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Reaching key adolescent populations

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Abstract

Purpose of review—Adolescents and young people who fit within key populations face some of the greatest barriers to HIV care, but are frequently overlooked. We review the recent literature on these young, vulnerable populations including HIV risk factors, barriers to care and strategies for engagement.

Recent findings—Common risk factors include age, risky sexual practices, poor education and high levels of alcohol and drug abuse. Barriers to care include limited data, criminalization and high levels of stigma. Strategies to increase engagement include incorporating adolescents into biological and behavioral surveys and the use of social media. Digital innovations for HIV prevention and testing show promise, and pre-exposure prophylaxis (PrEP) may be acceptable. At a policy level, decriminalizing same-sex activity and commercial sex work are priorities. Differentiated models of care including HIV self-testing, after-hour services, community-based delivery and multi-month dispensing of antiretroviral therapy (ART), should be combined into holistic care.

Summary—There has been limited success in reaching these key adolescent populations largely due to criminalization and stigma. Accurate, generalizable data are needed to inform the development of innovative strategies for holistic care.

Keywords

Adolescents; young people; key populations; HIV care

Introduction

Adolescents (10-19 years) and young people (15-24 years) continue to be left behind in HIV testing and treatment services,¹ despite an array of new service delivery strategies such as universal treatment, HIV self-testing, and community ART groups. In sub-Saharan Africa

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Conflicts of interest

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(SSA), only 30% of adolescent girls and 10% of adolescent boys have ever been tested for HIV.² This is concerning since adolescent girls have some of the highest rates of seroconversion in SSA.³ In addition, the extremely low rates of testing among boys reflects their limited access to HIV services and means that they will not be socialized to access health services during adulthood when they are at highest risk of HIV infection.^{4,5}

Adolescents who fit within key populations (KPs) face some of the greatest barriers to HIV service utilization, experiencing the same challenges as adult KPs as well as specific barriers related to adolescence.⁶ Despite their increased vulnerability, key adolescent and youth populations (KAYPs) are largely neglected by HIV programs and health policies. Programs focusing on youth frequently overlook KPs, and those focusing on KPs similarly overlook younger individuals. In 2014, the World Health Organization (WHO) included KAYPs for the first time in its work on KPs, issuing guidelines on HIV prevention, diagnosis, treatment and care with annexures on KAYPs,⁷ updated in 2016.¹ Despite increased recognition of KAYPs by global donors and policy makers in recent years,^{8,9} there are still gaps in knowledge about the double burden experienced by KAYPs, and, more importantly, strategies to overcome these barriers. In this review, we provide an overview of the recent literature on the status of KAYPs, barriers to HIV care, and strategies to engage these key populations.

Common risk factors for HIV

The literature describes numerous common risk factors that reflect the overlapping contexts of these vulnerable and fluid populations: age, risky sexual practices, low levels of education, and high levels of alcohol and drug abuse. There is a consistent pattern of increasing risk with age among men who have sex with men (MSMs)¹⁰⁻¹³ and commercial sex workers (CSWs).^{14,15} A study from Nigeria among MSMs and transgender (TG) women with a median age of 24 years¹⁰ found a 38% increased relative risk of HIV in those aged 22-30 years compared with those under 22 years; similar results were found in Tanzania.¹² Far higher estimates were reported in Colombia: MSMs aged 35 vs 18-24 years old had a 20-fold higher odds of HIV infection after adjusting for numerous risk factors (aOR 19.2, 95% CI 7.2-50.8).¹³ Among CSWs in Mozambique, 2 in 10 of whom were younger than 18 years old, HIV prevalence rose with each year of age,¹⁴ as it did in the three largest cities in South Africa, where over one-third of CSWs were aged 16-24 years.¹⁵

