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eHARTS: A qualitative assessment of the acceptability and feasibility of a mobile application for transition readiness assessment for adolescents living with HIV in South Africa

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Doctor of Medicine
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Abstract

eHARTS: A qualitative assessment of the acceptability and feasibility of a mobile application for transition readiness assessment for adolescents living with HIV in South Africa

By Messaline Fomo

Background: South Africa bears one of the world's highest burden of adolescents living with HIV (ALHIV). ALHIV have low rates of retention in care and viral suppression after transition from adolescent-based care to adult care, leading to poor health outcomes. Transition readiness assessments are required to identify and prepare ALHIV for transition. The study's objective is to evaluate the acceptability and feasibility of a mobile application in transition readiness assessments for ALHIV in South Africa.

Methods: We conducted in-depth interviews with 15 ALHIV and 15 healthcare providers at three government-supported hospitals in KwaZulu Natal, South Africa. The semi-structured interview guide comprised of open-ended questions based on the theory of the mobile acceptance model. We used a thematic analysis approach to develop themes that were representative of the participants' perspectives on the acceptability and feasibility of eHARTS.

Results: Most participants found eHARTS to be acceptable because of its simplicity and lack of stigma. Participants believed eHARTS was feasible as it could easily be administered within a hospital setting and integrated into regular clinic activity without disrupting patient care. eHARTS was also found to have great utility for adolescents and healthcare providers. Healthcare providers saw it as a valuable tool to engage adolescents and prepare them for transition to adult care. Despite fears that eHARTS may give adolescents a wrong idea about how quickly ALHV have to move to adult clinics, participants suggested that eHARTS can be framed in a way that empowers adolescents as they prepare for transition to adult care.

Conclusion: Research on transition readiness assessment for ALHIV in South Africa and other low-income countries is limited. Our findings show that eHARTS is a simple mobile transition assessment tool that is acceptable and feasible for use in HIV clinics in South Africa for transition readiness assessment for ALHIV. In assessing the acceptability and feasibility of eHARTS, this study aims to inform further research on transition readiness assessments for ALHIV. It also serves as a catalyst to increase transition readiness assessments by healthcare providers to identify gaps in transition readiness for ALHIV and transitioning to adult care.

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List of Abbreviation

AIDS	Acquired Immunodeficiency Syndrome
ALHIV	Adolescents Living with HIV
ART	Antiretroviral therapy
COREQ	COnsolidated criteria for REporting Qualitative research
eHARTS	Electronic HIV Adolescents Readiness to Transition Scale
HARTS	HIV Adolescents Readiness to Transition Scale
HIV	Human Immunodeficiency Virus
mHealth	Mobile health
NACOSA	Networking HIV & AIDS Community of South Africa
PEPFAR	President's Emergency Plan for AIDS Relief
PMTCT	Prevention of Mother to Child Transmission
TAC	Treatment Action Campaign
TRAQ	Transition Readiness Assessment Questionnaire
UTAUT	Unified Theory of Acceptance and Use of Technology
WHO	World Health Organization

Chapter 1: Introduction and rationale

In South Africa, lack of access to antiretroviral treatment (ART) prior to 2004 resulted in over 400,000 perinatal HIV infections in the early and mid-2000s.[1–3] With the rapid scale-up of potent ART, many perinatal HIV infections have been averted, and the burden of pediatric HIV has shifted into adolescence and beyond.[4,5] South Africa currently has the highest number of adolescents living with HIV (ALHIV) of any other country in the world.[6] ALHIV have to deal with the challenges of living with a stigmatizing chronic condition, such as starting or continuing to take drugs for the rest of their lives, drugs side effects, retention in care, disclosing their HIV status, and mental health problems resulting from HIV related stigma, discrimination and feeling of not belonging.[7–9] These difficulties impact the quality of life and social interactions of adolescents, contributing to poor clinical outcomes.[10,11]

ALHIV have had to attend pediatric and adolescent-centered clinics for most of their childhood and adolescence where they built intimate bonds with peers and health care providers, providing them with a supportive environment in which to navigate various challenges related to their condition.[9,12] As more perinatally and behaviorally infected adolescents reach adulthood, they will inevitably have to transition to busy and overcrowded adult HIV clinics.[12,13] This movement, like with other chronic diseases, has been associated with increased mortality, high treatment failure rates, and loss to follow-up, all of which have an impact on social and educational outcomes[14–16].

ALHIV face many challenges during transition, including changing healthcare providers, losing relationships with peers and healthcare providers from the pediatric or adolescent clinic, the absence of adolescent-friendly services, and tight clinic schedules that interfere with school. They are also exposed to increasing responsibility, neurocognitive problems, and lack of supervision from adult caregivers which may significantly affect their health and clinical

outcomes.[14,17–19] Studies in Europe and North America have shown that ALHIV have higher death rates and virological failure as they transition from pediatric to adult care[20–22]. In South Africa, less than 50% of adolescents have clinically suppressed viral load with lower suppression rates for adolescents greater than 15 years compared to their younger counterparts at the time of transition[23,24]. These findings highlight the need to design effective interventions to improve clinical outcomes for this extremely vulnerable population as they transition from pediatric to adult care.

Unfortunately, many ALHIV transition to adult HIV care at varying ages and stages of development, without the necessary support.[25] Evidence-based interventions, transition risk assessments, or transition preparation protocols for successful transition are lacking. Additionally, there is no consensus on the best age, timing or preparation of adolescents, caregivers or their healthcare providers on the transition process.[25–27] As a result, the timing of the transition to adult care is often arbitrarily assigned based on age with many adolescents transitioning between the ages of 12 and 24, and frequently occurs with little or no preparation. Adolescents with chronic illness can undergo transition readiness assessments to determine the ideal time for transition. In Rwanda, findings from transition readiness assessment among ALHIV were utilized to develop a transition model that can be used as a checklist to ensure adolescents are ready for transition.[28] Transition risk assessment scales have been developed and used clinically for adolescents living with chronic illnesses including HIV.[29–32] One of such scales is the HIV Adolescent Readiness to Transition Scale (HARTS) that was developed and validated among ALHIV in South Africa. It takes into account the complex and behavioral issues surrounding HIV, such as stigma and disclosure.[32] HARTS can be used to identify factors such as disclosure, health literacy, health navigation, and self-advocacy that are associated with transition readiness. Adolescents were prospectively followed up for one year using the HARTS to identify factors associated with viral suppression, which served as a proxy

measure of transition readiness. The HARTS were combined with predictors of successful transition were used to create an electronic HARTS. eHARTS is a user-friendly mobile app that employs a transition risk score to help healthcare providers in determining which adolescents are ready to transition, when they should transition, and what preparations can be made for those who are not ready to transition to adult care.

Problem statement

As more adolescents with perinatally acquired HIV survive, the need for support as they transition from adolescent- to adult-centered HIV care grows. Unfortunately, these adolescents are not prepared due to a lack of evidence-based interventions, transition risk assessments, or clearly defined guidelines to prepare adolescents, caregivers, or health care providers for successful transition. Existing transition assessment tools were developed in high-resource settings and are inapplicable in low-resource settings because they do not account for socio-cultural and institutional differences. Furthermore, they were developed for other chronic diseases but not HIV. As a result, they fail to account for the complexities of HIV infection, such as stigma, disclosure, and varying health literacy. Because of the lack of validated transition readiness assessment tools, transitions assessments have not been routinely conducted in sub-Saharan Africa. Additional challenges include limited resources, manpower, inadequate infrastructure, and high patient load. Most adolescent-centered HIV clinics in South Africa do not perform transition assessments, and the use of the validated HARTS has not been adopted for adolescents living with perinatally acquired HIV. Typically, healthcare providers rely on age as a measure of transition readiness. Consequently, unprepared adolescents who transition to adult HIV tend to face numerous challenges or drop out of care entirely.

Purpose statement

The purpose of this research is to assess the acceptability and feasibility of using eHARTS as a transition readiness assessment tool for ALHIV in routine HIV care settings in South Africa. This research is part of a larger research conducted in collaboration with researchers from Emory University, Nelson Mandela School of Medicine and Georgia Tech to improve upon the eHARTS for transition readiness assessments and develop interventions to assist ALHIV with transition.

Research objectives

Specific objective: To evaluate the usefulness of eHARTS in transition readiness assessments for ALHIV in hospital-based settings in South Africa

Aim 1: To investigate the acceptability and feasibility of eHARTS for conducting transition assessment in HIV clinics for ALHIV in South Africa

Aim 2: To improve eHARTS transition assessments in HIV clinics for ALHIV in South Africa

Significance statement

As adolescents transition to adult-oriented care, transition readiness assessment will allow patients, caregivers and health care providers to plan the transition process while ensuring that adolescents are ready to manage their health condition independently, such as scheduling appointments, arriving on time at clinic visits, refilling ART prescriptions, and making medical decisions about their lives.[33] Transition assessments and planning have been found to help adolescents become more transition ready over time.[33] These findings will shed light on the usefulness of eHARTS, including whether or not clinicians will use it and how it can be integrated into routine care. Dedicated transition services tailored to the needs of various chronic illnesses can benefit the healthcare system while also enhancing the personal

development of adolescents, particularly those living with HIV.[34] This tool will assist clinicians in determining when an adolescent is ready to transition from pediatric to adult care and identifying areas that might require intervention prior to transition

Definition of terms

Transition: "the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems" (Blum et al, 1993)

Transition readiness: "encompasses the specific decisions made and actions taken in building the capacity of the adolescent and those in his or her primary medical microsystems (parental caretakers/family and providers) to prepare for, begin, continue, and finish the process of transition"

Adolescents: an individual between 10-19 years old (WHO, 2021)

Perinatally infected: acquisition of HIV infection from mother either during pregnancy, delivery, or immediately after delivery

Behaviorally infected: acquisition of HIV infection through high-risk behaviors

Chapter 2: Comprehensive literature Review

This chapter will review the literature on adolescents living with HIV and provide evidence on how different factors have shaped the HIV epidemic among adolescents in South Africa.

