Is There No Place for Us? The Psychosocial Challenges and Rewards of Aging with HIV

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Abstract

According to the Centers for Disease Control and Prevention (CDC), nearly half a million people aged fifty years and older have human immunodeficiency virus (HIV) in the US. This population will continue to grow and some estimates suggest that approximately 70% of all persons with HIV (PWH) in the US will be 50 and over by 2030. This pattern is found globally, as access to antiretroviral therapy becomes widespread. This population includes newly infected older adults and long-term survivors aging with HIV. This article reviews the challenges and opportunities for older PWH, focusing primarily on psychosocial issues. While the growth of this population testifies to the success of HIV treatments, older PWH encounter numerous difficulties in later life, including high rates of multi-morbidity, behavioral health issues, HIV stigma, and social isolation. Many older PWH face difficulties finding care in fragmented systems poorly aligned for the dual challenges of aging and having HIV. We address these structural problems and misalignment with eight policy recommendations to improve access to care and support healthy aging. These recommendations fall into three main categories: 1) increased recognition of this population in planning and the National HIV/AIDS Strategy, 2) improved access to programs through the Ryan White and Older American's Act programs, and 3) better surveillance data on this population globally. Short of a cure, the dramatic increase in the population of older PWH will continue for the foreseeable future. It is the duty of advocates, gerontologists, health and social service providers, and policymakers to meet the needs of those growing older with HIV.

Keywords: HIV/AIDS, older adults, systems of care, Older Americans Act, Ryan White HIV/AIDS program, aging policy

¿No hay lugar para nosotros? Los desafíos y recompensas psicosociales del envejecimiento con VIH

Resumen

Según los Centros para el Control y la Prevención de Enfermedades (CDC), casi medio millón de personas mayores de cincuenta años tienen el virus de la inmunodeficiencia humana (VIH) en los Estados Unidos. Esta población continuará creciendo y algunas estimaciones sugieren que aproximadamente el 70 por ciento de todas las personas con VIH (PWH) en los EE. UU. Tendrán 50 años o más para 2030. Este patrón se encuentra en todo el mundo, a medida que el acceso a la terapia antirretroviral se generaliza. Esta población incluye adultos mayores recién infectados y sobrevivientes a largo plazo que envejecen con VIH. Este artículo revisa los desafíos y las oportunidades para las personas con discapacidad mayores, centrándose principalmente en cuestiones psicosociales. Si bien el crecimiento de esta población atestigua el éxito de los tratamientos contra el VIH, los PWH mayores se enfrentan a numerosas dificultades en la edad adulta, incluidas las altas tasas de morbilidad múltiple, problemas de salud conductual, estigma del VIH y aislamiento social. Muchos PWH mayores enfrentan dificultades para encontrar atención en sistemas fragmentados mal alineados para los desafíos duales del envejecimiento y el VIH. Abordamos estos problemas estructurales y la desalineación con ocho recomendaciones de políticas para mejorar el acceso a la atención y apoyar el envejecimiento saludable. Estas recomendaciones se dividen en tres categorías principales: 1) un mayor reconocimiento de esta población en la planificación y la Estrategia Nacional contra el VIH / SIDA, 2) un mejor acceso a los programas a través de los programas de la Ley Ryan White y Older American's Act, y 3) mejores datos de vigilancia sobre esta población globalmente A falta de una cura, el aumento dramático en la población de personas mayores con PWH continuará en el futuro previsible. Es deber de los defensores, gerontólogos, proveedores de servicios sociales y de salud y formuladores de políticas satisfacer las necesidades de las personas mayores con VIH.

Palabras clave: VIH / SIDA, adultos mayores, sistemas de atención, Ley de Estadounidenses Mayores, programa Ryan White sobre VIH / SIDA, política de envejecimiento

我们没有立足之地吗？携带艾滋病毒衰老的心理社会挑战与回馈

摘要

根据疾病预防控制中心（CDC），美国近50万50岁及以上的成人患有人类免疫缺陷病毒（HIV）。这一人口将继续增加，并且一些预测暗示美国HIV携带者（PWH）总数中近70%将在2030年达到50岁及以上。随着抗逆转录病毒疗法的可及性得以扩散，该模式在全球都是如此。这一人口包括新感染的中老年人和长期伴随HIV衰老的生存者。本文审视了中老年PWH的挑战与机遇，主要聚焦于心理社会问题。尽管这一人口的增长证实了HIV治疗的成功，但中老年PWH在之后的生活中面临诸多困难，包括多种疾病的高发病率、行为健康问题、HIV耻辱、以及社会隔离。许多中老年PWH在分散的医疗卫生体系中寻求护理时面临困难，这些体系无法良好应对老龄化与HIV的双重挑战。我们提出八项政策建议应对这些结构性问题和不一致，以期提高护理可及性并支持健康老龄化。这些建议分为三个主要类型：1） 在规划国家艾滋病毒/艾滋病战略时提高对这一人口的重视；2） 通过瑞安·怀特项目和《美国老年人法案》项目提高相关项目的可及性；3）提升全球在这一人口上的监测数据。鉴于无法痊愈，中老年PWH人口的显著增加情况将在可预见的未来中继续存在。满足那些携带HIV衰老的人口的需求，是倡导者、老年学家、卫生与社会服务提供者、以及决策者的职责。

