) comprises descriptive pictures; whilst the reverse side provides guides for the facilitator through the topic in a series of easy-to-follow steps.

Treatment literacy

The Flipster method contains age-appropriate training materials on treatment literacy, HIV knowledge, nutrition, drugs and substance abuse, and medication adherence strategies with picture codes showing illustrations of the topics under discussion. The Flipster method facilitates the process of adolescents in the support groups to talk openly about sexual and reproductive health concerns while opening pathways for discussions about HIV, stigma and life challenges. This approach keeps ALHIV interested and engaged in the topics discussed.

> The health education that they [ALHIV] receive when they are in the facility to receive their treatment, is tailored in such a way that it does not push them [ALHIV] away, but rather make them [ALHIV] want to come to the facility because it is a place where they [ALHIV] can actually get answers, get to understand certain things they might not be able to understand from their parents - Program coordinator

Self-management of ART

Adherence reminder strategies, such as phone alarm, reminders and TV shows were suggested to adolescents to help them remember to take their medication daily.

> Also, we tell them [ALHIV] that when Generations plays- we must take our treatment and we both take it together so creating that kind of cultures and behavior in the home can be really a form of support - Community system technical officer (1), Langloop CHC

> We always tell parents to someone who is on treatment to make sure that there is a phone alarm - Community system technical officer, Kanyamazane CHC

According to one of the professional nurses, these strategies mentioned above were observed to be effective in ART self-management among ALHIV.

> I think they [ALHIV] were able to take care of themselves, knowing that they [ALHIV] should take treatment every day. I would ask them “what time do you take treatment”? they [ALHIV] knew the time they [ALHIV] should take treatment. The fact that they could adhere to the time and the treatment, I think that they were able to take care of themselves - Professional nurse, Kanyamazane CHC

In the focus group discussions, the adolescents expressed that they (ALHIV) were better placed to take ART seriously by freely discussing their challenges with facilitators and peers.

> We should continue with the group because it helps. And we learn from each other, and it becomes easy for us to meet and collect our ART -13-year-old female, Langloop CHC

Similarly, the ALHIV expressed the benefit of TV programs in reminding them that it is time to take their medication.

> Television also helps, like I know every time generations plays on TV it automatically reminds me to take my ART - 13-year-old, male Langloop CHC

The adolescents also recounted how they could take responsibility for their health and get all reminders from family members. For example, one adolescent reported that:

> I am taking responsibility of my health and I remind myself every time and even my little sister does remind me and if I don't take, she would even report to my mom. So, I thank her a lot she is always there to remind me - 18-year-old female, Kanyamazane CHC

The Flipster educational component of the intervention enabled a conducive environment for the ALHIV to discuss crucial topics on HIV treatment literacy and address challenges to medication adherence.

Social support

The aim of the PSS intervention is to facilitate social support for improved access to ART (medication pick up and clinic attendance) and retention in care by strengthening the ALHIV's support networks.

Strengthen adherence support network

The PSS intervention is implemented in an adolescent-friendly and safe space in the clinics. The support groups provide an enabling environment for ALHIV to bond with clinicians, peers in the PSS group and their caregivers throughout their treatment journey.

> The peer educators are very young. So our young people and our children can relate with them and don't feel intimidated. I think it has done good for our program - Community system technical officer, Kanyamazane CHC

> Their [ALHIV] interactions with me was very good. They [ALHIV] were open enough to interact with me, like they [ALHIV] knew that everything was fine when

> they [ALHIV] are at the clinic, they [adolescent] feel safe, they [adolescent] can say anything that they [adolescent] are facing - Professional nurse, Kanyamazane CHC

Caregivers of ALHIV are encouraged to take their medication together with their children as role models and as such motivate their children to adhere to treatment.

> We always encourage parents/caregivers in the disclosure sessions to take treatment with the child because that always help[s] them to see, okay, mummy always does it, so I can do it too - Community system technical officer, Langloop CHC

Ease of accessing antiretroviral

The PSS intervention provides ALHIV with quick access to ARVs at the clinic, so that they have reduced waiting times when they visit the clinic.

> And the fact that it was welcoming for them [ALHIV] to come to the clinic, they [ALHIV] did not have to stay in long queues in the clinic. They [ALHIV] come to me [professional nurse] and I help them with their medicines and have sessions with them [ALHIV], and after an hour they [ALHIV] leave. It is not like sitting on the benches waiting for their medicine - Professional nurse, Langloop CHC

During the focus group discussions, most adolescents expressed a sense of belonging and camaraderie with peers on their HIV journey. The sense of belonging and camaraderie made them forget about their fears, hurt, worries, anger and bitterness.

> What I like about the group is that I met friends who are also taking ART -14-year-old, female Kanyamazane clinic

> We help one another by encouraging each other to take medication every day - 13-year-old female, Langloop CHC

Other challenges in the implementation of the PSS intervention

Although the psychosocial support intervention was implemented as planned with promising benefits, other challenges encountered in the implementation of the PSS intervention identified were due to staff's workload challenges, disruptions and restrictions due to COVID-19, as well as lack of transport [money] to attend support group sessions.

Workload challenges

Though the staff implementing the adolescent program were trained on disclosure and skills to facilitate adolescent support groups, consistently implementing it was a challenge because of competing workloads at the clinic.

> Some people have been trained but are not implementing maybe because of some of the challenges with the workload. So is not always that people don't know what to do, but it is just that they are not doing it because of other responsibilities that they have, so that is what I would say it is a challenge - Program coordinator

The community system technical officers also narrated how competing work demands had hindered the continuous implementation of the program especially with the emergence of COVID 19.

> The workload also affected a lot, because we were short staffed, I could not continue with the support groups to attend to COVID cases - Community system technical officer, Langloop CHC

Impact of COVID-19 on program implementation

The implementation of the program was severely disrupted by COVID-19 restrictions and lockdown regulations in South Africa. These restrictions and lockdown regulations led to the discontinuation of support group sessions; which hindered access to the health facility and medication pickup.

> A huge disrupter for this implementation has really been COVID-19, because like I said previously, I had quite a few facilities that were implementing support groups, and the goal was to expand to more facilities so that we have more supports groups in more facilities - Program coordinator

> …but because of COVID-19 restrictions, implementation of support groups came to a halt, as a result medication pickup among our children dropped - Professional nurse, Langloop CHC

Lack of transport money to attend support groups

Apart from the competing workload and COVID-19 disruptions and regulations, their lack of money for transport to the clinic hindered ALHIV from attending support group sessions.

> The other challenge is transport, every time they [ALHIV] meet once in a month. You find that they [ALHIV] don't have money to come to the facility to attend the support group - Professional nurse, Langloop CHC.

The implementation of the PSS intervention was constrained because of the competing workload and COVID-19 regulations and restrictions.

Discussion

In this study, we set out to qualitatively explore the implementation of a psychosocial support intervention designed to improve adherence and retention of adolescents on ART and the impact on ALHIV in the Ehlanzeni district. The intervention components were facilitated disclosure, support for treatment adherence, health education using the *Flipster method*, and facilitated social support. We also reported on some constraints encountered while implementing the psychosocial support intervention.

Evidence suggests that non-disclosure of adolescents' HIV status compromises adherence and retention in ART care among ALHIV.[20] "Full" disclosure is a crucial component of the psychosocial support intervention. The World Health Organization (WHO) recommends full disclosure of HIV-positive status to adolescents who acquired HIV perinatally by age of 12 years.[34] The evidence on the association between disclosure and adherence to ART among ALHIV are mixed. While a study found positive association between disclosure and adherence to ART among ALHIV[21], another study conducted in the Eastern Cape province of South Africa observed that awareness of HIV-positive status was not associated with higher rates of adherence, or lower rates of viral suppression among adolescents.[34] In this study, disclosure provided through the PSS program is age-specific and culturally sensitive to proffer disclosure support to ALHIV and these ALHIV are subsequently recruited into the PSS support group. Through this disclosure approach, ALHIV are supported to accept their positive HIV status and are motivated to adhere to and remain engaged in ART.

Adherence monitoring requires approaches that effectively measure patient compliance, and at the same time, identify the non-compliant patients. While studies have assessed the effectiveness of indirect methods of measuring medication compliance such as viral load test, pill count, self-report and electronic monitoring devices.[22] WHO recommends viral load testing for monitoring people living with HIV on ART. Studies have reported that routine viral load monitoring and enhanced adherence counseling are effective in improving the viral suppression rate among people living with HIV. [23,24] Nevertheless, no significant association has been found between enhanced adherence counselling and viral suppression among people living with HIV.[25,26] We did not find any study that explores routine body weight monitoring in managing adherence among ALHIV. In the PSS intervention, support for treatment adherence was implemented through four mechanisms, routine viral load monitoring, enhanced adherence counseling for defaulting adolescents, routine body weight monitoring, and regimen switching for ALHIV who failed first-line treatment. Routine body weight monitoring helped identify adolescents on ART who were under dosed because of their rapid growth and then adjusted to correct ART dosage. Similarly, adolescents on ART who were resistant to the first-line regimen quickly were timeously switched to a second-line regimen. These mechanisms are crucial to ensuring effective management of ALHIV adherence to ART.

We found the health education component of the PSS intervention to encompass several sessions that educate on psychological wellbeing, HIV knowledge, nutrition, drugs and substance abuse, and treatment literacy (importance of medication adherence),[8] which are posited to impact the immediate determinants to adhere to ART.[27] it is observed that people with lower health literacy were less likely to have undetectable viral load.[28] The intervention provides ALHIV with HIV knowledge, treatment and management skills to alter negative attitudes and understand the benefits of sharing positive feedback with peers. Additionally, enhanced counselling is a mechanism used to motivate ALHIV to continue adhering to their medication.[29,30]

The intervention utilized peer educators, and professional nurses to provide HIV treatment care and support for ALHIV, thus strengthening the relationship between treatment supporters/clinicians and ALHIV.[8] In addition, parents/caregivers are trained on how to support the ALHIV on their treatment journey.[8] Therefore, the network support provided to ALHIV is designed to improve their adherence and retention in ART care.[8] In some studies, it has been suggested that ALHIV who receive support from clinicians, peers, and caregivers improve their psychosocial wellbeing, which, in turn, improves adherence and retention in ART.[31–33] In addition, caregivers' support, support from peer educators and clinicians, and the ease of accessing ARVs are found to be effective strategies for improving adherence and retention in ART care.[34–37]

No doubt that the COVID-19 pandemic disrupted the uptake of HIV services such as HIV testing and ART initiations during the COVID-19 restrictions and lockdowns,[33] and particularly access of HIV services among ALHIV.[34] In our exploration, we observed disruptions in holding support group sessions because of lockdown and restrictions. Competing work demand in terms of clinician's level of effort concentrating on attending to COVID-19 infected patients and vaccination exercises also acted as a barrier to the implementation of the PSS intervention. Thus, attending to the HIV treatment needs of newly HIV diagnosed adolescent and existing ALHIV on ART was compromised. However, recent studies have documented innovative strategies to help combat the decline in uptake of health care service amidst an outbreak such as COVID-19. For example, sanitization and use of masks (cloth or surgical) when attending support group sessions, and differentiated service delivery-adopting patient centered approach such as pre packing of medications for either home or community center delivery (depending on the preferred choice and need of the ALHIV),[38,39] as well as increasing access to multi-month dispensing (MMD) of ARTs.[40]

Limitations of the study

This work contains several limitations and opportunities for further research. Despite our efforts to involve broad samples from each participant category (i.e., adolescents, professional health care workers, and peer educators), the final sample did not include peer educators because they were no longer in the employ of RTC at the time of data collection. Therefore, our findings on the implementation of the PSS intervention are mainly derived from accounts of professional nurses, community system technical officers, and adolescents. In addition, the current analysis did not investigate how gender identities and age may influence experiences of the PSS intervention. We suggest that future work focuses on exploring gender and age differences in experiences of the PSS intervention.

Conclusions

The PSS intervention was implemented as planned with a promising positive impact on ALHIV adherence and retention in ART care. However, the implementation of the intervention was challenged by disruptions caused by the COVID-19 restrictions and regulations and competing work demands attributable to the health systems' response to the COVID-19 pandemic. Judiciously strengthening the implementation of the PSS intervention is needed before wide-scale roll-out. We recommend innovative approaches to alter delivery modes of interventions to account for systemic disruptions, as evidenced by the COVID-19 pandemic.

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Paper 6: Psychosocial support programme improves adherence and health systems experiences for adolescents on antiretroviral therapy in Mpumalanga, South Africa

Citation: Psychosocial support programme improves adherence and health systems experiences for adolescents on antiretroviral therapy in Mpumalanga, South Africa (under review), International Journal of Environment Research and Public Health (IJERPH)

Introduction: This paper presents a qualitative exploration of the experiences of adolescents on antiretroviral therapy who participated in the psychosocial support (PSS) programme implemented by Right to Care in Ehlanzeni District Municipality, Mpumalanga, South Africa. The study investigates the experiences of these adolescents pre- and post-enrolment into the intervention. The PSS programme facilitated the process of full HIV disclosure to these adolescents with support from their parents or guardians, while motivating adherence through peer support groups and health education for improved treatment literacy. It was found that the PSS programme improved the ALHIV's understanding of HIV and its treatment and enabled them to build stronger bonds with peers, parents/caregivers, and clinicians. Participants reported positive health systems experiences, improved healthcare provider-client relations, and prompt access to health services. The PSS programme was successful in keeping ALHIV engaged in ART and care despite health service disruptions encountered during the COVID-19 pandemic.

Contribution of candidate: EFO and BvW designed the study. EFO analysed the data and developed the manuscript with editorial and content input from BvW, FCM, and GDH.

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Article

Psychosocial Support Programme Improves Adherence and Health Systems Experiences for Adolescents on Antiretroviral Therapy in Mpumalanga Province, South Africa

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Abstract: (1) Background: Psychosocial support (PSS) plays a significant role in persistent adherence to and retention in antiretroviral therapy (ART) for adolescents living with the human immunodeficiency virus (ALHIV). This paper qualitatively explores the experiences of ALHIV on ART, who participated in a PSS programme in five public primary healthcare facilities in Mpumalanga Province in South Africa during the COVID-19 pandemic. (2) Methods: Data were collected through 24 focus group discussions with 173 ALHIV on ART and subjected to inductive thematic analysis. Informed consent was obtained before all data collection. (3) Results: The PSS programme facilitated the process of full HIV disclosure to these adolescents with the support of parents/guardians while motivating adherence through peer support groups and health education for improved treatment literacy. Participants reported positive health systems experiences, improved healthcare provider–client relations, and prompt access to health services. (4) Conclusions: The PSS programme successfully kept ALHIV engaged in ART care despite the health service disruptions encountered during the COVID-19 pandemic. We recommend rigorous evaluation of the effects of the PSS intervention on adherence to and retention in ART among ALHIV in HIV-endemic settings.

