



Position Paper

Improving Outcomes for Adolescents and Young Adults Living With HIV

Society for Adolescent Health and Medicine



A B S T R A C T

Adolescents and young adults living with HIV (AYLHIV), ages 10–24, experience inferior outcomes across the HIV care continuum compared to adults. Inferior outcomes are caused by clinical systems that are not tailored to AYLHIV, structural barriers that prevent equitable care, and lack of engagement of AYLHIV by care teams. This position paper outlines three recommendations to bridge these gaps in care outcomes. The first advocates for offering differentiated and integrated health services. The second addresses structural changes that can improve outcomes for AYLHIV. The third calls for actively including input from AYLHIV about the care designed for them.

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Positions of the Society for Adolescent Health and Medicine

1. Adolescents and young adults living with HIV (AYLHIV) should be provided differentiated and integrated HIV services to ensure improved outcomes across the continuum of care.
2. Structural changes that can improve outcomes for AYLHIV should be actively pursued.
3. AYLHIV should be included in the conceptualization, design, implementation, monitoring, and evaluation of HIV services designed for them.

Statement of the Problem

Globally, AYLHIV are a large and diverse population. According to the most recent United Nations AIDS Executive Summary, 4,000 people acquire HIV every day around the world, including 1,100 young people ages 15–24 [1]. There are over five million AYLHIV world-wide [2]. AYLHIV are diverse in age (younger adolescents, older adolescents, and young adults), and self-identified sex, gender, and sexual orientation, and include vulnerable persons across countries, cultures, races, ethnicities, and backgrounds. Adolescents and young adults acquire HIV

through varied modes of transmission, including perinatal transmission, consensual sexual contact, sexual assault, injection drug use, and contaminated blood products or procedures. They could be parents or have parents and/or other family members living with HIV.

AYLHIV have significant disparities in outcomes across the HIV care continuum, higher rates of attrition from care, and higher rates of HIV-related mortality compared to other ages [1]. Consistently poor outcomes across the HIV care continuum lead to higher rates of HIV-related mortality rates among AYLHIV [3]. In fact, HIV/AIDS remains a top five leading cause of death among adolescents living in Africa [4].

To understand the disparities that AYLHIV face, it is important to understand the multiple steps along the HIV continuum of care as defined by the Centers for Disease Control and Prevention: Step 1—diagnosis refers to the young person being aware of their HIV status; Step 2—linkage to care means completion of a first medical visit after diagnosis; Step 3—initiation of treatment means the young person has been provided an appropriate antiretroviral treatment (ART); Step 4—retention in care means actively participating in medical care by attended scheduled medical visits; Step 5—viral suppression means achieving an undetectable viral load less than 200 copies/ml; and Step 6—transition to adult care which is unique to adolescents and young adults and refers to the young person successfully establishing care in an adult-based clinical setting.

AYLHIV face significant barriers to access of quality health services. Barriers include inadequate access to health care teams trained in adolescent and youth friendly services, non-tailored

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health information, difficulty navigating adult-oriented health systems, legal requirements for parental or caregiver consent, and challenges with direct and associated service costs. These individuals often face age, gender, race, ethnic, and/or sexuality-based discrimination, and subsequent stigma associated with living with HIV. HIV-related stigma and discrimination is pervasive and a main facilitator to disparities in access to HIV services. For example, gender and sexual diverse individuals report considerably greater incidence of violence in work and education environments compared to their peers [5]. Over 90% of AYLHIV live in African countries, and many AYLHIV across the world are living in poverty or near poverty conditions. AYLHIV experience difficulties with adhering to treatment and remaining engaged in care often due to numerous mental, behavioral, and social issues, including depression, anxiety, self-harm, stigma, isolation, and substance use [6]. In the face of these challenges, clear and concerted efforts are needed to improve the health of AYLHIV and to achieve joint global goals by 2030 [7]. In 2014, the Joint United Nations Programme on HIV/AIDS (UNAIDS) launched the 95–95–95 targets. The aim was to diagnose 95% of all people living with HIV, provide ART for 95% of those diagnosed, and achieve viral suppression for 95% of those treated by 2030. AYLHIV fall short of these targets and must be prioritized in local and global HIV response efforts.

Methods

The positions and recommendations of this paper are based on a consensus of all coauthors. The positions were developed through consultations with internationally recognized experts in the field of adolescent and young adult HIV care and augmented by a review of the literature using consensus search terms including adolescent, teen, youth, and young adult in combination with HIV, AIDS, disclosure, health care transition, adolescent-friendly, youth-friendly, differentiated care, mental health, interventions, confidentiality, and autonomy.

Positions and recommendations

AYLHIV should be provided differentiated and integrated HIV services to ensure improved outcomes across the continuum of care.