关键词：艾滋病毒/艾滋病，中老年人，护理体系，《美国老年人法案》，瑞安·怀特艾滋病毒/艾滋病项目，老龄化政策

Introduction

Advances in the management of the human immunodeficiency virus (HIV) have altered the care and treatment for people with HIV (PWH) globally (Emlet, O'Brien, & Fredriksen-Goldsen, 2019). Due to new HIV infections among older adults and increased longevity among PWH, the number of adults fifty years and over with HIV is growing rapidly wherever access to anti-retroviral therapy (ART) is widely available (Heckman & Halkitis, 2014; Mahy et al., 2014). Historically, older PWH are defined as being fifty years and older in surveillance data and by specific clinical markers, including

immunological response to medication and poorer survival rates (CDC, 2018; Blanco et al., 2012; High et al., 2012). In the US, 17% of all new HIV diagnoses annually are among older adults (CDC, 2019a). While new diagnoses of HIV have decreased over the past five years (CDC, 2019b), the rate of new infections among older adults has remained stable.

At the end of 2017, there were approximately 495,569 PWH age 50 and older in the US (CDC, 2019b), representing 49% of PWH. Some estimates suggest that by 2030, 70% of PWH will be fifty or over (Gilead, 2019). Globally, in 2016 there were 5.7 million PWH age fifty and older [range=4.7 to 6.6 million] representing 16% of this population; a proportion expected to rise to 21% by 2020 (Autenrieth et al., 2018).

Health Inequalities

Health disparities or inequalities have been a hallmark of HIV since early in the epidemic. HIV impacts various communities disproportionately, fostering health disparities in comparison to community members without HIV. Since the beginning of the epidemic, gay and bisexual men and transgender women (also included in the term men who have sex with men or MSM) have been disproportionally impacted by HIV (CDC, 2019b). Recent CDC data (2019b) indicates that 69.7% of all new diagnoses of HIV in the US are among MSM and MSM who inject drugs, and 49.5% of PWH over the age of fifty have MSM as their transmission category (CDC, 2018). Classifying transgender women as MSM has led to a lack of specific information about this population (Porter & Brennan-Ing, 2019), but available data indicate they are at a high risk for HIV (Dragon et al., 2017; Operario, Soma, & Underhill, 2008). Women comprise 23% of older PWH in the US, with most infections due to heterosexual contact (70%), followed by injection drug use (29%) (CDC, 2018). Overall, 16% of US infections were due to injection drug use and 12% were due to heterosexual contact in older adults (CDC, 2018).

Globally, most HIV infections are the result of heterosexual transmission and injection drug use. In sub-Saharan Africa, heterosexual transmission is the most common vector for HIV (Piot et al., 2001). However, in China and Eastern Europe, HIV started among injection drug users and then spread to their heterosexual partners (Piot et al., 2001). Regional differences also exist. Injection drug use is the primary mode of HIV infection in Pakistan, Iran, Libya, Afghanistan, and Egypt. In the Eastern Mediterranean, female sex workers, gay and bisexual men, and injection drug users are the primary groups affected by HIV (Sprague & Brown, 2016).

HIV disparately affects older adults of color. At the end of 2015, Blacks/African Americans made up the largest percentage of older PWH (39%) in the US, compared with Whites (37%), or Latinxs (18%) (CDC, 2018). Older adults of color are disproportionally impacted by late HIV diagnosis; the highest percentage of older adults with a Stage 3 (AIDS) classification at the

time of HIV diagnosis was among persons of multiple races (47.3%) (CDC, 2018).

HIV long-term survivors are another important subpopulation of older PWH. There is no single definition for long-term survivors, but many define these individuals as PWH who acquired the virus before ART became widely available in 1996. This was a time when HIV diagnosis meant early death (The Well Project, 2018). These older PWH lived through significant trauma that had lasting effect on their physical and mental wellbeing.

It is important to consider the impact of intersectionality on older PWH. For example, Emlet et al. (2019) analyzed data from the National Health, Aging, Sexuality/Gender Study (NHAS) in order to better understand health disparities among older gay and bisexual men. They found that compared to their HIV negative counterparts, those living with HIV were more likely to be men of color and to have lower levels of resilience and social support, a past diagnosis of anxiety or drug addiction, poorer general health, and increased levels of depressive symptoms. Data from the Health Resources and Services Administration (HRSA) found that older Black/African American and Latinx PWH were more likely to live below the federal poverty level and to experience greater housing instability (Cohen et al., 2019), which in turn impacted viral suppression. Older transgender adults with HIV also experience health disparities, including unstable housing, higher rates of poverty, and lower levels of viral suppression (Cohen et al., 2019). The impacts of gender/gender identity, race/ethnicity, sexual orientation, and length of time with HIV are complex and a detailed analysis is beyond the scope of this article.

