

Emerging Issues in HIV and Aging

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Introduction

The human immunodeficiency virus (HIV), which causes Acquired Immune Deficiency Syndrome (AIDS), was first identified in 1983 and is believed to have originated earlier in the 20th century (Melhuish & Lewthwaite, 2018). In the early days of the HIV epidemic, treatment was limited and most people infected with the virus developed AIDS and died (Melhuish & Lewthwaite, 2018). With the development of effective anti-retroviral therapies (ART) in the mid-1990s, HIV became a treatable although serious condition, and people who are adherent to ART can attain normal or near-normal life expectancies (Melhuish & Lewthwaite, 2018; Samji et al., 2013). Older people with HIV (PWH), defined as those age 50 and older, are increasingly dominating the epidemic (High et al., 2012). Because of the success of ART, people 50 and older now likely make up the majority of PWH in the U.S. (High et al., 2012) and other countries where ART is accessible. The aging of the HIV epidemic is a global trend that is also being observed in low- and middle-income countries (Mahy, Autenrieth, Stanecki, & Wynd, 2014). The most current global estimate, from 2016, is that there were 5.7 million PWH age 50 and older [range = 4.7 to 6.6 million] representing 16% of PWH (Autenrieth et al., 2018). This proportion is expected to rise to 21% by 2020 (Autenrieth et al., 2018). The growth in the population of older PWH is also fueled by new HIV infections. In 2018, 17% of new HIV infections in the U.S. were diagnosed in people 50 and older (CDC, 2019).

Given the current and projected growth of the population of older PWH in the U.S. and globally, it is imperative that we develop an effective policy response to address their unique needs. However, due to ageism and other factors, older PWH have been largely invisible. This invisibility has resulted in a lack of investment and resources in education and prevention programs addressing HIV and aging, and our current medical and social service systems are largely unprepared to deal with growing numbers of older people with HIV (DeMarco, Brennan-Ing, Sprague, & Brown, 2017). The purpose of this report is to highlight current knowledge and emerging issues in HIV and aging to serve as a foundation on which to develop policy and program recommendations that will address the needs of older PWH.

Socio-Demographic Profile of an Aging Epidemic

Older PWH are not a monolithic group but represent a diverse population with regard to age, gender identity, race and ethnicity, sexual orientation, and socio-economic position (Brennan-Ing, 2019). According to the most recent data from the Centers for Disease Control and Prevention (CDC), in the U.S. the largest proportion of older PWH were age 50 to 54 years (33%), followed by those 55 to 59 years (29%), 60 to 64 years (19%), and 65 and older (18%) (CDC, 2019). Over three-quarters of older PWH are male (77%) and 23% are female (CDC, 2018). Older people of color are disproportionately affected by HIV. Non-Hispanic Blacks are the largest racial/ethnic group of older PWH (39%), followed by non-Hispanic Whites (37%), Hispanics/Latinx (18%), people of multiple race/ethnicities (4%), Asians (1%), and less than 1% each who are American Indians/Alaska Natives or Native Hawaiians/other Pacific Islanders (CDC, 2018). Among older male PWH, 64% were infected through male-to-male sexual contact, 12% through heterosexual contact, 16% through injection drug use (IDU), and 8% from male-to-male sexual contact and IDU (CDC, 2018). Among older female PWH 70% of infections were through heterosexual contact and 29% through IDU (CDC, 2018). Historically, CDC included transgender women

in the classification “men who have sex with men” (MSM), making it difficult to estimate the numbers of older transgender and gender diverse (TGD) older PWH (Porter & Brennan-Ing, 2019). More recently the CDC has included “transgender” as a response option in HIV surveillance data and found higher HIV infection rates among TGD people (range = 1.7%–4.7%) when compared to both cisgender men (range = 0.9%–1.4%) and cisgender women (range = 0.2%–0.4%) (Porter & Brennan-Ing, 2019). These findings confirm other research that people who are TGD are disproportionately affected by HIV (Dragon, Guerino, Ewald, & Laffan, 2017), and we can infer this is true of older adults as well. This disparity is due in part to a high proportion of sex workers in this population because employment opportunities are limited by transphobia and discrimination (Operario, Soma, & Underhill, 2008).