Historical context of the HIV epidemic in South Africa

The HIV epidemic in South Africa began in 1982 with the discovery of the first case[35]. Because it was initially common among the gay and black communities, the apartheid regime paid no serious attention to it.[35] HIV prevalence was low during this period due to a lack of movement and mixing of people. It was largely concentrated in cities and around mines in Johannesburg due to their work and migration patterns. By 1987, HIV infection had extended to heterosexuals and heterosexual intercourse became the most popular mode of transmission of HIV in South Africa. After the fall of the apartheid regime, the HIV epidemic became "explosive" characterized by its rapid spread. Prior to the fall of the apartheid and democratic elections in South Africa, nationwide prevalence's kept rising from 0.76% in 1990 to 10.4% in 1995 and 22.4% in 2000, according to data from antenatal surveys.[36]

Despite this rising prevalence, the HIV epidemic was not recognized until a decade after the first deaths in the early 1990s.[37] Besides, knowledge about HIV and the availability of prevention strategies were even limited at the time. In addition, apartheid-era racial and socioeconomic inequities exacerbated the problem, making it difficult for the government to address the epidemic. Although the end of the apartheid in 1994 brought hope to the country, it hampered the efforts to combat the HIV epidemic since the new regime was focused on dismantling the apartheid-related inequalities, rebuilding the country, preventing civil war, and building an economy.[37]

HIV prevention and anti-retroviral programs

The first HIV prevention strategy developed by the ruling party of the new administration marked the beginning of the progress in combatting the epidemic in South Africa. The ruling party established a National Advisory Group (NACOSA) to advocate for and draft a National AIDS plan outlining preventive strategies in order to reduce the rising incidence. Unfortunately, the plan was ineffective due to a lack of information on HIV.[37] HIV prevalence across the nation rose from 4% in 1994 to 22.8% in 1998, with 700,000 new infections occurring in 1997 alone.[38,39]

The aforementioned event led to the distribution of condoms and education on safe sex practices as HIV preventive and treatment measures. Stigma, fear, and other behavioral and social issues undermined these preventive strategies. Added to these factors was president Thabo Mbeki's public denial of the link between HIV and AIDS, and his unwillingness to act, despite available evidence and scientific opinion.[37,40] At the time, it was illegal to treat women pregnant women with zidovudine to prevent maternal transmission of HIV. They also turned down free nevirapine and grants from the Global Fund because of government sponsored denialism. According to modeling research by Chigwedere et al, the government's inability to provide timely ART to its population resulted in the unnecessary deaths of nearly 330,000 South African's living with HIV by 2008[41]. This hostile political environment made it even difficult to successfully advocate, implement, and make real achievements in lowering the HIV epidemic in South Africa.

Added to this hostile environment was the problem of cost, which the government singled out as the primary reason for not implementing comprehensive HIV/AIDS prevention and treatment programs.[42] As a result, the experimental testing of the drug zidovudine, which potentially lessens HIV transmission from mother to child was suspended. Worsening of the

HIV epidemic grabbed the attention of civil society and international organizations. Despite the pressure, the government remained indifferent, prompting the Treatment Action Group (TAC) to file a lawsuit in response to the government's claim of unaffordability. The case was eventually heard in court, and TAC won. Only then, beginning in 2004, could people access ART, albeit slowly owing to the government's continuous obstruction.

In 2002, the South African government implemented the prevention of mother-to-child transmission of HIV (PMTCT) and established a Joint Health and Treasury Task Team in response to persistent pressures from international communities and national activists.[37] Beyond PMTCT and post-exposure prophylaxis, the Task force devised measures to enhance access to ART. The US President's Emergency Plan for AIDS Relief (PEPFAR) was launched in 2003.[43] The availability of PEPFAR funds aided the nationwide deployment of treatment and prevention services, allowing a huge number of vulnerable people in South Africa to benefit. With support from the World Bank, the Global Fund, Clinton Foundation and other international partners, the South African government designed the Operational Plan for Comprehensive HIV and AIDS Care, Management and Treatment for South Africa.[37] In 2007, the government launched a new HIV/AIDS and Sexually Transmitted Infection Strategic Plan to combat the HIV epidemic. By the end of 2007, about 424,000 South Africans living with HIV had received ART, with the figure rising to more than 5 million in 2019, making South Africa the country with the largest ART program in the world.[37,44]

Several health indices have improved as a result of South Africa's HIV prevention and treatment programs. Life expectancy has increased by 7 years by 2012, with a 25% drop in child and newborn mortality. A considerable drop in maternal mortality and a significant reduction in HIV transmission rates have been observed too[45]. Between 2003 and 2014, South Africa saw a 48% drop in HIV-related fatalities, and 43% of individuals living with HIV were

on treatment, making it the lowest incidence rate since the pandemic was officially declared in 1992.[37,39]

Despite apparent improvements in HIV prevention and treatment, South Africa remains the country with the world's greatest HIV epidemic, with 20% of all people living with HIV living in the country and 20% of new HIV infections.[46] Of special concern are the hyperendemic areas of South Africa, as well as the concentration in key populations such as adolescents, girls and young women. Around 60% of the 7.2 million people living with HIV in South Africa are women aged 15 and above.[46] Adding to this complexity, adolescents experience a multitude of biological and social challenges that puts them at higher risk of contracting HIV.

HIV infection among adolescents

Adolescents are defined as people aged 10 to 19 years old by the World Health Organization (WHO).[47] Adolescence is the period between childhood and adulthood when a person's physical, cognitive and psychological development is accelerated, interfering with their thought process and interaction with others. These developmental changes are accompanied by sexual maturation and involvement in intimate relationships. All these changes take place in a fast-changing social environment, making adolescents more vulnerable to HIV infection and exposing them to a multitude of problems.[48]

HIV disproportionately affects adolescents worldwide. In 2020, there were 1.75 million adolescents aged 10 to 19 years living with HIV globally, with 170,000 new infections. Eighty-eight percent of these adolescents reside in Sub-Saharan Africa, with four times as many adolescent girls as boys newly infected.[49] Although the proportion of boys and girls living with HIV aged 10-14 years is comparable, those aged 15-19 years are more likely to be female.[50] In 2020, older female adolescents accounted for 6 out of every 7 new infections, and they were two times more likely to be infected than their male counterparts.[51] Furthermore, 65% of older

female adolescents living with HIV were estimated to be horizontally infected compared to 44% of men. This disparity is due to the high biological and structural vulnerabilities, as well as the susceptibility to HIV infection through sexual intercourse.[50]

Adolescents living with HIV are a diverse and complicated group that face a variety of issues because of their HIV infection. Some adolescents have been infected perinatally or behaviorally. Adolescents living with perinatally-acquired HIV frequently have more advanced HIV infection and have had to deal with the difficulties of delayed HIV treatment and lifelong infection, putting them at a higher risk of treatment failure and mortality as they get older.[52,53] Adolescents living with behaviorally acquired HIV, on the other hand, are more likely to face various social, economic, and sexual risk factors associated with HIV infection during adolescence.[54] Both populations of teenagers must traverse the developmental changes of adolescence while also dealing with a chronic and sexually transmissible illness, regardless of the mechanism of transmission.[50]

HIV infection among adolescents in South Africa

Before 2004, delays in accessing ART contributed to the high number of perinatal HIV infections and deaths of infants with perinatally acquired HIV infection in the late 1990s and early 2000s.[55,56] Even after the South African National Antiretroviral Treatment Program was established, uptake remained slow for political, cultural, infrastructure, geographic and economic reasons.[41,57] With the improved access to ART, many infants with perinatally-acquired HIV are now surviving into adolescence and adulthood.[55] At the same time, adolescents and young adults, especially females aged 15-24 years have a high incidence of new HIV infections.[36]

South Africa is currently dealing with two types of HIV epidemics among adolescents: adolescents living with behaviorally and perinatally acquired HIV, and these two groups make

up a significant portion (11%) of the total number of HIV infections in South Africa. HIV prevalence among adolescents aged 12-19 years old has risen from 3.0% in 2008 to 3.2% in 2012 and 4.1% in 2017.[58] According to recent estimates, there are around 720,000 youths aged 15-25 living with HIV in South Africa.[2] The prevalence was higher among female adolescents, those residing in KwaZulu Natal, and those who were not in school and unemployed. Adolescent girls aged 15-24 years were more than twice as likely to be infected with HIV as boys of the same age.[59]

Young girls are biologically susceptible because their vaginal tracts are immature and can easily tear during sexual intercourse. Additionally, the risk increases when sexually transmitted infections are present, and a higher proportion of STIs occur in girls under the age of 25 years[60]. Added to this biological vulnerability are structural factors that contribute to HIV transmission in this population. In South Africa, 33.6% of girls aged 15-19 years engage in transactional sex with men at least five years older than them. These men are more likely to be living with HIV, have more sexual partners, and engage in condomless and coercive sex[36]. During relationships, these girls are also victims of abuse and power imbalances, which increases their chances of contracting HIV.[61] More specifically, these girls have limited awareness about HIV transmission and prevention, have a low-risk perception of contracting HIV, and face age and gender-specific barriers to accessing HIV services. Stigma, disclosure, mental health issues, adherence to ART, and retention in HIV care are additional risk factors affecting ALHIV.