Burden of Disease

Older PWH not only face the challenges of aging with the virus, but also must contend with other comorbid conditions, some HIV-related and others experienced by the general population. Multi-morbidity is related to how ongoing HIV infection impacts health. Fülöp et al. (2017) proposed that ART transforms HIV into a chronic inflammatory disease, and that changes to the immune system resulting from HIV infection render it less able to protect the body from a host of threats.

Older adults with HIV average three or more comorbid conditions in addition to HIV (Balderson et al., 2013; Havlik, Brennan, & Karpiak, 2011). Common comorbid conditions include cardiovascular disease, certain cancers, hepatitis C, fractures, and depression (Karpiak & Havlik, 2017). It is unclear if this higher burden of disease is due to accelerated aging with HIV (i.e., increased disease incidence at earlier ages), or accentuated aging (i.e., disease incidence at similar ages as non-HIV infected persons, but a greater number of comorbidities) (Karpiak & Havlik, 2017). Globally, tuberculosis (TB) is a prevalent comorbidity and progresses more rapidly among PWH compared with HIV-negative peers; in 2016, there were an estimated 1 million new

cases of HIV-TB co-infections among PWH, with 374,000 deaths (Dolai, Roy, & Roy, 2020). As the population PWH grows older, they are increasingly likely to experience geriatric syndromes associated with vulnerabilities in physical, psychological, and environmental domains (Greene et al., 2015). Geriatric syndromes include falls, urinary incontinence, functional impairment, sensory loss, depression, cognitive impairment, and frailty, and are associated with HIV disease severity, greater multi-morbidity, and minority race/ethnicity (Brothers et al., 2014; Greene et al., 2015). The high level of disease burden among older adults with HIV requires new policy and programmatic approaches to meet the social care needs of this aging population.

Prevention Challenges

An important element of creating a system of HIV care for older adults must include relevant, sensitive, and evidence-based prevention strategies. Seventeen percent of all new HIV diagnoses in the US are among people fifty and over (CDC, 2019a). It is estimated that only 69% of those over fifty-five living with HIV receive some HIV care (CDC, 2019b), creating opportunities for older PWH to transmit HIV. A recent analysis of HIV transmission in the US estimates that over 50% of HIV infections in 2016 originated from people age forty-five and older (Li et al., 2019). In the Research on Older Adults with HIV (ROAH) using a diverse sample of older PWH (83% people of color, 29% women, 67% heterosexual), 50% had been sexually active in the past three months, and 80% of those who were sexually active engaged in penetrative anal or vaginal sex (Golub, Grov, & Tomassilli, 2009). Among the sexually active, many had unprotected sex: 21% with HIV-positive partners and 20% with serodiscordant partners (HIV- or HIV status unknown). In ROAH, safer sex practices and HIV risk management behaviors were associated with better psychological wellbeing, with unprotected sex linked to recent substance use and loneliness (Golub et al., 2010; Golub et al., 2013).

Among older PWH in the US, 30 to 40% are classified as having a "dual diagnosis" of HIV and AIDS (CDC, 2019a). A dual diagnosis is a "late" diagnosis, as HIV has been present long enough to progress to AIDS. In addition, because these individuals did not know they were HIV-positive, they may have placed others at risk (CDC, 2018, Cohen et al., 2011; Li et al., 2019). A dual diagnosis of HIV/AIDS is associated with greater morbidity and mortality given the damage caused to the immune system by untreated HIV (Chadborn et al., 2005; Egger et al., 2002). Ageist beliefs that older adults are not sexually active or engage in other HIV risk behaviors are likely factors in late HIV testing, as providers may believe HIV symptoms in older patients arise from other health conditions (DeMarco, Brennan-Ing, Brown, & Sprague, 2017).

Recent local, national, and global policy initiatives to end the epidemic (ETE) have the potential to reduce HIV infections, late testing, and dual HIV/AIDS diagnoses among older adults (Bain, Nkoke, & Noubiap, 2017; Facen-

te, 2016; HHS, 2019; New York State Department of Health, 2015). ETE policies share a common framework of universal testing and getting people who test positive engaged in care, on ART, and virally suppressed. Prompt HIV testing and initiation of ART to achieve viral suppression result in better clinical outcomes for older PWH. Further, PWH who sustain undetectable viral loads cannot infect others through sexual contact and are referred to as Undetectable = Untransmittable (U=U) (Cook, Davidson, & Martin, 2019; Eisinger, Dieffenbach, & Fauci, 2019). Successful implementation of ETE policies has the potential to greatly improve the health of older adults with HIV and reduce HIV incidence. Yet among older PWH, rates of viral suppression are approximately 60% (Crepaz et al., 2017; Muthulingam et al., 2013; Yehia et al., 2015), well below public health targets of 73 to 85% (Bain et al., 2017; Facente, 2016; New York State Department of Health, 2015).

