# **PrEP** as a Lifestyle and Investment for Adolescent Girls and Young Women in Sub-Saharan Africa

lournal of the International Association of Providers of AIDS Care Volume 18: 1-5 © The Author(s) 2019 Article reuse guidelines: sagepub.com/journals-permissions DOI: 10.1177/2325958219831011 journals.sagepub.com/home/jia

(\$)SAGE

Jessica E. Haberer, MD, MS<sup>1,2</sup>, Nelly Mugo, MBChB, MMED, MPH<sup>3,4</sup>, Jared M. Baeten, MD, PhD<sup>4</sup>, Maria Pyra, PhD<sup>4</sup>, Elizabeth Bukusi, MBChB, MMED, MPH, PhD, FAAS<sup>4,5</sup>, and Linda-Gail Bekker, MBChB, DTMH, DCH, FCP(SA), PhD<sup>6</sup>

## Abstract

Adolescent girls and young women (AGYW) are highly affected by the HIV epidemic, yet standard approaches to pre-exposure prophylaxis (PrEP) delivery will not meet their needs. This commentary highlights key characteristics of AGYW related to PrEP use and delivery, including typical neurocognitive development, lack of experience with sustained medication use, and the social and connected nature of AGYW's lives. We then suggest ways for programs to embrace these characteristics, such as presenting PrEP as a lifestyle choice and not a biomedical tool, making access to PrEP simple and easy, and recognizing the many influences AGYW face in taking PrEP. We also suggest ways for programs to identify AGYW at the highest risk of HIV acquisition. Adolescent girls and young women have an important role to play in ending the HIV epidemic and they deserve considerable, tailored investment.

## **Keywords**

PrEP, adolescent girls and young women, HIV, sub-Saharan Africa

Date received: 18 August 2018; revised: 3 December 2018; accepted: 10 December 2018.

# What Do We Already Know about This Topic?

Adolescent girls and young women (AGYW) in sub-Saharan Africa are a large, high priority population for the roll out of HIV pre-exposure prophylaxis (PrEP). Innovative methods for PrEP delivery are needed to meet their unique needs and thereby encourage PrEP uptake and use.

## How Does Your Research Contribute to the Field?

This commentary highlights key characteristics of AGYW that relate to PrEP uptake, use, and delivery and suggests ways for PrEP delivery programs to embrace them.

# What Are your Research's Implications toward Theory, Practice, or Policy?

Our recommendations provide guidance for the development of tailored PrEP delivery programs that will meet the needs of African AGYW and thus further global HIV prevention goals.

# Introduction

Adolescent girls and young women (AGYW; aged 15-24 years) currently account for one-third of all new HIV infections globally and three-quarters of all new HIV infections in sub-Saharan Africa.<sup>1,2</sup> With the impending youth bulge, the adolescent population will reach >300 million by 2050.<sup>2</sup> Clearly, effective means for HIV prevention are needed for AGYW in sub-Saharan Africa.

Pre-exposure prophylaxis (PrEP) is one of the most promising, currently available HIV prevention tools for AGYW. It is

- <sup>3</sup> Kenya Medical Research Institute, Thika, Kenya
- <sup>4</sup> University of Washington, Seattle, WA, USA
- <sup>5</sup> Kenya Medical Research Institute, Kisumu, Kenya
- <sup>6</sup> Desmond Tutu AIDS Foundation, Cape Town, South Africa

#### **Corresponding Author:**

Jessica E. Haberer, Massachusetts General Hospital, 125 Nashua St, Suite 722, Boston, MA 02114, USA. Email: jhaberer@partners.org



Creative Commons Non Commercial CC BY-NC: This article is distributed under the terms of the Creative Commons Attribution-NonCommercial 4.0 License (http://www.creativecommons.org/licenses/by-nc/4.0/) which permits non-commercial use, reproduction and distribution of the work without further permission provided the original work is attributed as specified on the SAGE and Open Access pages (https://us.sagepub.com/en-us/nam/open-access-at-sage).

<sup>&</sup>lt;sup>1</sup> Massachusetts General Hospital, Boston, MA, USA

<sup>&</sup>lt;sup>2</sup> Harvard Medical School, Boston, MA, USA

woman-controlled and can be delivered as part of a tailored, combination package of education, counseling, and HIV prevention options. Oral PrEP has been shown to be highly effective for women when adherence is high<sup>3</sup>; additional PrEP options, such as a vaginal ring, will likely reach the hands of AGYW in the foreseeable future.<sup>4,5</sup> And while adherence was challenging for young women in placebo-controlled clinical trials of both oral PrEP and vaginal rings, adherence may improve now that efficacy has been established<sup>6</sup> and much can be done to support adherence as we move forward from research studies into implementation and scale-up.