Keywords: adolescents living with HIV; psychosocial support; HIV; AIDS; adherence; retention

check for updates

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1. Introduction

Adolescents account for 5.9% of the burden of HIV, thus representing the fastest-growing age group of people living with HIV globally [1]. In 2016, an estimated 1.2 million HIV-positive children and adolescents lived in eastern and southern Africa, constituting approximately 90% of those living with HIV in Africa [2]. Despite tremendous gains in

Psychosocial Support Programme Improves Adherence and Health Systems Experiences for Adolescents on Antiretroviral Therapy in Mpumalanga Province, South Africa

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Abstract

Background: Psychosocial support (PSS) plays a significant role in persistent adherence to and retention in antiretroviral therapy (ART) for adolescents living with the human immunodeficiency virus (ALHIV). This paper qualitatively explores the experiences of ALHIV on ART, who participated in a PSS programme in five public primary healthcare facilities in Mpumalanga Province in South Africa during the COVID-19 pandemic. (2)

Methods: Data were collected through 24 focus group discussions with 173 ALHIV on ART and subjected to inductive thematic analysis. Informed consent was obtained before all data collection.

Results: The PSS programme facilitated the process of full HIV disclosure to these adolescents with the support of parents/guardians while motivating adherence through peer support groups and health education for improved treatment literacy. Participants reported positive health systems experiences, improved healthcare provider–client relations, and prompt access to health services.

Conclusions: The PSS programme successfully kept ALHIV engaged in ART care despite the health service disruptions encountered during the COVID-19 pandemic. We recommend rigorous evaluation of the effects of the PSS intervention on adherence to and retention in ART among ALHIV in HIV-endemic settings.

Keywords: adolescents living with HIV; psychosocial support; HIV; AIDS; adherence; retention

Introduction

Adolescents account for 5.9% of the burden of HIV, thus representing the fastest-growing age group of people living with HIV globally [1]. In 2016, an estimated 1.2 million HIV-positive children and adolescents lived in eastern and southern Africa, constituting approximately 90% of those living with HIV in Africa [2]. Despite tremendous gains in reducing AIDS-related deaths by 43%, AIDS-related deaths among adolescents in eastern and southern Africa have increased in the last decade [2]. The reason is that adolescents fail to adhere to treatment and find it challenging to remain engaged in antiretroviral therapy (ART).

The World Health Organization defines adolescence as a period of life between 10 and 19 years [3]. Adolescence is when the child transits into adulthood and moves towards greater independence [3]. Concurrently, the adolescent develops a sense of autonomy and a desire to establish an individual identity [4]. In this period of life, many physiological and emotional changes occur within the individual [5]. Adolescents living with HIV (ALHIV) face complex challenges as they explore their sexual identity and form relationships [6], along with challenges with HIV status disclosure [7] and understanding the importance of effective treatment options while on ART [8]. On the other hand, this period is also characterised by high-risk sexual and other behaviours that could be detrimental to their health and well-being [9]. It is argued that despite the well-known need for HIV prevention and reducing reproductive health risks, their age, social, and financial status often limit adolescent access to information and services in many settings [10].

Mental health issues, including neurodevelopmental and cognitive deficits, are also common among ALHIV because of the chronic nature of the disease, fear of HIV disclosure, stigma and discrimination, and depressive disorders [11,12]. Research indicates that HIV-positive adolescents tend to have high levels of common mental health problems that directly affect adherence to ART and retention in care negatively [13,14]. Thus, the impact of common mental health illnesses on the quality of life, in turn, affects adherence to ART and retention in care [12].

While psychosocial interventions for HIV-affected adults have shown improved adherence to and retention in care [15], the knowledge base for ALHIV is sparse. The few studies reported little to moderate impact of psychosocial support (PSS) on adherence to and retention in care among ALHIV. In this paper, we aim to qualitatively explore the experiences of a PSS intervention delivered to ALHIV in five primary healthcare facilities in the Ehlanzeni District of Mpumalanga, South Africa, during the COVID-19 pandemic.

Methods and Materials

Study setting

According to the 2017 National HIV Prevalence, Incidence, Behaviour and Communication survey, the Ehlanzeni District has the second-highest HIV prevalence in South Africa, with an estimated prevalence rate of 17.3%. In our baseline study, we found a 74% viral suppression rate (confidence interval: 73.1–74.8%) among ALHIV on ART in 2019 [16], and retention in care rates at 6, 12, 18, and 24 months of 90.5%, 85.4%, 80.8%, and 76.2%, respectively [17], which remain far from the UNAIDS target of 95- 95-95 by 2030. This study was conducted in five public primary healthcare facilities, Buffelspruit Clinic, Kanyamazane Community Health Centre (CHC), Cunningmoore Clinic, Langloop CHC, and Naas CHC.

2.2. Overview of the Right to Care Psychosocial Support Intervention

Right to Care (RTC) is a registered South African non-governmental organisation that provides quality healthcare services, including prevention, treatment care, and support services for people living with HIV. RTC developed a PSS programme consisting of adolescent and youth-friendly services that aim to improve adherence and retention to ART care among ALHIV. The comprehensive PSS programme package comprises services to address disclosure, treatment adherence, social support, and HIV treatment literacy among adolescents and young adults (ages 10 to 24 years) who are unaware of their HIV-positive status. Adolescents and young adults living with HIV are enrolled on adherence support groups (Figure 1) [18].

The intervention utilises peer supporters to support participants' adherence to and retention in ART care. The peer supporters work with the healthcare system and obtain the names and addresses of adolescents and young who have tested positive for HIV from local healthcare facilities. With the adolescents' assent and consent from their parents/caregivers, the peer supporters register them into the Right to Care psychosocial support (PSS) programme. As participants, the adolescents and young adults are guided and counselled on the importance of adherence to and retention in care and are followed up regularly. In most cases, the peer supporters also fast-track the collection of ARVs for the beneficiaries when they visit the health facilities.

Participants are organised into groups by age (10–13, 14–16, and 17–24 years). The support groups aim to empower adolescents and young people living with HIV to become resilient, better informed, and better able to make well-informed choices about managing their HIV status. The peer supporters are trained to use the psychosocial-oriented Flipster facilitation model developed by RTC to facilitate support group sessions with participants at selected 'safe spaces'.

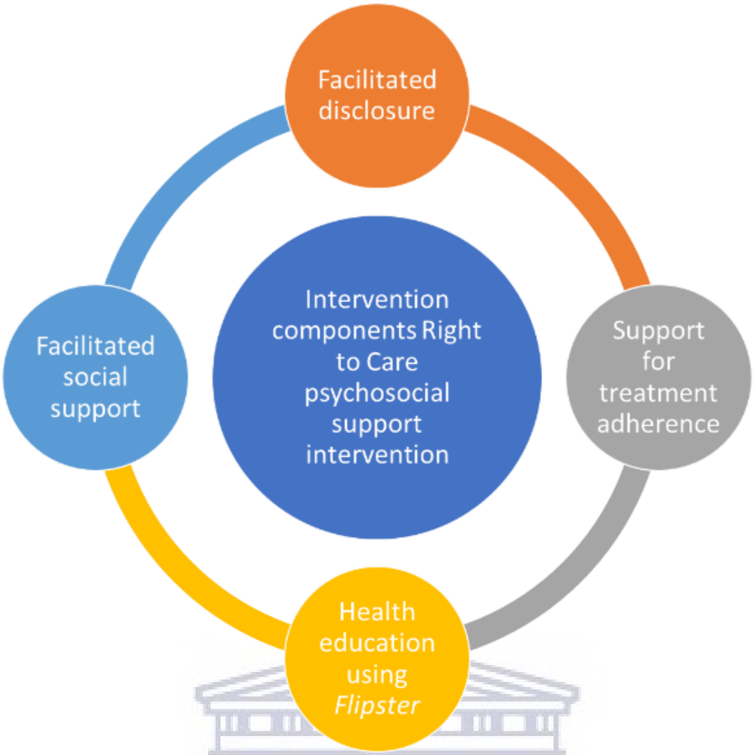

Figure 1. Intervention components of the Right to Care psychosocial support intervention.

2.3. Study Design, Sampling, and Data Collection

Between the 1st and 30th of November 2021, 24 focus group (FGD) discussions were conducted with ALHIV (10–19 years old) on ART who received the PSS programme in five public primary healthcare facilities in Ehlanzeni District. All seven facilities that implemented the PSS programme were included in this study. We applied a qualitative descriptive research design. Participants were purposively selected from five facilities implementing the PSS intervention to obtain a diverse experience of ALHIV receiving the PSS programme. Face-to-face contact was made with participants, their parents/caregiver to brief them on the aim of the research.

FGDs were conducted in the clinics with four groups of ALHIV (*n* = 173); females 10–14 (*n* = 42) and 15–19 years old (*n* = 49); and males 10–14 (*n* = 33) and 15–19 years old (*n* = 49) (Table 1). Those who did not participate gave reasons for being busy on the day of the FGD. ALHIV at Mashinshing and Masibeka clinics did not honour their appointments due to heavy rains and flooding that affected their households. At Buffelspruit Clinic, while only nine

ALHIV females (10–14 years old) participated in the FGD, four male ALHIV (10–14 years old) who came for the FGD discontinued because they became emotional and were referred to a counsellor.

FGD guides were developed in English, translated into Tsonga, back-translated into English, revised, and piloted for clarity. FGDs were conducted in Tsonga and facilitated by two researcher assistants who took notes during the discussion. FGDs were audio-recorded, transcribed, and translated into English by the researcher who facilitated that group's discussion. Local research assistants participated in a week-long training workshop on qualitative data collection techniques and had daily de-briefings with a trained supervisor and ongoing supervision.

Table 1 Age and gender breakdown of ALHIV participating in the focus group discussions

	Females		**Males**	
Facility Name	**10 to 14 years**	**15 to 19 years**	**10 to 14 years**	**15 to 19 years**
Buffelspruit Clinic	9	-	-	-
Kanyamazane CHC	9	12	9	12
Cunningmoore clinic	-	3	-	3
Langloop CHC	4	4	4	4
Mashinshing CHC	-	-	-	-
Naas CHC	20	30	20	30
Masibeka clinic	-	-	-	-
Total	**42**	**49**	**33**	**49**

2.4. Data Analysis

Two researchers coded the data from the FGD, and they were analysed using an iterative process. An initial codebook was developed deductively from the interview guide and inductively from transcripts. The inductive content analysis technique we conducted is suitable for analysing qualitative data collected without the guidance of a theoretical framework but deriving purely from emergent data and formulating themes [19]. Data were captured in an Excel table with five columns in the order of categories, themes, subthemes, codes, and quotations or remarks (Appendix A). We developed codes from the responses provided by the participants. Data codes were reviewed by the authors and later organised into subthemes, themes, and categories (pattern coding). We further read and cross-checked the transcribed data to confirm the developed pattern coding. Data saturation was achieved where no new themes and subthemes emerged from the FGD at a group and individual level.

2.5. Trustworthiness and Credibility

The trustworthiness and credibility of the study were ascertained by doing the following. First, we piloted the interview questionnaires with ALHIV to ensure that the questions were culturally relevant and sensitive to solicit a response. Second, we conducted iterative questioning in data collection dialogues with the study participants. Third, to ensure that all ALHIV participated in the discussion, they were assured that there were no wrong answers as their experiences were paramount. Finally, we followed the relevant aspects of the consolidated criteria for reporting qualitative research (COREQ) outlined by Tong et al. [22,23]. The COREQ checklist aimed to promote clear and comprehensive reporting guidelines for qualitative studies.

2.6. Ethics Approval and Informed Consent

The researchers sought verbal and written consent from all study participants and parents/caregivers when participants were younger than 18. Pseudonyms were used to identify study participants in the transcription of FGD. In addition, participants consented to the publishing of their responses if their identities were kept anonymous. No personal information was collected from participants during the research process.

3. Results

The objectives of the PSS programme were to facilitate and support disclosure, optimise treatment effectiveness, and provide health education and social support to improve adherence to and retention in ART among ALHIV. The themes, subthemes, and codes derived are aligned with these programme objectives and illustrated in Appendix A. A fifth category (recommendations) was formed to capture those themes that did not fit into the initial ones identified but captured “recommendations” to improve the PSS intervention. In this section, we started by capturing the experiences of the ALHIV pre-PSS era and then during the PSS implementation era.

3.1. Pre-PSS Programme

The adolescents were asked how they felt after learning about their HIV status (including those who got to know about their HIV status by themselves) before joining the PSS programme. The participants (ALHIV) reported that they felt depressed, hopeless, confused, and angry, became reclusive, blamed their parents, had low self-esteem, and started smoking. In addition, they had poor health/treatment literacy about HIV, which negatively impacted adherence to and retention in ART.

3.2. Psychological Distress and Maladaptive Behaviours

After knowing their HIV status and before enrolling on the PSS programme, the typical psychological challenges experienced by ALHIV included poor mental health, social and emotional difficulties, and substance abuse.

3.2.1. Poor Mental Health

ALHIV, who reported challenges with their mental health, reported having depressive symptoms because of frequent crying because of knowing their HIV-positive status. Some of them expressed that they cried a lot after learning about their HIV status:

I cried [frequently cried] *and did not want to go to school*. 15-year-old, female Kanyamazane CHC

Additionally, others expressed feelings of hopelessness:

I felt like dying as I thought it’s over with my life: I was nine years [old] *when I found out*. 17-year-old female, Langloop CHC

3.2.2. Social Challenges

ALHIV who learned about their HIV status on their own before a formal disclosure no longer wanted to interact with peers or relatives. They blamed their parents for their HIV status.

I no longer wanted to interact with anyone. 14-year-old female, Buffelspruit Clinic

Another stated:

I was angry at my parents, so I did not want to speak. 17-year-old female, Cunningmoore Clinic

3.2.3. Emotional Challenges

The ALHIV experienced emotional challenges in the form of low self-esteem, feeling confused and angry, and lack of affection from parents and relatives after being disclosed their HIV status.