Psychosocial Issues: Social Isolation, Stigma and Mental Health Issues

Older PWH face multiple psychosocial challenges that can be exacerbated by aging, such as social isolation, stigma, and mental health concerns. These issues are both intrapersonal and interpersonal, and we have chosen to focus on issues that are of major concern.

Social Isolation

Social isolation is common among older PWH. The Caring and Aging with Pride project (Fredriksen-Goldsen et al., 2011) found that 64% of older LGBT adults with HIV lived alone. In the ROAH 2.0 study (53% people of color, 15% female, 22% heterosexual), 67% of participants lived alone and 43% were lonely (Erenrich et al., 2018). Social isolation arises from a variety of sources, including the death of partners/spouses (Emlet et al., 2019), stigma (Brennan-Ing, Seidel, & Karpiak, 2017), and disconnection from family (Brennan-Ing et al., 2017a; Brennan-Ing, Seidel, Larson, & Karpiak, 2017). Many older PWH find it difficult to locate and identify their community (Johnson Shen et al., 2018). A recent study of social isolation among older adults living with HIV found that increased social isolation is associated with increased hospitalizations and mortality (Greysen et al., 2013), reinforcing the tie between social wellbeing and physical health.

Stigma

HIV stigma is a serious social problem among older PWH (Emlet, 2017; Foster & Gaskins, 2009; Haile, Padilla, & Parker, 2011). HIV stigma involves a complex array of intrapersonal and interpersonal experiences, including enacted stigma (prejudice/discrimination), internalized stigma (internalization negative attributes and beliefs), and anticipated stigma (the expectation of enacted stigma and resulting anxiety and fear) (Earnshaw & Chaudoir, 2009). HIV stigma among older adults is associated with depression, poorer quality of life, lack of disclosure, and loneliness (Grov et al., 2010; Haile et al., 2011). Older PWH may

face the intersectionality of HIV stigma with other forms of discrimination, including ageism (Emlet, 2006), racism, sexism, homophobia, ableism, and/or transphobia (Johnson Shen, Freeman, Karpiak, Brennan-Ing, Seidel, & Siegler, 2019; Porter & Brennan-Ing, 2019). Ageism, namely discrimination toward older people on the basis of age, has deleterious effects on older PWH, rendering them invisible in HIV education, testing, and treatment settings, and when internalized, leads to poorer health outcomes (DeMarco et al., 2017).

Healthcare and HIV providers working with older PWH must assess stigma and carefully consider the intersection of HIV and other stigma and how these forms of discrimination are mitigated. In a recent study of older adults, Emlet and colleagues (2013) note the importance of social support and mastery as a means of counteracting HIV stigma.

Mental Health

Mental health concerns, particularly depression, anxiety, and substance misuse, are common among older PWH. Rates of depression greater than 50% have been identified in numerous studies, including ROAH (Brennan, Karpiak, & Cantor, 2009; Frontini et al., 2012; Justice et al., 2004). In ROAH 2.0, 62% reported feeling depressed during the past year (Erenrich et al. 2018). Rates of substance use and misuse among older PWH are higher than among older HIV-negative individuals (Justice et al., 2004). Emlet et al. (2019) found that older sexual minority men with HIV more likely to have a history of substance use disorders, alcoholism, and depression compared with HIV-negative peers. Commonly used illicit substances among older PWH include marijuana, cocaine, and methamphetamines (Erenrich et al., 2018; Frontini et al., 2012). Anxiety is a serious and prevalent mental health issue among older PWH; in ROAH 2.0, 65% of participants experienced anxiety in the past year (Erenrich et al., 2018). The NHAS found anxiety to be twice as common among older PWH compared to HIV-negative counterparts (Emlet, et al., 2019).

Behavioral health problems can be risk factors for HIV infection or result from the crisis of an HIV diagnosis. Substance use complicates HIV care. Using alcohol or other substances is a barrier to ART adherence in younger and older PWH alike (Azar et al., 2010; Reda & Biadgilign, 2012; Spaan et al., 2018). Parsons et al. (2014) found that older PWH who used alcohol and other substances were significantly more likely to be non-adherent to ART and have detectable viral loads. In a sample of middle-aged and older PWH, Sinha and colleagues (2017) found that marijuana, alcohol, and heroin use were significantly related to poor ART adherence. Further, there is evidence that the use of alcohol and other substances decreases the efficacy of ART, potentially impacting clinical outcomes (Michel et al., 2010).