Hard work is going into the early days of the PrEP rollout for AGYW in sub-Saharan Africa and efforts are laudable. At the same time, programmatic prioritization is largely piecemeal and, in many cases, not focused on the specific needs of AGYW. Utilizing standard, clinic-based models with biomedical messaging to deliver PrEP will not work for most AGYW. We, as clinicians, policy implementers, and researchers need to adopt novel approaches that will enable this highly vulnerable population to achieve the benefits of PrEP.

In this commentary, we highlight key characteristics of AGYW that relate to PrEP use and delivery and suggest ways for programs to embrace them. Our objective is to change the way we think about the provision of PrEP and other services for AGYW. Namely, we need to invest in a paradigm in which we meet AGYW where they are and offer them PrEP as a lifestyle choice to achieve their personal goals.

### Key Characteristics of AGYW Related to PrEP

First, *typical adolescent brain development calls for framing HIV prevention in terms of their daily lives*. Adolescents commonly seek novelty and sensation, often through interactions with their peers. They tend to have a present bias, focusing on day-to-day concerns such as food, shelter, and love.<sup>7-9</sup> They are not thinking of a risk of something that may or may not happen in the future. These behaviors are part of normal neurocognitive development, primarily arising from the limbic system and dopamine-rich brain circuitry. Adolescent girls and young women' worldviews and priorities should be the starting point in determining how PrEP can best be presented to them and in assessing how it can fit into their lives.

Second, *adolescents are usually healthy and have not taken medication for sustained periods of time.* The concept of persistent medication adherence for the prevention of disease is new for most AGYW, and many do not understand how PrEP works. Some confuse PrEP with postexposure prophylaxis, while others alternatively think it the same as HIV treatment (eg, something that has to be taken for life).<sup>10</sup> Many AGYW may be aware of various methods to prevent pregnancy, yet access and uptake of contraceptives is limited (see below), and HIV has important differences from pregnancy in AGYW's lives. Adolescent girls and young women need education about their personal vulnerabilities for HIV acquisition, the mechanisms by which PrEP can prevent HIV acquisition, and the underlying concept of proactive and persistent HIV prevention through PrEP.

Third, *AGYW live social and connected lives*. Adolescent girls and young women are heavily influenced by their peers, sexual partners, families, and communities. Decisions are frequently made in conjunction with others, and opinions can be readily swayed.<sup>11</sup> Moreover, AGYW often physically present for health care services with their peers. Services need to be prepared to accommodate and harness these multifaceted influences to support PrEP uptake and adherence.

Additionally, AGYW are subject to the common factors that impact anyone's ability to take medications, including those at the individual (eg, side effects, depression) and structural levels (eg, availability of PrEP, ability to get to clinic to access PrEP).<sup>3,12,13</sup> We must consider all these potential factors when designing effective means for making PrEP relevant, appealing, and available to AGYW.

## **Redesigning PrEP Delivery for AGYW**

Numerous studies and demonstration projects are currently providing PrEP to AGYW in sub-Saharan Africa, and national programs have begun with Kenya and South Africa leading the way; others are starting in Zimbabwe, Lesotho, and Namibia.<sup>14</sup> While these programs are learning valuable lessons for reaching and retaining AGYW at risk of HIV acquisition, some key areas are emerging for improvement.

First, PrEP should be presented as a lifestyle choice, not a biomedical HIV prevention tool. Data from thousands of participants have shown that PrEP is safe for the vast majority of users.<sup>15</sup> Pre-exposure prophylaxis delivery should therefore move away from emphasizing it as biomedical intervention (eg, percent risk reduction) and focus on what it can do for those who take it. Recalling typical adolescent development, we need to convey the personal benefits of PrEP for the priorities that matter most to AGYW.<sup>16</sup> For instance, PrEP can be messaged as a way for clever and wise young women to stay healthy, so they may attend university or care for family members. Pre-exposure prophylaxis can help AGYW reduce worry in their sexual relationships and achieve sexual health. Even the novelty of PrEP itself can be leveraged to help AGYW reenvision their lives and thus promote PrEP uptake. Adolescent girls and young women need to know that PrEP works to prevent HIV and is safe and acceptable; they can then see how it can work for them.

To complement this concept, PrEP delivery should be part of comprehensive programs designed to support the many challenges AGYW face. DREAMS (ie, Determined, Resilient, Empowered, AIDS-free, Mentored, and Safe women) is already moving in this direction.<sup>1</sup> This initiative acknowledges factors such as economic disadvantage, discriminatory cultural norms, gender-based violence, and school drop-out as contributors toward AGYW's vulnerability to HIV. While not all programs can provide such comprehensive services, the potential impact of a broad-based approach to HIV prevention is inspiring and motivational.