An important subpopulation among older PWH are HIV long-term survivors (LTS). There are a variety of definitions of HIV LTS. According to the Well Project (The Well Project, 2018), one definition is people who have been living with HIV since before effective ART became available (pre-ART LTS). This group was infected with HIV when the virus was incurable and resulted in early death, and they experienced significant trauma, with lasting effects on physical and mental health and overall well-being. Another definition is people who were diagnosed after effective ART was available (i.e., 1996) and have been living with HIV for ten years or more (post-ART LTS). The post-ART LTS group has had very different experiences with HIV due to the availability of effective treatment. For example, one study found that given the lack of treatment options, pre-ART LTS were more engaged in activism, education, and support groups to deal with HIV infection compared to their peers, and suffered greater personal loss (Rai, Bruton, Day, & Ward, 2018). In contrast, post-ART LTS had relatively little collective engagement with others affected by the virus and tended to keep their HIV infection a private matter, in some cases to avoid stigma and discrimination. A third group of LTS are those who were infected through childbirth and have been HIV-positive their entire lives, and are relatively young adults (The Well Project, 2018). The last group are HIV-negative LTS who have been profoundly affected by the impact of HIV in their lives, through caregiving, loss of significant others, or other involvement in combatting the epidemic (The Well Project, 2018).

Data from Ryan White HIV/AIDS program participants illustrates the fragile economic status of many older PWH. Older women and TGD with HIV are more likely to be living in poverty (71% and 74%, respectively) than older men with HIV (57%) (Cohen et al., 2019). Further, non-Hispanic Blacks and Hispanics/Latinx were more likely to be living in poverty compared to non-Hispanic Whites regardless of gender identity (Cohen et al., 2019). In comparison, overall poverty rates for U.S. adults in this age group are approximately 9% or less (U.S. Census Bureau, 2020). These high levels of poverty are directly related to low levels of employment, with research finding that over half of older PWH are on disability (Erenrich, Seidel, Brennan-Ing, & Karpiak, 2018; Karpiak & Brennan, 2009), as compared to between 7% to 17% of people in this age group in the general population (Center on Budget & Policy Priorities, 2019). In line with the proportion in poverty, three-quarters of older PWH report inadequate incomes (Erenrich et al., 2018; Karpiak & Brennan, 2009). Older PWH in the Ryan White program also reported high rates of housing instability. Older cisgender men and women with HIV were less likely to report unstable housing (10% and 9%, respectively), compared to TGD PWH (15%). Rates of unstable housing were highest among non-Hispanic Blacks, men, and TGD people (Cohen et al., 2019). In a study of older PWH in San Francisco, 7% reported not having a permanent residence, and 42% were spending half or more

of their income on housing costs (Erenrich et al., 2018). Nearly two-thirds of older PWH in this study were receiving some form of financial assistance. And only slightly more than half of older PWH in the San Francisco study reported food security (56%), while one-quarter reported food insecurity and being hungry (Erenrich et al., 2018). In the U.S., approximately 12% of the overall population and 9% of those 65 and older are food insecure (U.S. Department of Agriculture, 2018).

In the U.S., the largest number of older PWH are concentrated in regions that have had historically high rates of HIV infection. These include the Northeast, South, Southwest, and West Coast, and major metropolitan areas in the Midwest and Western states (AIDS Vu, 2020). At the end of 2015, New York State had the greatest number of older PWH (67,920), followed by California (59,994), Florida (51,894), and Texas (30,508) (CDC, 2018). In terms of rural/urban variation, in metropolitan statistical areas (e.g., New York City) the prevalence rate of older people with HIV is twice the rate of metropolitan areas (e.g., Riverside Co., CA), and four times the rate of non-metropolitan areas or rural areas (CDC, 2018). Globally, the greatest number of older PWH are in sub-Saharan Africa (3.7 million), followed by North America and Western/Central Europe (880,000), Asia and the Pacific (450,000), Latin America and the Caribbean (370,000), Eastern Europe/Central Asia (280,000), and the Middle East/North Africa (27,000) (Autenrieth et al., 2018). HIV largely impacts heterosexuals in sub-Saharan Africa (Piot, Bartos, Ghys, Walker, & Schwartländer, 2001). IDU and infection of heterosexual sex partners of drug users is responsible for most HIV infections in Eastern Europe and China (Piot et al., 2001). In the Eastern Mediterranean, HIV infections are mostly among sex workers, gay and bisexual men, and IDU (Sprague & Brown, 2017). IDU HIV transmission is highest in Pakistan, Iran, Libya, Afghanistan, and Egypt, while same-sex transmission is increasing in North Africa. In Morocco, Djibouti, and Somalia female sex workers are increasingly at risk for HIV (Sprague & Brown, 2017).

