HIV/AIDS and aging: the new frontier for HIV/AIDS research and care

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Since the first reported cases of AIDS in the United States in the Centers for Disease Prevention and Control Morbidity and Mortality Report 40 years ago [1], an HIV diagnosis has been transformed from a ‘death sentence’ to a manageable chronic illness, largely because of the availability of effective combination antiretroviral therapy (ART). People with HIV/AIDS (PWHA) are now able to live long, healthy, and productive lives [2] motivating researchers, clinicians, and policy makers not only to gain a deeper understanding of the intersectional experiences of aging with HIV, but also to prioritize the needs of older PWHA (OPWHA).

Although the increasing life expectancies of PWHA is a major accomplishment, the ‘greying of the epidemic’ has led to the emergence of a unique set of challenges, particularly in terms of access to and engagement in HIV treatment, prevalence of comorbid conditions and the risks associated with polypharmacy [3]. For example, 90% of OPWHA in the United States aged 55 years and above in 2018 knew their HIV status, just over half (57%) were engaged in routine care, and only 64% had viral load suppression [4]. Although these rates are slightly higher than the national average for United States PWHA and global PWHA, respectively, they fell significantly short of the 2020 UNAIDS ‘90-90-90’ goals [5,6]. This has led some to advocate that healthy aging among OPWHA should be incorporated into the UNAIDS ‘90-90-90’ goals as the ‘4th 90’ [7].

In addition to challenges associated with ART adherence, viral suppression, and HIV-care engagement, OPWHA who identify as racial/ethnic minorities have less favorable treatment outcomes; perhaps in part because of the long history of HIV as a stigmatizing condition for such communities. For instance, in the early days of the HIV epidemic, at a time when the majority of current OPWHA were first diagnosed, HIV was highly stigmatized for certain subsets of the population (e.g. ‘the 4 Hs’: homosexuals, hemophiliacs, Haitians, and heroin-users) [8]. Forty years later, it is imperative that this same population does not face new impediments to their overall health and well being.

Despite limited research on the experiences of OPWHA globally, certain universal challenges have been noted. First, OPWHA experience higher rates of comorbid health conditions possibly because of accelerated aging compared with both their HIV-negative age-matched peers and younger HIV-positive peers [9]. Second, OPWHA compared with age-matched HIV-negative peers, have been reported to be at elevated risk of certain geriatric syndromes like increased frailty, neurocognitive decline, and reduced functional mobility, which hampers their ability for ongoing engagement in care and treatment, in addition to contributing to their overall functional impairment [10]. Third, OPWHA may experience significant mental health challenges including depression, anxiety, substance use, and loneliness [11], which may be aggravated by aging-specific social issues like isolation, ostracism from certain communities, and reduced social support [12]. These barriers are particularly stark for OPWHA from racial/ethnic and sexual/
gender minority groups who face significant structural instability like low income, housing instability, food insecurity because of intersecting systems of oppression. For example, data show that approximately 80% of all OPWHA live in low-income and middle-income countries, highlighting the importance of developing culturally informed, context-specific interventions [13]. Finally, the effects of overlapping intersectional stigma related to aging, living with HIV, and marginalized identity status may lead to additional, and potentially more severe, physical, mental, and social challenges. Thus, it is crucial, to further our understanding of the synergistic effects of the syndemic clustering of issues that arise with aging and HIV.

A necessary step towards addressing the unique challenges rooted in identity-based social inequities that OPWHA face is the use of minority stress and intersectionality frameworks. First, the minority stress model posits that the stress associated with daily living is exacerbated for communities that experience chronic identity-based stigma entailed in living in a society that holds stigmatizing views of their identities [14]. This model complements with intersectionality theory, which hypothesizes that individuals experience various systems of oppression because of their unique identities, and that these experiences must be understood and explored [15]. As every OPWHA’s experience can be entirely unique, it is critically important to consider the multitude of stressors and layers of discrimination that individuals face based on HIV status and other intersecting identities whenever designing research studies and developing interventions. Cultural values and behaviors, such as respecting boundaries with elders and prioritizing family above all else, health beliefs influenced by religion, and the burden carried by histories of prejudice cast upon an individual because of their sexual orientation interact with age-related bias to influence the way older individuals approach participating in research or accessing services. With this in mind, it is important to appreciate how ageism in the lives of OPWHA may interact with other forms of marginalization, stigma, and oppression, such as sexism, homophobia, transphobia, and racism to exacerbate poor treatment outcomes among this population.

Complementing the centering of intersectionality and minority stress theories in HIV and aging research, it is critically important to engage OPWHA in defining a relevant research agenda. Use of community-based participatory research, which aims for full and equal community participation in the design, implementation, dissemination, and evaluation of community-based research, should play a pivotal role in the next chapter of research for this unique population [16]. This collaborative approach provides an ideal approach for research grounded in intersectionality and minority stress theories because of its emphasis in fully integrating community priorities into research. As such, this approach is conducted for and by communities themselves. In the realm of HIV and aging, this methodology allows researchers to hear directly from community members themselves to understand how their experiences as OPWHA, as well as their experiences at the intersections of systems of oppression (e.g. ageism, racism, homophobia), affect their access to and engagement with HIV services [17,18]. Beyond the engagement in research prioritization and design, similar community engagement is critical in shaping interventions that support the health and wellbeing of OPWHA, thus, increasing their potential for successful implementation and scale-up [19].

As we stop to acknowledge the 40-year anniversary of the identification of the first AIDS cases in the United States, we are compelled to take into account the unique needs of OPWHA if we are to reach the end of AIDS [20]. We must endeavor to learn directly from OPWHA as we develop, implement, disseminate, and evaluate feasible and acceptable evidence-based interventions that meet their needs. Rather than taking the resiliency and lived experiences of OPWHA for granted, we must instead invest time, resources, and funding towards the ‘4th 90’ to realize our potential in ending the global HIV epidemic [7].

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