Exploring the Deficit in Social Resources

The issues of social isolation and fragile social networks have been well documented in the HIV and aging literature. Moving forward with a useful and thoughtful approach is also necessary. Using the original ROAH study data, Brennan-Ing and colleagues (2017a) developed a typology of social networks of older PWH. Three network types emerged, with each type accounting for approximately one-third of the sample. The first group, the "Isolated," reported no friends or community involvement, but had intermittent contact with a few family members. This group was predominantly composed of heterosexual women and men. The "Friend-centered" group had frequent contact with friends, but little contact with family or community involvement. This group was dominated by gay and bisexual men who tend to have so-called families of choice, regardless of their HIV status (Brennan-Ing et al., 2017b). The "Integrated" group had a large proportion of heterosexual women and the broadest spectrum of support from family and friends and was involved with their communities. Older PWH in the Isolated group reported the lowest levels of perceived instrumental and emotional social support, and did more poorly with regard to psychosocial functioning (HIV stigma, depression, loneliness) compared to their peers. Those in the Friend-centered group had similar psychosocial functioning compared to the Integrated group. While social support from friends can be vital when family support is not available, support from friends does not fully compensate for a lack of assistance from family (Brennan-Ing et al., 2017b).

Given the lack of informal social resources among older PWH, it is questionable whether their needs for caregiving and other forms of support can be met as they age. Nearly half of the ROAH 2.0 sample (45%) indicated they either had needed caregiving help in the past (24%) or currently needed such help (21%) (Erenrich et al., 2018). Of those needing caregiving, 31% said they received help from a partner/spouse, 25% indicated a family member, 67% said a friend, and 21% received help from neighbors (participants could select more than one category). However, 23% said they had no one to turn to for caregiving assistance. Thus, a sizeable proportion of older PWH appears to lack critical caregiving resources. A fragile informal support system can be mitigated through the use of formal services, such as home care or case management (Cantor & Brennan, 2000). For older PWH however, turning to formal services may be difficult. Experiences of fear, discrimination, marginalization, invisibility, and distrust may serve as a barrier in accessing needed services (Cox & Brennan-Ing, 2017; Johnson Shen et al., 2019).

Not only must older PWH access treatment for HIV and common health conditions of old age, but they also must access dual systems of care. Unfortunately, that coordination across systems is often difficult. DeMarco and colleagues (2017) suggest that "ageism perpetuates the invisibility of older adults which renders current medical

and social service systems unprepared to respond to the needs of aging people with HIV infection" (235). For example, in a statewide survey of area agencies on aging (AAA) in Washington state, more than 80% of AAAs felt they had limited or no experience in working with older PWH and agreed they needed more training (Emlet, Gerkin, & Orel, 2009).

Similarly, when older adults access AIDS service organizations, they often find that the programming is not framed to fit their needs (Johnson Shen et al., 2018). Even though older adults living with HIV may be more likely to seek services from the network of care designed for those with HIV, as opposed to services for older adults (Emlet, 2004), services in that arena may not be a good fit. As an example, one seventy-year-old Black heterosexual male participant in a study of service needs among older PWH stated "Yah, and I went to the thing called ... I forget the name of it, but when I met the group of young, young people, 21 years old, you know, 24, 25 years old, I was like ... as soon as I got there it's 'Oh, we got a grandpa.' When they called me grandpa, I said that's it, done" (Johnson Shen et al., 2019).

Social and Interpersonal Resources

Strengths and resilience can aid in adjustment and serve as protective factors against the deleterious impacts of HIV among older adults. Interpersonal and intrapersonal factors have been associated with decreased psychological distress and improved quality of life in this population. Social support has been repeatedly found to benefit older PWH. Emlet et al. (2013) found emotional and informational social support to be associated with decreased HIV stigma among 378 older male and female PWH. These results parallel Logie and Gadalla (2009), who found a negative relationship between HIV stigma and social support. Recently Emlet and colleagues (2017) found social support to be associated with both mastery and resilience in 335 older gay and bisexual men living with HIV. Both mastery and resilience were associated with increased psychological health-related quality of life.

Increasingly, researchers are examining successful or optimal aging among PWH. Successful aging among older PWH requires us to rethink classic models of this concept (Rowe and Kahn 1998), and acknowledge that diverse older adults, particularly those with late-life disability, will require a redefinition of what it means to age successfully (Romo et al., 2013). Kahana and Kahana (2010) developed the "preventative and corrective model of successful aging" specific to HIV. Unlike earlier models, this model presented HIV more positively, with a focus on prevention and on "corrective" activities that would realize meaning and success in the aging process.

Vance and colleagues (2019) adapted Baltes and Baltes' (1998) model of successful aging to older adults with HIV by proposing that a more productive approach would be to examine how people manage challenges and losses while maintaining well-being as they age (Vance et al. 2019). Vance and colleagues (2019) concluded that to enable

successful aging, older PWH require information and support to manage their HIV and other comorbid conditions. Further, health and social service providers should be mindful of both deficits and strengths that characterize this population, and utilize the latter to help these individuals age successfully.