Physical and Mental Health

Physical Health. While ART is effective at controlling HIV infection, it does not spare older PWH from experiencing other health conditions, sometimes called comorbidities. These comorbidities may be diseases commonly experienced by people as they age, or they may be related to HIV infection and its treatments. As we grow older, the strength of our immune system tends to weaken, a process known as immunosenescence (Nasi et al., 2014). This weakening is due to immune system activation as well as chronic inflammation; a process that is exacerbated in PWH (Fülöp et al., 2017; Nasi et al., 2014). It has been posited that ART turns HIV into a chronic inflammatory disease (Fülöp et al., 2017). In non-HIV-infected persons, chronic inflammation is responsible for a variety of age-related diseases, including cardiac disease, cancer, and dementia (Bolós, Perea, & Avila, 2017; Fava & Montagnana, 2018; Mantovani, 2018). Thus, the combination of HIV infection and normal changes to the immune system due to aging may place older PWH at greater risk of developing comorbidities. The impact of HIV on immune health and inflammation is related to research finding that older PWH report three comorbid conditions on average in addition to HIV (Balderson et al., 2013; Havlik, Brennan, & Karpiak, 2011). Among older sexual and gender minority adults in Chicago, those with HIV reported 3.1 comorbid conditions in addition to HIV as compared with 2.4 conditions overall among their HIV-negative peers (Brennan et al., 2011). Schouten and colleagues (2014) found that the average number of comorbidities was greater among PWH compared to non-infected peers (1.3 vs. 1.0 across all age groups), and was

greater among older PWH compared with their younger counterparts. Among older PWH, common comorbidities include certain cancers (lung, anal, oral, Hodgkin's lymphoma), cardiovascular diseases, fractures, and hepatitis C (Havlik et al., 2011). In addition, over 50% of older PWH show signs of HIV-associated neurocognitive problems, ranging from asymptomatic to HIV-associated dementia. Neurocognitive problems are related to other comorbidities as well as behavioral risk factors (e.g. substance use) (Vance, Cody, & Moneyham, 2017). The occurrence of multiple comorbid health conditions is known as multimorbidity. Being treated for multiple comorbid conditions can result in polypharmacy, or the use of multiple medications by one individual (Siegler & Brennan-Ing, 2017). Polypharmacy can result in a number of adverse outcomes including liver and kidney failure (Abe et al., 2017), as well as greater risk of falls and fractures (Dhalwani et al., 2017; Kim et al., 2018).

One explanation for the presence of multimorbidity in older PWH is "accelerated aging." The accelerated aging theory proposes that PWH experience disease conditions at earlier ages than their non-HIV-infected peers (Karpiak & Havlik, 2017). An alternative explanation is that PWH experience "accentuated aging": rather than experiencing the onset of diseases at earlier ages, PWH experience a greater number of conditions at the same time compared to those without HIV. While there is some evidence that accelerated aging exists among PWH, this phenomenon has only been observed in a limited number of diseases and organ systems (Karpiak & Havlik, 2017). Available evidence suggests that accentuated aging is the better explanation for the high levels of multimorbidity observed among older PWH (Karpiak & Havlik, 2017).

Behavioral Health. Older PWH face a number of behavioral health challenges in addition to physical illnesses, including depression, anxiety, and substance use disorders. Research finds that older PWH have rates of depression up to five times greater than non-HIV-infected peers (Applebaum & Brennan, 2009a). Numerous studies have found that more than 50% of older PWH may experience clinically significant levels of depressive symptoms (Applebaum & Brennan, 2009a; Erenrich et al., 2018; Justice et al., 2004). While we lack a good understanding of the origin of depression in older PWH, contextual factors such as poor physical health, stigma, and loneliness are related to greater levels of depression in this population (Brennan-Ing, Seidel, & Karpiak, 2017; Grov, Golub, Parsons, Brennan, & Karpiak, 2010; Havlik et al., 2011; Khambaty et al., 2016). Social determinants of health, such as race/ethnicity and age, may also be related to the likelihood of depression in older PWH (DelaCruz, Karpiak, & Brennan-Ing, 2015; Rabkin, 2008).

