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# Peer Support for Adolescents and Young People Living with HIV in sub-Saharan Africa: Emerging Insights and a Methodological Agenda

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## Abstract

**Purpose—**Despite clear need and disproportionate risk, adolescents, and young people living with HIV (AYPLHIV) are underserved within the HIV response. “Peer support” increasingly forms part of adolescent and youth-responsive service packages as a class of implementation strategies that can support adolescents to access, engage, and sustain treatment. This paper examines examples of peer support for AYPLHIV within sub-saharan Africa to explore the determinants of successful implementation, outcomes and scale-up, as well as policy and programmatic implications.

**Recent Findings—**Although adolescent peer support has been observed to be widely implemented, there are few examples of detailed program descriptions describing operational logistics or outcomes around peer support interventions. Nevertheless the few examples available provide preliminary support for the potential utility of peer support to improve AYPLHIV outcomes.

**Summary—**Implementation science research is an urgent imperative to examine applicability of peer support for this priority population. In the meantime, programs should move forward with implementation based on promising outcomes, programmatic experience, contextual understanding of challenges and gaps, and best practice examples.

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**Keywords**

HIV; Adolescent; Peer; Adherence; Retention; Implementation science

## Introduction

Despite growing optimism towards achieving 95–95–95 targets, the HIV epidemic in adolescents and young people aged 10–24 years remains one of the most persistent global public health challenges today. Adolescents and young people living with HIV (AYPLHIV) account for approximately 45% of new HIV infections globally, with 70% of this population residing in sub-Saharan Africa [1]. Despite clear need and disproportionate risk, AYPLHIV continue to be underserved within the HIV response, facing major barriers to service access and use at each step of the HIV care and treatment cascade. Over the past few years, it has been increasingly recognized that the unique needs of adolescents, and young people are not adequately addressed within standard pediatric or adult HIV service delivery models. Data from research, surveillance, and program monitoring have shown that HIV-infected adolescents and young people have lower rates of knowing their HIV status, linkage to care and treatment, retention, and viral suppression [2].

To improve these poor outcomes, there has been an effort in many countries with large HIV burdens to prioritize and scale up new adolescent and youth-targeted models of service delivery. The World Health Organization (WHO) defines adolescent-friendly health services (AFHS) as equitable, accessible, acceptable, appropriate, and effective [3]. “Peer support” is increasingly featured as part of AFHS as a class of implementation strategies that can support adolescents to access, engage, and sustain treatment.

For adolescents specifically, peers can be a unique and powerful source of empathic support. Social acceptance may be more critical for this age group than any other [4], yet many AYPLHIV experience stigma and peer violence, leading to depression, anxiety, and suicidality [5]. In this context, peer support has a protective effect, buffering the effects of stigma [6] and positively influencing behavior. Peer supporters function as credible and affirming role models, who share similar experiences and/or backgrounds, helping AYPLHIV to feel less alone, while they gain an increased understanding of positive coping strategies [5]. These egalitarian peer relationships promote health and well-being while providing a supportive complement to traditional health system cadres.

While there are significant variations in implementation approaches to peer support, what programs tend to have in common is that they regard and position AYPLHIV not merely as vulnerable and passive recipients of care, but rather a potent social asset that should be engaged, harnessed, and enabled to form a critical part of the solution [7].

However, there are unique challenges inherent to delivering peer support services for AYPLHIV in sub-Saharan Africa. Observed bottlenecks related to insufficient financing, planning, coordination, and evidence impede national scale-up, and there remains a need to identify the most effective and sustainable programmatic approaches for the region.

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This paper highlights examples of peer support models in sub-saharan Africa, and examines determinants of successful implementation, outcomes and scale-up, including policy and programmatic implications. Finally, we highlight methodological strategies that will help to advance the knowledge base on peer support for AYPLHIV in sub-Saharan Africa.