Stigma

Adolescence is a critical time for accepting one's HIV diagnosis and learning to live with it into adulthood, but stigma and lack of psychosocial support, as well as other problems of living with HIV, may undermine this developmental transition for ALHIV.[62,63] HIV stigma acts through different mechanisms either in combination or independently.[64] People living with

HIV and their families continue to face stigma, with the effects being particularly damaging in adolescents. Stigma can interfere with disclosure of HIV status, adherence to ART, retention in care, and use of HIV prevention strategies.[65] HIV-related stigma also has detrimental impacts on adolescents' mental health and can jeopardize every aspect of the HIV continuum of care and treatment, leading to increased HIV transmission.

Differences in stigma-related health outcomes have been noted between adolescents living with behaviorally and perinatally acquired HIV.[66] They have a variety of psychological vulnerabilities that might affect adherence, retention in care and mental health problems. Adolescents with behaviorally acquired HIV are more likely to be depressed, anxious, report internalized stigma and substance use than adolescents living with perinatally acquired HIVs. They are also less likely to adhere to their treatment and remain engaged in care.

Disclosure

As the HIV epidemic continues to increase among adolescents, new challenges emerge in determining how and when to inform adolescents about their HIV status. Disclosure of HIV status among adolescents is very complicated and fluid, and it must take into account their cognitive abilities and emotional maturity.[67] It covers not only the ability of adolescents to learn about their HIV status but also the ability of adolescents to disclose their status to others and the ability of caregivers to disclose their HIV status to the adolescents[67].

Adolescents need to learn about their HIV status so that they can manage their condition in the long run, especially as they transition to adult HIV care. Disclosure facilitates multiple mechanism that are critical to achieving engagement in care.[68–73] Firstly, it removes the secrecy and stigma of their HIV diagnosis.[68,72] Adolescents who have had early successful disclosure can access social support from their carers for example. Secondly, the absence of HIV related rejection helps in the preservation of their self-worth and mitigation of internalized stigma.

Thirdly, disclosure allows ALHIV to participate in HIV discussion in order to better grasp the reason for using ART and adhering to it. All this can help ALHIV in forming important relationships that foster a sense of belonging and improve mental health, resulting in better engagement in care.[74]

The benefits of disclosing HIV status to adolescents have been documented through improved adherence to ART, increased self-esteem, more autonomy, higher CD4 counts, and lower mortality.[68,75] It can also be used to prevent HIV and reduce high-risk behaviors among adolescents. Cluver et al found that early and full disclosure was associated with improved treatment adherence among adolescents[76]. Adolescents' understanding of their HIV status was independently associated with higher adherence, and so was disclosure by the age of 12. A study conducted in Zimbabwe and South Africa found disclosure to be an important tactic in overcoming stigma, changing family and community beliefs about pre-exposure prophylaxis and improving prep use among adolescents, girls and young women over time.[77]

Although the benefits of disclosing HIV status to adolescents are obvious, caregivers and healthcare workers still encounter significant challenges to do so.[78] Common reasons stated by caregivers and health care providers for non-disclosure are that they believe adolescents are too young and are concerned about the psychosocial effects on the child and family.[79] Caregivers may also be concerned about the right timing for disclosure, the type of HIV information to communicate with adolescents, or simply lack the adequate skills to do so.[78] Regardless, planned and careful disclosure is required for adolescents to live with and manage their disease.

Adherence to HIV care and treatment

Intertwined with these challenges faced by ALHIV is the problem with adherence to ART. ALHIV must adhere to their treatment regimen in order to achieve the therapeutic benefits of

ART. Poor adherence increases the likelihood of drug resistance and treatment failure, morbidity from opportunistic infections, and lowers the number of treatment alternatives available.[80] HIV is a chronic disease and adhering to ART for the rest of one's life is difficult, worst still for adolescents, for known social, economic, and psychological reasons.

Poor linkage to healthcare, low retention rates, HIV stigma, and fear of disclosing their HIV status are all common barriers to adherence to ART.[62] Among adolescents receiving ART in public clinics in Johannesburg, traveling distance, long waiting times in clinics, unfriendliness or distrust of healthcare workers, treatment fatigue, forgetfulness, and disclosure of HIV status to adolescents and by adolescents to their family, friends and community were significant barriers for missed visits and treatment.[81] Treatment clinics with shorter travel time, perceived healthcare confidentiality, and no exposure to physical or emotional violence were associated with better adherence to HIV care and treatment for ALHIV.[82]

Retention in care

To maintain viral suppression, people living with HIV must remain engaged in care. Despite having the world's largest ART program, South Africa's proportion of ALHIV who are receiving treatment remains low. A meta-analysis among ALHIV found that just 14% of the 867,283 HIV-infected youths aged 15-25 years had access to ART in 2013. Approximately 83% of those on therapy were retained in care, and 81% were virally suppressed.[2] The retention and viral suppression rates were even higher among those attending adolescent clinics than the typical pediatric clinics[83], but the impact wanes over time, making viral load suppression more difficult to achieve.[84] According to a study by Van Wyk et al, the proportion of adolescents who were retained in care after starting ARVs reduced with time, from roughly 68% at four months to 51% after a year and 36% after two years.[84] Within the same time range, viral load suppression levels showed a similar declining trend.

In terms of treatment outcomes, youths living with HIV between 15 to 24 years have significantly higher virological failure rates, poor virological response and high proportions of loss to follow up when compared to adults.[11] Factors such as the age at ART initiation, gender, pre-ART CD4 count, length of time on ART, and history of tuberculosis were linked with higher retention rates among ALHIV[83]. Having to attend clinics during school hours, delayed or inadequate disclosure, fear of disclosure, denial, lack of disclosure to others and social support, and conflicts with health care staff were important barriers to retention in care, whereas being able to access clinics outside of school hours, early disclosure, sense of belonging, peer relationships and ties with clinic staff facilitated engagement in care.[74,85]

In addition to issues relating to stigma, disclosure, adherence, and retention in care, other potential barriers to HIV care among adolescents include mental health problems, substance use, lack of social and family support, and behavioral problems[86]. All these issues must be addressed to ensure an optimal HIV care continuum and reap its benefits. There is a need to optimize care for ALHIV in preparation for transition to adult care, improving the transition process, and improving long-term outcomes.

Transition to adult HIV care

Improvement in and accessibility to ART has transformed the once fatal perinatal HIV infection into a chronic and manageable disease.[87] This is an additional hurdle for adolescents living with perinatally and behaviorally acquired HIV who will eventually move to adult care. By 2028, an estimated 320,000 adolescents in South Africa will need to be transferred to adult HIV care.[88] The success of ART in adolescents and young adults will be heavily influenced by a successful transition. For adolescents, this involves not only changes in health clinics but also models of care and health care providers, all of which can lead to disruption of care during this vulnerable period. If the transition is not handled properly, there will be a higher chance of

non-compliance with ART, viral resistance, and loss to follow-up. Studies have reported disengagement from care during transition, as well as low retention and viral suppression rates among adolescents after transition to adult care.[22,24,89] Davies et al., for example, found that older ALHIV over the age of 15 had lower viral suppression and decreasing retention rates at 1 and 2 years after transitioning to adult care than younger adolescents.[24]

Attempts to ensure a smooth transition from adolescent-centered HIV care to adult HIV care have been met with challenges such as inadequate staff training on transition, lack of pediatric ART formulations in adult clinics, and poor clinical monitoring. Adolescents also face the issue of rigid clinical scheduling in adult clinics that interferes with school, as well as the loss of clinic relationships with peers and staff from the adolescent-centered clinics.[14] On the other side, health care providers have a hard time letting go of their ties with the younger ones. They are concerned about sending unprepared adolescents into an environment that is judgmental, depersonalized and overburdened.[25] Addressing these challenges are important to ensure that ALHIV have the knowledge, confidence and are self-empowered to take care of their health. Despite these obstacles, successful transition has been linked to many individual, social and healthcare system factors. In Cambodia and Uganda, older age adolescents, knowledge of ART regimens, social support, trusting friends or family for HIV treatment, getting prepared, and satisfaction with the transition process were independently associated with successful transition.[90,91]

The current drawback is that transition guidelines lack clarity on the appropriate age of transition, timing, or the preparedness of adolescents' caregivers or health care providers.[25–27] Although all the guidelines agree that transition plans should be adaptable to the patient's age and developmental stage and that key stakeholders should be involved in the transition process, health care providers cannot rely on evidence-based data to ensure best practice of transition, and transition readiness assessments are also lacking. Transitions are usually determined

haphazardly based on age, with little or no planning. As a result, many adolescents tend to transition between the ages of 12 and 24. The absence of clear, evidence-based transition protocols could result in higher rates of loss to follow-up, virological failure, and mortality among ALHIV once they move to adult care.[2,21,22,92]

Transition readiness assessment

The goal of transition readiness assessments is to identify adolescents' support needs and intervenable targets in order to improve the likelihood of successful engagement in adult HIV care following transition, as well as to track progress in transition readiness over time.[33] The creation of individualized transition protocols to assess transition readiness and identify barriers for each patient has been the focus of current transition models.[13,93–95] These approaches are however resource-intensive and have limited feasibility in low resources settings. In most African hospitals, children are followed in pediatric care until they reach the age of 15, following which they are expected to transition to an adult clinic, but for individuals living with HIV, this transition is frequently delayed.[13] Although national guidelines do not define the age, data from practice shows that most transitions tend to occur between the ages of 13 and 22, with a majority occurring after the ages of 18, 20 or 22.[96–99] While chronological age is important, patient's maturity must also be considered.