I became emotional and had low self-esteem after knowing my status. 14-year-old male, Naas CHC

I was furious and upset. 15-year-old female, Kanyamazane CHC

I was confused, not knowing what implications that [I] *was supposed to have in my daily life*. 13-year-old male, Cunningmoore Clinic

Back in the day, I was not getting much love [from family] *before I even knew my status. It's not nice for me, and it's painful*. 18-year-old male, Naas CHC

3.2.4. Substance Abuse

Behavioural challenges in the form of smoking and drinking were common coping strategies used by ALHIV upon learning about their HIV-positive status.

This [knowing my HIV-positive status] *changed my life, and I started smoking and drinking (laughing). I even started smoking weed to make me high and come back late from friends going home*. 16-year-old female, Langloop CHC

3.3. Health Literacy

Health literacy is people's knowledge, motivation, and competencies to access, understand, appraise, and apply health information to make judgments and decisions in everyday life. Decisions concern health care, disease prevention, and health promotion to maintain or improve quality of life during the course of life [24]. In the FDG with ALHIV, we found that inadequate health literacy had a negative impact on medication adherence.

Since it was flu medication, I would skip it since I didn't know that I am[was] *to drink* [it] *for a long time*. 14-year-old male, Cunningmoore Clinic

ALHIV who knew their HIV status commonly reported having poor psychological well-being and inadequate health literacy, leading to sub-optimal adherence to and retention in ART care.

3.4. Post-Intervention

As part of the post-intervention, we recounted the experiences of the ALHIV attending the PSS programme. Based on our findings, the PSS programme facilitated disclosure of HIV status to the ALHIV. It provided health education and an opportunity for a strengthened social support network to improve adherence to and retention in ART care.

3.5. Facilitated Disclosure of HIV Status

Adolescents who were perinatally infected with HIV lacked an understanding of continuous medication intake. Full disclosure was a vital component of the PSS programme in assisting the parents/caregivers to overcome the fear of disclosing to their children. It also clarified the need for adherence and a criterion for recruiting ALHIV into adolescent support groups. The disclosure component of the intervention was facilitated by trained clinicians, providing clarity to ALHIV on their continuous ART intake, enhancing their ability to take responsibility for this, and subsequently improving medication adherence.

The ALHIV narrated how they felt content after disclosure and knowing that they were not alone, also that their positive HIV status could be managed with accurate knowledge and support. One ALHIV stated:

The white Doctor told me, and I was happy because I finally got an answer about what this medication was for, unlike not knowing. 14-year-old female, Langloop CHC

Another ALHIV reported:

…. because on the day they disclosed to me, other children were in the old clinic, and we were told that we were all the same. We all have the virus, and there is nothing to be afraid of. That made me feel happy because there were lots of us that day. 13-year-old female, Langloop CHC

It was noted that facilitating disclosure and counselling encouraged the ALHIV to accept their HIV status.

My mother told me it does not start with me, and it does not end with me. I should also accept because it is not her fault, and as time went by, I started coming to the clinic and accepted since I am not the only one and I shall overcome it. 18-year-old female, Kanyamazane CHC

Furthermore, the ALHIV reported having renewed hope after receiving counselling and knowing that HIV is not an end to life. Additionally, that one can live an ordinary life if one continues to adhere to and remain in ART care.

We feel like we have our whole life and future ahead of us irrespective of our status. 15-year-old male, Naas CHC

Disclosure of their HIV status facilitated by a trained clinician and the counselling received from clinicians was observed to improve the psychological well-being of ALHIV, also renewing their expectations for the future.

3.6. Health Education

The PSS programme enabled a conducive environment for the ALHIV to discuss crucial topics on HIV treatment literacy and address challenges to medication adherence. We present ALHIV's responses on how the health education they received, using a *Flipster* training manual, improved their treatment literacy about HIV and the importance of antiretroviral (ARV) drugs, a better understanding of the virus, and improved adherence to and self-management of ART.

Importance of ARV Medication Adherence

The health education provided to the adolescents enabled them to understand the importance of ARV medication. One ALHIV narrated:

I would get sick, and they [clinicians] *found out that I was not taking my pills, and I was reprimanded for not taking my medications. I was told these pills would help me live … without the ART. I would get sick, lose weight, and end up dead. I continued taking them. I was also told always to eat my food so that by the time I take my pills, I have something in my stomach and should drink a lot of water. So, I took that and continued up until now*. 13-year-old male, Naas CHC

A Better Understanding of the Virus

Similarly, the health education provided to the ALHIV gave them a better understanding of the virus. They recounted how their perceptions of the virus improved based on what they had been taught in the PSS programme.

It is important to take the medication, so you don't have AIDS. The treatment makes the body strong and improves the immune system. 13-year-old female, Kanyamazane CHC

I think it's fine so that the soldiers of the body can stay strong in our bodies. 18-year-old male, Kanyamazane CHC

Improved Adherence

The health education provided to ALHIV reportedly improved their adherence to ART. According to the ALHIV, they explained what could happen to them if they do not adhere to their medication.

I was taking my treatment well, but when I got to grade 7, the problem began since I was not taking it well. At times I would take it, and other times I wouldn't, so I would have a week without taking it, which happened for a month. When I went back to the clinic for my blood, that was when it was explained to my mother and me that I was not taking my treatment, so they explained more what happens when I do not take it, I will die, and from that day, I don't miss taking my pills. 16- years-old male, Naas CHC

Self-Management of ART

As a result of the health education and counselling received during the PSS programme, the adolescents living with HIV were able to take responsibility for their medication intake.

According to an ALHIV, it was noted that:

I am taking responsibility [for] *my health, and I remind myself every time, and even my little sister does remind me, and if I don't take* [it], *she would even report to my mom. So, I thank her a lot she is always there to remind me*. 18-year-old female, Kanyamazane CHC

The health education sessions provided to ALHIV taught them about the importance of ARV, empowered them with a better understanding of HIV, improved adherence to ARV drugs, and aided self-management of ART.

3.7. Counselling and Encouragement

During the health education sessions, ALHIV were counselled and encouraged to continue taking ARV drugs and never miss clinic appointments.

They encourage and tell us every day that we should take care of ourselves and take treatment on time so that we can be healthy kids, and sometimes they take us out for fun walks so that we can relieve stress, and that is very helpful to us as kids. 14-year-old female, Cunningmoore Clinic

3.8. Strengthened Social Support Network

One of the objectives of the PSS programme was to facilitate social support for improved access to ART (medication pick up and clinic attendance) and retention in care by strengthening the ALHIV's support networks. The PSS programme facilitated peer support, parents/caregivers support, and improved client–clinician relationships and health service delivery.

3.8.1. Peer Support

ALHIV, who attended the support group sessions, expressed the feeling of not being alone and, as such, are motivated to take their medication regularly. Being motivated resulted from their interaction with other children who share similar HIV-positive experiences and face similar challenges, such as fears of stigma and discrimination.

This support group has helped me a lot. It is no longer like before, and I know that I am not *alone and there's more of us, and I can talk to someone about a challenge I have and ask if they have the same challenge and if so, we can get to share the solutions and remind each other to take treatment. At least now I have someone with experience just like me, and I can share [discuss] everything I encounter, and I am happy*. 18-year-old male, Kanyamazane CHC

I like the fact that we meet and discuss similar problems. We are open to each other and share similar problems, and it's nice to know there are others who are going through the same problems. 13-year-old female, Naas CHC

I take my treatment regularly because I am attending with others that are taking treatment. 13-year-old male, Kanyamazane CHC

In addition, the ALHIV expressed improved self-esteem because of the support they received from each other and their parents/caregivers during their treatment journey.

Now I feel proud of myself. I no longer look down on myself. The support I'm getting from this group and home has significantly helped. 13-year-old female, Cunningmoore Clinic

3.8.2. Enhanced Parent/Caregiver Support

Support group sessions attended by ALHIV revealed them being supported by their parents/caregivers to take their medication regularly, as these carers acted as their role models. Being reminded and using reminder strategies such as TV programmes and emotional support also played a role. This is because the parents/caregivers were involved during the disclosure process.

Since both my parents are taking it [ARV drugs],-that made me continue taking it because I know that I am not alone. 14-year-old male, Buffelspruit Clinic

She [mother] *always makes sure that I take my ART regularly; even if she is at work, she calls to check if I have taken my ART*. 13-year-old male, Langloop CHC

Television also helps. I know that every time 'Generations' plays on TV, it automatically reminds me to take my ART. 13-year-old male, Langloop CHC

I used to cry a lot and always wanted to be alone and not talk to anyone. I had a difficult time with my anger, but the person who was very supportive in my life was my grandmother. She helped me with the burden and made me understand that this virus was not a death sentence. 13-year-old female, Buffelspruit Clinic

3.8.3. Client–Clinician Relationship

ALHIV attended the support group sessions, bonding with clinicians and having quick access to treatment. The result was their interaction with friendly healthcare workers who facilitated the support group sessions and pre-packed their ARV medication for pick-up.

Yes, it does help me because I can ask the nurse a lot of things, and with my peers as well, I can share whatever is bothering me, and if I forget to take my pills, I ask them what they do if they forget or if they don't. So, it [is] *beneficial*. 18-year-old female, Buffelspruit Clinic

She [professional nurse] *is very open and easy to talk to, and she is not the type of person who gets angry or even shout*[s] *at us. She behaves like us so that she can understand us better*. 11-year-old female, Cunningmoore Clinic

On the experiences of quick access to health services, ALHIV stated that:

It's great to meet in groups, we get assisted very fast and arrive home early because you don't queue. 12-year-old male, Langloop CHC

So far, it is working for me because I don't take time to queue when I am here, and here, I sit for an hour or 30 min. 15-year-old female, Kanyamazane CHC

The PSS programme provided ALHIV with facilitated support and care from peers, parents/caregivers, and clinicians, as well as prompt access to ART, improving adherence to ART and retention in care.

3.9. Recommendations to Improve PSS

ALHIV provided suggestions to improve the PSS programme being implemented. These include reminders to collect medication, psychological motivation, help with transport to the clinic, and confidentiality of clients' clinical files.

The ALHIV indicated that they would like to receive reminder calls or messages to collect their medication.

Before, if I am supposed to come on Sunday, they can call me in the morning and remind me. 13-year-old male, Langloop CHC

ALHIV also suggested they needed a motivational speaker for regular motivation and encouragement.

We will appreciate [it] *if we* [ALHIV] *can have counsellors to motivate us maybe once or twice a year so that we can continue to take our ART with confidence because that encourages and give*[s] *us hope*. 15-year-old female, Buffelspruit Clinic

If we can get a motivational speaker to motivate us about taking our ART, even if it can be twice a year. 14-year-old female, Naas CHC

The ALHIV suggested transportation to enable them to attend support group meetings and pick up their medications at the clinics, especially those far from the clinic.

Maybe help us [ALHIV] *with transport to the facility because we are far*. 14-year-old, female Langloop CHC

ALHIV offered ways that they would like to see clinicians or healthcare workers handle their clinical files in a confidential manner. The ALHIV said they would prefer the clinic to be discreet in handling their clinical files when visiting the clinic.

Our concern is that when we collect our medication, we have files, while those not on treatment don't have files. So, we suggest a plan be made for us not to be publicised by files. 17-year-old female, Cunningmoore Clinic

4. Discussion

In this study, we qualitatively explored the experiences of a PSS programme designed to improve adherence and retention of ALHIV on ART in the Ehlanzeni District in Mpumalanga Province, South Africa. The programme components included facilitated disclosure and social support, as well as support for treatment adherence and health education. We found that the PSS programme improved their understanding of HIV and its treatment and enabled them to build stronger bonds with peers, parents/caregivers, and clinicians. However, there is a need for motivational messaging to create renewed hope for the future and provide transport to attend clinic visits.

Disclosure is found to be empowering and essential for improving adherence and medication acceptance, besides increased responsibility for self-management [25]. However, the evidence base for the association between disclosure and adherence is mixed. While some studies found a positive association between disclosure and adherence [26–30], others reported no association [31–35]. Interestingly, some studies found an opposite effect between disclosure and adherence [36–39], which was linked to depressive symptoms [36] and denial of HIV status [38]. Our study revealed that before enrolment of ALHIV into the psychosocial support intervention, they knew their HIV-positive status without proper counselling, experienced poor psychosocial well-being, mental health, social, emotional, behavioural challenges, and poor treatment literacy. However, ALHIV who were disclosed to (facilitated disclosure) by a trained clinician and recruited into the PSS intervention showed better psychosocial well-being, such as feelings of happiness and not being alone, leading to improved adherence.

A plethora of evidence suggests that health literacy improves medication adherence to and retention in care. A lack of basic HIV knowledge associated with non-adherence was found in a Zambian study [40]. The ALHIV in our study better understood HIV [the virus] and the importance of taking ARV drugs after attending the PSS programme. In this sense, improved treatment literacy about HIV led to improved adherence to and self-management of ART.

We found that the PSS programme facilitated peer-to-peer support, parents/caregivers support, and client–clinician relationships and aided quick access to health service delivery. A study found peer support groups, counselling, supportive healthcare workers, and short waiting times were found to improve adherence to ART [32]. Another study found that family cohesion and social support from caregivers/family were associated with self-reported adherence to ART among HIV-infected adolescents [41]. While one study found the potential of social support interventions to improve mental health [42], another found that a sense of belonging facilitated engagement in ART [43]. Adherence support improved by having a biological mother as a direct supervisor [43].

Limitations of the Study

This work contains several limitations and opportunities for further research. The current analysis did not investigate how gender identities, age, and duration of attending the support groups may influence experiences of the PSS programme.

In addition, the data saturation technique is mainly employed when analysing and reporting qualitative research based on grounded theory. The study adopted the data saturation technique to strengthen the trustworthiness of the research findings.

5. Conclusions

The PSS programme successfully kept ALHIV engaged in ART care despite the health service disruptions encountered during the COVID-19 pandemic. We recommend rigorous evaluation of the effects of the PSS intervention on adherence to and retention in ART among ALHIV in HIV-endemic settings.

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Chapter 4: Discussion and Conclusion

4.1 Introduction

This chapter presents a summary of the main findings of the studies conducted within this doctoral research project and their implications for policy and practice. The limitations of the research project are discussed. The chapter also presents recommendations for programme implementers and policy makers, and for further research.

