



Addressing challenges facing adolescents in knowing and managing their HIV status in sub-Saharan Africa





“ I want to give a sense of hope that there is still life if you are HIV-positive [...] I have a vision of keeping the next generation alive

”
 Kananelo
 22, Lesotho

LSHTM-Sentebale roundtable meeting in July 2017
 Sentebale Let Youth Lead advocates with Prince Harry;
 from left to right: Kananelo, Ts'epang and Tlotlo

Photo credit: Chris Jackson, Getty Images

Introduction

In 2016, around two million adolescents aged 10–19 years were living with HIV, nearly 85% of whom live in sub-Saharan Africa. An estimated 260,000 adolescents were newly infected with HIV globally in 2016.¹ In sub-Saharan Africa, three in four new HIV infections among 15–19 year olds were among girls, and HIV-related illnesses remain the second leading cause of death for young women aged 15–24 years in Africa.² Adolescents living with HIV (ALHIV) include both those perinatally infected and those infected sexually,³ and these young people face distinct challenges at all stages of the HIV care pathway including diagnosis, linking to HIV care services, staying in care and maintaining treatment.

Adolescents frequently fall between the cracks of paediatric and adult HIV care services,⁴ and large proportions of ALHIV do not know their status. Treatment adherence among adolescents is generally lower and treatment failure rates are comparatively higher than in other age groups.⁵ Sadly, the main barriers are the psychosocialⁱ circumstances in which adolescents live, the deeply entrenched stigma surrounding HIV, adolescents' limited personal resources and dependence on caregivers, and the health systems which are unprepared to address the specific needs of ALHIV.⁶

This policy paper was conceived at a joint LSHTM-Sentebale roundtable meeting in July 2017; three young people from Lesotho and Botswana presented their personal experiences and challenges of living with HIV to an audience including Prince Harry, leading HIV researchers, and senior staff from organisations such as UNAIDS, PEPFAR and the Global Fund to Fight AIDS, TB and Malaria. This paper profiles some promising approaches to address challenges and barriers identified by ALHIV, which are divided into three categories. Under **services and environment**, we discuss approaches for addressing health system barriers to ALHIV accessing testing and treatment; in **language and discourse**, we consider messaging about HIV/AIDS as experienced by ALHIV, including public health campaigns that resonate with ALHIV, interventions seeking to mitigate stigma, and sensitive and sanguine ways to talk about and disclose HIV status.

Finally, under **agency**, we consider approaches that aim to boost resilience, self-efficacy, knowledge and awareness, and mental wellbeing among ALHIV that can empower them to live happy, healthy and productive lives.

This brief is aimed at organisations working with ALHIV who wish to implement evidence-based programmes.ⁱⁱ The paper provides a snapshot of some promising interventions in sub-Saharan Africa profiled in the recent literature (2010 onwards). It is crucial that interventions make a difference not only to the treatment outcomes but also to the quality of life of ALHIV. Such interventions need not be complex or costly, if they are sustainable, and listen to and work closely with young people living with HIV and their communities.⁷



In partnership with Ministry of Health in Lesotho, Sentebale train “peer educators” who are recruited to deliver support such as HIV testing and counselling services.

ⁱ ‘Psychosocial support’ addresses psychological and social issues experienced by people living with HIV (WHO definition).

ⁱⁱ Many highly effective interventions evaluated and reported on before 2010 or from regions outside sub-Saharan Africa are not covered in this paper. Prevention interventions or approaches are only considered when they concern secondary prevention or onward transmission of HIV. As the emphasis of the paper is on psychosocial support interventions, it does not consider biomedical approaches that could improve adherence such as the development of long-acting antiretroviral drugs, or interventions to reduce their side effects.

Services and environment

Challenges expressed by ALHIV	Promising approaches and interventions
<p>Health services</p> <p>“The health services are open during school hours and we don’t have the time to go for check-ups”</p> <p>Ts’epang, 19, Lesotho</p> <hr/> <p>Accessibility: Opening hours which conflict with school days, the distance of the clinic from home, and particular access challenges for disabled ALHIV.⁹ Concerns about confidentiality, or fear of stigma or judgemental attitudes of healthcare staff.⁹ Difficulties of transition from paediatric to adult HIV services.¹⁰ Health system challenges (e.g. drug stock-outs, health worker shortage and lack of training).¹¹</p>	<p>Youth and adolescent friendly services (YAFS) may help retain adolescents in care, reducing attrition among youth after ART initiation.^{12,13} Testing and counselling at youth centres shows promise for certain age groups, for example using a points-based rewards system to incentivise use of youth centre services.¹⁴ Co-location of services can help integrate HIV care into other sexual and reproductive health services for young people; integrating HIV care and contraception services may reduce adolescent girls’ discomfort with seeking contraception.¹⁵ HIV services for ALHIV should be integrated and co-ordinated with services supporting adolescents with disabilities.¹⁶ Changing opening hours (e.g. a “night clinic” for female sex workers and long-distance truck drivers) has positive impact on engagement with services,¹⁷ while close proximity to healthcare facilities is associated with improved ART adherence.¹⁸ Mobile clinics can help to reach and provide diagnosis to ALHIV.¹⁹ Small ‘nudges’ like appointment reminders delivered through SMS, phone-calls or face-to-face can help increase adolescents’ uptake of repeat testing.²⁰ Helplines specifically for ALHIV, such as the one2one Integrated Digital Platform, can allow ALHIV to engage with a professional and youth-friendly counsellor confidentially at flexible times.²¹</p>
<p>The role of the home environment</p> <p>Unstable family structures: Orphanhood; frequent change of caregivers; caregivers overburdened with competing priorities.²²</p> <p>Ethico-legal barriers: high age of consent can limit adolescents’ access to testing and care, which is mediated through guardians.²³</p>	<p>Providing home-based testing and counselling can identify young people with HIV earlier in the disease progression.²⁴ Supporting caregivers can improve linkage to healthcare and encourage retention; caregivers’ ability to support children in HIV care is facilitated by an open family environment, the availability of practical assistance and psychosocial support from community members.²⁵ Community-based support for caregivers can have a substantial effect on HIV virological suppression in ALHIV.²⁶ Framing access to treatment as a child rights issue, whereby the state or caregiver’s failure to facilitate access is a rights violation, could help in cases where families or religious groups raise objections to the child’s treatment.²⁷ Self-testing at home could improve diagnosis among ALHIV, as these tests are feasible and acceptable to adolescents,²⁸ particularly those wishing to avoid visiting clinics, obtain fast results and for those in non-monogamous relationships.²⁹ For orphaned, HIV-positive children, there is some evidence that group homes may improve wellbeing, and resilience to cope with stigma.³⁰</p>
<p>Psychosocial support groups</p> <p>“We need capacity building and we need finances to support our activities. You need to invest in us if we’re to be the future”</p> <p>Thato, 27, Lesotho</p> <hr/> <p>Lack of knowledge and understanding, and resources and time constraints, may limit the engagement of ALHIV with support groups.³¹</p> <p><i>For the broader mental health challenges faced by ALHIV, see “Mental Health” in the Agency section.</i></p>	<p>PEPFAR highlights youth clubs or youth corners as “points of health access for adolescents, although many were described as dysfunctional or small-scale”.³² Successful clubs often combine sports and games activities with access to knowledge and information on HIV treatment, reproductive health, and on coping with discrimination and stigma, with trained health personnel available to answer questions.³³ ALHIV and carers often perceive support groups as a safe social space for learning and acquiring HIV information as well as gaining confidence, particularly when they can participate consistently.³⁴ These groups can facilitate difficult conversations about sexuality and sexual health.³⁵ Behavioural support groups using laypersons can also facilitate linkage to care for ALHIV and secondary prevention.³⁶ Peer support group therapy may be beneficial, for example by using trained treatment-supporters to deliver structured, community-based psychosocial and adherence support.³⁷ Mobile phone-based support groups can decrease internalised stigma, and increase perceived social support and self-reported adherence.³⁸ Social networking platforms are acceptable to many ALHIV, but could better interface with media like WhatsApp and Facebook, and provide more relevant, topical information.³⁹</p>
<p>The school environment</p> <p>Frequent missed school due to illness⁴⁰ or caring for ill relatives. Stigmatisation by students and teachers. Teachers face difficulties in how to deal with HIV-related issues in pupils.⁴¹</p>	<p>Testing and counselling (HTC) in schools could help increase uptake and scale of HTC,⁴² although protection of testers’ confidentiality and privacy is key.⁴³ Schools may be able to capitalise on the novelty associated with technology- and internet-based HIV education.⁴⁴ Teachers should be supported to acquire basic knowledge and skills in caring and paying attention to learners affected by HIV and AIDS.⁴⁵ School-based education programmes on HIV should link with local communities, to increase effectiveness and influence change among ALHIV not attending school.⁴⁶ Teachers working in partnership in school-based networks can be empowered to promote resilience among ALHIV.⁴⁷</p>
<p>Poverty</p> <p>Leading to missed clinic appointments, poor nutrition, and elevated stress for caregivers.⁴⁸</p>	<p>Economic empowerment programmes such as the conditional and unconditional cash transfers for orphaned and vulnerable children could be scaled up to enhance ALHIV’s wellbeing and to prevent onward HIV transmission.⁴⁹ Interventions like combination social protection (involving child savings accounts, workshops, and mentorship) can reduce sexual risk-taking intentions among ALHIV.^{50,51} Economic incentives for caregivers can improve testing and counselling uptake by adolescents.⁵²</p>