Second, AGYW should be able to access PrEP simply and easily. Pre-exposure prophylaxis should be delivered in AGYW-friendly, attractive, and enjoyable environments. The standard clinic with long benches and long queues will keep AGYW away. Clinic staff should present themselves as people who AGYW can trust and potentially even identify with. For example, some clinics are engaging nontraditional staff, such as "PrEP queens" or "PrEP champions"-young women who use PrEP themselves who share their experiences and help create a comfortable environment. Moreover, counseling and education should be provided in the context of sexual health, not lectures on behavior. Lessons can be learned from family planning programs, which also falling short in their efforts to reach this population.<sup>17</sup> Adolescent girls and young women often fear judgment, especially if they are not married, and/or have difficulty getting to and from clinic. Many AGYW instead opt for emergency contraception (ie, "the morning after pill"), as it is available in relatively anonymous, convenient pharmacies.

To overcome these barriers, innovative means of PrEP (and contraceptive) delivery are needed. For example, the Dean Street Clinic in London provides comprehensive, confidential, free services in a friendly environment geared toward men who have sex with men (MSM).<sup>18</sup> This clinic is visually appealing and has rapid test turnaround time, as well as appealing amenities, such as free WiFi; this model could be adapted for AGYW in sub-Saharan Africa. Use of lay providers with physician oversight may also increase the feasibility of these novel PrEP delivery methods, including taking PrEP out of traditional medical setting altogether. The Thai Red Cross, for instance, is another clientfriendly center committed to avoiding stigma and discrimination that is sponsoring a program for PrEP delivery with MSM (NCT02437981). Such nonclinical environments may help make connecting to providers and to PrEP itself easier. Some programs for PrEP delivery to AGYW in sub-Saharan Africa are already exploring the use of mobile vans and communitybased venues that AGYW frequently attend, as well as AGYWfriendly family planning clinics.<sup>19,20</sup> Additionally, legislation to enable AGYW at high risk of HIV infection to access PrEP without parental or caregiver permission is critical.<sup>21</sup> HIV testing is available without parental consent in many settings<sup>22</sup> and should be a goal for PrEP delivery programs.

Third, *PrEP programs need to recognize socio-ecological influences on the lives of AGYW*. An AGYW can best take PrEP when her peers and sexual partner encourage her to use it, when her parents help her get to clinic and/or help her remember to take it, and when her community sees PrEP as a way to protect her well-being. Adolescent girls and young women may be anxious about including their sexual partners or family members in their PrEP experience, and in some cases, they may face social harms. Yet PrEP programs can provide them with counseling to help ameliorate these concerns, while advocates concurrently work with communities and health systems to promote social change and reduce gender-based violence. Group-oriented PrEP counseling and peer support groups may help reinforce positive messaging (eg, PrEP as a lifestyle

choice) and may be conducted in person or through technology (eg, WhatsApp groups), as some programs are exploring.<sup>19</sup> Preexposure prophylaxis programs should also actively include outreach and education to the larger community to address social norms and reduce stigma and confusion about PrEP. Beliefs that PrEP use indicates promiscuity or sex work<sup>23</sup> need to be replaced with messages about HIV-free lives for the next generation. The prevailing desire of parents and elders to protect young women needs to be channeled into protecting them from HIV, not from sexual health.

Fourth, efforts are needed to find AGYW at highest risk of HIV acquisition. Even in endemic populations, not all AGYW need PrEP. We can channel the peer-oriented nature of AGYW by encouraging them to bring in their friends who may have similar sexual behaviors or vulnerabilities. Adolescent girls and young women presenting with other sexually transmitted infections (STI) or post-pregnancy, including abortions, should be invited to consider PrEP. Nontraditional venues, such as night clubs and hair salons, may offer further inroads into populations that do not currently seek HIV prevention services. Encouragingly, as access becomes easier (as is the case in many resource-rich settings like North America, Australia, and Thailand), those who present for PrEP appear to be at high risk.<sup>24,25</sup> Importantly, the cost of PrEP and associated services, as well as restrictive insurance coverage in some settings, may pose barriers to those at risk and warrant ongoing attention.<sup>26,27</sup>

#### **Future Further Improvements**

As daily tablets of PrEP are provided to AGYW in sub-Saharan Africa and vaginal rings move closer to public availability, concurrent research is ongoing to make HIV prevention even more attractive to AGYW. One promising area is co-formulation of PrEP with contraception and/or STI treatment. Current efforts include both tablets (NCT01694407) and rings (NCT03467347). Such "multipurpose prevention technologies" may attract AGYW at risk of HIV acquisition, but more focused on pregnancy or other STI prevention. Multipurpose prevention technologies may also encourage effective and desirable service delivery for all aspects of sexual health, when combined with the above suggested for AGYWfocused approaches.