## Examples of Adolescent Peer Support

Peer support can be provided in a variety of ways. For this paper, we included examples of peer support where AYPLHIV provided support to other AYPLHIV, whether via individual and group support, community- or facility-based, and in-person or virtual support models. While robust reach and coverage data are not readily available, it appears that many health facilities in low- and middle-income countries within sub-Saharan Africa are implementing peer support for AYPLHIV. A survey of 218 facilities in 23 countries in the region found 49% offered some form of peer support for AYPLHIV clients [8]. While peer support has not been consistently effective for adolescent and youth HIV prevention [9] or sexual health education [10], some peer support programs have demonstrated impact on improving health-seeking behavior and HIV treatment outcomes for AYPLHIV, such as linkage, adherence to antiretrovial therapy (ART), retention in care, and viral suppression. However, observations from implementation have shown challenges in understanding the effects of peer support on these outcomes due to the heterogeneity of peer support terminology and variety of implementation approaches. Peer support can include various peer supporter cadres and roles, individual and group support models, in person and virtual support, and a variety of training, supervision and approaches to institutionalization. Furthermore, observation shows that peer support is rarely implemented as a standalone intervention, but typically provided as one component of a multifaceted package of youth-focused services, such as training health workers on AFHS and youthfriendly scheduling, each of which may influence HIV treatment outcomes. Distilling the specific impact of each service element is thus difficult, and there is a need for more investigation on the component of peer support.

There are few documented descriptions of peer support or their effectiveness, but there are several examples primarily from large facilities and centers of excellence. Most information on outcomes has come from program reports, evaluations, and conference abstracts with very few described in peer reviewed literature.

Although peers are often used to support linkage, there are few examples describing peer support’s influence on linkage to care after HIV diagnosis [11]. Most examples focus on retention in care and/or adherence to ART as outcomes, showing promise in improving both. In South Africa, investigators found enrolment into a three-session peer support group improved linkage to care compared with youth who chose not to participate (100% vs 58%, $p < 0.001$) [12]. A recent study describing the Zvandiri model in Zimbabwe also indicated that implementing a peer support model improved linkage to ART. The model engages a cadre of 18–24-year-olds living with HIV, known as community adolescent treatment supporters (CATS), to deliver adherence and psychosocial support through weekly home visits, monthly peer support groups, and linkage to other services [13].

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Zvandiri also found that in addition to supporting linkage, CATS were also effective at improving retention and adherence. Young people receiving the CATS intervention were 3.9 times more likely to self-report adherence to ART compared with the control group [13]. A follow-up trial of the model is currently underway, evaluating spacing of monthly home visits and the addition of a weekly, individualized short message service (SMS) [14]. Another study from Malawi described Teen Clubs—a popular model for AYPLHIV peer support groups in sub-Saharan Africa—and noted the impact of Teen Club on improving retention. AYPLHIV with exposure to Teen Clubs had 3.7-times lower odds of attrition than those that did not participate [15]. Additional descriptions of AYPLHIV peer support groups and peer supporters have observed improved clinic attendance and/ or retention after implementation [16–19]. A systematic review of factors influencing adherence to ARTamong AYPLHIV corroborated these examples by identifying peer support as a facilitator of adherence [20].

Few examples of peer support report on viral load suppression (VLS) as an outcome. A survey of 71 health facilities in 13 countries in sub-Saharan Africa revealed that facility-based peer support was associated with a seven-fold increase in likelihood of aggregate VLS in AYPLHIV when compared with the regional VLS rate (adjusted OR 6.95, $p = 0.02$, CI 1.28–37.59) [21]. Kenya has been rapidly scaling a program called Operation Triple Zero (OTZ) that has observed increases in VLS rates among AYPLHIV. OTZ engages peer supporters known as OTZ Champions to empower young people to take charge of their own health and achieve a treatment goal of three zeroes: zero missed appointments, zero missed drugs, and zero viral load. After 6 months of OTZ implementation, pooled data from six sites in Kenya saw increases in VLS from a baseline of 71 to 82%, with some program achieving VLS rates of up to 96% [7].