Language and discourse

Challenges expressed by ALHIV	Promising approaches and interventions
<p>How health workers talk to young people</p> <p>“Stop treating HIV like a wound – the bandage doesn’t work”</p> <p>Masedi, 23, Botswana</p> <hr/> <p>Language to discuss a sexually-transmitted, incurable infection rarely emphasises positive, healthy ways to live with HIV.⁵³ Health workers may struggle with their role in disclosing an adolescent’s HIV status.⁵⁴</p>	<p>Tailored, age-appropriate guidelines for health workers on disclosure to ALHIV could help to clarify their roles and responsibilities, and legal and ethical implications.⁵⁵ Disclosure in a healthcare setting can overcome issues associated with caregivers disclosing at home, make a diagnosis more credible to ALHIV, and help ALHIV gain more information about their status from shared experiences with peers at the clinic.⁵⁶ Healthcare providers need continuous training and resources to support disclosure.⁵⁷ Healthcare providers can support and empower caregivers to take the lead in disclosure, and also help caregivers accept their own HIV status, so that they can more effectively support ALHIV.⁵⁸</p>
<p>Adults’ (parents/caregivers’) language towards young people</p> <p>Discussion of sex and HIV is often taboo, and complicated by use of overly polite language and euphemisms.⁵⁹ Different modes and capabilities of communication across generations also present a barrier.⁶⁰ Parents/caregivers’ fear of disclosing their child’s status. While disclosure can improve ALHIVs’ retention in care,⁶¹ caregivers may fear young person will not understand, will not keep their HIV status confidential,⁶² will face stigma, blame the parent/caregiver,⁶³ or experience psychological distress.⁶⁴ For similar reasons, parents may struggle with disclosure of their own HIV status to children.⁶⁵</p>	<p>Improving parent-child communication through structured programmes (e.g. Let’s Talk!, a worksite-based programme) can help parents feel more comfortable discussing HIV-focused topics with their children.⁶⁶ Interventions should support caregivers to feel in control when discussing HIV and sexual health with their children.⁶⁷ Providing both adolescents and caregivers with basic HIV and sexual health knowledge, communication and negotiation skills may facilitate discussions.⁶⁸ Family-based interventions can encourage family cohesion, and HIV testing and linkage to care for all family members.⁶⁹ Tangible support for parents/caregivers to disclose the young person’s status may include tools like a “disclosure book” e.g. a comic book which emphasises healthiness, hope and resilience, avoids medical language and includes cues for caregiver-child discussion.⁷⁰ Caregivers need support to gauge adolescents’ capacity to understand their status, to decide on an appropriate time for disclosure.⁷¹ Caregivers disclosing their own status may benefit from home-based interventions involving the whole family,⁷² and from specific disclosure tools, training and support for parents/caregivers (e.g. the Amagugu intervention).⁷³</p>
<p>Coping with stigma</p> <p>“The moment people start knowing you’re HIV positive, they will try to pull themselves away from you”</p> <p>Tlotlo, 18, Botswana</p> <hr/> <p>Stigma is the overwhelming reason why young people are lost to follow up more than any other age group,⁷⁴ and plays a key role in non-adherence to medication and morbidity.^{75,76} Stigmatising beliefs also undermine HIV testing among adolescents,⁷⁷ with fear of stigma and discrimination following a positive result.⁷⁸</p>	<p>Home-based, community-level universal test and treat approaches (e.g. the PopART intervention) may help destigmatise and normalise HIV testing and care,⁷⁹ especially if targeted testing for adolescents is provided in combination.⁸⁰ Interventions should seek to weaken the association between HIV/AIDS and death, to reduce fear of HIV/AIDS, and to recast HIV as a chronic manageable disease.⁸¹ Participatory workshops and activities in the community have been shown to reduce both stigma felt by PLHIV and stigma enacted by people living close to them.⁸² Targeted education and training sessions on stigma (e.g. through workshops and computer-based resources) for adults who work with ALHIV, such as teachers, can significantly reduce their levels of stigma.⁸³ Research on internalised stigma (where ALHIV accept negative attitudes towards people with HIV as applicable to themselves) suggests that protection from violence within homes, communities and schools is key to combating psychological distress and internalized HIV stigma.⁸⁴ Mass media interventions for stigma reduction may be more effective for young people than older people, as found through the “Radio Diaries” intervention in Malawi, where PLHIV tell stories about their everyday lives.⁸⁵ The soap opera MTV Shuga has helped reduce stigmatising attitudes, e.g. belief that HIV represents “divine punishment”.⁸⁶</p>
<p>Language of (self-)disclosure by ALHIV to family/friends/partners</p> <p>“People struggle to find the right time to disclose”</p> <p>Kananelo, 22, Lesotho</p> <hr/> <p>ALHIV may fear stigma, isolation and lack of acceptance from loved ones or peers if they disclose.^{87,88} Unintended disclosure is a significant fear.⁸⁹</p>	<p>ART programmes should consider disclosure counselling for caregivers/family-members to appreciate and respect the privacy and disclosure concerns of their HIV-infected children,⁹⁰ especially given that disclosure can enable adolescents to better engage with their ART treatment and support groups.⁹¹ Programmes could emphasise the importance of gradual disclosure starting at younger ages,⁹² with ALHIV frequently seeing disclosure as a continuous process, specific to particular relationships and environmental contexts, rather than a one-off event.⁹³ One promising approach could be to provide safe environments for ALHIV to practise disclosure skills.⁹⁴</p>
<p>Limited messaging and campaigns aimed at ALHIV and their peers</p>	<p>Communication programmes can create an environment that encourages open HIV-related discussions, and improve testing uptake.⁹⁵ It is worth noting that HIV campaigns may facilitate difficult conversations, but it is not given that this will change attitudes and beliefs as intended.⁹⁶</p>