Another area of research is long-acting PrEP. Infrequent dosing of pills, rings, or injectables will make many aspects of adherence easier, and choice of formulation will be important for increasing acceptability. Current studies include injectable PrEP and quarterly infusions (NCT02720094, NCT03164564, NCT03422172, NCT02478463). However, all of the above-noted positive framing of PrEP delivery will still be needed, even with more convenient dosing, if persistence on PrEP and the expected robust HIV protection is to be achieved.

#### **Return on Investment**

Improving delivery of PrEP for AGYW as described above will not be cheap. We recognize that most health care delivery models achieve sustainability through minimized cost and maximized efficiency. However, this vulnerable population needs and deserves more than the minimum services. We must make PrEP attractive and meaningful; the extra cost will be worth it. We cannot allow AGYW in sub-Saharan Africa to continue at such high vulnerability to HIV acquisition. Nor can we ignore the potential for this highly fertile population to pass HIV on to their babies. The cost of inadequate and ineffective services is simply too high and the potential return on investment is too great.

## Conclusion

Adolescent girls and young women in sub-Saharan Africa have a critical role to play in ending the HIV epidemic. It is our responsibility to give them the tools to make a difference and help them achieve the lives they seek. We should meet them where they are, acknowledge their needs, and tailor our support accordingly. Multipurpose prevention technologies and novel formulations for PrEP will help, but delivery of all HIV prevention tools will require fundamental changes in the way we engage with and invest in AGYW.

#### Acknowledgements

Authors would like to thank all of the PrEP delivery programs that are investing in the lives of adolescent girls and young women in sub-Saharan Africa, as well as all of the adolescent girls and young women themselves who are using PrEP. Authors would also like to thank Lindsey Garrison for her support in writing this manuscript.

#### **Declaration of Conflicting Interests**

The author(s) declared the following potential conflicts of interest with respect to the research, authorship, and/or publication of this article. J.E.H. has received consulting fees from Merck and Natera.

## Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: Received funding from National Institute of Mental Health: R01MH109309.

#### **ORCID** iD

Jessica E. Haberer D https://orcid.org/0000-0001-5845-3190

#### References

- President's Emergency Plan For AIDS Relief. *Priority Areas, Adolescent Girls and Young Women: Creating Gender Equality*; 2016. www.pepfar.gov/priorities/girlswomen. Accessed August 16, 2018.
- United Nations Programme on HIV/AIDS. *The Youth Bulge and HIV*; 2018. http://www.unaids.org/en/resources/documents/2018/ the-youth-bulge-and-hiv. Accessed August 16, 2018.
- Thomson KA, Baeten JM, Mugo NR, Bekker LG, Celum CL, Heffron R. Tenofovir-based oral preexposure prophylaxis prevents HIV infection among women. *Curr Opin HIV AIDS*. 2016;11(1):18–26. doi:10.1097/COH.00000000000207.
- 4. Baeten JM, Palanee-Phillips T, Brown ER, et al. Use of a vaginal ring containing dapivirine for HIV-1 prevention in women. *N*

*Engl J Med.* 2016;375(22):2121–2132. doi:10.1097/01.ogx. 0000489577.60775.40.