In support of these examples, some qualitative work has also underscored the benefits of peer support for AYPLHIV. Adolescents and young people have reported that peer support plays a significant role in improving adherence [22, 23], retention [24], and reducing viral load [23]. Both AYPLHIV and their caregivers have described support groups as safe spaces and an acceptable intervention [12, 25]. There is limited discussion highlighting the positive impact of peer support on reducing perceived stigma [16] and improving psychosocial well-being [13], and further investigation is needed in these areas.

In addition to in-person peer support, there has been growth in virtual peer support using SMS, telephone calls, WhatsApp, and other social media [26]. With the rapid increase in mobile phone availability in sub-Saharan Africa, virtual support has potential to assist AYPLHIV to access regular support and remain connected between face-to-face meetings without significant effort or cost. One example from South Africa [27] piloted a virtual support group through a now discontinued social networking platform called Mxit, and found high acceptability, although users preferred more ubiquitous platforms such as WhatsApp. Further data is needed on the potential of virtual peer support to augment or substitute for in-person peer support across contexts and technologies.

Although most examples found peer support to positively influence AYPLHIV outcomes, one study in Kenya [28] reported no significant improvement in retention after monthly peer

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support groups, health provider training in AFHS, and a dedicated adolescent and youth clinic day. The authors suggested that the null finding may have been due to the heterogeneity of peer support services across the facilities investigated.

## Knowledge Gaps

With few program descriptions and operational evaluations published on peer support interventions in low- and middle-income countries [29–31], there is often a reliance on anecdotal evidence to suggest that peer support interventions for AYPLHIV provide an effective mechanism for improved linkage, ART adherence, retention within HIV services, VLS, and psychosocial well-being. Furthermore, the highlighted examples may not be generalizable and had shortcomings within their program descriptions that may limit the extent to which implementers can utilize their findings to change healthcare practice.

First, the heterogeneity of terminology around the operationalization of peer support poses a major challenge to literature reviews and meta-analyses, delaying the establishment of a body of evidence to promote peer support. In the examples highlighted here, peer support was not well labeled, defined or described. Programs and studies refer to peer supporters, peer educators, peer mentors, and peer facilitators to denote the same/similar cadre, with a diverse array of peer-led or peer-supported services evaluated using a range of patient, provider, and service outcomes, all of which are imprecisely specified.

Second, most examples of peer-support are facility based with the exception of Zvandiri, which provided peer support both in the facility and community. More information is needed to assess whether physical location impacts effectiveness.

Third, further description is needed around the use of technology to enhance peer support. None of the highlighted examples included a description on the extent to which SMS, WhatsApp, and other social media are being used to enhance or replace in-person peer support (if at all). As this has been observed to be common practice, more information is needed in this area.

Fourth, descriptions of peer support may be limited due to potential publication bias, since most reports, evaluations, and articles were authored by the program owners. Among the examples highlighted, it was often unclear whether technical review or external evaluation had taken place.

Lastly, most examples that included evaluation of outcomes had small sample sizes—both number of peer supporters and clients—making it difficult to extrapolate generalizations that can be confidently applied to populations beyond those of the said programs.

There is an urgent need for operational research to assess the effectiveness of, and best practices within, peer support programs.

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## Emerging Lessons for Programmatic Scale-up: What Do We Know So Far?

Across the available examples of peer support for AYPLHIV, there is a paucity of operational detail included in program descriptions. Studies and program evaluations tend to report on programmatic approaches at a conceptual level, with insufficient granularity to ascertain the specifics of program implementation. Where these are reported, significant variation exists in terms of peer supporter characteristics, what qualifies and enables them to provide peer support, if and how they are compensated, the way in which peer support activities are structured, and the platforms used for delivery.