Agency

Challenges expressed by ALHIV	Promising approaches and interventions
<p>Age of consent</p> <p>Age of consent at 18 may restrict access to HIV counselling and testing, and creates ambiguity for health professionals working with ALHIV.⁹⁷</p>	<p>Changes are needed at the policy level; countries like Lesotho, South Africa and Uganda have lowered the age of consent to 12, so that adolescents can consent to HIV testing and counselling services without additional parental/caregiver consent. In Uganda this has facilitated comprehensive home- and community-based testing strategies that have increased prevalence of testing among adolescents.⁹⁸ Consent for self-testing by adolescents 12 and over in countries like South Africa could be lawful provided pre- and post-test counselling and psychosocial support were offered in conjunction with self-tests.⁹⁹</p>
<p>Mental health impacts of living with HIV</p> <p>ALHIV may grow up with a “medicalised” identity,¹⁰⁰ and prevalence of anxiety, depression, suicidal ideation and conduct disorders is often high among ALHIV.¹⁰¹ Many psychological problems may be linked to self-directed stigma, shame, and anger among ALHIV.¹⁰² AIDS orphans may be at particularly high risk of mental distress.¹⁰³ Victimisation through bullying may particularly impact on mental distress experienced by adolescents affected by HIV.¹⁰⁴</p>	<p>Contact with community-based organisations (at least monthly) in high-HIV prevalence areas has been shown to reduce suicidal ideation, depression, problems with peers, and perceived stigma.¹⁰⁵ Interventions to improve mental health are also likely to improve medication adherence,¹⁰⁶ and limit onward HIV transmission.¹⁰⁷ Psychosocial interventions may improve certain psychological wellbeing outcomes but not others e.g. a community art programme in South Africa for ALHIV improved self-efficacy but not self-esteem, depression or emotional/behavioural issues.¹⁰⁸ Cognitive behavioural therapy (CBT) can reduce anxiety among ALHIV, although there was limited impact on depression compared to controls receiving standard group counselling.¹⁰⁹ Models of problem-solving therapy delivered by lay health workers (e.g. the “Friendship Bench”), which can successfully reduce depression and anxiety symptoms in adults, may in future prove suitable for ALHIV.¹¹⁰ Participatory activities based on narrative therapy, such as digital storytelling, where ALHIV narrate their experiences on film,¹¹¹ or Photovoice,¹¹² where participants photograph scenes which capture their lived experience, can foster self-understanding, self-control, resilience and hope for the future. The challenging contexts in which ALHIV and their caregivers frequently live necessitates involvement of the whole family¹¹³ e.g. the VUKA family programme aims to improve mental health of young ALHIV, using a cartoon-based curriculum and step-by-step guidance for counsellors to encourage families to launch difficult conversations, on topics such as bereavement, self-acceptance and sexuality.¹¹⁴ Empowering ALHIV to develop their skills and voice can foster wellbeing and agency; ALHIV should be involved in setting programmes, policies and strategies,¹¹⁵ and be supported to work with policymakers and scientists to set research agendas.¹¹⁶</p>
<p>Non-medical barriers to adhering to HIV medication</p> <p>Stigma, lack of disclosure, busyness and peer pressure/influences can affect ALHIVs’ adherence.¹¹⁷ Mental health problems can negatively impact on adherence.¹¹⁸ Denial of the illness when ALHIV feel healthy may be a factor,¹¹⁹ and many ALHIV do not want to be seen taking medication. Certain barriers may be very different for perinatally and behaviourally infected ALHIV.¹²⁰ Alcohol use and violence are associated with missing doses,¹²¹ in both adolescence and later life. Barriers may also be structural, such as lack of nutritional support,¹²² or treatment fees.¹²³</p>	<p>Adults and healthcare providers need to approach non-adherence with empathy, understanding the difficulties associated with taking life-long treatment, rather than a discourse of perfect adherence which obscures the social challenges faced by ALHIV. Parents or guardians accompanying ALHIV to clinic appointments, ALHIV’s participation in group sessions,¹²⁵ supportive healthcare workers, and short waiting times at health services,¹²⁶ can all facilitate better adherence among ALHIV. SMS messaging may be effective at weekly intervals (rather than daily intervals)¹²⁷ to improve ART adherence among ALHIV and reduce treatment interruptions.^{128,129} Combined with social support, SMS reminders can mitigate forgetfulness – but it is crucial to respect the privacy and confidentiality of ALHIV given that they may share phones with family members.¹³⁰ Acceptability of SMS reminders may not always be high, and can depend on factors such as educational level, disclosure and use of internet.¹³¹ Community-based adherence support, such as home visits by patient advocates to address household challenges impacting on adherence among children, may be a low-cost approach to help ALHIV achieve virological suppression.¹³² A home-based nursing programme has shown impact on knowledge and medication refills but had no effect on viral load.¹³³</p>
<p>Sexual health, sexuality and romantic relationships</p> <p>Misinformation and rumours about how ALHIV can minimise risk of onward transmission of HIV (e.g. the idea that circumcision is 100% effective at preventing HIV transmission). Sexual risk-taking among ALHIV is relatively high.¹³⁴ Fears around disclosure, rejection by partners and potential for transmission create challenges for ALHIV engaging in dating and relationships. Health services rarely engage openly with the romantic and sex lives of ALHIV.¹³⁵ Caregivers may express negative attitudes about sex with HIV, and there is limited access for ALHIV to appropriate information and guidance.¹³⁶</p>	<p>“We need more appropriate sexual and reproductive education, and it should be done frequently” Kananelo, 22, Lesotho</p> <p>Relatively short counselling interventions (for example, a 180 minute session among circumcised young men) can reduce sexual risk behaviours in the short-term.¹³⁷ Participatory community events to provide information about sexual health and HIV can empower ALHIV to cope with a diagnosis.¹³⁸ Alongside individual CBT-style approaches, interventions should be mindful to address contextual and structural issues such as gender equality and livelihoods strengthening, and engage with ALHIV’s sexual identity.¹³⁹ ALHIV need support from families, caregivers and service providers to strengthen their self-esteem and pursue romantic and/or sexual relationships in an affirming way.¹⁴⁰ Care programmes should seek to facilitate communication about sexuality between ALHIV, their caregivers, health providers and HIV-positive peers.¹⁴¹ Positive prevention programmes like “Positive Living for a Brighter Future”,¹⁴² or “Supporting Youth and Motivating Positive Action”,¹⁴³ can support young people to better understand sexual risk and learn about assertive communication in the context of sex.</p>

Recommendations for implementing organisations

- Recognise that adolescents living with HIV (ALHIV) face unique challenges that are different to those facing children and adults
- Ensure psychosocial support is reaching ALHIV as they transition into adult care
- Adopt a human rights-based approach to testing, care, virological suppression, and supporting mental wellbeing of ALHIV
- Recognise the crucial role of peers, caregivers, families, teachers and communities, and equip them to best support ALHIV
- Emphasise that ALHIV, while a heterogeneous group facing myriad challenges, can live healthy, happy and productive lives
- Empower ALHIV to lead, participate in and shape youth-friendly services, policies and research
- Find ways to sensitively discuss sex, dating and relationships for ALHIV, as this is a clear gap in current interventions
- Interventions need to consider and address the contextual and structural factors (e.g. unstable family structures, poverty, malnutrition, disability) which limit ALHIV’s ability to manage their status
- Look to reach the “hard-to-reach”, marginalised ALHIV who may not be using any kind of formal or informal health service
- The evidence base around adolescents to support ALHIV needs to be strengthened, through participatory and action-oriented research to overcome key barriers (e.g. stigma among ALHIV; marginalisation of certain ALHIV groups)
- Tailor media, campaigns and approaches used in interventions to age range, geographical/cultural context and (potentially) mode of HIV infection in order to enhance their sustainability and scalability



Sentebale’s Co-Founding Patron Prince Seeiso and youth advocates at the launch of Let Youth Lead, Lesotho.

Photo credit: Michelly Rall, Getty Images

A call to action

“

HIV needs to be treated exactly the same as any other disease, and between us hopefully we can eradicate the stigma and give these young people an opportunity to stand up and say, I've lived it [...] and I want to come forward and make a difference.

”

Prince Harry

at LSHTM-Sentebale roundtable, July 2017



Professor Peter Piot, Director of LSHTM, with Prince Harry in July 2017.

Photo credit: Chris Jackson, Getty Images

London School of Hygiene & Tropical Medicine

Keppel Street, London WC1E 7HT
United Kingdom

Switchboard: +44 (0)20 7636 8636
Fax: +44 (0)20 7436 5389
www.lshtm.ac.uk

Sentebale

136 Sloane Street, London SW1X 9AY
United Kingdom

Tel: +44 (0)20 7730 0226
www.sentebale.org

For references accompanying the policy brief with details of supporting papers and reports, please see: www.lshtm.ac.uk/HIVadolescents

This paper is intended to profile promising approaches and good practices for supporting ALHIV to overcome psychosocial, ethico-legal and structural challenges associated with knowing and managing their HIV status. One limitation must be stressed, namely that many of the approaches discussed above are preliminary studies of feasibility or acceptability, and are yet to be tested at scale or in other contexts. Furthermore, many of the studies rely on a small sample of adolescents and have methodological issues.¹⁴⁴ There is particularly limited research on the adherence, retention in care and treatment outcomes of young people from marginalised populations.¹⁴⁵ Nonetheless it is hoped that the approaches profiled will spark some new ideas to integrate into existing or new programmes, or inspire collaborations with the organisations involved. The paper looked only at promising interventions for ALHIV in sub-Saharan Africa, but ALHIV themselves or organisations working with them may wish to learn from interventions in other parts of the world or with other groups.