Only a few transition readiness programs have been developed in Africa, and they have mostly focused on using peer counselors, social media, and financial incentives[9,13] In Botswana, for example, an HIV transition program was run by a hospital-based multidisciplinary team that included adolescents as peer educators. Five tools were included in the program to assess adolescents' knowledge, skills and adherence; to screen for risk factors of adherence and/or treatment failure before transition; to enable health care providers to ask two or more questions about transition readiness during each visit; homework assignments to be completed during

clinic visits; and an educational module on transition used during peer group meetings. Only 3% of the 1000 adolescents enrolled aged 13-19 years were deemed ready for transition three years after the program began. In Malawi, a similar initiative was launched to equip ALHIV with economic, psychological, and self-care skills in order to ensure a healthy and successful transition into adulthood. Even with the availability of different transition models in SSA, existing HIV care services are overcrowded and understaffed making it difficult to provide adolescents and youths living with HIV individualized and sustainable HIV care during the transition process.[12]

HIV transition readiness assessment scale

The HIV Adolescent Readiness to Transition Scale (HARTS) questionnaire was created to assist health care providers in conducting transition readiness assessments[32]. HARTS was developed by iteratively adapting existing transition readiness scales for other chronic diseases using focus group discussions with health care providers and adolescents in South Africa. The scale was then validated by administering it to a separate cohort of adolescents in a different setting in South Africa during their last visit in the pediatric care before they transitioned to adult care, and viral loads were measured one year after transition. Disclosure, health navigation, self-advocacy and health literacy were the domains that were identified to be relevant for transition.

In the validation cohort, each 10-point increase in the overall HARTS score was associated with lower odds of viral failure among participants not using illicit drugs. With respect to the individual HARTS domains, self-advocacy, disclosure, health navigation and health literacy were independently associated with viral failure. HARTS parameters in addition to other parameters assessing adolescents' drug and alcohol use, social support and self-esteem, which are predictive factors of successful transition were used to calculate a transition readiness score.

In partnership with Georgia Tech students, eHARTS, a novel, easy-to-use mobile app that incorporates the HARTS questionnaire and other parameters associated with successful transition was developed to assess transition preparedness based on a transition risk score.

The transition risk score is calculated using a point scoring system, with the final transition score ranging from -8 to 11, grouped as high, intermediate, and low transition readiness. In determining viral suppression one year after transition to adult care, the intermediate and high transition readiness categories (score > -2) had 96.4% and 27.7% sensitivity and specificity respectively, when compared to the low transition readiness category (score ≤ -2). The transition readiness score had a sensitivity of 56% and a specificity of 86.6% in predicting viral suppression one year after transition to adult care when comparing those in the high category (score ≥ 5) to those in the intermediate and low categories (score < 5)[100]. Healthcare providers can potentially use this score to determine whether an adolescent is ready to transition to adult care and to identify adolescents who need more preparation before transition in order to improve their clinical outcomes post-transition.

Mobile Health Interventions

Mobile health (mHealth) interventions are becoming more common in health-related fields. With over 90% of the world's population residing in areas with mobile phone service and two-thirds of these people having data access on their mobile devices, mHealth provides an effective approach to engaging different populations.[101,102] Mobile access penetration in South Africa is up to 95% and 61% of the population uses their mobile device to access the internet.[103,104]. Successful interventions across the HIV continuum of care have been developed thanks to the widespread availability of mHealth in developing countries. [105–107] A *WhatsApp-based* intervention in a youth clinic in South Africa showed that 60% of the 90 participants actually

used it, despite showing enthusiasm for the platform and the desire to communicate with peers.[108]

Any mHealth intervention must be acceptable, easy to use and seen as useful in order to be successful.[109] End-users must also be able to fit it into their everyday routines; otherwise, even the most powerful and creative health technology will fail. According to the Unified Theory of Acceptance and Use of Technology (UTAUT), behavioral intention to use health technology is influenced by performance expectancy, effort expectancy, social influence and facilitating conditions, which leads to actual use by end-users.[110] This research will assess the usefulness of the eHARTS in transition readiness assessments for ALHIV in South Africa based on the UTAT model.

Conclusion

When it comes to HIV care, ALHIV are a vulnerable population. They face numerous challenges, including stigma, disclosure, substance abuse, and mental health issues, all of which affect their engagement in the HIV continuum of care cascade. Though previous research has focused on understanding and addressing the various challenges that ALHIV face in order to improve their health outcomes, a critical gap still exists in transition care for ALHIV, particularly for those living in resource-limited settings. Previous studies have acknowledged the difficulties that adolescents may face if they are not adequately prepared for transition. Only one study has successfully validated transition readiness assessment questionnaire among adolescents living with perinatally acquired HIV in South Africa. There is a lack of evidence-based interventions or guidelines in place to prepare adolescents for the transition from adolescent-focused HIV clinics to adult-focused HIV clinics. Furthermore, there is a lack of information on how such tools could potentially be incorporated into regular clinic activities.

The goal of this study is to investigate the acceptability and feasibility of integrating a mobile-based transition readiness assessment tool into routine HIV care in South Africa.

Chapter 3: Manuscript

Contribution of the student

The student contributed to writing the Emory Global Health Institute grant for funding of the project; developing the interview guide; coding transcripts; analyzing data; and leading authorship of the manuscript. We intend to publish this manuscript in PLoS One.

Abstract

Background: South Africa has the highest burden of adolescents living with HIV (ALHIV) in the world. The transition from pediatric to adult center HIV care is a vulnerable period during which many clinical outcomes of ALHIV suffer as a result of sub-optimal HIV care engagement. Transition readiness assessments are required to prepare ALHIV for transition in order to improve their health outcomes. In this study, we evaluate the usefulness of a mobile application in transition readiness assessments for ALHIV in South Africa.

Methods: We conducted 30 in-depth interviews with adolescents and healthcare providers (15 interviews in each group) at three government-supported hospitals in KwaZulu Natal, South Africa. The semi-structured interview guide comprised of open-ended questions based on the theory of the mobile acceptance model. We used thematic analysis through an interactive team coding approach to develop themes that were representative of participants' perspectives on the acceptability and feasibility of eHARTS.

Results: The majority of participants found eHARTS to be acceptable because of the simple navigation features and the fact that it will not add to the stigma associated with living with HIV. Participants believed eHARTS was feasible as it could easily be administered within a hospital setting and integrated into regular clinic activity without disrupting patient care. eHARTS was also found to have great utility for adolescents and healthcare providers. Healthcare providers saw it as a valuable tool to engage adolescents and prepare them for transition to adult care. Despite concerns that eHARTS may give adolescents a wrong impression about immediate transition, participants suggested that eHARTS can be framed in a way that empowers adolescents as they prepare for transition to adult care.

Conclusion: Our findings show that eHARTS is a simple mobile transition assessment tool that is acceptable and feasible for use in HIV clinics in South Africa for transition readiness assessment for ALHIV. It is particularly useful for ALHIV and transitioning to adult care as it can help identify gaps in readiness for transition.

Keywords: Adolescents; HIV; transition readiness; South Africa; mHealth

Introduction

According to recent estimates, 360,582 South African adolescents aged 10–19 years were living with HIV in 2020[111]. ALHIV will all go through health care transition from pediatric to adult-based care to ensure continuity of care. A well-planned transition allows ALHIV to optimize their health, manage their disease independently and assume adult roles and function on issues related to their health[26,112]. Conversely, poor transition planning can lead to disengagement from care, which for people living with HIV will lead to drug resistance, declining immune status, increased morbidity and mortality, and increased risk of secondary HIV transmission to other individuals[113]. This period is crucial for ALHIV to successfully engage in the HIV continuum of care and improve clinical outcomes. To improve the health of ALHIV and prevent HIV transmission to wider communities, effective transition planning from pediatric to adult-based care is needed.