What follows is therefore a summation of existing written descriptions, as well as the personal observations and views of the authors, about the specific elements of successful programs that should be adopted, as well as programmatic pitfalls and challenges. We provide this synopsis using Proctor and colleagues' [32] framework for naming, defining, and operationalizing implementation strategies according to seven dimensions: actor, action, action targets, temporality, dose, implementation outcomes, and theoretical justification.

### Actor

Programs should recruit peer supporters based on explicit criteria, such as living openly with HIV and adhering successfully to treatment and care [33]. Peer supporters can be age-matched to their target client population, although we recommend that programs opt for peer supporters who are a few years older but still relatable as near-peers [34]. Peer supporter gender must also be carefully considered in relation to target population.

Peer supporters require preparation, training and skills-building around how to provide psychosocial support for adolescents and young people, facilitate support groups, deliver health, HIV and adherence education, identify urgent cases of treatment failure and psychosocial need, operate within a professional environment, support bi-directional referrals between facility-based teams and community-based services, manage ethical dilemmas, and build leadership skills and confidence [34, 35]. Programs should have defined training curricula and standards.

### Action

It is important for peer support to be included in existing health facility structures, processes, and activities [34]. This means that peer supporters should be integrated as fundamental members of the health team, and for example included in case reviews when appropriate [36]. The rest of the health team should be trained and oriented to AFHS, and sensitized to appreciate the value of the peer supporter role [36]. These measures enable meaningful engagement between peer supporters and other health workers, and provide opportunity for peer supporters to sensitize health workers to the needs of AYPLHIV and advocate for AFHS [36, 37].

Peer supporters need clear terms of service as well as defined supervision and reporting lines, with regular performance review [36]. In practice, the role necessitates consistent and ongoing supportive supervision and mentorship to minimize harm, leverage its potential, and improve performance [35]. The risks to adolescents and young people, themselves living

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with HIV, of providing support at the coalface of the HIV response, where they are confronted daily with their peers' psychosocial stressors, are high, and programs must invest in safeguards such as mental health support and regular debriefing to support this cadre. Programs should have plans in place to deal with potential harms, including intimidation, harassment, and coercion of female peer supporters in particular. Additional safeguarding measures are needed where peer supporters are drawn from key populations [34].

The nature of peer support activities varies by type, intensity, and duration of contact. Peer supporter duties tend to include providing health education, basic one-on-one psychosocial and adherence counseling, leading or co-facilitating support groups, assisting with disclosure to the adolescent or young person and/ or supporting them in onward disclosure, recognizing signs of poor coping and trauma, and referral to sources of professional support [34, 35]. These activities may take place at the facility, community-based locations or home visits. Often, peer supporters are required to trace AYPLHIV who have missed appointments. In some cases, peer supporters are tasked with supporting referrals between the health facility and community-based services, and frequently participate in facility outreach events and activities. Peer supporters may be responsible for linking key and other hyper-vulnerable groups of AYPLHIV with appropriate and intensified services and support. Finally, peer supporters may play a formal or informal advocacy role for improved service environment, access and quality at the facility, district, and even national or global level [37]. Programs must have a standardized scope of work for the role [35].

Peer support is not a silver bullet, and providers cannot task-shift beyond peer supporter capacity. The role requires clear boundaries in appreciation of the limitations in peer supporter training, their young age, and heightened vulnerabilities [34]. Careful attention must be paid to maintaining these boundaries in peer supporter training, supervision, and monitoring.

It is essential to standardize peer support group curricula, which should be purposeful, with intended participation outcomes. Experience reveals that many AYPLHIV peer support groups include adolescents or young people not yet aware of their HIV status, which limits discussion of HIV-related topics, and other groups focus only on social activities such as games without supportive discussion time. These pitfalls severely limit support group impact.

Program design should be robust and evidence-informed, using optimal implementation approaches to ensure that the elements of peer support interventions that have been shown to work are scaled, and programs uphold high quality standards.

