Addressing challenges facing adolescents in knowing and managing their HIV status in sub-Saharan Africa
Adolescents frequently fall between the cracks of paediatric and adult HIV care services, 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. Sadly, the main barriers are the psychosocial 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. 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.

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. 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. Adolescents living with HIV (ALHIV) include both those perinatally infected and those infected sexually, 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.

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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.

This brief is aimed at organisations working with ALHIV who wish to implement evidence-based programmes. The paper provides a snapshot of some promising interventions in sub-Saharan Africa professed 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.

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

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.
Challenges expressed by ALHIV

Promising approaches and interventions

**Health services**

“The health services are open during school hours and we don’t have the time to go for check-ups”

Pepe, 10, Lesotho

Lack of knowledge and understanding, and resources and time constraints, may hinder the engagement of ALHIV with support groups.

**Poverty**

Leading to missed clinic appointments, poor nutrition, and elevated stress for caregivers.

**Psychosocial support groups**

“We need capacity building and we need financiers to support our organisations. We need financiers to support our organisations. We need financiers to support our organisations. We need financiers to support our organisations. We need financiers to support our organisations.

Kananelo, 22, Lesotho

Improving parent-child communication through structured programmes (e.g. Let’s Talk), a worker-based programme can help parents feel more comfortable discussing HIV-focused topics with their children.

**The role of the home environment**

Unstable family structures; caregivers or members of the family may leave home to seek work, and caregivers may be absent for long periods of time.

**The school environment**

Frequent missed school due to illness or caring for ill relatives. Stigmatisation by students and teachers. Teachers face difficulties in how to deal with HIV-related issues in pupils.

**Language and discourse**

Challenges expressed by ALHIV

Promising approaches and interventions

**Language and discourse**

“People struggle to find the right language and euphemisms. Different discussion of sex and HIV is often taboo, and complicated by use of overly polemic language and euphemisms.”

Different models and capabilities of communication across generations also present a barrier. Parents/caregivers’ fear of disclosing their child’s status. While disclosure can improve ALHIVs’ retention in care, caregivers may fear young persons will not understand, will not respect confidentiality, or will not keep their HIV status confidential.

For similar reasons, parents may struggle with disclosure of their own HIV status to children.

**Poverty**

Leading to missed clinic appointments, poor nutrition, and elevated stress for caregivers.

**The environment**

“The school environment”

Co-location of services can more effectively support ALHIV. Small ‘nudges’ can improve testing and counselling uptake by adolescents.

**Peers, family, friends**

Peers can be especially influential among adolescents, and social networking platforms can overcome psychological barriers to engaging in testing. Using targeted testing for adolescents is provided in combination. 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.

Participatory workshops and activities in the community have been shown to reduce both stigma and disclosure barriers. Healthcare providers need continued training and resources to support disclosure. Healthcare providers can support and empower caregivers to take the lead in disclosing.

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Family-based interventions can encourage family cohesion, and HIV testing and linkage to care for all family members.

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### Challenges expressed by ALHIV

<table>
<thead>
<tr>
<th>Age of consent</th>
<th>Mental health impacts of living with HIV</th>
<th>Non-medical barriers to adhering to HIV medication</th>
<th>Sexual health, sexuality and romantic relationships</th>
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<td>Age of consent at 18 may restrict access to HIV counselling and testing, and creates ambiguity for health professionals working with ALHIV.</td>
<td>Fears around disclosure, rejection, stigma, and prejudice.</td>
<td>Stigma, lack of disclosure, peer pressure/influences can affect ALHIV's adherence.</td>
<td>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.</td>
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<td>Consent for self-testing by adolescents 12 and over in countries like South Africa may be lawful provided pre- and post-test counselling and psychosocial support were offered in conjunction with self-tests.</td>
<td>Mental health problems may be linked to self-directed stigma, shame, and anger among ALHIV.</td>
<td>Alcohol use and violence are associated with missing doses, and in both adolescence and later life. Barriers may also be structural, such as lack of nutritional support, or treatment fees.</td>
<td>Sexual health, sexuality and romantic relationships may be a low-cost approach to help ALHIV achieve virological suppression.</td>
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<td>Participation in community-based organisations (at least monthly) in HIV-prevalence areas has been shown to decrease suicidal ideation, depression, problems with peers, and perceived stigma.</td>
<td>Interventions to improve mental health are also likely to improve medication adherence.</td>
<td>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.</td>
<td>Recognise that adolescents living with HIV (ALHIV) face unique challenges that are different to those facing children and adults.</td>
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<td>Psychological interventions may improve certain psychosocial 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.</td>
<td>Cognitive behaviour therapy (CBT) can reduce anxiety among ALHIV, although there was limited impact on depression compared to controls receiving standard group counselling.</td>
<td>Models of problem-solving therapy can deliver 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.</td>
<td>Find ways to sensitively discuss sex, dating and relationships for ALHIV, as this is a clear gap in current interventions.</td>
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<td>Community-based adherence support may be effec tive at weekly intervals (rather than daily intervals).</td>
<td>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.</td>
<td>A home-based nursing programme has shown impact on knowledge and medication refills but had no effect on viral load.</td>
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### Agency

- 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, viral 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.

### Recommendations for implementing organisations

- 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, marginalisation) 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.
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. There is particularly limited research on the adherence, retention in care and treatment outcomes of young people from marginalised populations. 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. 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. 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.

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

For further information about the London School of Hygiene & Tropical Medicine, please visit: www.lshtm.ac.uk

For further information about Sentebale, please visit: www.sentebale.org

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

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References

Introduction


Services and Environment


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