Other strong predictors of HIV include age at first male or commercial sex,¹⁰⁻¹⁴ unprotected anal sex,¹¹ assuming a receptive position during anal sex and having a female partner.¹² Risky sexual practices may be particularly pronounced among TG women. In three African countries, 54.6% of TG women vs 6.5% of MSMs practiced receptive-only sex, and 33% did not use a condom at last anal sex.¹⁶ Alcohol and drug abuse^{15,17} and low levels of education^{11,14,18} also predict HIV infection. Transactional sex, excluded from traditional definitions of commercial sex work, may also increase HIV risk among young women^{19,20} and children living on the street.²¹

Barriers to reaching KAYPs

It is clearly critical that HIV prevention and treatment strategies reach KAYPs. In what follows, we review key barriers that limit KAYP engagement in HIV services.

Lack of data

The allocation of funding and delivery of services are informed by available national and global data. Limited and inaccurate data on KAYPs makes it impossible to reach these populations effectively, and reduces the availability of KAYP-specific strategies.¹ Population sizes may be underestimated in countries with punitive laws that criminalize key populations.²³ Prevalence estimates are unreliable in the absence of accurate denominators and may not be representative if the populations are not properly sampled.¹ Only 15 of 29 countries surveyed had publicly available MSM population estimates and even UNAIDS estimates may be unreliable.²² Furthermore, ART programs do not commonly issue patients with an identifier that would allow disaggregation by sub-groups, limiting knowledge on KAYP uptake and retention in care. Even if they did, definitions of adolescence and youth are not standardized: 26% of facilities surveyed in SSA did not have an official working definition of adolescence, and among those that did, it ranged from 8-21 years.²³

Criminalization of KP identity

Key populations are criminalized in many countries. Criminalization restricts how interventions can target KAYP, restricts KAYPs from freely accessing existing services, and contributes to the limited and unreliable data on KAYP.²⁴ One study that included data from 27 European countries found that criminalizing all aspects of sex work was positively associated with HIV prevalence among sex workers, even after controlling for economic and IDU measures.²⁵ A systematic review found that out of all social determinants, the decriminalization of sex work would have the greatest effect on reducing HIV infections, averting 33–46% of HIV infections in the next decade.²⁶

Although there has been some progress on decriminalization of same-sex sexuality, anti-gay legislation and criminalization of sex work has increased in recent years in some countries,²⁴ including Nigeria, Russia and The Gambia.²⁷ In Tanzania, home to the fourth largest population of HIV+ adolescents,²⁸ lawyers were recently arrested for challenging a ban on drop-in health centers for high-risk individuals.²⁹

Stigma

Perceived and enacted stigma is well-documented for KPs³⁰ and sexually active adolescents and young people.³¹ Key populations who experience high levels of stigma are more likely to participate in riskier sexual behavior³² and may find it difficult to interact openly with social institutions such as the health system.^{31,33,34} The burden of stigma is doubled for KAYP who are also HIV-positive.³⁵ Individuals fear stigma and discrimination from health care workers,³¹ family and community members,³² and teachers and classmates.³⁵ Given their marginalized and often illegal status, a primary barrier to HIV care is how to identify KAYPs without stigmatizing them.

Access to services

Key adolescent and young populations have limited access to health facilities if they are studying or working and have limited resources for transport costs.³⁶ Adolescents also have limited autonomy to make decisions for themselves. Although the donor and NGO communities have highlighted the need for targeted KAYP services,^{1,8,9} to date very few countries include targeted KAYP services into national policy.¹ Without specific strategies for reaching KAYP, programs fail to meet their needs.³⁷ Low coverage and impact of prevention programs for KAYP^{13,14,17} may partly explain inconsistent condom use,^{14,17,38} low awareness despite high levels of HIV testing,²⁰ and distressingly high rates of recent infection.^{15,18}

Individual and familial barriers

Populations who fit within KAYP categories are often disadvantages across multiple sociodemographic variables. Poverty, low education, and poor social support are common among KAYP and are known risk factors for limited access to and use of health services.¹ One study found that sex workers in countries with the lowest average income among the poorest populations were at increased risk of HIV infection than sex workers in other countries.³⁹ In addition, adolescents living with HIV face unique mental health challenges,⁴⁰ again compounding the numerous systematic barriers to care listed above. Structural changes are needed to address these sociodemographic disparities.