In addition to being evidence-based, peer support programs should also be evidence-generating. Monitoring should focus on strengthening understanding of both the clinical and psychosocial benefits and harms associated with the specific peer support model being implemented, as well as its acceptability, feasibility, and sustainability, including cost-effectiveness. It is key for facilities, implementing partners, ministries of health, and other stakeholders to routinely collect, review, and share 5-year age band and sex disaggregated data to inform future programmatic decisions and policy revisions.

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Because young peer supporters age out of the youth category, it is important to communicate and plan for this from recruitment. Programs should link peer supporters to skillsbuilding, livelihood strengthening, career development, and mentorship opportunities throughout their term of service.

Finally, participation of adolescents and young people themselves as leaders in design, implementation, and monitoring is the key. Young peers, support groups, and networks need to be meaningfully engaged towards a sustainable approach to peer support interventions [36].

## Action Targets

The emerging literature and the authors' experience suggest that peer support programs should attempt to impact the extent to which services are experienced as friendly and responsive by AYPLHIV, as well as their ongoing health-seeking behavior, including completed linkage to care, successful treatment initiation, long-term adherence to ART, and retention in care.

Peer support programs are of value for all AYPLHIV age 10–24 years, but within this age group, programs should acknowledge and provide for the diversity of AYPLHIV, including young key populations as well as other vulnerable groups of AYPLHIV, such as pregnant and breastfeeding adolescents and young people. This should be operationalized through flexibility and adaption of services and approaches [26, 36]. Peer supporter profiles should reflect this heterogeneity. In many countries, a large proportion of the population has delivered their first child by the age of 19 [38], and antenatal services are often unfriendly to young people or result in early transition to adult services in the postnatal period, which can lead to poor retention and higher risk of mother-to-child transmission. Both Zvandiri and OTZ have started programs targeting young mothers, to be able to provide peer support and other responsive services to this vulnerable population. Preliminary data from these programs around improved adherence, retention, and VLS are promising.

## Temporality

While "peer education" may be a helpful strategy early in the HIV cascade by promoting HIV prevention and testing, "peer support" as discussed throughout this paper should be provided from HIV diagnosis onwards, i.e., across the treatment and care cascade, including linkage to care, treatment initiation, retention in care, and transition to adult care.

## Dose

The often voluntary structure of peer supporter engagement, and the generally informal nature of peer support activities pose challenges for investigator reporting. The examples included here do not sufficiently describe or address "dosing" (frequency) of peer support, nor—critically—evaluate doseresponse. We are therefore left with the question: How often, and at what intensity, must peer support be provided to result in positive outcomes? This question is critical, especially in the era of multi-month ART prescription. Based on the authors' programmatic experience and best practice examples, peer support should be provided monthly until the adolescent or young person is clinically stable, thereafter at ART

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refills which may be every one to three months. In addition, mechanisms should be in place for the adolescent or young person to access additional in-person or remote support as needed.

### Implementation Outcomes

The prevailing sentiment within the field suggests that peer support enhances the appropriateness and acceptability of HIV services for AYPLHIV. The examples in this paper suggest that this increase in acceptability leads to improved adoption of and adherence to HIV treatment and care services by AYPLHIV, leading to higher rates of viral suppression in this age group. Programs should prioritize evaluation, utilizing implementation science to assess the impact of peer support for AYPLHIVon these outcomes.

### Theoretical Justification

Given their developmental stage, AYPLHIV have a profound need for psychosocial support as part of their HIV care. Peer support relies on the shared life experiences of the peer supporter and young person (such as receiving the diagnosis or experiencing stigma) as the basis for building connection and trust within which the peer supporter can provide basic emotional and social support. This often results in better engagement with care.

## Policy Implications: Creating a Favorable Landscape for Peer Support Services

To pave the way for adoption and delivery of successful peer support programs for AYPLHIV, countries should have conducive legal and policy environments [39].