Differentiated models of care are a person-centered approach to HIV service delivery including services that exist within and outside of health care facilities and are provided by health care professionals, lay providers, and/or community members, including young people themselves [8]. The building blocks of differentiated models of care should address the critical questions of who delivers the services, where the services are delivered, what package is delivered, and when they are delivered [8]. An example of this model is the Zvandiri intervention in Zimbabwe, which improved viral suppression by offering peer supporters, monthly support groups, texts messages, and home visits [9]. Another study “FANMI” in Haiti demonstrated improved retention in care for AYLHIV by providing streamlined community-based HIV care that enabled consistent patient-provider relationships [10]. The Multi-month scripts program for AYLHIV who are stable and adherent on ART, is another example of a differentiated service delivery model which showed success in several countries [8].

A very important aspect of offering differentiated models of care includes the delivery of youth-friendly health services for

AYLHIV. This means services are “*acceptable* (young people are willing to obtain the health services), *equitable* (all young people, not just select groups, are able to obtain these health services), *appropriate* (the right health services), and *effective* (the right health services are provided in the right way, making a positive impact on young people)” [11]. Friendly health services should be tailored to meet the needs of AYLHIV across age-specific stages. Thus, there are expected differences between services for a 12-year-old living with HIV acquired through perinatal transmission compared to a 24-year-old with sexually acquired HIV. One example is Malawi’s “Teen Club” which consisted of youth-friendly ART care (including prescriptions, refills, labs, and medication counseling), while also incorporating individual psychosocial support, peer activities, assistance with disclosure, and sexual and reproductive health education [12]. This program found that individuals ages 15–19 who participated were more likely to be retained in care compared to those who did not participate. Another example is the “Red Carpet Program” in Kenya which improved linkage to care and retention in care for AYLHIV through multiple interventions centered on providing catered adolescent and youth-friendly services [13]. These services included very important person express cards which allowed clients to speed through clinic registration, have personalized tours, and have a fast-track to other health services within the clinic [13].

Integrated HIV services are broadly defined as the combination of HIV care services and at least one other health condition such as mental health or contraceptive health [14]. Comprehensive and integrated services can help destigmatize clinical environments for AYLHIV because both AYLHIV and young people without HIV receive services in the same space. Although there are limited data showing integrated HIV services improve outcomes across the continuum, successful programs such as the Zvandiri intervention, the “Red Carpet Program,” and the FANMI model, included psychosocial support and sexual and reproductive health integration as part of the intervention [9,10,13]. These studies and others have shown improvement in mental health and reproductive outcomes from integration of care [15].

Differentiated and integrated service delivery models should be analyzed for effectiveness based on impacted measures on the continuum of care defined above in the Statement of the Problem. Monitoring needs to be iterative and continuous and include each element of the continuum of care and account for attrition and HIV-related mortality [9,16,17]. Further outcomes should be meaningfully disaggregated by age (e.g., by 5-year age bands - 10–14; 15–19; 20–24) and transmission risk factors to better understand how interventions impact important patient subgroups. It is vital to have AYLHIV engaged in this monitoring and iterative change process.

Structural changes that can improve outcomes for AYLHIV should be actively pursued

Structural changes (in policies, practices, and legislative approaches) that can positively impact outcomes for AYLHIV include early disclosure to young adolescents with perinatally acquired HIV, economic support, transition to adult care preparedness, elimination of legal barriers to HIV testing and treatment for minors, and elimination of discriminatory laws against individuals living with HIV, and individuals who are sexually or gender diverse.

Early disclosure of HIV status for young adolescents living with HIV should be supported by psychosocial support and age-appropriate disclosure counseling. There is evidence of health benefit and little evidence of psychological or emotional harm from disclosing HIV status to school age children (6–12 years). Early disclosure removes the secrecy and stigma associated with HIV, allowing adolescents to access social support and mental health services and to actively participate in a dialogue about HIV to understand the rationale behind adherence [18]. Early disclosure from caregivers to adolescents has shown to improve adherence, immunologic response, and lower mortality [19].

AYLHIV need educational and economic support. Educational support refers to assistance for school performance, providing accommodations for health care-related absences, and eliminating barriers to staying in school. There is increasing evidence that economic support may be effective in increasing HIV testing, ART initiation, and maintenance of viral suppression for AYLHIV. For example, young mothers living with HIV often have substantially lower rates of ART access and viral suppression, as well as lower rates of HIV testing and viral suppression for their children [15]. Research among young women living with HIV suggests that economic support, assistance to remain in education, and mental health services are essential components to optimize health outcomes [20]. Moreover, economic supports combined with positive parenting training can influence retention in care possibly due to improved mental health and educational outcomes [21].

Transition readiness assessments and clear transition protocols are needed to assist AYLHIV transitions from pediatric to adult services. The process of transitioning to adult-based care is widely variable depending on the local setting, and its timing is often based exclusively on the young person's age. Potential interventions include engagement of young people in the process of care transitioning, clear communication among care teams, starting the process of transitioning as early as feasible, and using assessment tools and resources to identify AYLHIV experiencing structural vulnerabilities who could benefit from additional services prior to and after transition [22,23].