Research has noted the importance of intrapersonal characteristics, including mastery, optimism, and spirituality, in aging successfully with HIV. Moore et al. (2013) utilized self-ratings of successful aging in 166 HIV-positive and HIV-negative older adults. They found that optimism and mastery were associated with improved self-rated successful aging and other indicators of physical and psychological functioning. Mastery has also been associated with reduced stigma in HIV-positive older Canadians (Emlet et al., 2013). Other researchers have taken a more naturalistic approach, allowing older PWH to self-define successful aging (Solomon et al., 2018; Emlet et al., 2017).

A recent inquiry has identified the importance of resilience in coping and managing HIV disease. Porter et al. examined the mediating effects of spirituality and complimentary and integrative health practices (CIH) on the relationship between HIV stigma and psychological wellbeing in the original ROAH study (Porter et al., 2015). Greater HIV stigma was related to poorer psychological wellbeing. However, results found that both spirituality and CIH buffered the impact between stigma and wellbeing. In a follow-up study, Porter et al. compared the relationships of these factors between older gay/bisexual men and older heterosexual men with HIV (Porter et al., 2017). They found that spirituality was a stronger mediator of stigma relative to wellbeing in sexual minority men compared to heterosexuals. Social workers and other health and social service providers need to ensure that their assessment processes identify and capitalize on strengths and resilience in this population.

Policy Recommendations

Older PWH are not typical of the general aging population (Cox & Brennan-Ing, 2017), and thus it is not surprising that Brennan-Ing et al. (2014) found that older PWH used three times as many non-HIV services as their community-dwelling HIV-negative counterparts. Despite the complex needs of this population, there are problems associated with the coordination of services across systems. What follows are recommendations for policy changes in eight domains, ranging from worldwide HIV reporting structures to the provision of more localized services in the United States.

Recommendation #1. Explicitly address the support and care needs of older HIV-positive adults in the US National HIV/AIDS strategy.

The National HIV/AIDS Strategy for the United States (White House Office of National AIDS Policy, 2017) clearly identifies older adults as an important group of people regarding HIV prevention and treatment. While it is laudable that older adults are specifically mentioned in the updated strat-

egy, older adults are identified as part of a long list of at-risk groups. Despite this important recognition, of the ten indicators identified in the National HIV/AIDS Strategy, none address the specific needs of older PWH. Thus, the impact that HIV has on older adults is not proportionately represented in the current strategy. For example, the strategy continues to recommend that all individuals between fifteen and sixty-five years be tested for HIV. CDC data indicate that in 2017, more people age sixty-five and over were living with HIV (approximately 90,000) than those up to twenty-four years of age. With some estimates that upward of 70% of PWH in the US will be fifty years old and older by 2030, specific approaches for this population are needed. HIV advocates and older consumers should work more closely to identify the prevention and care needs of this population before the next strategy update occurs.

Given the extent of health challenges among older PWH, the National HIV/AIDS Strategy should also address universal healthcare coverage. Engagement in care is a key component of HIV treatment and addressing age-related multi-morbidity, yet this is not possible without access to healthcare. The Affordable Care Act (ACA) increased health insurance participation among PWH through Medicaid expansion, reducing uninsured rates from 19% to 5% (Dawson & Kates, 2019). However, Medicaid expansion has occurred on a state-by-state basis, and many states in the southern US, where HIV infection rates are growing, chose not to expand Medicaid (Reif et al., 2017). Approximately nine out of ten PWH who fall into the Medicaid coverage gap, i.e., have an income that is too high to qualify for Medicaid, but too low for an ACA subsidy, live in the Deep South (Reif et al., 2017). Without addressing these gaps and without working to guarantee universal health insurance coverage for younger and older PWH, the National HIV/AIDS Strategy falls short.

Recommendation #2. Reconvene the National Institute of Health Office of AIDS Research (NIH OAR) workgroup on HIV & Aging.

In April 2011, the NIH OAR convened a working group to address the aging of the HIV epidemic in anticipation of adults fifty and older making up a majority of PWH. The working group developed four priorities for NIH to address in HIV and aging research: 1) mechanisms and triggering of functional decline/aging in HIV-infected persons; 2) biomarkers and clinical indices as predictors/surrogate outcome markers; 3) aging with HIV infection; multi-morbidity and the clinical research agenda; and 4) societal infrastructure, mental health/substance abuse, and caregiving issues (High et al., 2012). Reflecting the scientific disciplines of the working group, three of the four priority areas were focused on biomedical and clinical research, and NIH support for HIV and aging research has reflected this predisposition since the working group report was issued. As we have highlighted in this paper, the psychosocial issues around HIV and aging are key policy considerations in meeting the needs of this growing population, and this policy

needs a robust evidence base to ensure that recommendations will be relevant and efficacious. Given the growth of older PWH in the last decade, the NIH OAR should reconvene this working group to update research priorities on HIV and aging, with a greater focus on psychosocial challenges.

Recommendation #3. Insure that ETE initiatives address the special needs of older adults.