- Nel A, van Niekerk N, Kapiga S, et al. Safety and efficacy of a dapivirine vaginal ring for HIV prevention in women. *N Engl J Med.* 2016;375(22):2133–2143. doi:10.1056/NEJMoa1602046.
- Amico KR, Stirratt MJ. Adherence to preexposure prophylaxis: current, emerging, and anticipated bases of evidence. *Clin Infect Dis.* 2014;59(suppl 1):55–60. doi:10.1093/cid/ciu266.
- Steinberg L. A social neuroscience perspective on adolescent risk taking. *Dev Rev.* 2008;28(1):1–27. doi:10.1016/j.dr.2007.08.002.A.
- Sisk CL, Foster DL. The neural basis of puberty and adolescence. *Nat Neurosci.* 2004;7(10):1040–1047. doi:10.1038/nn1326.
- Casey BJ, Jones RM. Neurobiology of the adolescent brain and behavior: implications for substance use disorders. *J Am Acad Child Adolesc Psychiatry*. 2010;49(12):1189–1201. doi:10.1016/ j.jaac.2010.08.017.
- Thuo N, Ngure K, Ogello V, et al. "So that I don't get infected even if I have sex with someone who is positive": factors influencing PrEP uptake among young women in Kenya. In: Research 4 Prevention. Madrid, Spain; 2018.
- Newman MB, Lohman BJ, Newman PR. Peer group membership and a sense of belonging: their relationship to adolescent behavior problems. *Adolescence*. 2007;42(166):241–263.
- Amico KR, Wallace M, Bekker LG, et al. Experiences with HPTN 067/ADAPT study-provided open-label PrEP among women in Cape Town: facilitators and barriers within a mutuality framework. *AIDS Behav.* 2017;21(5):1361–1375. doi:10.1007/ s10461-016-1458-y.
- Osterberg L, Blaschke T. Adherence to medication. N Engl J Med. 2005;353(5):487–497. doi:10.1056/NEJMra050100.
- PrEP Watch: Country Updates. www.prepwatch.org/countryupdates/. Accessed August 16, 2018.
- Riddell J, Amico KR, Mayer KH. HIV preexposure prophylaxis: a review. *JAMA*. 2018;319(12):1261–1268. doi:10.1001/jama. 2018.1917.
- Celum CL, Delany-Moretlwe S, McConnell M, et al. Rethinking HIV prevention to prepare for oral PrEP implementation for young African women. *J Int AIDS Soc.* 2015;18(suppl 3):1–10. doi:10.7448/IAS.18.4.20227.
- Aviisah MA, Norman ID, Enuameh Y. Facilitators and barriers to modern contraception use among reproductive-aged women living in sub-Saharan Africa: a qualitative systematic review protocol. *JBI database Syst Rev Implement reports*. 2017;15(9): 2229–2233. doi:10.11124/JBISRIR-2016-003024.
- 56 Dean Street. http://dean.st/56deanstreet/. Accessed August 16, 2018.
- Celum C, Baeten J. Sex, intimacy and HIV prevention: what do women and their partners really want? In: *HIV Research 4 Prevention*. Chicago, IL; 2016. www.prepwatch.org/wp-content/ uploads/2016/11/hivr4p-mpii-satellite-session-power-presenta tion.pdf. Accessed August 16, 2018.
- 20. Mugwanya K, Pintye J, Kinuthia J, et al. Uptake of PrEP within clinic providing integrated family planning and PrEP services: results from a large implementation program in Kenya. In: *International AIDS Conference*. Amsterdam, Netherlands; 2018. Abstract TUAC0304.

- Hosek S, Celum C, Wilson CM, et al. Preventing HIV among adolescents with oral PrEP: observations and challenges in the United States and South Africa. *J Int AIDS Soc.* 2016;19(suppl 6): 1–7. doi:10.7448/IAS.19.7.21107.
- Johnston L, Sass J, Acaba J, et al. Ensuring inclusion of adolescent key populations at higher risk of HIV exposure: recommendations for conducting biological behavioral surveillance surveys. *JMIR Public Heal Surveill*. 2017;3(2). doi:10.2196/ publichealth.7459.
- Calabrese SK, Underhill K. How stigma surrounding the use of HIV preexposure prophylaxis undermines prevention and pleasure: a call to destigmatize "truvada whores." *Am J Public Health.* 2015;105(10):1960–1964. doi:10.2105/AJPH.2015. 302816.
- 24. Holt M, Lea T, Mao L, et al. Community-level changes in condom use and uptake of HIV pre-exposure prophylaxis by gay and

bisexual men in Melbourne and Sydney, Australia: results of repeated behavioural surveillance in 2013-17. *Lancet HIV*. 2018;5(8):e448–e456. doi:10.1016/S2352-3018(18)30072-9.

- Stack C, Oldenburg C, Mimiaga M, et al. Sexual behavior patterns and PrEP dosing preferences in a large sample of North American men who have sex with men. *J Acquir Immune Defic Syndr*. 2016; 71(1):94–101. doi:10.1097/QAI.00000000000816.
- Goparaju L, Praschan NC, Warren-Jeanpiere L, et al. Stigma, partners, providers and costs: potential barriers to PrEP uptake among US women. *J AIDS Clin Res.* 2017;8(9). doi:10.4172/ 2155-6113.1000730.
- Calabrese SK, Magnus M, Mayer KH, et al. Putting PrEP into practice: lessons learned from early-adopting U.S. providers' firsthand experiences providing HIV pre-exposure prophylaxis and associated care. *PLoS One.* 2016;11(6):e0157324. doi:10. 1371/journal.pone.0157324.