The complexity of needs faced by ALHIV requires a holistic approach that takes account of factors at all levels of the health and social system that adolescents are part of, including their family, their broader community and the policy environment which can facilitate their wellbeing.¹⁴⁶ Some of the most effective interventions work closely with caregivers or families, and emphasise resilience and the possibility of ALHIV to live healthy, happy and productive

lives. That said, it is crucial that the human rights of ALHIV are front and centre, to ensure that adolescents can access testing and link quickly to care in cases where their home or economic circumstances may directly or indirectly limit engagement with HIV services.¹⁴⁷ It is also crucial that the needs of adolescents who do not engage at all – perhaps because of marginalisation, disability, or lack of awareness, resources or independence – are considered and included when planning support interventions.

Most crucially, the literature consistently demonstrates that programmes and services need to step up the engagement of adolescents in programming, going beyond token involvement to listen to youth in meaningful and profound ways. This may involve uncomfortable or unfamiliar conversations about adolescents' rights, consent, autonomy and sexuality, but these can underpin the most transformative initiatives. It is important to recognise that adolescents do not live their lives in healthcare facilities, and effective models of supporting ALHIV need to move away from a predominant focus on access to drugs to addressing the interlocking complexities of the family, community, school, work or social environments in which adolescents are situated. Adolescents living with HIV can thrive just like any of their HIV-negative peers in all walks of life, but only when provided with support and opportunities that enable them to overcome the challenges they face.

Addressing challenges facing adolescents in knowing and managing their HIV status in sub-Saharan Africa

References

Introduction

1. International AIDS Society. IAS and WHO identify the most critical research needs for infants, children and adolescents living with HIV. Available at: <http://www.ias2017.org/Media-Centre/Press-Releases/ArticleID/90/IAS-and-WHO-identify-the-most-critical-research-needs-for-infants-children-and-adolescents-living-with-HIV>
2. UNICEF For every child, end AIDS – seventh stocktaking report. New York; 2016
3. Williams S, Renju J, Ghilardi L, Wringe A. Scaling a waterfall: a meta-ethnography of adolescent progression through the stages of HIV care in sub-Saharan Africa. *Journal of the International AIDS Society*. 2017 Jan 1;20(1).
4. Lowenthal ED, Bakeera-Kitaka S, Marukutira T, Chapman J, Goldrath K, Ferrand RA. Perinatally acquired HIV infection in adolescents from sub-Saharan Africa: a review of emerging challenges. *The Lancet infectious diseases*. 2014;14(7):627-639. doi:10.1016/S1473-3099(13)70363-3.
5. UNAIDS. Ending AIDS: progress towards the 90-90-90 targets. 2017. Available at: http://www.unaids.org/sites/default/files/media_asset/Global_AIDS_update_2017_en.pdf
6. Hudelson C, Cluver L. Factors associated with adherence to antiretroviral therapy among adolescents living with HIV/AIDS in low-and middle-income countries: a systematic review. *AIDS care*. 2015 Jul 3;27(7):805-16.
7. Bernays S, Jarrett P, Kranzer K, Ferrand RA. Children growing up with HIV infection: the responsibility of success. *The Lancet*.383(9925):1355-7.

Services and Environment

8. Abimanyi-Ochom J, Mannan H, Groce NE, McVeigh J. HIV/AIDS knowledge, attitudes and behaviour of persons with and without disabilities from the Uganda Demographic and Health Survey 2011: Differential access to HIV/AIDS information and services. *PLOS ONE*. 2017;12(4):e0174877.
9. E.g. in the academic literature: Mburu G, Ram M, Oxenham D, Haamujompa C, Iorpenda K, Ferguson L. Responding to adolescents living with HIV in Zambia: A social-ecological approach. *Children and Youth Services Review*. 2014;45(Supplement C):9-17. E.g. from an NGO: <http://chiva-africa.org/our-youth-our-future-adolescent-programme/>
10. Kung TH, Wallace ML, Snyder KL, Robson VK, Kalombo CD, Bekker LG, Mabud TS. South African healthcare provider perspectives on transitioning adolescents into adult HIV care. *South African Medical Journal*. 2016 Aug 1;106(8):804-080.

Services and Environment

11. Dahourou DL, Gautier-Lafaye C, Teasdale CA, Renner L, Yotebieng M, Desmonde S, Ayaya S, Davies MA, Leroy V. Transition from paediatric to adult care of adolescents living with HIV in sub-Saharan Africa: challenges, youth-friendly models, and outcomes. *Journal of the International AIDS Society*. 2017 May 1;20(S3).
12. Lamb MR, Fayorsey R, Nuwagaba-Birbonwoha H, Viola V, Mutabazi V, Alwar T et al. High attrition before and after antiretroviral therapy initiation among youth (15–24 years of age) enrolled in HIV care. *AIDS*. 2014;28(4):559–568.
13. Teasdale CA, Alwar T, Chege D, Fayorsey R, Hawken MP, Abrams EJ. Impact of Youth and Adolescent Friendly Services on Retention of 10–24-Year-Olds in HIV Care and Treatment Programs in Nyanza, Kenya. *Journal of acquired immune deficiency syndromes (1999)*. 2016;71(2):e56–e9.
14. Black S, Wallace M, Middelkoop K, Robbertze D, Bennie T, Wood R, Bekker LG. Improving HIV testing amongst adolescents through an integrated Youth Centre rewards program: insights from South Africa. *Children and Youth Services Review*. 2014 Oct 31;45:98–105.
15. Hagey JM, Akama E, Ayieko J, Bukusi EA, Cohen CR, Patel RC. Barriers and facilitators adolescent females living with HIV face in accessing contraceptive services: a qualitative assessment of providers' perceptions in western Kenya. *Journal of the International AIDS Society*. 2015;18(1):20123.
16. Health Economics and HIV/AIDS Research Division (HEARD). Psychosocial Support for Children with Disability and their Carers. 2013. Available at: [http://www.repssi.org/download/REPSSI%20Discussion%20Papers\(2\)/REPSSI%20Discussion%20Paper_PSS%20for%20Children%20with%20Disability%20&%20their%20Carers.pdf](http://www.repssi.org/download/REPSSI%20Discussion%20Papers(2)/REPSSI%20Discussion%20Paper_PSS%20for%20Children%20with%20Disability%20&%20their%20Carers.pdf)
17. Lafort Y, Geelhoed D, Cumba L, Lázaro CdDM, Delva W, Luchters S, et al. Reproductive health services for populations at high risk of HIV: Performance of a night clinic in Tete province, Mozambique. *BMC Health Services Research*. 2010;10:144–
18. Arage G, Tessema GA, Kassa H. Adherence to antiretroviral therapy and its associated factors among children at South Wollo Zone Hospitals, Northeast Ethiopia: a cross-sectional study. *BMC Public Health*. 2014;14:365.
19. Kadede K, Ruel T, Kabami J, Ssemmondo E, Sang N, Kwarisiima D, et al. Increased adolescent HIV testing with a hybrid mobile strategy in Uganda and Kenya. *AIDS (London, England)*. 2016;30(14):2121–6.
20. Mugo PM, Wahome EW, Gichuru EN, Mwashigadi GM, Thiong'o AN, Prins HAB, et al. Effect of Text Message, Phone Call, and In-Person Appointment Reminders on Uptake of Repeat HIV Testing among Outpatients Screened for Acute HIV Infection in Kenya: A Randomized Controlled Trial. *PLoS ONE*. 2016;11(4):e0153612.