4.2 Summary of main findings

Using a multi-method study design, this doctoral research project assessed the implementation of a psychosocial support (PSS) intervention comprising multiple components that was designed and implemented by the South African NGO Right to Care (RTC). The intervention targeted ALHIV registered to receive ART at 136 public healthcare facilities – consisting of hospitals, community health centres (CHC) and primary health clinics – in the Ehlanzeni District Municipality in the province of Mpumalanga, South Africa. PSS interventions have been found to improve the mental health of people living with HIV, notwithstanding the evidence base for ALHIV is limited. Furthermore, the evidence on interconnectedness between PSS interventions and ALHIV health outcomes is scarce.

To meet the first objective of reviewing psychosocial support interventions to improve adherence to ART and retention in care among ALHIV – globally and in South Africa – described in the literature, a scoping review was conducted to map out existing psychosocial support interventions that were designed to improve adherence and retention in ART among ALHIV (Okonji et al., 2020). The review identified six published studies. The psychosocial support interventions that were employed included psychosocial education, group adherence counselling, individual counselling and peer-support groups and peer counselling (ibid). Three of these studies found retention in care at 6 months, 12 months, and 24 months to be significantly higher following exposure to the psychosocial interventions. Similarly, adherence to medication was reported as a significant outcome in three studies that implemented interventions such as family clinic day and peer support groups (ibid).

The second objective, to describe baseline viral suppression (proxy for adherence) and retention in care rates among ALHIV prior to enrolment into the PSS intervention, involved a cross-sectional analysis of viral load suppression and a cohort analysis of retention in care rates among ALHIV on ART in Ehlanzeni District Municipality (Okonji et al., 2021; Okonji et al., 2022). It was found that viral suppression among ALHIV was 74%, which fell short of the UNAIDS third 95:95% of people on ART to have effectively suppressed viral loads by 2030 (ibid). In this study, retention in care of ALHIV over a two-year period was found to be 90.5%, 85.4%, 80.8% and 76.2% at 6, 12, 18 and 24 months, respectively.

The third objective, to assess the contextual factors impacting the implementation of the psychological support (PSS) intervention, involved a description and assessment of the contextual factors impacting the implementation of the intervention in Ehlanzeni District Municipality. The biopsychosocial model was used to explore the relationships between the biological, psychological and social factors impacting adherence and retention in care among adolescents (Okonji et al., 2022). The interrelationships between the dimensions of psychological wellbeing, coping strategies, social support, treatment literacy (self-efficacy), and disclosure embedded in the PSS intervention were described. In addition, the thesis explored the mechanisms employed during the implementation of the PSS intervention (Okonji et al., 2022). The PSS intervention, with support from parents and caregivers, facilitated full disclosure of HIV status to adolescents and supported treatment adherence through health education, peer support, improved relations between healthcare providers and clients, and faster access to health service delivery.

The fourth objective of the research was to assess the experiences of adolescents in Ehlanzeni District Municipality living with HIV six months after they joined the PSS intervention. It was found that the PSS intervention improved their knowledge of HIV and its treatment and enabled them to build stronger bonds with peers, parents/caregivers and clinicians. The ALHIV reported positive experiences with healthcare systems, improved provider-client relationships in the healthcare systems, and prompt access to healthcare services.

4.3 Implications of this doctoral research project for policy and practice

The findings of this doctoral research project demonstrate that psychosocial support interventions can play a role in improving adherence to ART and retention in care among adolescents on ART care in the African context. PSS influences different aspects of life, including physical and material aspects, psychological, social, cultural and spiritual aspects. Understanding the behavioural pathways that influence adherence to ART – including the connections and links between biological, psychological, and social factors – can inform programme implementers to design tailored and context-specific interventions that meet the specific needs of adolescents in the South African context. This should be used to inform the development and roll-out of this kind of intervention in other parts of South Africa as well as in other countries in southern Africa that have similar experiences with the HIV epidemic, socio-demographic characteristics, and healthcare systems.

Several implications arise from this doctoral research project for implementers and policymakers.

4.3.1 A holistic and integrated suite of approaches may be needed to improve adherence

Adopting a combination of approaches to address the biological, psychological and social needs of ALHIV in an integrated way may be necessary to improve adherence (Okonji et al., 2022). These approaches may include, for example, providing social and psychological support in conjunction with a high standard of care in clinics (Simms et al., 2022); adherence monitoring (viral load and weight monitoring); ensuring the availability of medication through differentiated care methods, such as fast track or adherence clubs. A combination of these may bolster their self-esteem and self-efficacy, which in turn will improve their self-management regarding medication adherence and retention in care and subsequently improve their treatment outcomes.

In the psychosocial support intervention investigated in this doctoral research project, psychological wellbeing, coping strategies, social support, self-efficacy, and ‘full’ disclosure, coupled with biomedical related services such as viral load and weight monitoring that were provided as standard of care, were key components in the intervention to improve ART adherence and retention in care.

‘Full’ disclosure is a crucial component of the psychosocial support intervention. The World Health Organization (WHO) recommends ‘full’ disclosure of HIV-positive status to adolescents who acquired HIV perinatally by the age of twelve (Friedman et al., 2017). However, the evidence regarding the association between disclosure and adherence to ART among ALHIV is mixed. While Mi et al. (2020) found a positive association between disclosure and adherence to ART among ALHIV, another study conducted in the Eastern Cape province of South Africa observed that awareness of HIV-positive status was not associated with higher rates of adherence, or higher rates of viral suppression, among adolescents (Friedman et al., 2017). In the psychosocial support (PSS) intervention under study in this research, disclosure was made using an age-specific and culturally sensitive approach to offer disclosure support to ALHIV, and these ALHIV were subsequently recruited into the PSS support group after learning their HIV status. Through this disclosure approach, ALHIV were supported to accept their positive HIV status and to adhere to ART and remain engaged in care.

Adherence monitoring requires approaches that effectively measure patient compliance and identify non-complying patients (Jimmy & Jose, 2011). While studies have assessed the effectiveness of indirect methods of measuring medication compliance, such as viral load testing, pill count, self-reporting and electronic monitoring devices, the WHO recommends viral load testing for monitoring people living with HIV on ART (Laxmeshwar et al., 2020). Studies have reported that routine viral load monitoring and enhanced adherence counselling are effective in improving the viral suppression rate among people living with HIV (Bvochora et al., 2019; Laxmeshwar et al., 2020). Nevertheless, no significant association has been found between enhanced adherence counselling and viral suppression among people living with HIV (Nasuuna et al., 2018; van Loggerenberg et al., 2015). Therefore, psychosocial support interventions should be designed to complement the biomedically-oriented standard of care provided at the clinics to provide a more holistic approach to care to ALHIV.

Though the biopsychosocial model addresses the biological, social, and psychological aspects of the life of ALHIV, it fails to consider the economic needs of ALHIV such as poverty and unmet material needs.

4.3.2 High viral loads may persist among ALHIV on ART due to poor clinical care practice

A second implication arising from this research is that even where adherence to ART by ALHIV is high, high viral loads may persist if ARVs are not given in high enough doses for optimal efficacy (Okonji et al., 2022). In addition, the misclassification of latent TB cases among ALHIV can result in dropping out of care (i.e., mortality) among this age group (Okonji et al., 2022). This research also found that delayed identification and misclassification of viral non-suppression can result in the decision to switch to a second-line or third-line ARV; in addition to this course of action being costly; it is not always effective in achieving viral suppression and can thus result in continued viral non-suppression or viral rebound (Okonji et al., 2021). There is evidence that delayed detection of treatment failure may increase drug toxicity which can, in turn, lead to the accumulation of drug resistance-associated mutations, which may increase the probability of morbidity and mortality (Kantor et al., 2009). This is likely due to the quality of clinical care provided to ALHIV on ART.

In this research, the psychosocial (PSS) intervention implemented by Right to Care supported treatment adherence through four mechanisms: routine viral load monitoring, enhanced adherence counselling for defaulting adolescents, routine body weight monitoring, and regimen switching for ALHIV who failed first-line treatment (Okonji et al, 2022). Routine body weight monitoring helped identify adolescents on ART who were under-dosed because of their rapid growth and enable dosing to be corrected. Similarly, adolescents on ART who were resistant to the first-line regimen quickly were timeously switched to a second-line regimen. These mechanisms are crucial to ensuring effective management of ALHIV adherence to ART.

In South Africa, there is shortage of critical healthcare staff, which is exacerbated by the increasing burden of TB and HIV infections and other pandemics (Khan et al., 2021; Marchal et al., 2005). Even with task shifting to lower cadres of health care workers, studies have shown that staff shortage risks competing with other work demands – especially, healthcare workers' adherence to clinical treatment guidelines (Jeffery et al., 2014; Jin, Kovner & Stimpfel, 2016; Makhado et al., 2020; Makhado et al., 2018). In South Africa, the nurse-initiated management of anti-retroviral therapy (NIMART) training provides professional nurses with the skills to initiate ART. Nevertheless, the management of ART patients remains a challenge, creating a gap in the treatment continuum of care. Effective management of ALHIV on ART relies on proper implementation and adherence to the clinical treatment guidelines by NIMART-trained nurses (Makhado et al., 2020). Reliance on enhanced adherence counselling (EAC) alone to correct unsuppressed viral loads is insufficient to achieve the third 95: 95% of all ART patients having effectively suppressed viral loads.

4.3.3 A gap in treatment exists for older adolescents

This research identified a treatment gap among older adolescents (ages 15 to 19) as they transition from paediatric care to adult care: retention rates are lower for older adolescents than for younger adolescents (Okonji et al, 2022). While few studies have reported on the transition outcomes of ALHIV in southern and eastern Africa, those that have addressed this aspect have noted that barriers such as a lack of adequate clinic infrastructure, inadequate staff training and communication between paediatric and adult clinicians, as well as fear of stigma, have been found to hinder successful transitioning of adolescents from paediatric care to adult care (Dahourou et al., 2017). Zanoni et al. (2020) found that ALHIV receiving care in paediatric clinics had a higher retention rate compared to those transitioned to adult clinics. In South Africa, while the Department of Health (South Africa Department of Health, 2017) has adopted a blueprint for action to improve the transition from paediatric to adolescent adult care and down referral as part of the National Adolescent and Youth Health Policy, there is at the time of writing no implementation guideline on how the transitioning should be done.

4.3.4 Parents and caregivers play a crucial role in the disclosure of HIV status to ALHIV and treatment support

Involving parents/caregivers in the disclosure process by a trained health care worker helps the parent/caregiver overcome their fear of being blamed by their children and helps the parents/caregiver support the ALHIV through their treatment journey (Okonji et al., 2022). A recent study reported that family members play a key role in providing transportation to appointments and pill reminders for ALHIV (Malo et al., 2022). Furthermore, families provide both emotional support and assessment support, encouraging ALHIV to adhere to their medication regimen by reflecting upon the importance of this to their futures (Malo et al., 2022).

4.3.5 COVID-19 disruptions of health service uptake

It would be amiss not to discuss how the COVID-19 pandemic disrupted the uptake of HIV services – for example, the impact of restrictions and lockdowns on HIV testing and the initiation of ART in South Africa – and, in particular, access to HIV services for ALHIV (Okonji et al., 2022). The implementation of the PSS intervention was impacted as support group sessions were disrupted because of lockdown and restrictions. COVID-19 also competed for clinicians’ time as they attend to patients infected with COVID-19 and rolled out vaccines, thus compromising the treatment of newly diagnosed adolescents with HIV as well as those already on ART, negatively impacting the implementation of the PSS intervention. However, recent studies have documented innovative strategies to help combat the decline in the uptake of healthcare services during an outbreak such as COVID-19: for example, had sanitization and the use of face masks (cloth or surgical) when attending support group sessions, following a patient-centred approach to differentiate service delivery (such as offering ALHIV the choice of delivery of pre-packed medications to their homes or a nearby community centre) (Grimsrud & Wilkinson, 2021; Mukumbang et al., 2020), as well as increasing access to multi-month dispensing (MMD) of ART (Bailey et al., 2021).

4.4 Study limitations

The limitations of the various studies undertaken within this doctoral research project are discussed in the respective papers presented in Chapter 3. However, the following are acknowledged here:

1. The psychosocial support (PSS) programme had been implemented by Right to Care for about 6 months before the COVID-19 outbreak. This made it impossible to quantitatively assess the effect of duration of participation in the programme, as well as the effects other socio-economic and mental health variables that may have influenced the experiences of ALHIV participating in the PSS intervention.
2. The qualitative research was focused on data collected from five programme implementers selected from five health centres. While they described the implementation of the various components of the PSS intervention in detail, data was not collected from the peer educators because they were no longer in the employ of RTC at the time of data collection. This potentially limited the generalisability of findings. However, since the programme was implemented at the district level, it is possible that the results observed in this study would be similar in the other districts where RTC is implementing the PSS intervention. While this chapter has spelt out the wider contribution of this research to the body of knowledge, there is concern that the scale and context of the studies carried out within this doctoral research project were too limited for their findings to be generalised to other geographical contexts within South Africa.

3. Due to the COVID-19 outbreak and the disruptions which ensued, it was not possible to quantitatively assess the impact of the PSS intervention at 12 months after participants' entry into the programme. In addition, it was not possible to interview parents/caregivers of ALHIV as COVID 19 regulations prohibited gatherings.

4.5 Recommendations

The recommendations that emanate from the findings of this doctoral research project can be grouped into three categories: recommendations for policy, practice (programme implementation) and future research.

4.5.1 Key recommendation for policy

1. This research found that high viral loads persist among ALHIV on ART despite measures such as enhanced adherence counselling or switching to second-line or third-line ART regimens. This demonstrates that these measures are insufficient to achieve the third 95% target: 95% of all ART patients having effectively suppressed viral loads by 2030. It is recommended that the paediatric ART treatment guidelines be simplified in such a way that it is easy for NIMART-trained nurses to adhere, supporting the provision of quality clinical care to ALHIV which, in turn, will support the effective management of ALHIV on ART.
2. In light of the high rate of dropout from ART among older adolescents living with HIV, it is recommended that the Department of Health develop a standard guideline for transitioning adolescents from paediatric care to adult care.

4.5.2 Recommendation for practice (for clinicians or programme implementers)

1. This research revealed that the management of ALHIV on ART requires a holistic approach that considers the interaction of biological, psychological, and social factors in the design of interventions to improve the health outcomes of individuals within this age group.