Strategies for reaching KAYPS

KAYPs are missed at every point of the HIV service cascade. Below we review key overarching strategies that may improve HIV-related outcomes among this population.

Improve data on KAYPs

One strategy to systematically improve data on KAYPs is to incorporate adolescents and young adults into biological and behavioral surveillance surveys (BBSS), as has been done in India^{41,42} and South Africa¹⁵ with some success. The BBSS have provided representative epidemiological data on adult KPs for nearly 20 years.⁸ Linking behavioral and biological indicators, BBSS include some validation of self-reported behavior. They can be used to estimate prevalence in 'hidden' populations, and repeated surveys can be useful in assessing trends. BBSS commonly utilize two methods to access hard-to-reach populations while ensuring that results can be generalized beyond study participants: respondent-driven sampling (RDS),⁴³ originally used to study active IDUs,⁴³ and time-location sampling (TLS),⁴⁴ first used among young MSMs. Both methods require detailed knowledge about the study population: RDS requires a population that is socially networked, while TLS targets a population that congregates in specific locations. Historically, BBSS excluded children younger than 18 years, but a recent review provides practical strategies to ensure their inclusion in BBSS.⁸ Major recommendations include disaggregation of research by age and sex, tailoring recruitment to ensure representation of young people and selecting appropriate research methods. Other novel solutions for collecting accurate data on hard-to-reach populations could include web-based RDS,⁸ the use of social media,²² and the use of new technology to track KAYPs across the cascade of care.⁴⁵

Decriminalize KP identity

Decriminalizing KP identity must be prioritized.^{26,46,47} Efforts to decriminalize KP identity are difficult and have been reported with mixed success throughout low- and high-resource settings. In light of criminalization, interventions with police can reduce the number of arrests for sex workers,⁴⁸ and community mobilization and transformative leadership models can put pressure to adjust laws related to KP.⁴⁹

Increased focus on KAYP

To increase KAYP-focused services, KAYP must be explicitly included in global and national policy. UNAIDS presents four key elements to increasing effective programs for adolescents: (1) engage adolescents as agents of change; (2) improve data collection and analyses for adolescents; (3) foster strategies to improve adolescent engagement; and (4) advocate at all levels to position adolescent HIV on national agendas.⁵⁰

Reduce stigma

Strategies to address stigma among KP or adolescent populations are often multi-dimensional and resource-intensive. Health systems should take immediate steps to improve the privacy and client-centered approach of health services for KAYP. Strategies include human rights trainings for providers on HIV and sexual health rights,^{51,52} provider-sensitization on how to engage KAYP, and community-based services to reach populations who cannot access traditional health care services.¹

Long-term solutions include policy changes, national campaigns using agents of change, and community-based sensitization strategies utilizing local leaders and peer-to-peer approaches.⁵³ A systematic review for CDC and ICAP found that sensitization trainings for healthcare providers significantly changes provider attitudes toward people living with HIV, however the clinical significance of attitude change is unclear since most studies do not measure the quality of care provided.⁵⁴ More research is needed on provider knowledge and education on the sexual and human rights of youth and KPs.⁵⁴ The most successful interventions include a combination of strategies across multiple levels.^{53,54}

Using technology to reach KAYP

Digital innovations show tremendous promise for HIV testing⁵⁵ and use of HIV and sexual health services more broadly.⁵⁶ While research on digital innovations for KAYP is limited, emerging literature suggest this is an important venue to pursue: younger KP are more likely to use the internet than older KPs.⁵⁷ Digital innovations can improve HIV self-testing strategies among MSM⁵⁸ and web-based prevention strategies can increase reach of the intervention, while minimizing risk of unwanted disclosure.⁵⁷

Recent studies show promise for PrEP among young MSM and TG populations⁵⁹ and among adult CSWs.⁶⁰ Barriers to PrEP for MSM and TG adolescents and young adults include fear of side effects, fear of discussing gender identity with study or health care staff, concern about remembering to take daily medications, and believing they were not at risk for HIV.^{59,61} Injectable PrEP may address some of these barriers.⁶² Future research should examine the feasibility of PrEP, and barriers to PrEP, for other KAYPs.