Services and Environment

21. Gage AJ, Do M, Grant D. Best Practices for Adolescent-and Youth-Friendly HIV Services—A Compendium of Selected Projects in PEPFAR-Supported Countries. 2017. Available at: https://www.measureevaluation.org/resources/publications/tr-16-134/at_download/document
22. Bekker L-G, Hosek S. HIV and adolescents: focus on young key populations. *Journal of the International AIDS Society*. 2015;18(2Suppl 1):20076.
23. Busza J, Strode A, Dauya E, Ferrand RA. Falling through the gaps: how should HIV programmes respond to families that persistently deny treatment to children? *Journal of the International AIDS Society*. 2016;19(1):20789.
24. Govindasamy D, Ferrand RA, Wilmore SMS, Ford N, Ahmed S, Afnan-Holmes H, et al. Uptake and yield of HIV testing and counselling among children and adolescents in sub-Saharan Africa: a systematic review. *Journal of the International AIDS Society*. 2015;18(1):20182.
25. Busza J, Dauya E, Bandason T, Mujuru H, Ferrand RA. “I don't want financial support but verbal support.” How do caregivers manage children's access to and retention in HIV care in urban Zimbabwe? *Journal of the International AIDS Society*. 2014;17(1):18839.
26. Ferrand RA, Simms V, Dauya E, Bandason T, Mchugh G, Mujuru H, Chonzi P, Busza J, Kranzer K, Munyati S, Weiss HA. The effect of community-based support for caregivers on the risk of virological failure in children and adolescents with HIV in Harare, Zimbabwe (ZENITH): an open-label, randomised controlled trial. *The Lancet Child & Adolescent Health*. 2017 Nov 1;1(3):175-83.
27. Busza J, Strode A, Dauya E, Ferrand RA. Falling through the gaps: how should HIV programmes respond to families that persistently deny treatment to children? *Journal of the International AIDS Society*. 2016;19(1):20789.
28. Smith P, Wallace M, Bekker LG. Adolescents' experience of a rapid HIV self-testing device in youth-friendly clinic settings in Cape Town South Africa: a cross-sectional community based usability study. *Journal of the International AIDS Society*. 2016;19(1).
29. Brown W, Carballo-Diéguez A, John RM, Schnall R. Information, Motivation, and Behavioral Skills of High-risk Young Adults to Use the HIV Self-Test. *AIDS and behavior*. 2016;20(9):2000-2009. doi:10.1007/s10461-016-1309-x.
30. Fournier B, Bridge A, Kennedy AP, Alibhai A, Konde-Lule J. Hear our voices: A Photovoice project with children who are orphaned and living with HIV in a Ugandan group home. *Children and Youth Services Review*. 2014 Oct 31;45:55-63.
31. Dageid W. Support groups for HIV-positive people in South Africa: Who joins, who does not, and why?. *African Journal of AIDS Research*. 2014 Jan 2;13(1):1-1.
32. PEPFAR. Mapping HIV Services and Policies for Adolescents: A Survey of 10 Countries in Sub-Saharan Africa. 2013. Available at: <https://aidsfree.usaid.gov/resources/mapping-hiv-services-and-policies-adolescents-survey-10-countries-sub-saharan-africa>

Services and Environment

33. Midtbo, V. and Daniel, M. Disclosure as a positive resource: the lived experiences of HIV-positive adolescents in Botswana. In: Liamputtong, P. Children and young people living with HIV: a cross-cultural perspective
34. Mupambireyi Z, Bernays S, Bwakura-Dangarembizi M, Cowan FM. "I don't feel shy because I will be among others who are just like me...": The role of support groups for children perinatally infected with HIV in Zimbabwe. *Children and Youth Services Review*. 2014. pp. 106–113. doi: 10.1016/j.childyouth.2014.03.026
35. International HIV/AIDS Alliance. Lessons from Link Up!: Link Up experiences of reaching adolescents living with HIV. 2016. Available at: <https://www.aidsalliance.org/resources/848-link-up-experiences-of-reaching-adolescents-living-with-hiv>
36. Snyder K, Wallace M, Duby Z, Aquino LDH, Stafford S, Hosek S, et al. Preliminary results from Hlanganani (Coming Together): a structured support group for HIV-infected adolescents piloted in Cape Town, South Africa. *Child Youth Serv Rev*. 2014;45:114–21.
37. Mavhu W, Willis N, Mufuka J, Mangenah C, Mvududu K, Bernays S, Mangezi W, Apollo T, Araya R, Weiss HA, Cowan FM. Evaluating a multi-component, community-based program to improve adherence and retention in care among adolescents living with HIV in Zimbabwe: study protocol for a cluster randomized controlled trial. *Trials*. 2017 Oct 20;18(1):478.
38. Simpson N, Kydd A, Erzse A, Figerova Z, Koen J. Using digital psychosocial support groups to increase adherence behaviour among HIV positive adolescents in South Africa. *Frontiers in Public Health*. 2017. Available at: https://www.frontiersin.org/Community/AbstractDetails.aspx?ABS_Doi=10.3389/conf.FPUBH.2017.03.00070&eid=4089&sname=3rd_UCL_Centre_for_Behaviour_Change_Digital_Health_Conference_2017_Harnessing_digital_technology_fo
39. Henwood R, Patten G, Barnett W, Hwang B, Metcalf C, Hacking D, et al. Acceptability and use of a virtual support group for HIV-positive youth in Khayelitsha, Cape Town using the MXit social networking platform. *AIDS Care*. 2016;28(7):898–903.
40. Abubakar A, Van de Vijver FJR, Fischer R, Hassan AS, K Gona J, Dzombo JT, et al. 'Everyone has a secret they keep close to their hearts': challenges faced by adolescents living with HIV infection at the Kenyan coast. *BMC Public Health*. 2016;16:197.
41. Ebersöhn L, Ferreira R. Coping in an HIV/AIDS-dominated context: teachers promoting resilience in schools. *Health Education Research*. 2011;26(4):596–613.
42. Sanga Z, Kapanda G, Msuya S, Mwangi R. Factors influencing the uptake of Voluntary HIV Counseling and Testing among secondary school students in Arusha City, Tanzania: a cross sectional study. *BMC Public Health*. 2015;15:452.
43. Strauss M, Rhodes B, George G. A qualitative analysis of the barriers and facilitators of HIV counselling and testing perceived by adolescents in South Africa. *BMC Health Services Research*. 2015;15:250.

Services and Environment

44. Madiba S, Mokgatle M. "Students want HIV testing in schools" a formative evaluation of the acceptability of HIV testing and counselling at schools in Gauteng and North West provinces in South Africa. *BMC Public Health*. 2015;15:388.
45. Asikhia OA, Mohangi K. A case study of school support and the psychological, emotional and behavioural consequences of HIV and AIDS on adolescents. *SAHARA-J: Journal of Social Aspects of HIV/AIDS*. 2015;12(1):123-33
46. Amaugo LG, Papadopoulos C, Ochieng BMN, Ali N. The effectiveness of HIV/AIDS school-based sexual health education programmes in Nigeria: a systematic review. *Health Education Research*. 2014;29(4):633-48.
47. Ebersöhn L, Ferreira R. Coping in an HIV/AIDS-dominated context: teachers promoting resilience in schools. *Health Education Research*. 2011;26(4):596-613.
48. Abubakar A, Van de Vijver FJR, Fischer R, Hassan AS, K Gona J, Dzombo JT, et al. 'Everyone has a secret they keep close to their hearts': challenges faced by adolescents living with HIV infection at the Kenyan coast. *BMC Public Health*. 2016;16:197.
49. Abubakar A, Van de Vijver FJR, Fischer R, Hassan AS, K Gona J, Dzombo JT, et al. 'Everyone has a secret they keep close to their hearts': challenges faced by adolescents living with HIV infection at the Kenyan coast. *BMC Public Health*. 2016;16:197.
50. Ssewamala FM, Keun HC, Neilands TB, Ismayilova L, Sperber E. The Effect of Economic Assets on Sexual Risk Taking Intentions among Orphaned Adolescents in Uganda. *American journal of public health*. 2010;100(3):483.
51. Toska E, Cluver LD, Boyes ME, Isaacsohn M, Hodes R, Sherr L. School, Supervision and Adolescent-Sensitive Clinic Care: Combination Social Protection and Reduced Unprotected Sex Among HIV-Positive Adolescents in South Africa. *AIDS and Behavior*. 2016.

Language and Discourse

52. Kranzer K, Simms V, Bandason T, Dauya E, McHugh G, Munyati S, Chonzi P, Dakshina S, Mujuru H, Weiss HA, Ferrand RA. Economic incentives for HIV testing by adolescents in Zimbabwe: a randomised controlled trial. *The Lancet HIV*. 2017 Nov 20.
53. Bernays S, Seeley J, Rhodes T, Mupambireyi Z. What am I 'living' with? Growing up with HIV in Uganda and Zimbabwe. *Sociology of Health & Illness*. 2015;37(2):270-83.
54. Watermeyer J. 'Are we allowed to disclose?': a healthcare team's experiences of talking with children and adolescents about their HIV status. *Health Expectations: An International Journal of Public Participation in Health Care and Health Policy*. 2015;18(4):590-600.
55. Watermeyer J. 'Are we allowed to disclose?': a healthcare team's experiences of talking with children and adolescents about their HIV status. *Health Expectations: An International Journal of Public Participation in Health Care and Health Policy*. 2015;18(4):590-600.