2. This research found that the quality of clinical care provided to ALHIV by NIMART-trained nurses (such as proper classification or identification of latent TB cases and timely switching of ALHIV with persisting high viral load to second-line or third-line ART regimens) may be compromised due to competing work demands, including shorter consultation time with ALHIV with respect to the number of patients waiting for care. This indicates that greater emphasis must be placed on ensuring a dedicated NIMART-trained nurse is available for adolescents and that the ART guideline is followed; this can be achieved by instituting continuous training on the management of ALHIV on ART, supportive supervision, and improved communication among Department of Health clinicians and implementing partners.
3. To mitigate the negative impact of systemic disruptions, such as those caused by the COVID-19 pandemic, on treatment, it is recommended the healthcare facilities implement a range of strategies to ensure continuity of care. Strategies which may promote continuity of care include the use of face masks (cloth or surgical) and hand sanitizer by participants attending support group sessions; differentiated, patient-centred service delivery – for example, pre-packing of medications for delivery to homes or community centres, depending on the preference or need of the patient; and increased access to multi-month dispensing (MMD) of ARTs for stable patients to reduce the frequency of facility visits during pandemics.

4.5.3. Recommendation for future research

1. A rigorous quantitative evaluation of the impact of the PSS programme on adherence to ART and retention in care among ALHIV in HIV-endemic settings 12 months after entry into the programme is needed.
2. Further research is needed to explore the influence of gender, age and duration of the intervention on the experiences of ALHIV participating in the PSS programme.
3. Further research is needed to investigate best practices for transitioning adolescents from paediatric to adult care.

4.6 Conclusion

Globally, ALHIV have been found to experience the greatest challenges in accessing the HIV treatment cascade. To ensure no population is left behind in treatment, ALHIV have continued to remain the focus of programme implementers to achieve the UNAIDS second 95 (95% of all people living with HIV initiated on ART), and third 95 (95% of all ART patients having effectively suppressed viral loads) targets by 2030. There is a need to design interventions to provide psychosocial support to ALHIV to help them to improve their self-efficacy and self-competency so that they will be better equipped to be able to adhere to their ART regimens and follow through with regular visits to healthcare facilities.

This doctoral research project has established that the management of ALHIV for improved ART adherence and retention in care requires a recognition of, and response to, the complex biological, psychological, and social issues relevant to ALHIV. The Right to Care PSS programme facilitated full disclosure of HIV status to adolescents, supported treatment adherence through health education, facilitated peer support and family/caregiver support, promoted positive health care provider- and client relations, and fast-tracked quick access to health service delivery. The ALHIV participating in this intervention reported positive experiences with health systems with improved health care provider-client relations and fast-tracked access to health services. The PSS programme was found to be successful in keeping ALHIV engaged in ART and care despite the health service disruptions encountered during the COVID-19 pandemic. However, there is a need for further investigation to assess viral suppression and retention rates 12 months after enrolment in the PSS intervention.

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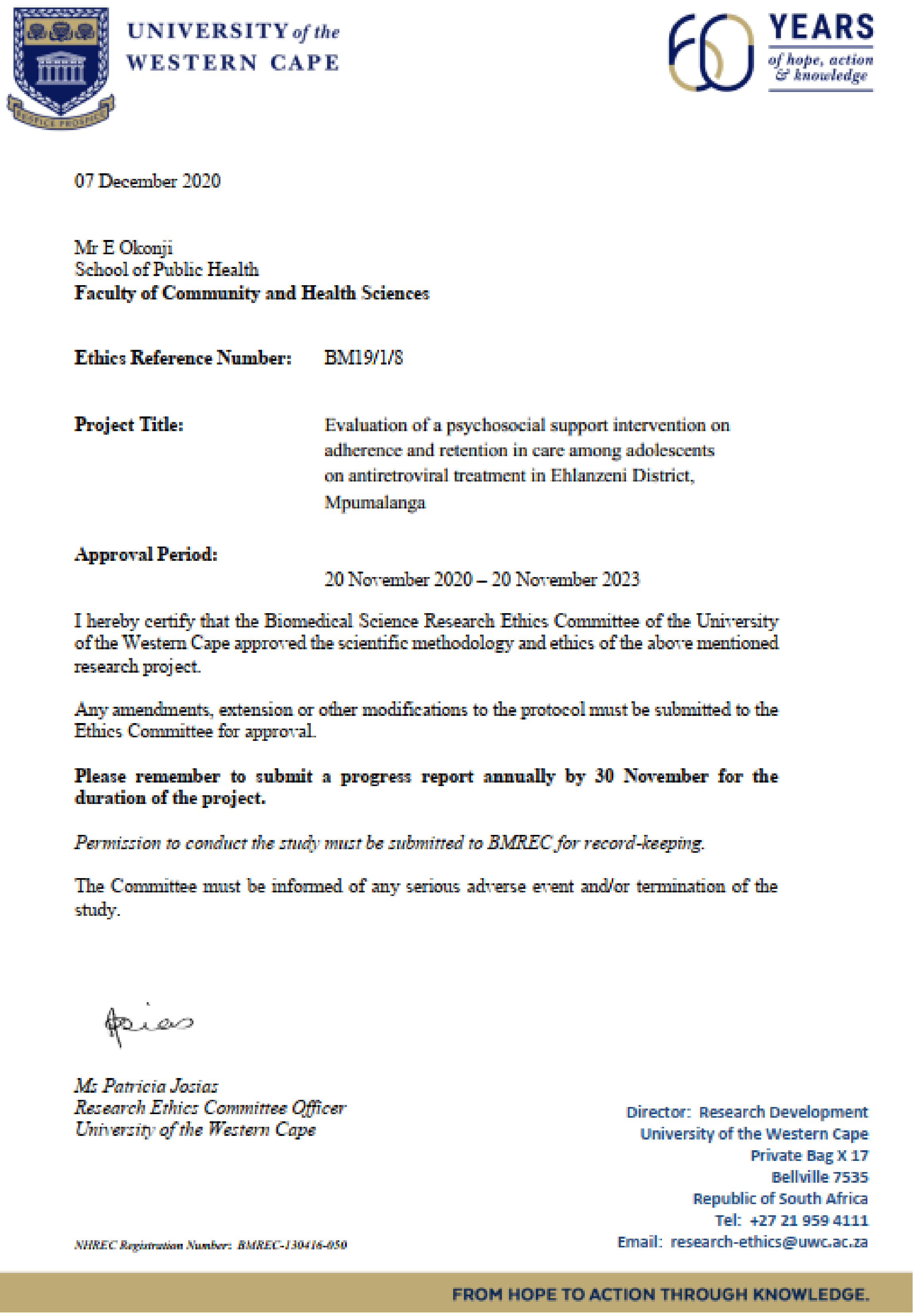
Appendices

Appendix 1: Ethical clearance from University of Western Cape



UNIVERSITY *of the* WESTERN CAPE

YEARS *of hope, action & knowledge*

07 December 2020

Mr E Okonji
School of Public Health
Faculty of Community and Health Sciences

Ethics Reference Number: BM19/1/8

Project Title: Evaluation of a psychosocial support intervention on adherence and retention in care among adolescents on antiretroviral treatment in Ehlanzeni District, Mpumalanga

Approval Period: 20 November 2020 – 20 November 2023

I hereby certify that the Biomedical Science Research Ethics Committee of the University of the Western Cape approved the scientific methodology and ethics of the above mentioned research project.

Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.

Please remember to submit a progress report annually by 30 November for the duration of the project.

Permission to conduct the study must be submitted to BMREC for record-keeping.

The Committee must be informed of any serious adverse event and/or termination of the study.

Ms Patricia Josias
Research Ethics Committee Officer
University of the Western Cape

Director: Research Development
University of the Western Cape
Private Bag X 17
Bellville 7535
Republic of South Africa
Tel: +27 21 959 4111
Email: research-ethics@uwc.ac.za

NHREC Registration Number: BMREC-130416-050

FROM HOPE TO ACTION THROUGH KNOWLEDGE.

Appendix 2: Research Approval Letter from Provincial Department of Health

health
MPUMALANGA PROVINCE
REPUBLIC OF SOUTH AFRICA

Indwe Building, Government Boulevard, Riverside Park, Ext. 2, Mbombela, 1200, Mpumalanga Province
Private Bag X11285, Mbombela, 1200, Mpumalanga Province
Tel I: +27 (13) 766 3429, Fax: +27 (13) 766 3458

Litiko Letemphilo | Departement van Gesondheid | UmNyango WezeMaphilo

Enq: 013 766 3766/3511
Ref: MP_202102_006

Research Approval Letter

Mr E Okonji
PO BOX 7560
11 Harvest Street. Normandie estate
Brackenfell, 7560

TITLE: APPLICATION FOR RESEARCH APPROVAL: EVALUATION OF A PSYCHOSOCIAL SUPPORT INTERVENTION ON ADHERENCE AND RETENTION IN CARE AMONG ADOLESCENTS ON ANTIRETROVIRAL TREATMENT IN MPUMALANGA SOUTH AFRICA

Dear Mr Okonji

The Provincial Department of Health Research Committee has approved your research proposal in the latest format you sent.

• Approval Reference Number:	MP_202102_006
• Data Collection Period:	01/03/2021 to 12/08/2021.
• Approved Data Collection Facilities:	* Ehlanzeni District Clinics

Kindly ensure that conditions mentioned below are adhered to, and that the study is conducted with minimal disruption and impact on our staff, and also ensure that you provide us with a soft or hard copy of the report once your research project has been completed.

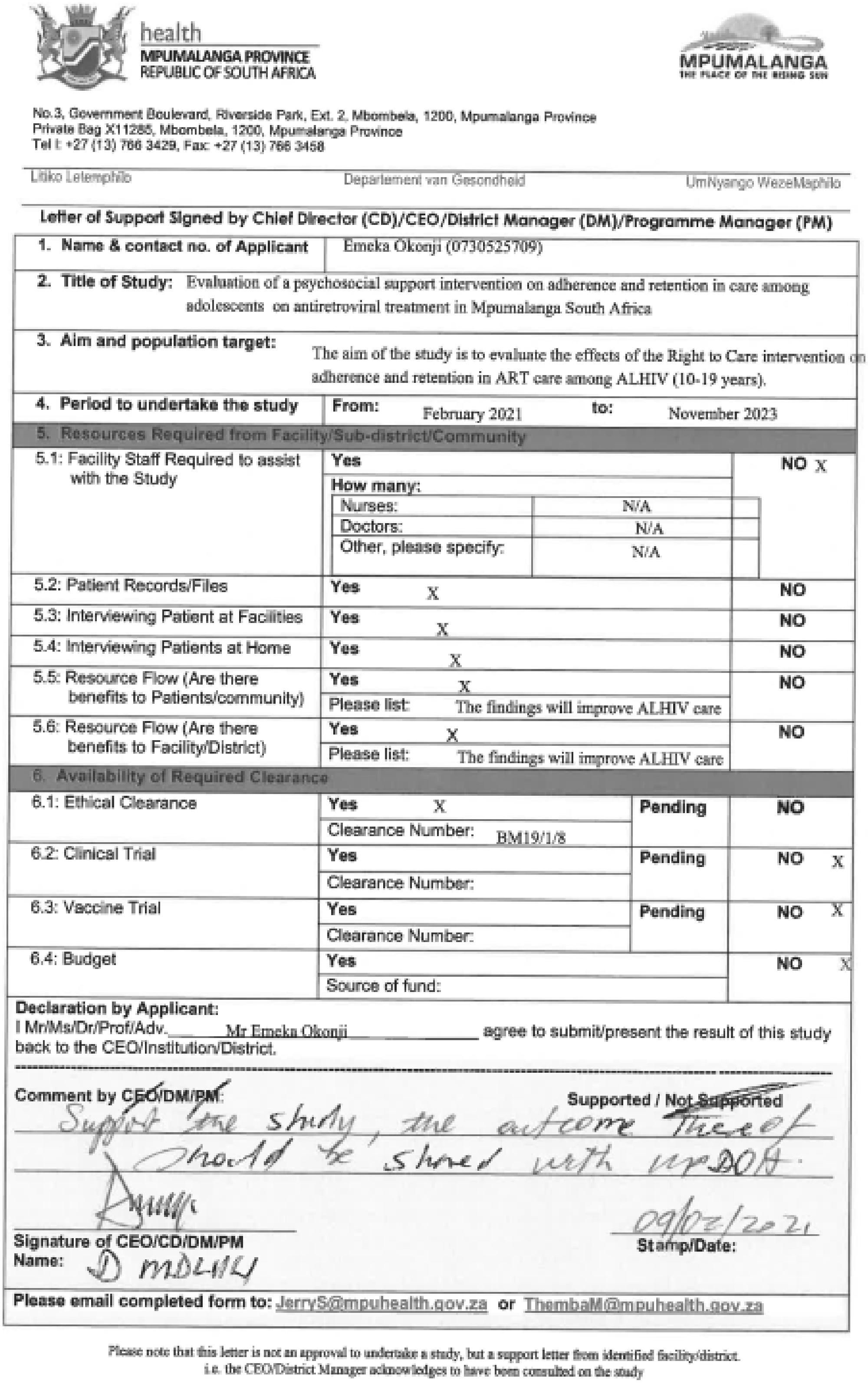
Conditions:
- *Researchers not allowed to make copies or take pictures of medical records.*
- *Kindly notify the facility manager a week BEFORE you start with data collection to ensure that conditions are conducive in the facility*

Kind regards

DR C NELSON
MPUMALANGA PHRC CHAIRPERSON
DATE: 19/02/2021

MPUMALANGA
THE PLACE OF THE RISING SUN

Appendix 3: Letter of support from provincial Department of Health



health
MPUMALANGA PROVINCE
REPUBLIC OF SOUTH AFRICA

MPUMALANGA
THE PLACE OF THE RISING SUN

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Litiko Letemphilo | Departement van Gesondheid | UmNyango WezeMaphilo

Letter of Support Signed by Chief Director (CD)/CEO/District Manager (DM)/Programme Manager (PM)

1. Name & contact no. of Applicant	Emeka Okonji (0730525709)	
2. Title of Study:	Evaluation of a psychosocial support intervention on adherence and retention in care among adolescents on antiretroviral treatment in Mpumalanga South Africa	
3. Aim and population target:	The aim of the study is to evaluate the effects of the Right to Care intervention on adherence and retention in ART care among ALHIV (10-19 years).	
4. Period to undertake the study	**From:** February 2021	**to:** November 2023

5. Resources Required from Facility/Sub-district/Community			
5.1: Facility Staff Required to assist with the Study	**Yes** **How many:** Nurses: N/A Doctors: N/A Other, please specify: N/A		**NO** X
5.2: Patient Records/Files	**Yes** X		**NO**
5.3: Interviewing Patient at Facilities	**Yes** X		**NO**
5.4: Interviewing Patients at Home	**Yes** X		**NO**
5.5: Resource Flow (Are there benefits to Patients/community)	**Yes** X Please list: The findings will improve ALHIV care		**NO**
5.6: Resource Flow (Are there benefits to Facility/District)	**Yes** X Please list: The findings will improve ALHIV care		**NO**
6. Availability of Required Clearance			
6.1: Ethical Clearance	**Yes** X Clearance Number: BM19/1/8	**Pending**	**NO**
6.2: Clinical Trial	**Yes** Clearance Number:	**Pending**	**NO** X
6.3: Vaccine Trial	**Yes** Clearance Number:	**Pending**	**NO** X
6.4: Budget	**Yes** Source of fund:		**NO** X

Declaration by Applicant:
I Mr/Ms/Dr/Prof/Adv. Mr Emeka Okonji agree to submit/present the result of this study back to the CEO/Institution/District.