The federal government, along with state and local jurisdictions have adopted ETE plans that involve universal HIV testing and having PWH be engaged in care, on ART, and virally suppressed. ETE plans promote HIV prevention by providing greater access to pre-exposure prophylaxis (PrEP) and post-exposure prophylaxis (nPEP). At the time this manuscript was being prepared, twelve states and the District of Columbia had ETE plans available, eleven states had plans in development, and twenty-three county or city jurisdictions had ETE plans in existence or in process (NASTAD, 2019). However, few of these plans explicitly address the HIV prevention and care needs of older adults. An example of how this can be achieved is provided by New York State, which convened advisory groups to develop ETE implementation strategies (New York State Department of Health, 2019). The New York State Older Adults Advisory Group noted various barriers and strategies to achieving ETE goals, including low rates of HIV testing, condom use, and PrEP uptake in adults fifty and older. Other challenges to meeting ETE goals were the recognition of high levels of multi-morbidity and concomitant polypharmacy in this population, along with high rates of unmanaged depression; factors with the potential to interfere with ART adherence and efficacy in the older population. Considering the proportion of older adults who comprise the current HIV population and substantial incident HIV in this group, it is imperative that ETE plans consider the special needs of older adults to ensure the success of these initiatives.

Recommendation #4. Increase CDC funding for primary and secondary HIV prevention.

The CDC published its first surveillance report on HIV among people fifty and older in 2013 (CDC, 2013), and the latest update was released in 2018 (CDC, 2018a). While the CDC is paying greater attention to older PWH, greater efforts should be made to address the prevention challenges faced by older adults. Older adults experience a delay between HIV infection and diagnosis, resulting in high rates of late dual HIV/AIDS diagnoses (CDC, 2018; Cohen et al., 2011). People 50 and older represent 17% of new HIV infections in the US (CDC, 2019a), and may be responsible for nearly half of all new HIV infections (Li et al., 2019). While the CDC supports the use of high-impact prevention approaches to reducing HIV infections in older adults (CDC, 2019a), these programs were developed for people under the age of fifty, and there has been little CDC-specific funding or prevention efforts targeting older individuals. The problem with this ap-

proach is illustrated in the case of PrEP. While PrEP could be an important prevention tool for older adults, given the prevalence of erectile dysfunction in older men, which can render condom use problematic, the active ingredient in PrEP—tenofovir—is associated with kidney toxicity, and such toxicity is more likely in people over fifty (Franconi & Guaraldi, 2018). Thus, general guidelines around PrEP uptake ignore enhanced screening and the consideration of other mitigating factors like the comorbid conditions that physicians should be aware of when prescribing this medication to older patients (Franconi & Guaraldi, 2018). To better meet the prevention needs around HIV and aging, the CDC should work to develop tailored strategies to address low rates of HIV testing and the prevention challenges facing older adults, rather than relying on a one-size-fits-all strategy. Other prevention efforts, such as the "Age is Not a Condom," campaign could be expanded as well.

Recommendation #5. Increase targeting of older adults in Ryan White-funded programs, with incentives to develop new programming for an older population.

The Ryan White HIV/AIDS program is administered through HRSA and serves over 500,000 PWH who are uninsured and underserved (HRSA, 2020a). Ryan White provides grants to entities that provide medical and supportive services to PWH. In 2018, 44% of Ryan White program participants were age fifty and older, most were people of color, and a majority had incomes at or below the federal poverty level (HRSA, 2018). A number of Ryan White grantees run programs targeting older PWH (HRSA, 2018); however, supportive services targeting psychosocial needs are not as common as those focused on medical care. As this population grows, their needs for these types of services will increase as they face the dual challenges of HIV and aging, and Ryan White funding for older adults programing needs to reflect this growing need (Cahill, Mayer, & Boswell, 2015). Unfortunately, Ryan White funding decreased between 2011 and 2019 (HRSA, 2020b). While HRSA provides limited online resources to train Ryan White providers to work with older adults (AETEC National Coordinating Resource Center, 2015), a greater commitment to cultural competency training for PWH over fifty is warranted (Cahill et al., 2015). The Ryan White program should also fund Special Projects of National Significance (SPNS) grants specifically geared toward programs for older adults, which could spur programmatic innovations.

Recommendation #6. Within the Older Americans Act (OAA), define older PWH and LGBTQ individuals as populations of greatest social need and relax age eligibility requirements for OAA program access

The OAA is an example of age-based public policy and has, since the beginning of the act in 1965, made services available to older people based on age (Greenfield & Giunta, 2016). The OAA also focuses resources on those older

adults with greatest social and economic needs, including those with (a) physical and mental disabilities; (b) language barriers; and (c) cultural, social, or geographical isolation, including isolation caused by racial or ethnic status, that (i) restricts the ability of an individual to perform normal daily tasks or (ii) threatens the capacity of the individual to live independently (42 USC §3002(23)-(24) (2016)). Older adults living with HIV have been defined as those fifty and over since very early in the epidemic (Poindexter & Keigher, 2004), with similar age criteria for older LGBT individuals based on health inequities and comorbidities (APA, 2020). Because many older PWH are under sixty years of age, but otherwise meet criteria for greatest social needs, it is recommended that individuals age fifty and over be included in eligibility for OAA programs. Title V of the act currently allows employment services to be made available to individuals who are fifty-five years of age and older. This recommendation is consistent with the purpose of developing the Administration for Community Living to assist those with disabilities younger than age sixty.