Language and Discourse

56. Kidia KK, Mupambireyi Z, Cluver L, Ndhlovu CE, Borok M, Ferrand RA. HIV Status Disclosure to Perinatally-Infected Adolescents in Zimbabwe: A Qualitative Study of Adolescent and Healthcare Worker Perspectives. *PLoS ONE*. 2014;9(1):e87322.
57. Aderomilehin O, Hanciles-Amu A, Ozoya OO. Perspectives and Practice of HIV Disclosure to Children and Adolescents by Health-Care Providers and Caregivers in sub-Saharan Africa: A Systematic Review. *Frontiers in Public Health*. 2016;4(166).
58. Beima-Sofie K, John-Stewart G, Shah B, Wamalwa D, Maleche-Obimbo E, Kelley M. Using Health Provider Insights to Inform Pediatric HIV Disclosure: A Qualitative Study and Practice Framework from Kenya. *AIDS Patient Care and STDs*. 2014;28(10):555-64.
59. Ndinda C, Uzodike UO, Chimbwete C, Mgeyane MTM. Gendered Perceptions of Sexual Behaviour in Rural South Africa. *International Journal of Family Medicine*. 2011;2011:973706. doi:10.1155/2011/973706.
60. Van Rooyen H, Essack Z, Rochat T, Wight D, Knight L, Bland R, et al. Taking HIV Testing to Families: Designing a Family-Based Intervention to Facilitate HIV Testing, Disclosure, and Intergenerational Communication. *Frontiers in Public Health*. 2016;4:154.
61. Arrivé E, Dicko F, Amghar H, Aka AE, Dior H, Bouah B, Traoré M, Ogbo P, Dago-Akribi HA, Eboua TK, Kouakou K. HIV status disclosure and retention in care in HIV-infected adolescents on antiretroviral therapy (ART) in West Africa. *PloS one*. 2012 Mar 21;7(3):e33690.
62. Mweemba M, Musheke MM, Michelo C, Halwiindi H, Mweemba O, Zulu JM. "When am I going to stop taking the drug?" Enablers, barriers and processes of disclosure of HIV status by caregivers to adolescents in a rural district in Zambia. *BMC Public Health*. 2015;15:1028.
63. Krauss BJ, Letteney S, Okoro CN. Why Tell Children: A Synthesis of the Global Literature on Reasons for Disclosing or Not Disclosing an HIV Diagnosis to Children 12 and under. *Frontiers in Public Health*. 2016;4:181. doi:10.3389/fpubh.2016.00181.
64. Gyamfi E, Okyere P, Enoch A, Appiah-Brempong E. Prevalence of, and barriers to the disclosure of HIV status to infected children and adolescents in a district of Ghana. *BMC International Health and Human Rights*. 2017;17(1):8.
65. Mkwanzazi NB, Rochat TJ, Bland RM. The Amagugu intervention: a qualitative investigation into maternal experiences and perspectives of a maternal HIV disclosure support intervention in rural South Africa. *Health Policy and Planning*. 2017;32(9):1231-40.
66. Bogart LM, Skinner D, Thurston IB, Toefy Y, Klein DJ, Hu CH, et al. Let's Talk!, A South African Worksite-Based HIV Prevention Parenting Program. *The Journal of adolescent health : official publication of the Society for Adolescent Medicine*. 2013;53(5):602-8.

Language and Discourse

67. Goodnight B, Salama C, Grim EC, Anthony ER, Armistead L, Cook SL, et al. Perceived control and communication about sex: A study of South African families. *African Journal of AIDS Research*. 2014;13(1):31-6
68. Soon CN, Kaida A, Nkala B, Dietrich J, Cescon A, Gray G, Miller CL. Adolescent experiences of HIV and sexual health communication with parents and caregivers in Soweto, South Africa. *SAHARA-J: Journal of Social Aspects of HIV/AIDS*. 2013;10(3-4):163-9.
69. Van Rooyen H, Essack Z, Rochat T, Wight D, Knight L, Bland R, et al. Taking HIV Testing to Families: Designing a Family-Based Intervention to Facilitate HIV Testing, Disclosure, and Intergenerational Communication. *Frontiers in Public Health*. 2016;4:154.
70. Brandt L, Beima-Sofie K, Hamunime N, Shepard M, Ferris L, Ingo P, et al. Growing-up just like everyone else: key components of a successful pediatric HIV disclosure intervention in Namibia. *AIDS*. 2015;29:S81-S9.
71. Mburu G, Hodgson I, Kalibala S, et al. Adolescent HIV disclosure in Zambia: barriers, facilitators and outcomes. *Journal of the International AIDS Society*. 2014;17(1):18866. doi:10.7448/IAS.17.1.18866.
72. Chaudhury S, Kirk CM, Ingabire C, Mukunzi S, Nyirandagijimana B, Godfrey K, Brennan RT, Betancourt TS. HIV status disclosure through family-based intervention supports parenting and child mental health in Rwanda. *Frontiers in public health*. 2016;4.
73. Rochat TJ, Stein A, Cortina-Borja M, Tanser F, Bland RM. The Amagugu intervention for disclosure of maternal HIV to uninfected primary school-aged children in South Africa: a randomised controlled trial. *The Lancet HIV*. 2017.
74. Wolf HT, Halpern-Felsher BL, Bukusi EA, Agot KE, Cohen CR, Auerswald CL. "It is all about the fear of being discriminated [against]...the person suffering from HIV will not be accepted": a qualitative study exploring the reasons for loss to follow-up among HIV-positive youth in Kisumu, Kenya. *BMC Public Health*. 2014;14:1154.
75. Martinez J, Harper G, Carleton RA, et al. The Impact of Stigma on Medication Adherence Among HIV-Positive Adolescent and Young Adult Females and the Moderating Effects of Coping and Satisfaction with Health Care. *AIDS Patient Care and STDs*. 2012;26(2):108-115. doi:10.1089/apc.2011.0178.
76. Denison JA, Banda H, Dennis AC, Packer C, Nyambe N, Stalter RM, et al. "The sky is the limit": adhering to antiretroviral therapy and HIV self-management from the perspectives of adolescents living with HIV and their adult caregivers. *Journal of the International AIDS Society*. 2015;18(1):19358
77. Corno L, de Walque D. Socioeconomic determinants of stigmatization and HIV testing in Lesotho. *AIDS Care*. 2013;25(Suppl 1):S108-S13.

Language and Discourse

78. Addis Z, Yalew A, Shiferaw Y, Alemu A, Birhan W, Mathewose B, et al. Knowledge, attitude and practice towards voluntary counseling and testing among university students in North West Ethiopia: a cross sectional study. *BMC Public Health*. 2013;13:714-.
79. Hargreaves JR, Stangl A, Bond V, Hoddinott G, Krishnaratne S, Mathema H, et al. HIV-related stigma and universal testing and treatment for HIV prevention and care: design of an implementation science evaluation nested in the HPTN 071 (PopART) cluster-randomized trial in Zambia and South Africa. *Health Policy and Planning*. 2016;31(10):1342-54.
80. Shanaube K, Schaap A, Chaila MJ, Floyd S, Mackworth-Young C, Hoddinott G, Hayes R, Fidler S, Ayles H. Community intervention improves knowledge of HIV status of adolescents in Zambia: findings from HPTN 071-PopART for youth study. *AIDS (London, England)*. 2017 Jul 1;31(3):S221.
81. Maughan-Brown B. Stigma rises despite antiretroviral roll-out: A longitudinal analysis in South Africa. *Social Science & Medicine*. 2010;70(3):368-74.
82. HC, Greeff M, Temane QM. Health behaviour change of people living with HIV after a comprehensive community-based HIV stigma reduction intervention in North-West Province in South Africa. *Sahara J*. 2014;11(1):222-232. doi:10.1080/17290376.2014.985700.
83. Chao L-W, Gow J, Akintola G, Pauly M. HIV/AIDS Stigma Attitudes among Educators in KwaZulu-Natal, South Africa. *The Journal of School Health*. 2010;80(11):561-9.
84. Pantelic M, Boyes M, Cluver L, Meinck F. HIV, violence, blame and shame: pathways of risk to internalized HIV stigma among South African adolescents living with HIV. *Journal of the International AIDS Society*. 2017;20(1):21771. doi:10.7448/IAS.20.1.21771.
85. Creel AH, Rimal RN, Mkandawire G, Böse K, Brown JW. Effects of a mass media intervention on HIV-related stigma: 'Radio Diaries' program in Malawi. *Health Education Research*. 2011;26(3):456-65.
86. World Bank: Development Impact Evaluation. *Experimental Evaluation of MTV Shuga: Changing Social Norms and Behaviours with Entertainment Education*. World Bank, 2016.
87. Daniel M. Keeping the secret: how HIV-positive children in Iringa, Tanzania, respond to the perceived need for silence and secrecy. *Journal of Child & Adolescent Mental Health*. 2015;27(1):11-23.
88. Madiba S, Mokgatle M. Perceptions and experiences about self-disclosure of HIV status among adolescents with perinatal acquired HIV in poor-resourced communities in South Africa. *AIDS research and treatment*. 2016 Sep 8;2016.
89. Denison JA, Banda H, Dennis AC, Packer C, Nyambe N, Stalter RM, et al. "The sky is the limit": adhering to antiretroviral therapy and HIV self-management from the perspectives of adolescents living with HIV and their adult caregivers. *Journal of the International AIDS Society*. 2015;18(1):19358.

