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Journal
AIDS Research and Human Retroviruses, 38(1)

ISSN
0889-2229

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Publication Date
2022

DOI
10.1089/aid.2020.0268

Peer reviewed

AIDS RESEARCH AND HUMAN RETROVIRUSES
Volume 38, Number 1, 2022

DOI: 10.1089/aid.2020.0268

COMMENTARY

Time to Engage Young People in HIV Cure Research

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Abstract

Antiretroviral treatments successfully suppress and control HIV but cannot eliminate the virus. In recent years, much research has gone into developing a cure for HIV. This research comes with significant risks and limited clinical benefits to study participants. Little is known about the knowledge, willingness, motivations, and barriers of participating in HIV cure-related research. This is particularly true among young people living with HIV (YLWH), despite those <30 years having the highest HIV infection rates in the United States. YLWH have experienced a different phase of the HIV epidemic from their older counterparts. To guide HIV cure research development, more resources need to be directed toward understanding the perspectives of YLWH and meaningfully involving them in research. As the field of HIV cure research continues to grow and innovate, it is critical that we proactively engage YLWH as they will soon be at the forefront of decision making toward ending the HIV epidemic.

Keywords: HIV cure, youth and young adults, social and behavioral research, engagement

After the first reported HIV cure case of Timothy Ray Brown (''the Berlin patient''), much research has gone into the biomedical discovery of an HIV cure.[1] Although antiretroviral therapy (ART) can suppress and control the virus, it cannot completely eliminate HIV from the body. HIV cure-related research aims to identify strategies to either eliminate HIV from the body completely or permanently suppress the virus without ART.[2,3] Although a biomedical research priority, HIV cure-related research may result in significant risks to participants. One notable example is the need for participants to interrupt ART, known as analytic treatment interruptions (ATIs).[4] These interruptions may have potential risks to participants[5] and their sexual partners who become at risk of acquiring HIV[6]; yet, ATIs are considered to be necessary in developing therapies that induce long-term HIV control in the absence of continuous ART.

Few studies, however, have explored the willingness, motivations, barriers, perceptions, and experiences of the people for whom a cure is being researched.[4] This gap in knowledge is especially pronounced among young adults under the age of 30 years who are living with HIV (YLWH). In the United States, youth and young adults represent nearly half of all new HIV diagnoses.[7] In 2018, the first and second highest rates of HIV infection were in persons between the ages of 25–29 and 20–24 years, respectively.[7] Furthermore, despite being at higher risk for HIV, YLWH are less likely to be retained in care and achieve virologic suppression compared with older adults living with HIV.[8] Despite these data, and the reality that YLWH will likely be most directly impacted by advances related to new curative interventions as they become available, people under the age of 30 years make up only a small proportion of samples in social science HIV cure research.[9–12]

Studies that have explored willingness to participate in cure research reveal differing perceptions of people living with HIV (PLWH) regarding their tolerance to accept risks to advance the search toward an HIV cure. Participants have indicated their willingness to partake in these trials and take on significant risks for the altruistic purposes of contributing to the science of developing enhanced HIV treatments or durable control regimens.[10] Although these prior studies have examined the perceptions of key stakeholders on the risks and benefits of HIV cure research,[13,14] they have remained largely focused on older PLWH[10,15] leaving a dearth of knowledge on the perceptions of YLWH.

We recently reported findings from a survey of people in two groups—those 50 years of age and older and those under the age of 50 years.[11] We found differences in motivations and willingness to accept risks between these two groups. For example, those <50 years were less willing to take on more

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serious risks and expressed concerns about the impacts of participation on their reproductive health and choices. In contrast, those 50 years and older were more motivated by altruism, and expressed greater willingness to take on risks.

YLWH are an important group to include and involve in HIV cure-related research, for several reasons. First, research suggests that YLWH are less engaged in HIV care than older adults[16] and are generally less represented in HIV research.[17] Second, given their younger ages, this generation of YLWH is likely to be the most affected by decisions related to the risks and benefits of HIV cure strategies versus continuing ART.[18] Third, most young adults under the age of 30 years came of age at a time of advanced highly effective HIV treatment and prevention strategies. Thus, their perception of the risks and benefits toward HIV cure research may drastically differ from older PLWH who witnessed the peak of the U.S. AIDS epidemic and may have experience with HIV treatments that were harder to tolerate. Indeed, some younger participants do not see potential advances in HIV cure-related research as significantly better than their current ART regimen.[11] We are at the cusp of important improvements in HIV therapeutics with long-acting ART formulations soon becoming available. Hence, understanding preferences and attitudes of YLWH toward improvements in HIV therapeutics is more critical than ever.

Importantly, engaging YLWH in cure research will require addressing known barriers to youth and young adults participating in HIV clinical research and adhering to ART. For example, some YLWH struggle with mental health challenges and lack of access to health care. Those who are members of marginalized communities may need to manage multiple intersecting vulnerabilities (e.g., homophobia, HIV stigma, substance use, and racism, homelessness).[19] Other research has found that not having staff that include members of the community of focus or staff who are not culturally competent are barriers to study participation.[20] In addition, study distance and travel costs can be a barrier to participation, especially for younger individuals.[11] These, and other barriers, must be taken into account and addressed by those seeking to engage this critical population in cure research.

Therefore, engagement of young people should go beyond participation in research and must include their involvement in community advisory boards, research consultation, and hiring and training more diverse youth into research teams. This need for engagement has also been noted by the ''litmus test'' of the *Meaningful Involvement of People with HIV/AIDS*,[21] which calls for leadership and representation of PLWH in the organization; consideration of stigma, racism, and other forms of oppression in the organization; and how PLWH are providing input. In addition, this level of engagement will assist with the retention of YLWH in research, which has historically been low.[22,23]

In summary, as the field of HIV cure research continues to grow and innovate, as data continue to reveal the high HIV incidence among youth, particularly among sexual and gender minorities and communities of color,[7] and as PLWH continue to age and become ineligible for participation in HIV cure studies (which usually exclude people >65 years), YLWH will soon be at the forefront of decision making on novel anti-HIV therapies. Given the dearth of data related to how YLWH perceive and understand HIV cure-related research and interruptions in HIV treatment, it is essential that HIV researchers, interventionists, clinicians, policy makers, social and behavioral scientists, ethicists, and community members proactively engage YLWH in such research, and ensure novel regimens are acceptable to the next generation.

Authors' Contributions

P.S. and K.D. wrote the first draft of the article; P.S., K.D., C.K.C., and M.V. edited and approved the final version.

Author Disclosure Statement

No competing financial interests exist.

Funding Information

Research reported in this publication was supported by the National Institutes of Health award numbers R21MH122280 (Saberi and Dubé). The National Institutes of Health had no role in this study besides financial support.

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