Recommendation #7. Relax Medicaid and public assistance income requirement to help older PWH return to the workforce without the loss of health and social benefits.

Before the advent of ART, an HIV diagnosis resulted in increasing levels of disability and eventual death. With effective treatments and near-normal life expectancies, many older adults with HIV are capable of returning to the workforce, but fear doing so would result in a loss of eligibility for Medicaid, Social Security Disability Insurance, and other forms of public assistance (Maestas, Mullen, & Strand, 2013). Workforce participation among older adults with HIV is low, with one study finding less than 10% being employed, 21% unemployed, and 56% on disability income (Karpiak & Brennan, 2009). Many older PWH would like to contribute to society in a meaningful way, yet lack the opportunity to do so (Emlet & Harris, 2019; Johnson Shen et al., 2019). Older PWH would like to return to the workforce, which would be psychologically beneficial and help restore a sense of purpose and meaning to their lives (Brennan, 2008; Porter et al., 2015). This situation was described to one of the authors as wearing *golden handcuffs*, namely, they wanted to rejoin the workforce, but were unable to do so for fear of losing critical sources of public assistance. To provide older PWH with a better quality of life and allow them to contribute to society, we should redefine income requirements for this population and those with other types of disabilities to encourage workforce participation without the loss of benefits that sustain health and wellbeing.

Recommendation #8. UNAIDS and the World Health Organization (WHO) should pay increased attention to addressing the global aging HIV epidemic.

Evidence suggests that while the population of older PWH is growing globally (Emlet, O'Brien, & Fredriksen-Goldsen, 2019; Sprague & Brown, 2017), a

unified examination of older adults and the impact of HIV on them is sporadic. Historically, and in the most recent report from UNAIDS (2019), adults living with HIV are defined as those fifteen to forty-nine years of age. While some reports from UNAIDS focus specifically on the older adult population (UNAIDS, 2013), overall reporting mechanisms of prevalence, incidence, and treatment targets do little to shed light on those age fifty and over. As an example, the UNAIDS most recent report from 2019 examines stigma and discrimination by country (when available), but gathers information from women and men aged fifteen to forty-nine who report discriminatory attitudes towards PWH (UNAIDS, 2019). Similarly, WHO places little focus or emphasis on older adults with HIV in their web-based material and does not list older adults as a key or vulnerable population.[1] This is not to say that WHO has not made important contributions through their SAGE Well-being of Older People Study (WOPS), which examined older people infected with or affected by HIV in Uganda and South Africa. While there have been many valuable scientific contributions from WOPS, other older PWH populations across the globe remain understudied. Thus, without consistent acknowledgement or hard data from global organizations, such as UNAIDS or WHO, our understanding of the impact of HIV on older people, and how county, culture, and social belief impact identification, care, and treatment will continue to be hampered.

Conclusion

The purpose of this paper was to shed light on the complex physical and psychosocial issues that impact older PWH and to craft policy recommendations to improve the lives of this population. These issues are complex and could not be fully addressed and explored within the length of this manuscript. For example, while an extensive examination of vulnerable and at-risk populations of older adults in warranted, it could not be fully explicated here.

Older PWH are a rapidly growing population comprised of several subpopulations, each with their own needs. Short of a cure, this population will continue to grow over the next several decades, regardless of the effectiveness of HIV prevention strategies. These individuals face multiple and complicated intersectional stigma and discrimination around age, HIV status, gender, race/ethnicity, sexual orientation, and gender identity. They also share in complex issues of comorbidity and unanswered questions concerning the interaction of HIV and aging in terms of both natural aging processes and age-associated diseases and treatments. The title of this paper came from comments made by multiple older adults living with HIV infection. Their experience is often one of "not fitting in anywhere." Programs developed and delivered under the OAA may not be sensitive to the needs of this population, and OAA service providers may not be knowledgeable and prepared to serve

1 https://www.who.int/news-room/fact-sheets/detail/hiv-aids.

these individuals. HIV related services often have gaps, whereby older adults do not fit well into social support and support group structures. Thus, older adults often voice frustration about not having a suitable place to obtain help and assistance.

Despite these complications, older PWH are positive, resilient, and interested in healthy and successful aging. If that goal is to be accomplished, however, policy changes at local, national, and global levels will need to take place. These changes range from the acknowledgement of older PWH worldwide down to the eligibility criteria for local OAA program need, with the participation of HIV consumers and advocates in this process. In service of this goal, we have presented eight policy recommendations that attempt to move toward more friendly and inclusive systems of education, care, treatment, and service delivery for this growing, vulnerable, and resilient population.

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42 U.S.C. §3002(23)-(24)

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