Language and Discourse

90. Siu GE, Bakeera-Kitaka S, Kennedy CE, Dhabangi A, Kambugu A. HIV serostatus disclosure and lived experiences of adolescents at the Transition Clinic of the Infectious Diseases Clinic in Kampala, Uganda: A qualitative study. *AIDS Care*. 2012;24(5):606-11.
91. Midtbø V, Shirima V, Skovdal M, Daniel M. How disclosure and antiretroviral therapy help HIV-infected adolescents in sub-Saharan Africa cope with stigma. *African Journal of AIDS Research*. 2012;11(3):261-71.
92. Atwiine B, Kiwanuka J, Musinguzi N, Atwine D, Haberer JE. Understanding the role of age in HIV disclosure rates and patterns for HIV-infected children in southwestern Uganda. *AIDS Care*. 2015;27(4):424-30.
93. Siu GE, Bakeera-Kitaka S, Kennedy CE, Dhabangi A, Kambugu A. HIV serostatus disclosure and lived experiences of adolescents at the Transition Clinic of the Infectious Diseases Clinic in Kampala, Uganda: A qualitative study. *AIDS Care*. 2012;24(5):606-11.
94. Nöstlinger C, Bakeera-Kitaka S, Buyze J, Loos J, Buvé A. Factors influencing social self-disclosure among adolescents living with HIV in Eastern Africa. *AIDS Care*. 2015;27(sup1):36-46
95. Do M, Figueroa ME, Lawrence Kincaid D. HIV Testing Among Young People Aged 16–24 in South Africa: Impact of Mass Media Communication Programs. *AIDS and Behavior*. 2016;20(9):2033-44.
96. Lubinga E, Maes AA, Jansen CJ. How peer conversations about HIV/AIDS media messages affect comprehension and beliefs of young South African women. *SAHARA-J: Journal of Social Aspects of HIV/AIDS*. 2016;13(1):68-80.

Agency

97. Fox K, Ferguson J, Ajose W, et al. Adolescent consent to testing: a review of current policies and issues in sub-Saharan Africa. In: *HIV and Adolescents: Guidance for HIV Testing and Counselling and Care for Adolescents Living with HIV: Recommendations for a Public Health Approach and Considerations for Policy-Makers and Managers*. Geneva: World Health Organization; 2013. ANNEX 15. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK217954/>
98. Asaolu IO, Gunn JK, Center KE, Koss MP, Iwelunmor JI, Ehiri JE. Predictors of HIV testing among youth in sub-Saharan Africa: a cross-sectional study. *PLoS one*. 2016 Oct 5;11(10):e0164052.
99. Strode AE, Van Rooyen H, Makusha T. Is it lawful to offer HIV self-testing to children in South Africa? *Southern African Journal of HIV Medicine*. 2013;14(4):151-4.
100. Bernays S, Seeley J, Rhodes T, Mupambireyi Z. What am I 'living' with? Growing up with HIV in Uganda and Zimbabwe. *Sociology of Health & Illness*. 2015;37(2):270-83.
101. Vreeman RC, McCoy BM, Lee S. Mental health challenges among adolescents living with HIV. *Journal of the International AIDS Society*. 2017 May 1;20(S3).

Agency

102. Pettit E, Pettitt ED, Greifinger RC, Phelps BR, Bowsky SJ. Improving Health Services for Adolescents Living with HIV in Sub-Saharan Africa: A Multi-Country Assessment. *African Journal of Reproductive Health/Revue Africaine de Santé de la Reproduction*. 2013 Dec 1:17-31.
103. Caserta TA, Pirttilä-Backman A-M, Punamäki R-L. Stigma, marginalization and psychosocial well-being of orphans in Rwanda: exploring the mediation role of social support. *AIDS Care*. 2016;28(6):736-44.
104. Boyes ME, Cluver LD. Relationships Between Familial HIV/AIDS and Symptoms of Anxiety and Depression: The Mediating Effect of Bullying Victimization in a Prospective Sample of South African Children and Adolescents. *Journal of Youth and Adolescence*. 2015;44(4):847-59.
105. Sherr L, Yakubovich AR, Skeen S, Cluver LD, Hensels IS, Macedo A, et al. How Effective Is Help on the Doorstep? A Longitudinal Evaluation of Community-Based Organisation Support. *PLoS ONE*. 2016;11(3):e0151305.
106. Dow DE, Turner EL, Shayo AM, Mmbaga B, Cunningham CK, O'Donnell K. Evaluating Mental Health Difficulties and Associated Outcomes Among HIV-Positive Adolescents in Tanzania. *AIDS care*. 2016;28(7):825-33.
107. Langhaug LF, Pascoe SJ, Mavhu W, Woelk G, Sherr L, Hayes RJ, et al. High Prevalence of Affective Disorders among Adolescents Living in Rural Zimbabwe. *Journal of community health*. 2010;35(4):355-64.
108. Mueller J, Alie C, Jonas B, Brown E, Sherr L. A quasi-experimental evaluation of a community-based art therapy intervention exploring the psychosocial health of children affected by HIV in South Africa. *Tropical Medicine & International Health*. 2011;16(1):57-66.
109. RM, Underwood L a, Suarez E, Musisi S, Grande TL. Cognitive behavioral therapy group intervention for HIV transmission risk behavior in perinatally infected adolescents. *Health (Irvine Calif)*. 2012;4: 1334–1345.
110. Chibanda D, Weiss HA, Verhey R, et al. Effect of a primary care-based psychological intervention on symptoms of common mental disorders in zimbabwe: A randomized clinical trial. *JAMA*. 2016;316(24):2618-26.
111. Willis N, Frewin L, Miller A, Dziwa C, Mavhu W, Cowan F. "My story"—HIV positive adolescents tell their story through film. *Children and Youth Services Review*. 2014;45(Supplement C):129-36.
112. Adegoke CO, Steyn MG. A photo voice perspective on factors contributing to the resilience of HIV positive Yoruba adolescent girls in Nigeria. *Journal of Adolescence*. 2017;56 (Supplement C):1-10
113. Mavhu W, Berwick J, Chirawu P, Makamba M, Copas A, Dirawo J, et al. Enhancing Psychosocial Support for HIV Positive Adolescents in Harare, Zimbabwe. *PLoS ONE*. 2013;8(7):e70254.