Anxiety has been found to be a serious and prevalent mental health issue among older adults living with HIV. Levels of anxiety among older PWH have been reported as high as 65% (Erenrich et al., 2018) and may affect twice as many in this population as compared with HIV-negative peers (Emlet, Fredriksen-Goldsen, Kim, & Jung, 2019). Older PWH also report significant levels of current and past use of alcohol and other substances (Applebaum & Brennan, 2009b; Frontini et al., 2012; Justice et al., 2004) and tend to use these substances at greater levels than HIV-negative peers (Justice et al., 2004). In addition to alcohol, commonly used substances include marijuana, cocaine, and methamphetamines (Erenrich et al., 2018; Frontini et al., 2012). Some studies indicate that high proportions of older PWH are currently

using substances and about the same proportion are in recovery, such as twelve-step programs (Applebaum & Brennan, 2009b; Parsons, Starks, Millar, Boonrai, & Marcotte, 2014).

Relation of Physical to Behavioral Health. Behavioral health issues not only impact quality-of-life among older PWH, but have implications for physical health as well. Depression remains one of the best predictors of non-adherence to medications (Goldstein et al., 2017; Sankar et al., 2018). Among PWH, depression and substance use have been found to interfere with ART adherence as well (Parsons et al., 2014; Safren et al., 2004; Sinha et al., 2017). The use of alcohol and other substances is related to decreased ART efficacy, which can lead to poorer clinical outcomes (Michel et al., 2010). Lastly, depression among older PWH is related to higher levels of contemplating suicide, and up to 25% of this population have recently thought of taking their own lives (Vance, Moneyham, Fordham, & Struzick, 2008).

HIV Stigma

Stigma remains a powerful and toxic factor in the lives of PWH, including older adults. Much of the work on HIV stigma is based on the work of Erving Goffman, who described stigma as a discredited or spoiled identity (Goffman, 2009). In the case of HIV, stigma originates from fears of becoming infected through contact with a PWH, as well as moral judgements about behaviors that may have led to HIV infection, such as sexual activity and substance use (Brennan & Karpiak, 2009a). Further, others may believe that HIV infection is a punishment for sin or moral failure (Jue & Lewis, 2001; Lichtenstein, Laska, & Clair, 2002; Reece, Tanner, Karpiak, & Coffey, 2007), and that PWH deserve their illness (Herek, Capitanio, & Widaman, 2002). As a result, HIV stigma contributes to the spread of HIV infection as it inhibits disclosure of HIV status to sexual partners, discourages people from HIV testing due to the consequences of a positive test result, and may inhibit prevention strategies like pre-exposure prophylaxis (PrEP) (Brennan & Karpiak, 2009a; Eaton et al., 2017; Kingori et al., 2012; Valdiserri, 2002). HIV stigma has global implications that interfere with public health initiatives such as HIV testing, engagement in care, and reducing new infections (UNAIDS, 2017).

HIV stigma for older PWH is described as *enacted* or *felt* (Emlet, 2006a). Enacted stigma is manifested as prejudice, maltreatment, and discriminatory behaviors that are directed at PWH by people or society as a form of punishment. Enacted stigma may be experienced by a PWH as rejection by family members, friends, clergy, service providers, and others in the community (Geter, Herron, & Sutton, 2018; Emlet, 2006b, 2008; Herek et al., 2002; Poindexter & Shippy, 2010). Felt stigma represents the fear, shame, and guilt that are internalized by PWH through experiencing enacted stigma. An additional expression of HIV stigma has been described as *vicarious* stigma, namely, that PWH may perceive high levels of discrimination based on how other PWH are treated (Steward et al., 2008). When PWH anticipate experiencing HIV stigma, they may try to blunt the experience of enacted stigma by withdrawing from social situations as a form of self-protection, isolating themselves socially, or fearing to disclose their HIV status in community spaces like religious congregations (Brennan, Strauss, & Karpiak, 2010; Emlet, 2006a; Poindexter & Shippy, 2010). Research is limited on how HIV stigma might differ by age, but one study found PWH 55 and older reported lower overall and internalized (felt) HIV stigma compared to

younger PWH, but age differences in terms of enacted stigma were not significant (Emlet et al., 2015). In the U.S. and abroad, older PWH have reported not disclosing their serostatus for fear of negative consequences such as losing a job, rejection, spousal abandonment, blaming, accusations, angry reactions, physical violence, and even death (Brennan & Karpiak, 2009a; Maeri et al., 2016).