Comment by CEO/DM/PM: **Supported / ~~Not Supported~~**

Support the study, the outcome thereof should be shared with MpDOH.

Signature of CEO/CD/DM/PM
Name: D MDLULI

09/02/2021
Stamp/Date:

Please email completed form to: JerryS@mpuhealth.gov.za **or** ThembaM@mpuhealth.gov.za

Please note that this letter is not an approval to undertake a study, but a support letter from identified facility/district. i.e. the CEO/District Manager acknowledges to have been consulted on the study

Appendix 4: ADOLESCENTS INFORMATION SHEET

Project Title: Evaluation of a psychosocial support intervention on adherence and retention in care among adolescents on antiretroviral treatment in Ehlanzeni, Mpumalanga south Africa.

Purpose of the study

This is a research project being conducted by Mr Emeka Okonji and Professor Brian Van Wyk at the University of the Western Cape. We are inviting you to participate in this research project because you have been identified to possess relevant information about the psychosocial support intervention being provided by Right to Care. The purpose of this research project is to gain a better understanding of the barriers and facilitators of adherence and retention in care, as well as the impact of the PSS intervention you are currently receiving. By learning more about this process, we hope to help service providers like RTC programme to better support adolescents living with HIV.

What will I be asked to do if I agree to participate?

You will be asked to participate in an interview. The interview will take between 1-2hrs and will be conducted at your support group sessions. The questions will reflect your understanding of how the RTC programme work and your opinion on whether it provides the psychosocial support you think will enable adolescents living with HIV adhere to ART and be retained in care.

Would my participation in this study be kept confidential?

The researchers undertake to protect your identity and the nature of your contribution. To ensure your anonymity, (1) your name will not be included on the interview recordings and transcripts; and (2) a code will be placed on the transcripts and other collected data.

To ensure your confidentiality, all the field notes, recordings and transcriptions will be locked up in a safe drawer during the studies, and when the study is completed. With the soft copies of the transcripts, the files will be protected using password-protected computer files.

If we write a report or article about this research project, your identity will be protected.

In accordance with legal requirements and/or professional standards, we will disclose to the appropriate individuals and/or authorities information that comes to our attention concerning child abuse or neglect or potential harm to you or others. In this event, we will inform you that we have to break confidentiality to fulfil our legal responsibility to report to the designated authorities.

This research project involves making audiotapes of you. The reason for this is because a lot of information is required and it would be easy for the investigators to keep track of all the information if the interviews are recorded. In this way, the investigators do not miss any important information that could help to understand the way the psychosocial support intervention works. These recordings will be stored in a locked drawer where only the investigators have access to and the transcribed copies of the interviews will be password coded. These recordings and the transcripts will be destroyed after a period of five years.

This study will use focus groups therefore the extent to which your identity will remain confidential is dependent on participants' in the Focus Group maintaining confidentiality.

What are the risks of this research?

All human interactions and talking about self or others carry some amount of risks. We will nevertheless minimize such risks and act promptly to assist you if you experience any discomfort, psychological or otherwise during the process of your participation in this study. Where necessary, an appropriate referral will be made to a suitable professional for further assistance or intervention.

What are the benefits of this research?

This research is not designed to help you personally, but the results may help the investigators learn more about the psychosocial support being provided by the peers in the Right to Care adolescent programme. We hope that, in the future, other people might benefit from this study through improved understanding of how the RTC programme work. The findings of the study could guide policy on the development, effective implementation and smooth running of the RTC programme across all the districts in South Africa.

Do I have to be in this research and may I stop participating at any time?

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.

What if I have questions?

This research is being conducted by Emeka Okonji of the School of Public Health at the University of the Western Cape. If you have any questions about the research study itself, please contact Emeka Okonji at: University of the Western Cape, Robert Sobukwe Road, Bellville, Tel; 0730525709; email: emekaokonji@yahoo.com or 3718602@myuwc.ac.za. Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

Director of UWC School of Public Health
Prof Uta Lehmann School of Public Health Head of Department
University of the Western Cape Private Bag X17
Bellville 7535
soph-comm@uwc.ac.za
Prof Anthea Rhoda

Dean of the Faculty of Community and Health Sciences University of the Western Cape
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BIOMEDICAL RESEARCH ETHICS ADMINISTRATION

University of the Western Cape
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Bellville 7535
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Appendix 5: ADOLESCENT FOCUS GROUP DISCUSSION CONSENT FORM

Title of Research Project: Evaluation of a psychosocial support intervention on adherence and retention in care among adolescents on antiretroviral treatment in Ehlanzeni, Mpumalanga south Africa

The study has been described to me in language that I understand. My questions about the study have been answered. I understand what my participation will involve, which include audiotape recording of the discussion and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits.

Audio taping/Videotaping/Photographs/Digital Recordings

This research project involves making [audiotapes/videotapes/photographs] of you. [Then explain why the tapes/photos are being made, who will have access to them, where they will be stored, and when (or if) they will be destroyed]

_____ I agree to be [videotaped/audiotaped/photographed] during my participation in this study.

_____ I do not agree to be [videotaped/audiotaped/photographed] during my participation in this study.

Participant's name………………………..

Participant's signature……………………………….

Date………………………

Appendix 6: ADOLESCENTS FOCUS GROUP CONFIDENTIALITY BINDING FORM

Title of Research Project: ***Evaluation of a psychosocial support intervention on adherence and retention in care among adolescents on antiretroviral treatment in Ehlanzeni, Mpumalanga south Africa***

The study has been described to me in language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone by the researchers. I understand that the discussion will be audiotape recorded. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits. I understand that confidentiality is dependent on participants' in the Focus Group maintaining confidentiality.

I hereby agree to uphold the confidentiality of the discussions in the focus group by not disclosing the identity of other participants or any aspects of their contributions to members outside of the group.

Audio taping/Videotaping/Photographs/Digital Recordings

This research project involves making [audiotapes/videotapes/photographs] of you. [Then explain why the tapes/photos are being made, who will have access to them, where they will be stored, and when (or if) they will be destroyed]

___ I agree to be [videotaped/audiotaped/photographed] during my participation in this study.

___ I do not

Participant's name……………………………………….

Participant's signature…………………………………..

Date………………………

Appendix 7: Focus group discussion guide

Focus group discussion guide for adolescents living with HIV Standard Information:

Name of Interviewer:

Position:

Date of interview:

Consent and anonymity: (document their preference)

1. In your opinion, is it good to take your ART always? If you say it is good, why do you think so. If not good, why do you think so.

2. In your opinion, what can make adolescents (children) take their ART regularly?

   Probe:

   a) Do they miss taking their ART at times?
   b) What situations can make adolescents (children) not take medication regularly (barriers)?
   c) What situations can make adolescents (children) take medication regularly (enhancers).

3. In your opinion, is it good to miss your clinic visit (appointment) to pick ART?

   Probe:

   a) Do they miss to pick up ART from clinics at times?
   b) What situations can make adolescents (children) miss to pick up ART from clinic (barriers)?
   c) What situations can make adolescents (children) regularly pick up ART from clinic (enhancers).

4. Can you tell me about your experience when you first learned you were HIV positive?

   Probe:

   a) HIV journey,
   b) Feelings, emotions, self-esteem.
   c) Coping strategies,

   d) Disclosed to whom,
   e) Substance (alcohol) abuse,
   f) Received support from parents/caretaker/relatives/friends.

5. In your opinion, what can you tell me about the adolescent support group you are attending at the clinic? **Probe:** *were you able to attend the groups? How often? What was good/not so good about the groups? Did you enjoy the group sessions? What would make the groups better?*

6. How can the adolescent support programme benefit adolescent's (children) to improve regular taking of ART and never miss clinic appointments?

Probe:

   a) what kind of support would you need to help you never miss taking your medication and never miss clinic appointments?

7. Anything else you would like to share?

Appendix 8: INFORMATION SHEET FOR PARENTS

Your child is invited to take part in a research study. Before you decide whether to allow him or her to participate, you need to understand why the research is being done and what it would involve. Please take the time to read or to listen as I read the following information. You may talk to others about the study if you wish. Please ask me if there is anything that is not clear, or if you would like more information. When all of your questions have been answered and you feel that you understand this study, you will be asked if you permit your child to participate in the study (if he or she wants to), and if yes to sign this Informed Consent form.

Purpose of the Study and Study Requirements

The purpose of the study is to gain a better understanding of the barriers and facilitators of adherence and retention in care, as well as the impact of the PSS intervention they are currently attending. We know that these decisions are not always easy, but we do not know enough about how caregivers make these decisions. By learning more about this process, we hope to help service providers like RTC PSS intervention to better support adolescents living with HIV.

Why have we invited your child to take part?

Your child has been invited to take part because s/he should be part of a support network for adolescents living with HIV.

What will happen if your child takes part?

If you agree to allow your child to take part in the study, we will invite him or her to join a private, small group discussion with several other adolescents from the adolescent support groups.

How long will the study last?

The focus group discussion will last 1-2 hours.

Risks/Benefits

What are the risks of the study? It is possible that some discussion questions or topics will make your child feel unhappy. We will explain to him or her that if we ask a question that he or she does not want to answer, he or she can just say so, and we will move over that one. Your child does not have to take part in any talk or things that he or she does not want to.

What are the benefits of participating? Findings from this study will be used to develop resources to help programmes like Right to Care and Department of Health support the needs of HIV-positive children, caregivers and families.

Confidentiality

Will my child's participation in the study be kept confidential?

The information that is collected during the study will be kept private. No one aside from the support group coordinator will be told that your child has participated in the study. The study team will make every effort to protect his or her privacy and maintain the confidentiality of all the information that he or she provides. This includes audio recordings of our discussions and any notes we take. When the session is over, we will transcribe the audio recording. We will remove his or her name and references to your family from this transcript. Once we verify that the recording is transcribed correctly, we will destroy the audio recording. The only thing linking your child to the documents will be a secret code that only the researchers will know. Once the study is over, this code will be removed permanently. We will never use his or her name or other identifiers in reports from this study. Throughout the study, we will store and transfer all documents in a manner that our institution has approved for studies like this one. Finally, while open and honest answers are appreciated and important to the research, your child should not feel obligated to share anything during the discussion that he or she would not want others in the room to repeat outside. We will encourage group members to keep discussions private, but we cannot guarantee this.

Voluntariness

What are his or her rights as a research participant/subject?

Your child does not have to take part in this study if you do not want him or her to participate or if the child does not want to participate. He or she can also stop at any time. Even if you or your child say yes now and then you change your minds later, that will be OK. If you or your child say no to the research or stop, it will not affect any other services or programmes that your child might receive from Y+ Network. If your child decides to stop taking part in the research, we will stop using the information your child has given us for the research, and we will remove any information that we have not used yet for the research or reports. If your child removes his or her name, it will not have any effect on any other services that your child receives.

Other Information

What will my child receive for participating? If your child participates in this study, he or she will receive travel reimbursement or some small incentive for each activity. If he or she comes to an activity and decides that he or she does not want to answer some questions or decides to stop participating, we will still be happy to give him or her this incentive in appreciation of his or her time.

Contacts and Questions:

If you have any questions or worries about the research/researchers, you can contact Emeka Okonji he works at RTC and can be reached at +27730525709. If you have questions about the rights of people who take part in research, you can contact______at the South Africa National Department of Health.

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Appendix 9: PARENTS STATEMENT OF CONSENT

I have read (or have had read to me) the contents of this consent form. I agree to allow my child to take part in the study if he or she wants to, and I understand that this is my choice and that my child can stop at any time.

Caregiver of Study Participant (Print Name and Sign) Date

If the caregiver cannot sign for himself or herself, a witness to the consent process may sign on his or her behalf.

Witness (Print Name and Sign) Date

READ TO CHILD: You are invited to participate in a discussion with some other kids from RTC programme. You do not have to join if you do not want to. If you agree to participate, we will ask you some questions about your experience living with HIV and also how you found out that you were HIV positive. If you don't want to answer a question we ask you, that is fine. You can stop at any time. Person obtaining informed consent: I confirm that I have personally explained the nature and extent of the planned research, study procedures, potential risks and benefits, and confidentiality of personal information. I also read the assent statement to the child and confirm that the child agreed to participate.

Person obtaining consent (Print Name and Sign) Date

Appendix 10: INFORMATION SHEET FOR PROGRAMME IMPLEMENTERS

Project Title: Evaluation of a psychosocial support intervention on adherence and retention in care among adolescents on antiretroviral treatment in Ehlanzeni, Mpumalanga south Africa.

Purpose of the study

This is a research project being conducted by Mr Emeka Okonji and Professor Brian Van Wyk at the University of the Western Cape. We are inviting you to participate in this research project because you have been identified to possess relevant information about the adolescent living with HIV attending the psychosocial support intervention being provided by DoH and Right to Care. The purpose of this research project is to gain a better understanding of the barriers and facilitators of adherence and retention in care among adolescents living with HIV, as well as the impact of the PSS intervention they are currently receiving. We know that these decisions are not always easy, but we do not know enough about how caregivers make these decisions. By learning more about this process, we hope to help service providers like DoH and RTC to better support adolescents living with HIV.

What will I be asked to do if I agree to participate?

You will be asked to participate in an interview. The interview will take between 1-2hrs and will be conducted at your office. The questions will reflect on your understanding of how the RTC adolescent programme work and your opinion on whether it provides the psychosocial support you think will enable adolescents living with HIV adhere to ART and be retained in care.

Would my participation in this study be kept confidential?