Agency

114. Bhana A, Mellins CA, Petersen I, Alicea S, Myeza N, Holst H, et al. The VUKA Family Program: Piloting a family-based psychosocial intervention to promote health and mental health among HIV infected early adolescents in South Africa. *AIDS care*. 2014;26(1):10.1080/09540121.2013.806770.
115. Mark D, Taing L, Cluver L, Collins C, Iorpenda K, Andrade C, et al. What is it going to take to move youth-related HIV programme policies into practice in Africa? *Journal of the International AIDS Society*. 2017;20(Suppl 3):21491.
116. Denison JA, Pettifor A, Mofenson LM, Kasedde S, Marcus R, Konayuma KJ, Koboto K, Ngcobo ML, Ndleleni N, Pulerwitz J, Kerrigan D. Youth engagement in developing an implementation science research agenda on adolescent HIV testing and care linkages in sub-Saharan Africa. *AIDS (London, England)*. 2017 Jul 1;31(3):S195.
117. Abubakar A, Van de Vijver FJR, Fischer R, Hassan AS, K Gona J, Dzombo JT, et al. 'Everyone has a secret they keep close to their hearts': challenges faced by adolescents living with HIV infection at the Kenyan coast. *BMC Public Health*. 2016;16:197.
118. Dow DE, Turner EL, Shayo AM, Mmbaga B, Cunningham CK, O'Donnell K. Evaluating mental health difficulties and associated outcomes among HIV-positive adolescents in Tanzania. *AIDS care*. 2016;28(7):825-33.
119. Lowenthal ED, Marukutira TC, Chapman J, Mokete K, Riva K, Tshume O, et al. Psychosocial Assessments for HIV+ African Adolescents: Establishing Construct Validity and Exploring Under-Appreciated Correlates of Adherence. *PLoS ONE*. 2014;9(10):e109302.
120. MacDonell K, Naar-King S, Huszti H, Belzer M. Barriers to medication adherence in behaviorally and perinatally infected youth living with HIV. *AIDS Behav*. 2013;17(1):86-93.
121. Kim MH, Mazenga AC, Yu X, Ahmed S, Paul ME, Kazembe PN, et al. High self-reported non-adherence to antiretroviral therapy amongst adolescents living with HIV in Malawi: barriers and associated factors. *Journal of the International AIDS Society*. 2017;20(1):21437.
122. Fetzer BC, Mupenda B, Lusiana J, Kitetele F, Golin C, Behets F. Barriers to and Facilitators of Adherence to Pediatric Antiretroviral Therapy in a Sub-Saharan Setting: Insights from a Qualitative Study. *AIDS Patient Care and STDs*. 2011;25(10):611-21.
123. Adejumo OA, Malee KM, Ryscavage P, Hunter SJ, Taiwo BO. Contemporary issues on the epidemiology and antiretroviral adherence of HIV-infected adolescents in sub-Saharan Africa: a narrative review. *Journal of the International AIDS Society*. 2015;18(1):20049.
124. Kawuma R, Bernays S, Siu G, Rhodes T, Seeley J. 'Children will always be children': Exploring perceptions and experiences of HIV-positive children who may not take their treatment and why they may not tell. *African Journal of AIDS Research*. 2014;13(2):189-95.

Agency

125. Gross R, Bandason T, Langhaug L, Mujuru H, Lowenthal E, Ferrand R. Factors associated with self-reported adherence among adolescents on antiretroviral therapy in Zimbabwe. *AIDS Care*. 2015;27(3):322–26.
126. Nabukeera-Barungi N, Elyanu P, Asire B, Katureebe C, Lukabwe I, Namusoke E et al. Adherence to antiretroviral therapy and retention in care for adolescents living with HIV from 10 districts in Uganda. *BMC Infect Dis*. 2015;15:520.
127. Mbuagbaw L, van der Kop ML, Lester RT, et al. Mobile phone text messages for improving adherence to antiretroviral therapy (ART): an individual patient data meta-analysis of randomised trials *BMJ Open* 2013;3:e003950. doi: 10.1136/bmjopen-2013-003950
128. Pop-Eleches C, Thirumurthy H, Habyarimana JP, Zivin JG, Goldstein MP, De Walque D, Mackeen L, Haberer J, Kimaiyo S, Sidle J, Ngare D. Mobile phone technologies improve adherence to antiretroviral treatment in a resource-limited setting: a randomized controlled trial of text message reminders. *AIDS (London, England)*. 2011 Mar 27;25(6):825.
129. Horvath T, Azman H, Kennedy GE, Rutherford GW. Mobile phone text messaging for promoting adherence to antiretroviral therapy in patients with HIV infection. *Cochrane Database of Systematic Reviews*. 2012(3).
130. Rana Y, Haberer J, Huang H, Kambugu A, Mukasa B, Thirumurthy H, et al. Short Message Service (SMS)-Based Intervention to Improve Treatment Adherence among HIV-Positive Youth in Uganda: Focus Group Findings. *PLoS ONE*. 2015;10(4):e0125187
131. Kebede M, Zeleke A, Asemahagn M, Fritz F. Willingness to receive text message medication reminders among patients on antiretroviral treatment in North West Ethiopia: A cross-sectional study. *BMC Medical Informatics and Decision Making*. 2015;15:65.
132. Fatti G, Shaikh N, Eley B, Grimwood A. Improved virological suppression in children on antiretroviral treatment receiving community-based adherence support: a multicentre cohort study from South Africa. *AIDS care*. 2014;26(4):448–53
133. Bain-Brickley D, Butler LM, Kennedy GE, Rutherford GW. Interventions to improve adherence to antiretroviral therapy in children with HIV infection. *The Cochrane Library*. 2011.
134. Toska E, Pantelic M, Meinck F, Keck K, Haghghat R, Cluver L (2017) Sex in the shadow of HIV: A systematic review of prevalence, risk factors, and interventions to reduce sexual risk-taking among HIV-positive adolescents and youth in sub-Saharan Africa. *PLoS ONE*12(6): e0178106. <https://doi.org/10.1371/journal.pone.0178106>
135. Dunbar MS, Chapwanya G, Willis N, Gibbs A, Mutasa-Apollo T, Langhaug L. The missing discourse of sexual pleasure in health programmes for young people living with HIV. 2016. Poster presentation. Available at: https://www.researchgate.net/publication/305639515_The_missing_discourse_of_sexual_pleasure_in_health_programmes_for_young_people_living_with_HIV

Agency

136. Busza J, Besana GV, Mapunda P, Oliveras E. "I have grown up controlling myself a lot." Fear and misconceptions about sex among adolescents vertically-infected with HIV in Tanzania. *Reproductive health matters*. 2013;21(41):87-96.
137. Peltzer K, Simbayi L, Banyini M, Kekana Q. HIV Risk Reduction Intervention Among Medically Circumcised Young Men in South Africa: A Randomized Controlled Trial. *International Journal of Behavioral Medicine*. 2012;19(3):336-41.
138. Hodgson I, Ross J, Haamujompa C, Gitau-Mburu D. Living as an adolescent with HIV in Zambia—lived experiences, sexual health and reproductive needs. *AIDS care*. 2012;24(10):1204-10
139. Pretorius L, Gibbs A, Crankshaw T, Willan S. Interventions targeting sexual and reproductive health and rights outcomes of young people living with HIV: a comprehensive review of current interventions from sub-Saharan Africa. *Global Health Action*. 2015;8:10.3402/gha.v8.28454.
140. Sharer MF. *A Transitioning of Care and Other Services for Adolescents Living with HIV in Sub-Saharan Africa*. Arlington, VA: AIDSTAR-One; 2012
141. Busza J, Besana GV, Mapunda P, Oliveras E. "I have grown up controlling myself a lot." Fear and misconceptions about sex among adolescents vertically-infected with HIV in Tanzania. *Reproductive health matters*. 2013;21(41):87-96.
142. Nöstlinger C, Jasna L, Sabrina B-K, Obong'o C, Eric W, Buvé A. Translating primary into 'positive' prevention for adolescents in Eastern Africa. *Health Promotion International*. 2016;31(3):653-64.
143. Parker L, Maman S, Pettifor A, Chalachala JL, Edmonds A, Golin CE, Moracco K, Behets F, Sympa Study Team Feasibility Analysis of an evidence-based positive prevention intervention for youth living with HIV/AIDS in Kinshasa, Democratic Republic of the Congo. *AIDS Education and Prevention*. 2013;25:135–50.

Call to Action

144. MacPherson P, Munthali C, Ferguson J, et al. Service delivery interventions to improve adolescents' linkage, retention and adherence to antiretroviral therapy and HIV care. *Tropical Medicine & International Health*. 2015;20(8):1015-1032. doi:10.1111/tmi.12517.
145. Lall P, Lim SH, Khairuddin N, Kamarulzaman A. Review: An urgent need for research on factors impacting adherence to and retention in care among HIV-positive youth and adolescents from key populations. *Journal of the International AIDS Society*. 2015;18(2Suppl 1):19393. doi:10.7448/IAS.18.2.19393.
146. Petersen I, Bhana A, Myeza N, Alicea S, John S, Holst H, McKay M, Mellins C. Psychosocial challenges and protective influences for socio-emotional coping of HIV+ adolescents in South Africa: a qualitative investigation. *AIDS care*. 2010 Aug 1;22(8):970-8.
147. UNAIDS. *Right to Health*. 2017. Available at: http://www.unaids.org/sites/default/files/media_asset/RighttoHealthReport_Full_web%202020%20Nov.pdf