Unfortunately, adolescents lack preparation for disease self-management skills, and the best timing for healthcare transition is not known. In addition, there are no clinical guidelines based on evidence to help healthcare providers in determining the best time to transition. Consequently, clinicians make decisions about transitioning adolescents based on their age rather than their individual transition readiness[25–27,114]. The high rates of loss to follow up, virological failure, and death among ALHIV following transition to adult care are likely due to a lack of evidence-based clinical guidance on transition, lack of preparation and the reliance on age for transition[2,14,21,23].

ALHIV in South Africa who transition to adult care have suboptimal retention rates.[14] A study found that about a third of adolescents who transition to other HIV institutions never record a visit at their transfer clinics, and another 20% of adolescents are lost to follow up after

successful transfer[92]. Similarly, adolescents who transitioned to adult care within the same institution had lower retention rates than those who stayed in pediatric care[23].

Transition readiness assessments are used in other settings for adolescents with other chronic medical conditions like sickle cell disease, cystic fibrosis, cancers, and chronic renal diseases to assist with the timing of transition to adult care. A practical transition readiness assessment tool is needed to guide clinicians in the decision-making process of identifying whether or not an ALHIV is ready to transition to adult HIV care. In South Africa, HARTS, a validated transition readiness assessment tool was recently developed for use among ALHIV[32]. Parameters from the HARTS were combined with factors associated with successful transition among ALHIV to develop a transition readiness score[100]. The transition risk score was then embedded in a mobile application. This score can aid clinicians in determining transition readiness of ALHIV and identifying modifiable factors that can help prepare them for transition.

To address this gap in adolescent transition care, we tested the acceptability and feasibility of a mobile app that uses a transition readiness score to help determine when an adolescent is ready to transition to adult care and to identify adolescents in need of additional preparation before transition.

Methods

Study setting

The study took place in Mahatma Gandhi Memorial Hospital, KwaMashu Poly Clinic, and King Edward Hospital, located in KwaZulu-Natal province in South Africa. All are public hospitals and in total, provide care to more than 2,000 children living with perinatally acquired HIV. As standard of care at each site, adolescents are typically transitioned to adult care between the ages of 15 and 19. According to data from the national antenatal sentinel survey, KwaZulu-Natal had the highest HIV prevalence (41.1%) and an estimated 25% of youths living with HIV aged 15-24 years live in KwaZulu Natal in 2017[115].

Study design

We conducted a qualitative study to determine the feasibility and acceptability of eHARTS in transition readiness assessments for ALHIV. In this paper, we adhered to the COREQ (COnsolidated criteria for REporting Qualitative research) Checklist in reporting our qualitative study (see appendix below). A total of 30 interviews were conducted with adolescents, clinicians, nurses, counselors, and social workers receiving or providing care in the above clinics. We chose in-depth interviews over focus group discussions because we wanted to demonstrate the app to each participant individually and solicit feedback on eHARTS's usefulness in transition readiness assessments.

Study Population and Sampling

We utilized a convenience sampling method to recruit adolescents (n = 15) who were receiving HIV care and healthcare providers (n = 15) providing HIV care in Mahatma Gandhi Memorial Hospital, KwaMashu Poly Clinic, or King Edward Hospital from January to March 2022. We purposively recruited adolescents aged 14 to 19, with perinatally acquired HIV, on ART for at least 6 months and fully aware of their HIV status. Additionally, we included healthcare

providers including adult and pediatric clinicians, counselors, nurses, and psychologists who provided care for ALHIV in the aforementioned clinics before or after they transition to adult care. Excluded from this study were participants unable to read and/or speak English or isiZulu or too mentally or physically unwell to provide informed consent. Adolescents and healthcare practitioners participated in separate interviews.

Participant Recruitment

HIV care clinicians from the three clinics referred eligible adolescents to participate in the study after each clinic visit. A research assistant then recruited study participants in person. We also included healthcare providers who were caring for ALHIV before or after transition to adult care. We enrolled participants only after they provided written assent with caregiver consent or informed consent, as appropriate. All participants agreed to participate, and efforts made to recruit an equal number of male and female participants.

Development of eHARTS

eHARTS is a mobile application used to conduct transition readiness assessments for ALHIV. It was developed by combining parameters from the HARTS and other demographic factors that predict successful transition among ALHIV. Based on the HARTS, adolescents were prospectively followed up for one year to identify factors associated with viral suppression rates as a proxy measure of successful transition to adult care such as documented HIV disclosure (AOR 2.75; 95% CI 1.21–6.23), first-line ART regimen (13.92; 95% CI 4.18–46.40), female sex (AOR 0.40; 95% CI 0.19–0.85), alcohol use (AOR 0.29; 95% CI 0.13–0.68), higher HARTS (AOR 1.60; 95% CI 1.17– 2.21) and older age at ART initiation (AOR 0.81; 95% CI 0.71–0.94)[100]. Using an app-assisted questionnaire, eHARTS collects information from adolescents based on a formative transition risk score. The questionnaire has a total of 23 questions and is divided into two sections. The first section only includes three

questions for the healthcare provider, while the second section is for adolescents. The adolescents' section contains questions on medical knowledge, medication appointments, and health. The eHARTS app then calculates a transition risk score based on the answers from the questionnaires and organizes the scores into low, intermediates and high.

Participants with a score of 5 or higher are regarded as highly transition ready, and they have the best chance of viral suppression one year after transitioning to adult care. Those with a score of -1 to 4 are deemed intermediate transition ready, while those with a score of -2 or lower are in the low transition readiness category and have the lowest odds of achieving viral suppression after transition.

The app will notify the clinician whether the adolescent is ready to transition or not, as well as the healthcare team of any areas that may need to be improved prior to transition to adult care. It can also alert them to potential interventions to help prepare adolescents for transition to adult care. This pilot version of the app was designed and administered in English.

Data collection

Each interview started with a demonstration of the prototype version of the app to participants. After each participant engaged with the app, we conducted in-depth, in-person, semi-structured interviews to obtain relevant information on the acceptability and feasibility of the eHARTS app in providing transition readiness assessments for ALHIV based on the Unified Theory of Acceptance and Use of Technology (UTAT) model of technology acceptance. Our research team developed, piloted, and iteratively refined the interview guide. Adolescents and healthcare providers used the same interview guide to explore relevant topics on the utility, practicality, functionality, and expectations of the eHARTS, as well as concerns and suggestions on how to improve the app.

Interviews took place in a private room in one of the three clinics. Two female multi-lingual bachelor's level South African research assistants and a female English-speaking, Master's level American research fellow who were not affiliated with the clinic performed all the interviews. The interviews lasted 30-60 mins and were conducted in the participant's preferred language, either English or Zulu. For each interview, one interviewer conducted and audiotaped the interview while others took field notes. Interviews were transcribed verbatim and, when necessary, translated into English. A research assistant not present during the interviews transcribed and translated the audio recorded interviews. The principal interviewer checked each transcript for quality and correctness.

Data management and analysis

All personally identifiable information was removed after transcription, and the transcripts were saved on a password-protected computer. We used Dedoose software (version 7.0.23, LA, California) to organize and code transcripts, as well as evaluate different themes.

We used an inductive thematic analysis approach derived from data review, coding, and interpretation. Two members of the research team created inductive codes based on themes that naturally emerged from the data. The research team members assigned operational definitions to each code and created a codebook containing illustrative codes. Any discrepancies were discussed among the team and resolved by consensus for the development of the final codebook. Following the completion of the codebook, we used Dedoose software to analyze the remaining transcripts and add new inductive codes to the codebook as new themes emerge. The process was repeated until saturation reached, at which point no new themes or codes were discovered. The senior researcher double-checked the coding for consistency across the dataset and accurate application of codes per the code definitions, and any additional conflicts resolved.

This study used the UTAT model to analyze the data and combine codes to form themes after coding all the transcripts. Categories were developed inductively by grouping similar codes that reflected representativeness and significant perspectives in the data. Categories were further organized, definitions developed through team discussions, and evidence was provided with illustrative quotes from research participants. We extracted themes within each category, and the results presented in the form of anonymized quotes. We classified interview content into five main themes through an iterative process: acceptability, feasibility, utility, challenges, and potential solutions. Acceptability is defined based on aspects of eHARTS that encourage or discourage adolescents and healthcare providers from using the app. Feasibility refers to the ease and difficulty of conveniently administering eHARTS to ALHIV during their visits to health facilities. Utility is defined as the ability of eHARTS to provide healthcare and/or adolescents with a useful function required to adequately conduct transition readiness assessment for ALHIV. It captures information on where and how the eHARTS, or its results will be used.

Ethics and Informed consent

The Institutional Review Board of Emory University in the United States, the Biomedical Research Ethics Committee of the University of Kwazulu-Natal and the KwaZulu-Natal Department of Health approved this study.

Unaccompanied adolescents aged 15 to 18 were offered participation in the study after they signed a written assent form. Following their assent, their caregivers were called by phone to gain verbal consent using a pre-written telephone consent script. Written consent was obtained at the next clinic visit. A trained research assistant fluent in English and isiZulu secured written consent from their guardians in English or Zulu, as well as assent from accompanied adolescents under the age of 18. For all adolescents under the age of 15, written parental

consent was obtained. Adolescents and healthcare practitioners aged 18 and above gave their own consent.