The researchers undertake to protect your identity and the nature of your contribution. To ensure your anonymity, (1) your name will not be included on the interview recordings and transcripts; and (2) a code will be placed on the transcripts and other collected data.

To ensure your confidentiality, all the field notes, recordings and transcriptions will be locked up in a safe drawer during the studies, and when the study is completed. With the soft copies of the transcripts, the files will be protected using password-protected computer files.

If we write a report or article about this research project, your identity will be protected.

In accordance with legal requirements and/or professional standards, we will disclose to the appropriate individuals and/or authorities information that comes to our attention concerning child abuse or neglect or potential harm to you or others. In this event, we will inform you that we have to break confidentiality to fulfil our legal responsibility to report to the designated authorities.

This research project involves making audiotapes of you. The reason for this is because a lot of information is required and it would be easy for the investigators to keep track of all the information if the interviews are recorded. In this way, the investigators do not miss any important information that could help to understand the way the psychosocial support intervention works. These recordings will be stored in a locked drawer where only the investigators have access to and the transcribed copies of the interviews will be password coded. These recordings and the transcripts will be destroyed after a period of five years.

This study will use focus groups therefore the extent to which your identity will remain confidential is dependent on participants' in the Focus Group maintaining confidentiality.

What are the risks of this research?

All human interactions and talking about self or others carry some amount of risks. We will nevertheless minimize such risks and act promptly to assist you if you experience any discomfort, psychological or otherwise during the process of your participation in this study. Where necessary, an appropriate referral will be made to a suitable professional for further assistance or intervention.

What are the benefits of this research?

This research is not designed to help you personally, but the results may help the investigators learn more about the psychosocial support being provided by the peer support in the RTC adolescent programme. We hope that, in the future, other people might benefit from this study through improved understanding of how the RTC programme work. The findings of the study could guide policy on the development, effective implementation and smooth running of the RTC programme across all the districts in South Africa.

Do I have to be in this research and may I stop participating at any time?

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.

What if I have questions?

This research is being conducted by Emeka Okonji of the School of Public Health at the University of the Western Cape. If you have any questions about the research study itself, please contact Emeka Okonji at: University of the Western Cape, Robert Sobukwe Road, Bellville, Tel; 0730525709; email: emekaokonji@yahoo.com or 3718602@myuwc.ac.za. Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

Director of UWC School of Public Health

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Appendix 11: CONSENT FORM FOR PROGRAMM IMPLEMENTERS

Title of Research Project: Evaluation of a psychosocial support intervention on adherence and retention in care among adolescents on antiretroviral treatment in Ehlanzeni, Mpumalanga south Africa.

The study has been described to me in language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits.

Participant's name……………………….
Participant's signature……………………………….
Date………………………

Appendix 12: Key Informant interview guide for programme coordinators Standard Information:

Name:

Position:

Date of interview:

Consent and anonymity: (document their preference)

Introduction: *Please give me a brief background of yourself (training, position, years of work experience, role in the psychosocial support programme). Please provide the recruiting process of the adolescents into the support groups (start from disclosure).*

Tell me about your perception on the adolescent psychosocial support intervention (using the flipster manual)-planning, resources, (what actions were taken to produce the expected desirable outcome)

Probe:

The way adolescents living with HIV adhere to ART and retained in care?

Biological (viral load and CD4 count monitoring, patient history and switching to second line).

Psychological (stressors that trigger the emotional, cognitive, physical and behavioural (coping), self-esteem and self-efficacy, and disclosure aspects of the ALHIV psychological wellbeing)

Social support (relationships with peer treatment supporters, clinicians, parents/caregivers, counselling i.e. motivational interviewing, any other)

In your opinion, what worked well during the implementation?

Probe:

Biological (viral load and CD4 count monitoring, patient history and switching to second line).

Psychological (stressors that trigger the emotional, cognitive, physical and behavioural (coping), self-esteem and self-efficacy, and disclosure aspects of the ALHIV psychological wellbeing)

Social support (relationships with peer treatment supporters, clinicians, parents/caregivers, counselling i.e. motivational interviewing, any other)

For each factor further probe on

How did it go?

What would you say worked well?

What aspect worked well?

What other things worked well?

Timing and readiness?

Was there anything in the (mention each factor, example disclosure support) that you think could be improved? Were there some people it did not work for?

How can the programme be better improved?

Probe:

improving the challenges encountered (for each factors mentioned)

Anything else you would like to share?

Appendix 13: Reviewers' comments and responses

Paper 1: Psychosocial Support Interventions for Improved Adherence and Retention in ART care for Young People Living with HIV (10-24): A Scoping Review

Citation: Okonji, E.F., Mukumbang, F.C., Orth, Z., Vickerman-Delport, S.A & van Wyk, B. (2020). Psychosocial support interventions for improved adherence and retention in ART care for young people living with HIV (10–24 years): a scoping review. *BMC Public Health, 20,* 1841. https://doi.org/10.1186/s12889-020-09717-y

Dear Editor,

We wish to thank you and the reviewers for the time that you have taken to review our manuscript and for the constructive comments provided to improve on the manuscript. In the sections that follow, we provide a description of how we have addressed the various suggestions and comments provided by the editor.

Reviewer 1:

This is an interesting contribution to the literature and the authors clearly demonstrate the need for psychosocial support for adolescents living with HIV. I only have a few minor comments.

Abstract:

Query 1: The authors use ALYHIV to describe adolescents and young people living with HIV (line 36), but in the rest of the manuscript, they use AHLIV. Perhaps stick to one acronym to avoid confusion.

Action: Thank you for the suggestion. We have changed all the acronym to A&YLHIV

Methods:

Query 2: Was there an a priori protocol?

Response: Yes, there was an a priori protocol but this protocol was used to register the study with PROSPERO (Registration No. CRD42018105057). Nevertheless, this protocol was not published in a peer-reviewed journal.

Query 3: Were any date restrictions applied? In your abstract, you mentioned 2006-2018 - are these the dates you searched? In your results, you report that there are papers between 2011-2018 - are these the results? Please clarify.

Action: Thank you for identifying this discrepancies. We have corrected them to 2005 to 2018. Please, see line 252.

Query 4: The authors have followed the PRISMA 2009 guidelines and I think it is important to emphasize that here, as it attests to the quality of their work. Please consider adding a line stating this.

Action: Thank you for the suggestion. We have added the sentence "Figure 1 shows the PRISMA diagram illustrating the selection process for inclusion of studies" -Line 221

Query 5: Was any attempt made to search for grey literature?

Response: Unfortunately, we did not consider searching the grey literature. Our focus was unfortunately on peer-reviewed literature.

Query 6: In the quality assessment (line 203), the authors describe including 6 articles in the final analysis, while everywhere else, only 5 articles are mentioned. Please clarify.

Action: Thank you for picking this up. We have corrected this to 5 studies. Line 257

Results:

Query 7: Line 296 - "Adolescent/youth-focused clinic visits [38, 40]." - this sentence is incomplete.

Action: Thank you for identifying this. We have rather deleted the incomplete sentence. It was supposed to address the red-carpet intervention. Line 294

Discussion:

Query 8: Use of SMS reminders (lines 409-419) has the potential to be effective in high income nations. Can you elucidate further on the situation in LMICs?

Action: Thank you for the suggestion. We have added in line 416- specifically due to lower cellphone network coverage in rural and remote areas in LMICs.

References:

Query 9: Some of the references are formatted incorrectly. These include the websites (ref # 5 & 6 - need to provide a link and date of access) and ref#4, 12 and others (journals are not included).

Action: Thank you for identifying this. We have reviewed the reference list and corrected the incorrect references.

Reviewer #2:

This article systematically reviewed the evidence underpins the types and effects of psychological support interventions on improving the adherence and retention in antiretroviral therapy among adolescent living with HIV. There are a few major comments that should be taken into consideration.

Abstract

Query 1: Authors should not have an abbreviation in the abstract without spelling out (e.g. ART, HIV, AYLHIV).

Action: Thank you for the suggestion, we have removed the abbreviations.

Background

Query 2: The background is long and difficult to follow. Authors should consider rewrite it to make it succinct, clear, and to the point.

Action: We have considered the reviewer's comments and reworked on the background. Please, consult the tracked changes made in this section in the main manuscript.

Methods

Query 3: I would suggest reframing the methods without mentioning the steps as it is. For example, "Step 3: Quality Assessment" to be "Quality Assessment". Because, these steps are not comprehensive; e.g. citation screening and data extraction are not considered.

Action: Thank you for the suggestion. We have considered this suggestion and have removed the various headings as suggested by the reviewer. Please, consult the main manuscript.

Query 4: The first research question: "what psychological interventions are available for ALHIV" is more of a scoping review that a systematic review?

Action: Thank you for your observation. We have thus deleted the question and only maintain the one related to the outcomes of existing psychosocial interventions designed for A&YLHIV

Query 5: Authors should report the detailed search strategy used for this review? Are the few lines reported in the methods all what they performed? Have they considered using any MeSH terms?

Action: We appreciate this suggestion. We have elaborated on the search strategy including the MeSH terms used on lines 204.

Query 6: Authors should justify their 2005 cut-off.

Action: Thank you for this suggestion. The sentence "Because the treatment of HIV only gained traction across the world around 2004, we estimated that intervention to address psychosocial issues among A&YLHIV would have only been conceived earlier a year later. Secondly, very few A&YLHIV were identified prior to 2005 - line 229

Query 7: The numbers reported in study selection section should be reported in the results instead. Similar, authors reported the results of quality assessment in the methods.

Action -We have considered this suggestion and moved to the numbers under results - line 237

Query 8: It is unclear all the way from the beginning till the end of the methods, whether they are doing a quantitative systematic review or a qualitative one? In the last paragraph in the methods, authors indicating that this is a qualitative systematic review by reporting that they employed a thematic content approach.

Action: We have considered indicating the nature of the systematic review as a qualitative systematic review earlier on -line 212

Results

Query 9: From the results, it reads more like a scoping review as the outcomes are not specific.

Action: Although we explored the nature of the types of interventions identified, we specifically indicated that the outcomes under investigation are Adherence to antiretroviral treatment (viral load); and retention in care, which we comprehensively reported on. Line-371

Query 10: Authors should highlight the design of the study.

Action: Thank you for this suggestion. We have indicated this as a qualitative systematic review in -line 229

Overlap:

We note that the current submission contains some textual overlap with other previously published works, in particular:

Methods:

Recent Interventions to Improve Retention in HIV Care and Adherence to Antiretroviral Treatment Among Adolescents and Youth: A Systematic Review, 2019, https://www.liebertpub.com/doi/10.1089/apc.2018.0320

Response: Thank you for the feedback. We could not find any overlap of texts that would constitute plagiarising in this section.

Results:

A youth-focused case management intervention to engage and retain young gay men of color in HIV care, 2011, https://www.tandfonline.com/doi/abs/10.1080/09540121.2010.542125?journalCode=caic20

This overlap exists in the Methods and Results sections of your manuscript.

Please rephrase these sections to minimise overlap and if there is overlap in the Methods section, please ensure that you summarize the methods and cite the original source in text.

Response: Thank you for the feedback.

Action: Rephrased to state -:

Wohl et al. [30], found that participants' HIV clinic visits significantly increased between baseline and at six months following the youth case management intervention ($p < 0.0001$). see line 260-262

Paper 2: Determinants of viral suppression among adolescents on antiretroviral therapy in Ehlanzeni district, South Africa: a retrospective cohort analysis

Citation: Okonji, E.F., van Wyk, B., Mukumbang, F.C., & Hughes, G.D. (2021). Determinants of viral suppression among adolescents on antiretroviral treatment in Ehlanzeni district, South Africa: a cross-sectional analysis. *AIDS Research and Therapy, 18*(66). https://doi.org/10.1186/s12981-021-00391-7

Dear Editor,

We wish to thank you and the reviewers again for the time that you have taken to review our manuscript and for the constructive comments provided to improve on the manuscript. In the sections that follow, we provide a description of how we have addressed the various suggestions and comments provided by the editor and reviewers.

Reviewer reports:

Dear Authors, many thanks for addressing the Reviewers' comments in a timely and exhaustive manner.

I have some additional comments: certainly you are looking retrospectively at a "cohort" of adolescents on ART for a variable period of time, but in its intrinsic nature the study design is more of a "cross-sectional". I don't see any retrospective longitudinal follow-up here – thinking about the platform you used, type of data you have ("last available VL"...essentially a measure of prevalence of viral suppression at the time of data extraction, 31 October 2019, rather than an incidence). I would strongly recommend revising accordingly: the title which might be misleading, and the relevant methods section in the abstract and the manuscript as well as in the study limitations section.

Action: Thank you for this feedback. We have revised the title to state cross sectional study" see title, lines 33, 123, and 324.

Please also bear in mind that Stata gives p values of .000 in its output, but this is likely due to automatic rounding off or truncation to a preset number of digits after the decimal point. So, consider replacing "p = 0.000" with "p < 0.001".

Action: Thank you for this feedback. We have revised the p-values to p<0.001.

Multivariate analysis table 2: you looking at variables associated with suppression, right? Because line 578 says NON suppression, so currently from this table I get that ie females have 1.21 times the odds of being UNsuppressed etc. Please double check.

Action: Thank you for this feedback. We have revised accordingly to state viral suppression.

Also not sure why the * is next to the baseline.

233-234: do you have an hypotheses for this?

Response: Thank you for this feedback. Studies have suggested that adolescents' defaulter rate is higher especially when they have been on ART for longer hence the recommendation by WHO for enhanced adherence counselling for adolescents who have showed virlogical failure.

244-246: please stick to "associated with" and do not assume causality.

Response: Thank you for this feedback. We did perform a multivariate logistic regression analysis and adjusted for confounders hence we were able to establish causality for variables that remained statistically significant after adjusting for cofounders.

In the discussion might be worth a comment about the pregnant teens who seem to do pretty well.

Response: Thank you for this feedback. We did consider commenting about the pregnant teen who seem to do pretty well. However, this variable was only statistically significant at the bivariate level. When we adjusted for cofounders, there was no statistical significance, hence we did not comment on it.

"Finding implications": these considerations are all correct, but it is not clear to me how your results imply this. Please reflect more on the evidence provided by your study findings and provide targeted implications and possible solutions (for the males less likely to be suppressed, for what in your setting can be improved in the second line counseling etc...)