Legal and policy barriers to HIV testing and medical care for adolescents need to be eliminated. Advancing the rights of adolescents to autonomous decision-making is a key strategy to address gaps, disparities, and inequities facing adolescents seeking HIV testing and care. Existing legal and policy barriers compound challenges between adolescent autonomy and confidentiality with parental consent. For example, despite World Health Organization recommendations to decrease age restrictions for adolescents independently seeking HIV testing, many national laws and policies governing HIV prevention, testing, and treatment explicitly or implicitly require that individuals be 18 years or older to access services [11]. Ambiguous and contradictory laws addressing the age of consent for HIV services contribute to concerns about protections, confidentiality, and legal risks to health care providers. Globally, there are numerous discrepancies between adolescents' ability to consent in order to access testing and treatment for sexually transmitted infections, while simultaneously prohibiting access to HIV testing and treatment without parental consent [24].

Eliminating discriminatory, punitive, and criminalization laws that target sexual and gender diverse individuals and individuals living with HIV is vital to advancing the health of AYLHIV [25]. Discriminatory laws such as criminalization of

same-sex sexual relationships; sex work; drug possession; and nondisclosure of HIV status, interfere with access to HIV services and increase HIV risks especially for young people. Jurisdictions with punitive laws against sexual and gender diverse people such as transgender individuals show less progress toward global HIV testing and treatment targets. Many countries, states, and jurisdictions criminalize HIV nondisclosure to sexual partners. Such discriminatory laws undermine efforts to prevent new infections and impede AYLHIV from achieving success on the continuum of care [26]. The Society for Adolescent Health and Medicine also advocates for the repeal of discriminatory laws and policies (e.g. abstinence-only education) prohibiting medically accurate sexual education addressing lesbian, gay, bisexual, transgender, queer, intersex, and asexual (LGBTQIA+) issues in schools which would allow for comprehensive discussion of HIV, its risk factors, and protective factors [27].

AYLHIV should be included in the conceptualization, design, implementation, monitoring, and evaluation of HIV services designed for them.

There is mounting evidence that adolescents and young adults can be agents of change and improvement in continuum of care outcomes. AYLHIV engagement should begin from the point of conceptualization and continue through all aspects of design, implementation, monitoring, and evaluation. Inclusion of digital technology and utilization of a framework in the engagement process are recommendations to assist in improving outcomes for AYLHIV.

The RIGHTS framework is an example which can be used in the global HIV response. Engagements should be Resourced (with time, training, and money), Impactful (ensuring that young people are clear on how their input will inform deliverables), Genuine (they understand the intentions and have a choice in participation), Harmless (ensuring responsiveness to the emotional and mental health needs of participants), Teen-friendly (enjoyable and relevant to young people), and Skills building (development of competencies for participants) RIGHTS [28]. This framework is applicable to clinical trials, observational studies, implementation science, service delivery, and policy development [28].

Peer-driven interventions focused on education, mentorship, counseling, and care navigation have followed the premise that peer relationships are based on trust and shared experiences to improve a variety of care outcomes. Supportive measures such as skills building, leadership training, and mentorship together with increased investment into networks of AYLHIV are needed to expand opportunities for youth to confidently contribute to decision-making, and to consult and represent the voices of peers in advocacy and programming [29]. These engagement opportunities should be conveniently offered wherever they are: for example at schools, clinics, and community gatherings.

There are multiple examples of peer-driven interventions. Resilient and Empowered Adolescents and Young People (READY) is a group that has successfully worked toward improved testing, diagnosis, and advocacy for legal changes to HIV testing consent laws in over 39 countries [30]. Another group employed novel strategies to improve uptake of testing options and interventions that was centered around youth crowdsourcing of ideas [31]. For linkage to care facilitation, there is evidence that peer navigators have helped AYLHIV traverse both structural and social barriers of complex care systems to ensure linkage [32]. Through the provision of emotional, social, and

practical support, peer mentors/supporters have improved retention in care and viral suppression via teen clubs, teen clinics, and prevention of perinatal transmission programs [9,12].

With respect to digital tools, AYLHIV must be fully engaged from the onset in the development, design, and application of these tools so that these are user driven, anchored within local settings, and grounded in safeguarding a human rights approach. User-centered digital and technology-based strategies, including social media, messaging, dating and “hook-up” applications, games, and music are options for engaging AYLHIV. These digital/technology strategies facilitate building agency for self-care and help to overcome service barriers and constraints relating to staffing, distance, time, infrastructure, and cost [33,34]. Electronic and mobile technologies that are already available to support young people across the continuum of care will need to be adapted to reduce unintended harms such as inadvertent disclosure of HIV status, spreading of misinformation, and intrusion into personal information by developers and government monitors. It will also be crucial to ensure the utility and availability of these technologies across different communities and contexts with varied information technology resources and infrastructure [35]. Finally, newer, more efficient methods of developing and testing interventions need to be promoted to ensure the contemporariness of these tools with emphasis on adaptability and integration [36].

Summary

In summary, the Society for Adolescent Health and Medicine proposes three recommendations to address the gaps in care and outcomes that are affecting AYLHIV across the world to achieve the UNAIDS 95–95–95 target for 2030. These positions and discussion take aim at improving clinical services, mitigating structural barriers, and involvement of AYLHIV in the entire spectrum of care and are designed to be applicable and relevant to diverse populations of AYLHIV and useful in various settings where they access care and live.

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