The consenting process took place in a private room. The consent form and telephone script included information on the consent process, nature and purpose of the study; explanation of study procedures; potential discomforts and risks, as well as plans to protect participants from these risks; potential benefits, and alternatives to participation in the study; confidentiality and privacy; and emphasis on the voluntariness of participating in the study. After explaining each section to participants, we asked for informed consent, assent, or caregiver consent.

Results

We interviewed 15 adolescents and 15 health care providers. The mean age was 16.2 (1.2) and 45.2 (10.8) for adolescents and health care providers respectively (table 1). Most adolescents were male (60%) while most healthcare providers were female (73.3%). Our findings are presented and organized under five broad themes: acceptability, feasibility, utility, challenges with using eHARTS and potential solutions to improve eHARTS.

Table 1. Descriptive characteristics of study participants (n=30)

Variable	**N (%) or Mean (SD)**
Adolescents	
Age (years)	16.2 (1.2)
Female	6 (40%)
Healthcare providers	
Age (years)	45.2 (10.8%)
Female	11 (73.3%)
Doctors	3 (20%)
Counsellors	4 (26.7%)
Nurse	5 (33.3%)
Social Worker	3 (20%)

Acceptability of eHARTS

A majority of participants found eHARTS acceptable. Adolescents and healthcare providers agreed they would use it because they found the app's navigation features and interface intuitive and easy to navigate.

> *"It's easy. It is intuitive to navigate."* - *Physician, KwaMashu Clinic*
>
> *"I like everything about the app, the questions are easy to answer."– 16-year-old adolescent, King Edward Hospital*

Only one participant struggled with the app at first but agreed that once anyone gets familiar with it, navigation becomes simple.

> *"It is simple for a person that will be answering. It is very clear. I got confused a bit in the beginning. But given time to learn it properly, it is not too hard to understand. Questions are clear and the options to choose from."* - *Nurse, KwaMashu Clinic*

Healthcare providers also thought the app will be used and well received by adolescents.

> *I think there are relevant questions, and I don't see any problems with it. It is straightforward because that is the thing, they don't want anything that will make them think. – Counselor, Mahatma Gandhi Memorial Hospital*

They also said*:*

> *"Adolescents can also use it. It is not too hard because it is straight forward questions. There are no paragraph questions here we only have 1-line questions. The answers are provided, the answers are provided at the end it is straight forward."* - *Counselor, Mahatma Gandhi Memorial Hospital*

Even adolescents themselves felt the app will be acceptable:

> *"I would say it is very private everything is on the phone. The generation of today likes phones, so this app being on the phone will encourage adolescents to do the quiz."* - *15-year-old adolescent, King Edward Hospital*

Participants also considered eHARTS acceptable because it was non-stigmatizing. Participants believed that eHARTS would not attract or worsen any stigma, and thus would easily be used by adolescents and health care providers in the health facility. One participant said:

> "*As long as it won't be published and kept personal and is kept as one on one… I don't see how they can be discriminated."*– Counselor, Philani clinic

Another participant appreciated the fact that the app does not contain any stigmatizing words:

> *"I don't think so, how can they be stigmatized because everyone in this clinic is taking ARVs. I would understand if they were mixed with other adolescents and there is no HIV…There is no HIV mentioned in the app, so I don't think there will be stigma." – Nurse, Mahatma Gandhi Memorial Hospital*

However, one physician cautioned that if the questionnaire is not delivered and framed properly, the questions may contribute to self-stigmatization:

> *"I can't see one in terms of stigma. Self-stigmatization is a different issue, so you have to make sure the child feels empowered after this. But in terms of stigma from other kids and other people at the clinic, I don't think so." - Physician, KwaMashu Clinic*

An adolescent stated that they will only feel discriminated against if the question is asked by someone else:

> "*I am not afraid to answer it. Like if I have to be talking to you, I get scared and not say other things." – 17-year-old adolescent, KwaMashu Poly Clinic*

Feasibility of using eHARTS

In terms of app administration, many adolescents saw eHARTS as feasible because many adolescents are tech-savvy and educated, hence they can complete the app on their own.

> *"I think adolescents can be able to use it themselves because most people can read now."– 16-year-old adolescent, King Edward hospital*

However, other healthcare providers felt only a few younger adolescents will most likely require assistance.

> *"They can need guidance, according to their age, they would require someone to assist them" Counselor, Kwamashu clinic*

Most participants noted that adolescents can easily be administered the app within hospital premises. One noted:

> *"Maybe it can be used here the clinic because when they are here, they want to be assisted in every way. It can be properly explained to them and the reasons why it is being done." - Nurse, KwaMashu Clinic*

Some healthcare providers felt that it will be preferable to administer the app while the adolescents are in the waiting area so that their transition risk scores are available before they see the doctor. It will also allow them to explain the app and its purpose to adolescents as a group before they are administered individually.

> *"While they are waiting, that is the best time. I will do it as a group, and they will be seen individual so that they will be aware when the counsellor administers the app. They should be informed that there will be asked question that prepare them to transition to adult clinic. It is better to prepare them while they are waiting outside, they come in with an idea that they will be asked questions." - Nurse, Mahatma Gandhi Memorial Hospital*

Most ALHIV preferred to do it in the health provider's office, where they could easily ask questions, or in a private room. Only one preferred to do it at home:

> "*I feel like it would be useful if I use it at home where I have enough time to think."- 17 year old adolescent, Kwamashu clinic*

Healthcare providers had mixed opinions on who should administer the app to adolescents. Some suggested that the app be administered by a doctor or a counselor because the majority of adolescents spent more time with them. Others believed that anyone could manage the app.

> *"Here, it could be at the waiting area, or it could be with the counselor and the doctor because it's who they interact with." - Counselor, Mahatma Gandhi Memorial Hospital*

> *"I don't know, I think it can be administered by the counselor, the nurse, or during the consultation. I also think it is important that the patient is able to talk to the doctor other than "are there new problems", "are you sick", "are you taking your medication", so I think it can be administered by anyone." – Physician, King Edward Clinic*

Another participant felt administering the app will be time-consuming and they will prefer to play a supervisory role rather than being the one administering it.

> *"I don't think it would be easy for us to just do it with them. That would take too much time. Maybe they can do it while I am there and then I check it." – Nurse, Kwamashu clinic*

Another reason why participants believed eHARTS was feasible was the way in which questions and answers were worded. Although most participants thought the app's questions

and answer options were "straightforward" and "understandable" for adolescents, others were worried that the answer options would be difficult for adolescents to understand or too confusing:

> "*Some answers are confusing so they can confuse the adolescent like the little bit that are repeated they might confuse them."– Counselor, Mahatma Gandhi Hospital*

Utility of eHARTS

Participants believed eHARTS had great utility. The app could be used to determine the best time to conduct the transition readiness assessment. Although there was no agreed-upon age at which adolescents should be given the app, participants suggested that eHARTS be given to adolescents aged 10 to 16. However, there were reservations about their literacy abilities. One doctor noted that adolescent literacy levels may vary, and patients with learning disabilities may have difficulty navigating the app:

> *"I think that it really depends on the kids, because you may have a 16-year-old who has learning problems, and many of our kids have learning problems. They will find it difficult to navigate through. I think they are quite good, but their language or reading skills might not be very good, and they may be shy to tell you that they are not able to read things…. It's a bit difficult because some kids will just love doing it, and they will really have fun doing it. But some might not."- Physician, KwaMashu Clinic*

Participants expressed the perceived usefulness of eHARTS both for ALHIV and for healthcare providers. One adolescent found the app useful because it gave him the chance to complete it on his own without him being asked questions by someone else*:*

> *"The fact that I am not asked questions by a person, I am reading them on my own and answer them on my own the way I want to respond."– 17-year-old adolescent, Kwamashu clinic*

Additionally, it will empower them to ask questions and know more about their health.

> *"I like that there are questions that you answer and at the end, it can show you your rate and how do you take your pills. You are also able to talk to a doctor or anyone and ask for help and advise you on how to take care of yourself." – 17-year-old adolescents*

> *"It will empower the adolescents as it asks if they are able to talk to nurses about their different conditions and if they know their viral load. I don't remember an adolescent asking me about their viral load. They wait for the health care worker to tell them. They will be empowered that they can ask the doctors questions, like doctor my blood was taken last month what are my results? They wait for us to tell them most of the time, I think the tool will be of much help." – Nurse, Mahatma Gandhi Hospital*

For the health care providers, it will be easier to engage adolescents using their responses since many adolescents are reluctant to share their needs with health providers.

> *"…At the same time, it will assist the workers including doctors and nurses because some of the adolescents doesn't talk. Maybe they don't talk to me but they are able to speak to a sister so we will be able to get everything from the app, and also it will help us to not repeat asking same questions because you will know from the app, it will be of much app." - Counselor, Mahatma Gandhi Hospital*

Healthcare providers saw eHART as a "wake-up call" for them to be more engaged in the care of ALHIV. The result will assist them in identifying gaps in order to prepare them not only for the transition to adult HIV care but also for the transition from one institution to another:

> *"Patients might have gaps, which if we do not attend to those issues, the patient might end up defaulting. Some of the questions here, do you understand, do you take your medications alone. If the patient does not take their medications alone, It, could cause some issues for adherence. And if they don't know why they are taking their medication, they might prefer to stop. So, it is not only helping with transitioning from pediatric to adult, but from institution to institution." – Physician, King Edward Hospital*

Another participant noted that even if the adolescent is not yet ready to transition, eHARTS results will assist providers to identify areas that have yet to be addressed:

> *"It would even just be useful to identify the areas where the kids are not mature enough in. Even if you're planning to keep the child, it gives you an idea of what issues you have not addressed yet. So, in that sense, it is very nice." - Physician, KwaMashu Clinic*

Challenges with using eHARTS

The majority of participants had no problems using eHARTS, but others complained about the font size, language, and the false impression eHARTS may give adolescents.