Implement differentiated models of care

Tailored care and service delivery are needed. Differentiated models of care (DMOC) include strategies that can increase KAYP engagement in HIV services. Services are client-centered and simplified to meet client needs and reduce the burden on health systems.⁶³ Examples of DMOCs include HIV self-tested, after-hour services, community-based delivery strategies, and multi-month distribution of ART drugs. HIV self-testing is highly acceptable among KPs⁶⁴ and promises better access and use of HIV testing for adult MSM and CSW,⁶⁵⁻⁶⁷ although it has yet to be testing among KAYPs. After-hours and community-based strategies are well established and are known to reach hard-to-reach-populations.^{1,68} Multi-month scripting has been proven to be safe, effective, and feasible for stable ART clients, with clients receiving 3-6 month scripting being less likely to miss their next ART appointment and less likely to have a gap in medication⁶⁹ Additional research is needed to assess if multi-month scripting improves ART retention and adherence among hard-to-reach and marginalized populations such as KAYP.

While DMOCs are promising,^{63,70} comprehensive models are needed to engage and retain KAYP throughout the HIV cascade. Isolated DMOC that target only one stage of the cascade may see high rates of loss to follow-up among hard-to-reach populations who face additional barriers to linking between different HIV services, or adjusting to different models of care across the various stages of the service cascade.³⁵ One intervention in Uganda (Linked Up) provided holistic services to young people living with HIV including peer-based education within communities, building and peer networks of young people, referral vouchers to health services that were redeemable at the local health facility, youth friendly corners at health facilities, and provider trainings on HIV and sexual health rights for youth living with HIV.⁷¹ The intervention showed significant increases in HIV knowledge, HIV disclosure, condom use, ART uptake, and use of other sexual and reproductive health services, although it is unclear what component of the intervention contributes to these gains. Future research is needed to develop comprehensive DMOCs across the continuum of care.

Conclusion

Our review found that there has been limited success in reaching KAYPs to date, despite the opportunity to prevent HIV in these young, vulnerable populations. Data are limited and variable, and there is frequent overlap between populations and risk factors. Criminalization and high levels of stigma prevent the collection of representative data and limit access to services. Accurate, generalizable data on hard-to-reach young populations are needed, possibly through including KAYP in the routine, repeated implementation of BBSS. Immediate solutions are needed to minimize the risk of disclosure and increase access to care. Strategies include DMOC, after-hour and community-based services, integrated care, multi-month scripting, and messaging and care tailored to KAYP. Long term solutions include decriminalization, campaigns to decrease stigma and discrimination, and prioritizing interventions among KAYPs. Research is needed on a comprehensive differentiated model specific to KAYPs. Notably, strategies to engage KAYP are the same strategies that could

work for other hard-to-reach populations such as boys and men who are also often missing from HIV prevention and treatment strategies.⁵

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Key Points

- There has been limited success in reaching KAYP largely due to criminalization and stigma.
- Limited and inaccurate data on KAYPs makes it impossible to reach these populations effectively, and reduces the availability of KAYP-specific strategies.
- In order to reach KAYP, we must prioritize decriminalizing same-sex activity and commercial sex work.
- Innovative strategies such as digital innovations for HIV prevention and testing and PrEP may show promise for reaching KAYP.
- Future research should examine the role of differentiated models of care for KAYP across the continuum of HIV services, such as HIV self-testing, after-hour services, community-based delivery, and multi-month dispensing of ART.