Intersectional Stigma. The experience of HIV stigma for PWH may be complicated by other stigmatized, discredited, or marginalized components of their identities, including race/ethnicity, sexual orientation, gender identity and expression, and behavior (e.g., substance use, sex work), resulting in intersectional or layered stigma (Emlet, 2017; Turan et al., 2016). For older PWH, this intersectionality also involves ageism, or discrimination and bias directed at older people (Jönson, 2013; Levy & Macdonald, 2016). In an article entitled, “You’re Awfully Old to Have This Disease,” Emlet found that nearly two-thirds of his sample had experienced both HIV stigma and ageism (Emlet, 2006a). In Emlet’s study, older PWH faced ageism in employment and dealing with financial institutions, and had internalized ageist beliefs about anticipated cognitive decline and health issues. Other research with older gay and bisexual men with HIV documented a convergence of HIV stigma, ageism, and homonegativity (Slater et al., 2015). One study of older sexual minority men, including PWH, found that internalized ageism promoted a form of *psychological* “accelerated aging” that was related to higher levels of depressive symptoms due to pervasive ageism in the gay community (Wight, LeBlanc, Meyer, & Harig, 2015). In fact, internalized ageism represents an additional health risk for older PWH who are already challenged by HIV disease and high levels of multimorbidity. Research finds that attitudes toward aging are related to health in older adults, with those having more positive perceptions of aging experiencing better functional health over the life course and increased longevity (Levy, 2009; Levy, Slade, Kunkel, & Kasl, 2002).

Porter and Brennan-Ing developed a conceptual framework of intersectional stigma for older PWH who are transgender or gender diverse (TGD) in their *Five Corners Model* (Porter & Brennan-Ing, 2019). The Five Corners Model represents the intersection of age, race/ethnicity, sexual orientation, gender identity, social class, and HIV stigma and describes how health disparities are associated with marginalized identities in older PWH who are TGD. The experience of intersectional stigma among older PWH may vary in different subpopulations (Johnson Shen et al., 2019). Older gay and bisexual male PWH may feel the greatest impact regarding HIV stigma and ageism. Older heterosexual male PWH report concerns with HIV stigma and behavioral stigma (perceptions that they have had sex with other men or are injection drug users). Older Spanish-speaking PWH express concerns about racial/ethnic discrimination and HIV stigma (Johnson Shen et al., 2019). Other research on older PWH found that having multiple marginalized identities was associated with greater levels of HIV stigma and psychological distress (Storholm et al., 2019). The intersection of HIV stigma and other marginalized identities may promote health disparities among older PWH, since this intersectionality can affect one’s ability to access health care resources and opportunities for wellness, such as engagement in care due to anticipated or experienced discrimination from service providers (Turan et al., 2017).

Psychological Well-being

Psychological wellness, or well-being, is not merely the absence of psychological distress (e.g., depression, anxiety), but refers to positive emotional experiences and satisfaction with life (Brennan & Karpiak, 2009b). Life satisfaction ratings are a combination of positive self-appraisals, and include feelings of self-worth or self-esteem, optimism, and a sense of being in control of one's life. When asked to rate life satisfaction on a scale of zero to ten with higher scores indicating greater satisfaction, the average score was 7.3 in a diverse sample of older PWH (Brennan & Karpiak, 2009b), indicating relatively high self-appraisals. While life satisfaction ratings in this study did not differ by gender identity or sexual orientation, older PWH who were non-Hispanic Black or Hispanic had significantly higher mean life satisfaction ratings (7.5 and 7.3, respectively) compared with non-Hispanic Whites (6.4).

Ryff and colleagues conducted extensive research on the nature of psychological well-being among older adults and proposed the following six dimensions: *Autonomy*, *Environmental Mastery*, *Personal Growth*, *Positive Relations with Others*, *Purpose in Life*, and *Self-Acceptance* (Ryff, 1989a, 1989b; Ryff & Keyes, 1995). These aspects of well-being reflect commonly described aspects of successful aging (Rowe & Kahn, 1997). Using Ryff's measures of psychological well-being in a diverse sample of older PWH, average scores on all six dimensions were significantly lower compared with a national probability sample of adults aged 25 and older. Like life satisfaction ratings, older non-Hispanic Black PWH had significantly higher average well-being scores on five of the six dimensions; non-Hispanic White PWH had the highest average score for Autonomy (Brennan & Karpiak, 2009b). While there were no significant differences regarding gender, older PWH who were sexual minorities had higher average scores on five of the six well-being dimensions (heterosexuals had higher average scores on Environmental Mastery). Overall, these findings suggest that among older PWH, people from historically marginalized groups in terms of race/ethnicity and sexual orientation tend to have higher levels of psychological well-being (Brennan & Karpiak, 2009b). This pattern in older PWH is consistent with Kimmel's *Crisis Competence* model, namely, people who have been able to cope with adversity over the life course are better able to adapt to the challenges of aging and demonstrate well-being in later life (Kimmel, 1978).