One adolescent complained that the font was too small and unreadable. A few healthcare providers expressed concern that adolescents may believe the app will be used to transfer them to adult clinics or transfer them to another clinic. This may prevent them from providing honest responses or participating in the transition assessment in general.

> *"They might want to stay here. They might not want to go to their local clinic where everyone from the community is going. So how do we introduce the app. Not thinking of it as a transitioning tool" - Physician, KwaMashu Clinic*

> *"It mustn't be like they are being chase away…Because we are trying to avoid them thinking they are being chased away." – Nurse, Mahatma Gandhi Hospital*

Lastly, a participant thought simply asking the child to complete the quiz without providing feedback for them to assess their level themselves may prevent them from being engaged in their own care:

> *"These are the areas that maybe you can, you know, because the child does it, now they are not empowered, they just give back the thing and the clinician makes the decision." - Physician, KwaMashu Clinic*

Suggested changes and proposed solutions to improve eHARTS

Participants proposed several ways to improve eHARTS and make it more useful for assessing transition readiness for ALHIV in South Africa. The proposed changes included changes to the app's design, formatting, framing of the application for adolescents, and language.

App design

Since healthcare providers were concerned that eHARTS might give adolescents the wrong impression. They suggested that the title be framed in such a way that adolescents do not perceive it as a tool for transferring them immediately to adult clinics.

> "*And you need to market it in such a way that they do not feel that if they pass today, they are going to send me to the other clinic, you know? Not thinking of it as a transitioning tool… but maybe as a maturity tool or a growing up with HIV tool. Rather than the readiness of transitioning. I know that is the point. But as a clinician, it is not just going to help me with transitioning, but also how the child is coping with HIV." - Physician, KwaMashu Clinic*

In addition, the purpose of the app should be clearly explained to adolescents, as they will eventually transition at some point. It can be written as an introductory statement on the app and further explained by the person administering the app. A healthcare provider suggested:

> "*I think an introduction will be of important you will decide that there will be a brief introduction we do before a person takes a quiz. There should be a brief introduction to what is the app is all about. Or perhaps a person who will be assisting with administering the app will explain to the adolescent that 'you are doing this app for these reasons… So, it is the same thing with this, it like you are doing this app because of A B C and D and we want to achieve A B C and D. So, the app itself is not aimed to decide to down refer you or not. The app aims to access what stage is your health level. What resources do you need, what support do you need? What can be done? It is just to give us a picture that what stage are you in as a person? It is not to decide for you to be referred. You can just leave that part out and just say the app is to make sure that we know your stage of health and what resources you need or support. I think it would be better if you put it like that." – Social Worker, King Edward Hospital*

Framing of eHARTS

Participants suggested that eHARTS may be improved by either adding reinforcing messages at the end of the quiz:

> *"I think for my kids, once you have completed this thing, you want something to pop up and say congratulations, you've completed the quiz…It is their score, they should see it and they should be able to decide what they want to make of it before the clinician, or together with the clinician?" - Physician, KwaMashu Clinic*

Or the scores can also be presented in a way that is empowering the adolescent:

> "*…reminding them if they did not reach a certain score, it does not mean they failed. It just means that there are gaps on our side as the physicians. And if they did not get a good score, they can take the quiz again in the future" - Physician, King Edward Hospital*

Alternatively, a reward system can be used:

> "*Maybe telling them if they get a certain score, reward them…So I think making a reward, if they reach a good score, there can be some sort of reward for them. They don't understand how the scoring works so I don't think they will be tempted to say the wrong thing just to get a higher score. So, I think that there is a certain reward for them if they reach a certain score. And if they don't, they need to understand that it is not their fault, it is just a reflection on us as service providers." - Physician, King Edward Hospital*

Language

Participants provided suggestions on how the language should be translated and integrated into the final version of the app. Many participants suggested that the app be translated into isiZulu so that adolescents can choose which language they want to use while still understanding the question and providing valid responses.

> *"It would be better if you use both languages. Write in isiZulu and include English as well. Other adolescents would read isiZulu and don't understand but they understand when they are reading in English. Others don't understate reading in English but when they are reading the same thing in isiZulu they understand." - 16-year-old adolescent, King Edward hospital*

Some participants suggested that both languages be included in eHARTS:

> "*It is fine but there are words that I don't understand… They should write in English and isiZulu underneath."- 17-year-old adolescent, Kwamashu clinic*

Others suggested a separate app be designed in isiZulu: *"There should be an app for isiZulu and another for English" – 16-year-old adolescent, King Edward Hospital*

or adolescents should be made to choose in which language they want to use the app: *"It has to be translated into isiZulu so that an adolescent can choose"- Social Worker, King Edward hospital*

One participant expressed the need for eHARTS' s language to accommodate even non-Zulu speakers:

> "*With the language, I think the 15-year-old understands English sometimes isiZulu is difficult, and we are not targeting Zulu speakers only, there are Sotho's' as well and many other languages, so the language should be right for everyone. - Nurse, Mahatma Gandhi Hospital*

Other factors to consider for transition readiness

Participants provided other suggestions that would not influence the transition risk score but are important to consider in transition readiness preparation. Topics covered include

adolescents' feelings in general and about treatment; acceptance of their HIV status; availability of support system; self-perceived readiness and sexuality.

> *"I think maybe, to see how they are feeling. I am feeling sad, or I am feeling stressed, or overwhelmed. One would have to see what sort of three or four words which can capture those emotions. Because you can see if they are coping emotionally or not. And if you send them to a strange place."* - *Physician, KwaMashu Clinic*
>
> *In terms of support, they can indicate how is their family support? Or how is their support system at home? - Social Worker, King Edward Hospital*
>
> *"…like readiness to go to another clinic."* - *Nurse, King Edward Hospital*
>
> *"...have you accepted your status?"* - *Social Worker, King Edward Hospital*

Discussion

This study presents a qualitative assessment of the acceptability and feasibility of the eHARTS for conducting transition readiness assessments, as well as opportunities for improving eHARTS for transition assessments. Overall, participants thought eHARTS was acceptable and feasible to implement in HIV clinics in South Africa because it was simple to use, non-stigmatizing, and could be implemented in the hospital without additional strain on the clinic. In addition, participants felt that the questions were straightforward, necessitating lesser efforts on the part of adolescents or healthcare providers. Participants also believed eHARTS had great utility since it could facilitate communication with adolescents and empower them to be more involved in their own care. Healthcare providers also felt that eHARTS will also be able to prepare ALHIV not only for transition to adult HIV clinics but also to other institutions.

Our findings are in line with three of the UTAUT constructs: performance expectancy, effort expectancy, and facilitating conditions.[110] Most participants agreed that eHARTS would measure transition readiness for ALHIV in South Africa as expected and could be used in the waiting room during routine clinic visits with minimal effort on the part of both adolescents and healthcare providers. Furthermore, participants believed that the HIV clinic organizational

structure in KwaZulu-Natal could facilitate the integration of the app into ordinary clinic activities without influencing wait times at the clinic. These constructs are strong determinants of users' behavioral intentions toward any technology, and they adequately capture participants' intentions to adopt and subsequently use eHARTS. According to Chao's research, students' behavioral intentions toward using mobile learning were significantly and positively associated with performance expectancy and effort expectancy[116].

This study fills an important gap in the realm of transition readiness assessment for ALHIV. eHARTS, like other transition readiness scales, can be used to assess adolescents' preparedness to transition to adult care and identify whether they have self-management skills. Existing transition scales are too general to be useful for people living with HIV. The Transition Readiness Assessment Questionnaire (TRAQ), for example, is the most widely used transition readiness assessment tool[30]. This scale is not disease-specific and its usage in developing countries has not been validated. It doesn't consider the complexities of living with a stigmatizing disease like HIV and the unique barriers to successful transition for ALHIV. Furthermore, the TRAQ is based exclusively on self-report from adolescents and contains no objective measure of whether the adolescents have truly acquired these skills. The UNC TR[x]ANSITION tried to overcome this problem by correlating results with medical data to validate participants' responses, but it fell short due to the targets being poorly correlated with their respective domains and the increased administrative burden of cross-referencing each domain with medical records[117]. In comparison to these generic tools, eHARTS uses HIV-specific features from the HARTS questionnaire, such as disclosure. It also incorporates the input of healthcare practitioners as well as measures that are highly predictive of successful transition to create a subjective and objective measure of transition preparedness. Moreover, the administration of eHARTS has a lower administrative burden.