### Policy Environment

Global frameworks and agendas, including the sustainable development goals (SDGs) and universal health coverage, provide the platforms needed for building consensus towards affirming healthy and empowered AYPLHIV as pivots for appropriate, responsive, and feasible AYPLHIV HIV services [40, 41]. The Global Strategy for Women's, Children's and Adolescent's Health (2016–2030), as well as the Global Accelerated Action for the Health of Adolescents (AAHHA!) present opportunities to address the major policy and programmatic barriers to delivering AFHS [42, 43].

The WHO HIV treatment guidelines strongly recommend, although with moderate quality evidence, offering a package of support interventions, including peer support, to ensure timely linkage to care for all people living with HIV [44]. Experience shows that this recommendation has not been universally adopted as policy nor implemented as standard of care across countries.

Translating global guidelines into national policy and practice remains a pervasive challenge. A review by Green and colleagues found the research to practice pipeline to be up to 17 years [45]. In public health areas of great need and urgency such as adolescent and youth HIV, for which there are limited evidence-based interventions, it is imperative that we strive to achieve the difficult balance between awaiting rigorous, GRADE-level research

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(which requires resourcing and takes time) before initiating implementation, and implementing intuitive, practical, and program-informed solutions without delay.

Closing the gap between WHO guidance to provide peer support and its widespread application at country level will require tailored advocacy targeted at enhancing national policymakers' understanding and recognition of the value of peer relationships in adolescence and youth, and the concomitant benefits of and rationale for peer-based service delivery models.

## Specific Policies

To systematically scale up country-owned peer support programs, countries require adoption of supportive policies and removal of policy barriers. Aside from Zimbabwe, countries have not adopted peer supporters within national systems. To facilitate widespread scale-up and long-term sustainability, countries should consider recognizing peer supporters as an official cadre embedded within national programs. Countries are urged to incorporate peer support roadmaps into national HIV plans and leverage technical and implementation support from NGO partners to ensure quality at scale. Countries require a well-defined package of peer support services and standardized implementation tools such as job aids, standard operating procedures, patient education materials, and documentation templates [46].

Where countries have yet to adopt a peer supporter cadre, programs should harmonize the role's scope of work and compensation with the most comparable cadre [34]. This may be challenging where, for example, peer supporter duties are more similar to lay counselors than community health workers, but where these young people do not have the requisite training, education and/or experience to be appointed to the lay counselor role. In all cases, peer supporters must be provided clear conditions of service and protections in the workplace.

National programs should invest in the operational costs of peer support, which include peer supporter training, compensation, and supervision, as well as peer support services themselves. Depending on prevailing practice in terms of compensation in country, peer supporter transport for outreach and home visits should also be financed [34].

Countries should review any age of service restrictions which may prohibit young peer supporters from being employed and/or recognized.

Exclusion of adolescents from national scale-up of service delivery models such as differentiated service delivery, community-based services, and community health workersupported service delivery is a critical issue that requires deliberation and policy review.

Finally, countries should re-examine and revise policies which limit the role of lay providers in HIV service delivery which have no basis in evidence.

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## Conclusions

Peer support interventions increasingly form a part of adolescent and youth-responsive service packages, but there are few examples of detailed program descriptions describing operational logistics or impact on outcomes such as linkage, adherence, retention, and VLS.

Although there are few program descriptions and operational evaluations published on peer support interventions in low- and middle-income countries, the available examples provide preliminary support for the potential utility of peer support to improve AYPLHIV treatment outcomes. This is consistent with the authors' collective experience. Further confirmation of this hypothesis through better evidence is an imperative for this high-priority population.

Rigorous implementation science research is urgently needed and should seek to answer questions around effectiveness and applicability of peer support for AYPLHIV on a larger scale within routine care settings in the region. Programs should prioritize evaluation, and standardize implementation [47] in order to identify the critical elements of and best practices related to peer support program implementation. Findings should be reported clearly, using consistent labeling harmonized with established terms in the literature, and precise operational descriptions that facilitate evaluation, comparison, and reproduction [32].

In the meantime, we must move forward with certainty based on programmatic experience, contextual understanding of challenges and gaps, and best practice examples.

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