Action: Thank you for this feedback. We have revised this secion to reflect the key intervention that could improve adherence which in turn improves viral load suppression. The points we making here is that 1. Psychosocial support intervention is crucial to improve self – management (i.e. self-efficacy and competence) to take their medications and subsequently improve adherence. Also provision of enhance adherence counselling for males, those on secondline regimen and being on ART for more than 18 months could also improve adherence which in turn improves viral load suppression.

Lines 327-328: please state this more clearly.

Action: Thank you for this feedback. We have added poor capturing of data to justify the reason for excluding type of drug regimen administered.

Finally, the fact that your EMR does not give you access to two consecutive VL is a limitation that deserves a comment. Currently, WHO recommends two consecutive VL three months apart for those with VL>50 cp/ml. And your data only capture one of those two, making it impossible to really tell what is going on for those who are not undetectable. cfr: 2021 WHO treatment monitoring algorithm. This difference is subtle but might be relevant for your conclusions on best management of the unsuppressed ones...

Action: Thank you for this feedback. We have added "*Lastly, the electronic medical record (Tier.net) only captures the last viral load test done, as a result, we are not able to measure two consecutive viral load test three months apart for those with VL>50 cp/ml making it impossible to explain what is going on for those who are not undetectable as recommended by WHO"* to the limitation section.

I was wondering if you could take a look at the subgroup of suppressed patients with undetectable VLs (currently included in the bigger group of those below 1000 cp/ml) and comment on that.

Thinking along these lines could give your results and conclusion more strength and be more generalizable with regards to psychosocial interventions (as WHO recommends intensive adherence counseling for VL between 50 cp/ml and 1000 cp/ml)

Action: Thank you for this feedback. We have looked at this category of supressed adolescents and found no statistical association between viral load and other variables. The sample size for this category of adolescents is small.

Please find enclosed the latest reviewer's comments and kindly address the below issues as well:

Reviewer #1: Thank you for addressing our comments. This manuscript is interesting and I hope will guide some future programming to address the needs of other similar clients in the region. I still think there is some room for the team to expand on the program targets that would address specific needs identified in this analysis where possible.

Action: Thank you for this feedback. We have included this statement "*Furthermore, providing enhanced adherence counselling for ALHIV who are males, on second line regimen and being on ART for more than 18 months is very crucial".*

Reviewer #2: I would like to thank the Authors for the detailed answers and explanations they gave to my comments.

Reading the actual version of the paper, I have the following comments for the authors:

- Thank you for the explanations about the platform Tier.net. Because not everybody knows it, do you think it may be of help if you explain in the paper what you explained me in order to better understand how it was realized (e.g. Tier.net data only records the last viral load test done; CD4 count at baseline and last ART visit -i.e. most recent CD4 count-; the viral load at 6 months from ART initiation) in the "Method" section?

Action: Thank you for this feedback. We have added the statement in the method section as suggested. See lines 121-139

- Line 164-165 and 245: is this sentence still true? You excluded from the analysis the group with viral load test done less than 6 months after ART introduction.

Action: Thank you for this feedback. We have revised accordingly

- Line 193: there is a typo, pregnant women are 9.60 here and 8.35 in table 1

Action: Thank you for this feedback. We have revised accordingly

- Line 232 and 270: you found that ALHIV who had been on ART for 18 to 24 months were less likely to achieve viral suppression, but not the ones who had been on ART for less than 18 months or more than 25 months. Do you have reasons to believe that 18-24 months is a particularly fragile moment for ART compliance in your setting or is just a statistical result with no clinical importance?

Response: Thank you for this feedback. Unfortunately, with the nature of our data we are unable to explore the context for why this is the case. However, we have noted it and will qualitatively explore from service providers the reason for this findings in our next study.

- Can you review the List of abbreviations? ALHIV is not included

Action: Thank you for this feedback. We have included ALHIV in the list of abbreviations. See line 362.

Paper 3: Two-year retention in care for adolescents on antiretroviral therapy in Ehlanzeni district, South Africa: a baseline cohort analysis

Citation: Okonji, E.F., van Wyk, B., & Mukumbang, F.C. (2022). Two-year retention in care for adolescents on antiretroviral therapy in Ehlanzeni district, South Africa: a baseline cohort analysis. *AIDS Care*, https://doi.org/10.1080/09540121.2022.2057409

Dear Editor

We wish to thank you and the reviewers for the time that you have taken to review our manuscript and for the constructive comments provided to improve on the manuscript. In the sections that follow, we provide a description of how we have addressed the various suggestions and comments provided by the reviewers.

Referee: 1

It would have been helpful for the discussion to have included the growing body of work based on qualitative data which look at adolescents living with HIV on ART - and adherence and retention. This material would have provided some insights for reflection in the consideration of your findings. Some pointers:

https://www.tandfonline.com/doi/full/10.1080/01459740.2017.1306856

https://www.tandfonline.com/doi/full/10.1080/09581596.2018.1550253

https://onlinelibrary.wiley.com/doi/full/10.1002/jia2.25552

A quick search yields several papers from South Africa and the region, so there is much that could be useful in the discussion.

Action: Thank you for this suggestion. We have included some qualitative studies in the discussion section of the manuscript. For example, "Furthermore, a recent qualitative study found that ALHIV drop out of care when they do not understand the reason for daily medication intake as a result of not being disclosed to (Lanyon et al., 2020)

I know using abbreviations saves words, but it does affect readability - RiC is not a standard abbreviation, it would be much better written in full. You introduce SDI on page 12... do we really need to have that abbreviated when it is used so little? Please do reduce the abbreviations where possible.

Action: Thank you for this feedback. We have written the abbreviations, RiC and SDI, in full with every use.

Referee: 2

The data was collected from 136 clinics in the Ehlanzeni district between September 2002 and October 2017; during this time period, there was a policy change of ‘test and treat’ by the WHO in 2015; this implies that patients who were recruited into the ART clinics after 2015 should have been on this approach, however the median time on ART was 8 months, implying significant delays of initiation in several cases; The authors also share information on the ‘same day initiation’ of treatment. It would be interesting to separate those whose treatment was ‘delayed’ vs those with ‘same day initiation’ of treatment.

Response: Thank you for this comment. Though South African government rolled out same day initiation in 2015, full implementation only commenced late 2017 and 2018. We generated our same day variable by subtracting date started ART from HIV diagnosis date. By using this approach, we have eliminated any bias that may arise from pre and post 2015 same day initiation policy.

It would also be useful if there was a clear understanding of this cohort regarding the transmission, since it included 10–19-year-olds, and pregnant adolescents. Was the transmission mostly vertical or horizontal?

Response: Thank you for this comment. The data was obtained from a medical electronic system where such information is not captured and so we could not determine the mode transmission.

On what regimens were the clients? Did the choice of regimens affect the retention in care? How many were on 1st line? How many were on 2nd line? and what were the regimens? Optimization of regimens with single daily doses improves adherence and possibly retention.

Response: Thank you for this suggestion. Unfortunately, the data quality for regimen is poor, hence will be difficult to delineate this category of patients. However, this will be noted in the limitation section. Furthermore, in South Africa children and adolescents are mostly initiated on ART based on body weight and the regimens mainly dispensed to this category of people living with HIV are TDF/FTC/EFV, ABC/3TC/EFV and ABC/3TC/LPV/r. However, we did not include regimens in the analysis because of inaccurate capturing of the regimen data. Regarding 2nd line –we recoded all patients on second line as yes, and No as those not indicated on Tier as 2nd line. The south African government is yet to implement single dose for adolescents.

The cohort includes 10-19 year olds and their issues by age vary; would the results be different if a sub-analysis was done by adolescent age groups eg early adolescent, middle and late? The authors chose a larger sub-division of 10-14 and 15-19, what informed this division?

Response: Thank you for this comment. This manuscript is part of a PhD study that looks specifically at retention rates among adolescents in the age group 10-14 and 15 to 19 years in Ehlanzeni district (Right to Care facilities). The health facilities are Right to Care (RTC) sites that uses a psychosocial oriented training material known as Flipster to facilitate support group session at selected safe spaces with adolescents and young people (i.e. Support groups) organized by age (10-14, 15-19, and 20-24-years age groups) as their needs vary. However, it will be a good idea to explore retention rates among early, middle and late adolescents in another study.

The analysis maintains a quantitative approach but could be improved by a mixed methods assessment to understand the qualitative views of retention. This doesn’t take away from the strength and rigor of this analysis.

Action: Thank you for this feedback. This manuscript is part of a PhD project (Title: *Evaluation of psychosocial support intervention for improving adherence and retention in ART care in Ehlanzeni*) that describes the predictors of retention among adolescents living with HIV accessing ART treatment in health facilities in Ehlanzeni, we have included published qualitative work in the discussion to substantiate the quantitative findings. The follow-up phase of the PhD project involves a qualitative exploration to provide insights on treatment outcomes for ALHIV who received psychosocial support.

In the same deliberation of a sub analysis, it would be interesting to see a difference in analysis between the males and the females, do the factors change? Especially since pregnancy is not a factor for the males. What were the predictors for RiC for the males?

Response: Thank you for this comment. We did do a sub analysis for males and females and found that the predictors did not change. See table 2 in the manuscript.

After controlling for confounders: the risk of dying or loss to follow up increased among the female adolescents. How did the authors treat loss to follow up or death in this cohort analysis? Secondly, adolescents described as lost-to-follow up in Tier.net maybe under-reported due to unrecorded mortality and silent transfers. Silent transfers were treated as still in care as they do not have outcome date and ART outcome as died or lost to follow-up. How did this analysis affect the results?

Action: Thank you for this feedback. Lost to follow up or deaths confirmed on Tier.net was treated as risk for dropping out of care. However, “*Silent transfers were dropped during analysis as they do not have outcome date and/or ART outcome as died or lost to”* we have revised this statement accordingly.

The authors propose an intervention to the lower rates of RiC among female and pregnant adolescents, and late initiation on ART.Is it possible for them to define ‘late initiation’? And be more specific about the intervention where possible? More specific recommendations at a policy, institutional and individual level into the proposed intervention of : ‘’Greater emphasis should be placed on designing interventions involving families or caregivers of ALHIV to promote early initiation and RiC through early case identification, quality clinical and psychosocial support, as they transition from adolescent to adult ART care.’’

Action: Thank you for this feedback. We have deleted the recommendation for late initiation (initiation 7 days after HIV diagnosis) because in this study there was no significant association between same day initiations. Furthermore, we have revised the conclusion to state:

“Retention in care among adolescents on ART over two-year period was considerably lower than the UNAIDS 2030 target of 95%. Of particular concern for intervention is the lower rates of retention in care among females and pregnant adolescents. Family or caregivers centred interventions designed to promote early initiation and retention in care through early case identification, quality clinical and psychosocial support, as they transition from adolescent to adult ART care”

The total number of adolescents initiated on ART during pregnancy were 536 (6.46%); how old were these adolescents who became pregnant? What is the age of majority in South Africa and is there a regulation guarding against under age pregnancy? In the discussion the authors mention that’’ half of the adolescents were pregnant’’ where does this come from if not shown in the results?

Action: Thank you for this feedback. The statement refers to the published paper we quoted. However, we have revised the statement to clearly state it was quoted. See line 301. Regarding the age of the adolescent girls when they became pregnant, the data was obtained from a medical electronic system where such information is not captured and so we could not determine the age at which the girls became pregnant.

I find the results in table one difficult to understand, for example the overall CD4; at 6mo;12mo;18mo; and 24mo and then the VL. The percentage values just don’t add up for the yes and no responses.

Response: Thank you for this comment. We performed a Chi-square test (crosstab) and reported row percentages (%) of ALHIV who were retained in care at 6, 12, 18 and 24 months when compared with the predictor variables. We did not include the % not retained. The proportion retained and proportion not retained make up 100%.

What explains the low IPT status in this cohort?

Response: Thank you for this comment. The cohort used included ALHIV who started ART before 21 Oct 2017. IPT initiation among ALHIV during this period was generally low in South Africa.

The history of TB was low that is 98% said No; but then TB was significantly associated with low RiC. How can this be resolved?

Response: Thank you for this comment. People living with HIV with TB comorbid are more likely to die compared to people living with HIV with no TB comorbidity. This is worse for adolescents, and more complicated in that diagnosing TB among children and adolescents requires sophisticated X-ray and Gene Xpert which, are rare and expensive in South Africa.

Is it possible to use odds ratios and not crude HR? Would the results differ?

Response: Thank you for this comment. We used hazard ratio (HR) because the dataset was set for survival analysis (time to event). Therefore, we thought it more appropriate to use HR approach to analyse the data instead of odds ratio.

Paper 4: Applying the biopsychosocial model to unpack a psychosocial support intervention designed to improve antiretroviral treatment outcomes for adolescents in South Africa

Citation: Okonji, E.F., van Wyk, B., & Mukumbang, F. C. (2022). Applying the biopsychosocial model to unpack a psychosocial support intervention designed to improve antiretroviral treatment outcomes for adolescents in South Africa. *Pan African Medical Journal*, *41*(166). https://doi.org/10.11604/pamj.2022.41.166.31985

Dear Emeka Okonji,

Manuscript: Applying the biopsychosocial model to unpack a psychosocial support intervention designed to improve antiretroviral treatment outcomes for adolescents in South Africa

We are pleased to inform you that your manuscript is now formally accepted for publication in Pan African Medical Journal and will soon be published, pending payment the of Manuscript Processing Charges (if applicable; see the Manuscript Processing Charges Summary below).

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Thank you for trusting the Pan African Medical Journal with your submission.

Paper 5: Implementation of a psychosocial support intervention for adolescents on antiretroviral treatment: Challenges and experiences from Ehlanzeni District, South Africa

Citation: Okonji, E.F., van Wyk, B., Hughes, G.D., & Mukumbang, F.C. (2022). Implementation of a Psychosocial Support Intervention for Adolescents on Antiretroviral Treatment: Challenges and Experiences from Ehlanzeni District, South Africa. *J Int Assoc Provid AIDS Care, 21*, 23259582221121094. http//doi: 10.1177/23259582221121094. PMID: 35993156; PMCID: PMC9403444

05-Aug-2022

Dear Mr. Okonji:

It is a pleasure to accept your manuscript entitled, "Implementation of a psychosocial support intervention for adolescents on antiretroviral treatment: Challenges and experiences from Ehlanzeni District, South Africa," in its current form for publication in Journal of the International Association of Providers of AIDS Care (JIAPAC).

Thank you for your fine contribution. I look forward to your continued contributions to JIAPAC.

Sincerely,

Dr. Chris Duncombe
Editor, JIAPAC

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