Many mHealth initiatives have been developed as a result of the fast adoption of mobile technology to ameliorate HIV care for people living with HIV in low- and middle-income countries. A recent systematic review (unpublished) identified various types of mHealth interventions that engage youths and adolescents living with HIV in low- to middle-income countries along the HIV continuum of care. These inventions varied from simple text messages to more complex interventions involving interactive games and peer engagement. The review found that there was no mHealth intervention addressing transition for adolescents and young people living with HIV. To the best of our knowledge, this is the first mHealth intervention that focuses on transition readiness assessments for ALHIV.

While the majority of these mHealth interventions have shown promise in terms of improving health-related outcomes, they face operational challenges and have limited sustainability in resource-constraint settings due to poor network access, rising mobile data cost, low mobile phone ownership among adolescents, and the ongoing need for training the persons in charge of administering the intervention or the participants themselves[118,119]. eHARTS provides numerous advantages in this regard in that it doesn't require any prior knowledge or training for its use. In addition, adolescents are not expected to own a phone or purchase mobile data. eHARTS could be readily accessible at HIV clinics, where it could be used by adolescents during their visits.

The findings of this study must be viewed in the context of their limitations. The research was carried out on a homogenous group of young adolescents who had acquired HIV perinatally. As a result, the findings do not reflect the perspective of adolescents who may have transitioned at a later age or those who acquired HIV through behavioral means. However, we were able to obtain findings that may reflect the perspective of those other adolescents by including healthcare practitioners with experience working with adolescents of various age groups and HIV transmission modes.

Another limitation was the sample size. A small sample of 15 teenagers and 15 healthcare providers participated in this qualitative study. Although the sample size is sufficient to qualitatively elicit participants' perspectives on the acceptability and feasibility of eHARTS, the results, however, cannot be extrapolated to all ALHIV because of the limited sample size.

Participants mentioned language as a major barrier for eHARTS. For practical reasons, given that this was a pilot test, we demonstrated the app in English. The next phase of the intervention will be to include participant comments, translate the app into other South African local languages, and retest its acceptability and feasibility.

Chapter 4: Conclusion and Public health implication

Conclusion

The findings of this study indicate that eHARTS is a promising tool for transition readiness assessment for ALHIV in South Africa. This study found that eHARTS has a high level of acceptability and feasibility among adolescents and healthcare providers. Our findings close a significant gap in practice and research on transition readiness assessments for ALHIV. It assessed the electronic delivery of a validated healthcare transition questionnaire that is disease-specific and region-specific. It also highlighted the potential efficacy of conducting transition readiness assessments for ALHIV in HIV clinics in South Africa.

Public health implications

eHARTS has the following public health implications:

Firstly, eHARTS will facilitate transition assessments in HIV care clinics in resource-limited settings like South Africa, where transition assessments are currently not done. The app provides healthcare practitioners with a reliable tool on which to base their judgment of an adolescent's readiness to transition to adult care. It will help health providers conduct transition assessments in a timely and efficient manner. With eHARTS, health providers can conveniently and repeatedly assess an adolescent's transition readiness and track changes in readiness over time. Also, it could potentially facilitate the decision-making process since the results may be available to health providers even before the adolescent arrives at their office, and it will foster collaboration with different members of the HIV care team.

Secondly, by conducting transition assessments, healthcare providers will be able to provide differentiated care for ALHIV. The transition score allows health providers to distinguish between adolescents who are ready to transition and those who are not. As a result, the

healthcare professional will know which aspects of care are lacking in each adolescent in order to develop individualized care plans for ALHIV that improve their transition readiness.

Thirdly, eHARTS will facilitate the transition of ALHIV from pediatric to adult care. It will address some of the individual-level challenges adolescents and healthcare providers are faced with during transition. One of the challenges with transition is the abrupt way adolescents and young people are asked to transition, using their age as a determining factor. Such adolescents confront numerous problems, which have an influence on their health along the HIV continuum of care. eHARTS provides an age-appropriate assessment to guarantee that adolescents who will transition are psychologically and developmentally ready to integrate into adult HIV clinics. Another challenge to transition is the fact that adolescents' health providers believe adolescents are unprepared and lack self-management skills. eHARTS has the potential to address this; it will identify gaps in self-management skills, and healthcare practitioners can improve on these gaps to improve transition readiness. Adolescents will feel empowered and health providers will feel more confident in transitioning ALHIV to adult care. More importantly, eHARTS was seen by participants as a great tool to engage with adolescents and empower them to be more self-reliant as they prepare for transition. Such self-management abilities have shown promise to improve outcomes for adolescents living with chronic diseases, including HIV.

Lastly, eHARTS would pave the way for future research to improve the transition readiness of ALHIV. Our transition readiness score would also help in identifying those adolescents who may be at higher risk for early poor outcomes following transition and who may need additional services prior to transition. Researchers can rely on this information to develop, test, and evaluate future interventions that can help ALHIV with low transition scores.

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Appendices

Appendix A: Interview guide for interviews with adolescents and health professionals

Questions:

First, let's talk about the idea of the eHARTS in general.

1. How do you think a transition readiness app would be useful? *Probe on use in healthcare providers and adolescents*
2. What do you like about the eHARTS app? *Probe on data storage and tracking, ease of use.*
3. What don't you like about the eHART app? *Probe font, scrolling, login, display*
4. What changes would you make to eHARTS?

Second, let's talk about the eHARTS App.

5. What data should be collected for monitoring transition progress? *Probe information to add or subtract*
6. What should the App look like? *Probe on font, scrolling, arrangement of questions.*

Third, I'd like to know how you'd want to use eHARTS.

7. How would you use the eHARTS App?
8. When should it be used? *ages of adolescents*
9. How should you arrange to use the app in clinic? *Probe use of nurses, counselors, administrators to begin use.*
10. Where should it be used? *Probe in clinic, waiting room, before visit.*

Fourth, I'd like to know how you'd like to get instructions on using the eHARTS App.

11. How should we explain the use of eHARTS? *Probe on pamphlet with cartoons versus photos, use of color, demonstration of App*
12. What language(s) should be used?
13. Who should be shown how to use the eHARTS App? *Probe on healthcare providers only or would adolescents know how to use it*

Finally, please tell me any other thoughts you have about the *eHARTS App.*

14. What are your concerns about the eHARTS App? *Probe on stigma/privacy.*
15. Tell me anything else you'd like about this program. Are there other things we should consider?

Thank you for your participation in this study.

Appendix B: COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

COREQ (COnsolidated criteria for REporting Qualitative Research) checklist

Developed from:
Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

No. Item	Guide questions/description	Reported on Page #
Domain 1: Research team and reflexivity		
Personal Characteristics		
1. Interviewer/facilitator	Which author/s conducted the interview or focus group?	Page 29 / paragraph 1 / Line 2
2. Credentials	What were the researcher's credentials? E.g., PhD, MD	Page 29 / paragraph 1 / Line 2 & 3
3. Occupation	What was their occupation at the time of the study?	Page 29 / paragraph 1 / Line 2 & 3
4. Gender	Was the researcher male or female?	Page 29 / paragraph 1 / Line 1 & 2
5. Experience and training	What experience or training did the researcher have?	
Relationship with participants		
6. Relationship established	Was a relationship established prior to study commencement?	Not reported on page **Yes**
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	Page 31 / paragraph 1 / Line 1-6 Part of it addressed in the informed consent process. Participants were briefed on the purpose of the study and gave consent
8. Interviewer characteristics	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	Not mentioned

Domain 2: study design		
Theoretical framework		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	Page 20 / paragraph1 / Line 3-7
Participant selection		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	Page 26 / paragraph 3 / Line 1
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	Page 28 / paragraph 3 / Line 2
12. Sample size	How many participants were in the study?	Page 26 / paragraph 3 / Line 1 & 2
13. Non-participation	How many people refused to participate or dropped out? Reasons?	None
Setting		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	Page 29/ Paragraph 1 / line 1
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	**No**
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	Page 31 Table 1
Data collection		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Page 28 / paragraph 3 (Line 5-6
18. Repeat interviews	Were repeat inter views carried out? If yes, how many?	**No**
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	Page 29 / paragraph 1 / Line 5-6
20. Field notes	Were field notes made during and/or after the interview or focus group?	Page 29 / paragraph 1 / Line 6
21. Duration	What was the duration of the inter views or focus group?	Page 29 / paragraph 1 / Line 3
22. Data saturation	Was data saturation discussed?	Page 29 / paragraph 3 / Line 8-9
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	No but they were returned to the principal interviewer for correction and comment
Domain 3: analysis and findings		
Data analysis		

24. Number of data coders	How many data coders coded the data?	**Two** Page 29 / paragraph 3 / Line 2
25. Description of the coding tree	Did authors provide a description of the coding tree?	Page 30 / paragraph 1 / Line 1-8
26. Derivation of themes	Were themes identified in advance or derived from the data?	Page 29 / paragraph 3 / Line 2-3) **Themes were derived from the data**
27. Software	What software, if applicable, was used to manage the data?	Page 29 / paragraph 2 / Line 2-3 (Dedoose)
28. Participant checking	Did participants provide feedback on the findings?	**No**
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Page 32-40
30. Data and findings consistent	Was there consistency between the data presented and the findings?	**yes**
31. Clarity of major themes	Were major themes clearly presented in the findings?	Page 32,33,35,36 **Yes**
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Page 37-40 **Yes**