Other factors related to psychological well-being among older PWH include HIV stigma and social support. HIV stigma is significantly associated with lower levels of well-being as assessed by Ryff's model (Porter, Brennan-Ing, Burr, Dugan, & Karpiak, 2017a, 2017b), as well as self-assessments of quality-of-life (Slater et al., 2015). Older PWH who are socially isolated report lower psychological well-being with regard to Personal Growth and Self-Acceptance in comparison with peers who are more socially integrated (Brennan-Ing et al., 2017), while those with higher perceived levels of social support report greater positive emotional well-being (Mavandadi, Zanjani, Ten Have, & Oslin, 2009). Psychological well-being among older PWH may also have important implications for public health. In one study of older PWH, higher levels of well-being were related to more consistent adherence to safer sex practices that help prevent the spread of HIV (Golub et al., 2011).

Social Supports and Social Isolation

Social supports are critical resources for people who are growing older, regardless of HIV status (Brennan-Ing et al., 2017; Cantor & Brennan, 2000). Social networks are valuable sources of assistance for older adults as they face the challenges of aging, such as caregivers in times of illness and frailty (Cantor & Brennan, 2000; Cantor, Brennan, & Karpiak, 2009). Early studies of social networks of older PWH characterized their social networks as “fragile,” with a heavy reliance on friends as opposed to family members, and high levels of social isolation (Schrimshaw & Siegel, 2003; Shippy & Karpiak, 2005a, 2005b). Many members of these social networks were also HIV-positive, which decreased the experience of enacted HIV stigma from social network members while at the same time limiting their ability to provide care and support (Poindexter & Shippy, 2008; Shippy & Karpiak, 2005a). Because the availability of social support was limited due to stigma and rejection, many were left with few options other than to turn to formal community-based service providers, which were perceived as largely unprepared to meet their needs (Poindexter & Shippy, 2008; Shippy & Karpiak, 2005b).

In general, social network configurations and the support available are largely shaped by context, including cultural, geographical, and interpersonal factors such as age (Brennan-Ing et al., 2016; Cantor & Brennan, 2000; Carstensen, 1992). To illustrate using living arrangements as a proxy for support availability, a study of older PWH in New York City found that 70% live alone as compared with 35% of New Yorkers age 65 and older. However, the proportion living alone varied significantly by gender identity (cisgender men-75%, cisgender women-58%, transgender-50%) (Karpiak & Brennan, 2009). In upstate New York, the proportion of older PWH living alone was lower (61%) (Nguyen, Nash, Brennan-Ing, & Karpiak, 2020). In San Francisco, 67% of older PWH lived alone as compared with 61% in Oakland (Erenrich et al., 2018; Nguyen, Nash, Brennan-Ing, & Karpiak, 2019). However, in sub-Saharan Africa proportions of older PWH living alone were substantially lower (South Africa-22%, Uganda-9%) (Brennan-Ing et al., 2016).

A critical factor affecting social networks and support resources for older PWH is HIV stigma, whether through outright rejection of the PWH by family, friends, and members of the community or through the process of self-isolation through self-protective withdrawal (Emlet, 2006b, 2008; Herek et al., 2002; Poindexter & Shippy, 2010). The impact of stigma on social network dynamics is evident when we examine the social networks of older PWH through the lens of *functionality*. Functionality goes beyond the idea of a person merely being part of one’s social network, but whether there is sufficient contact and interaction that this person could be reasonably assumed to provide support in times of need. Previous research on older adults defined a functional social network member as a person in face-to-face contact at least monthly or in telephone contact at least weekly (Cantor, 1979; Cantor & Brennan, 1993). Among older PWH, research finds a noticeable decline in the proportion with functional family members: 42% having a parent and 27% a functional parent; 54% having a child and 38% a functional child; 79% having a sibling and 44% a functional sibling, and 50% having other relatives and 31% having a functional other relative (Cantor et al., 2009). Only in the case of friends was there parity between having a friend in the network (69%) and having a functional friend (66%), which is logical given that friend relationships are voluntary and rely on engagement by both parties.

While early reports on the social networks of older PWH characterized them as friend-centered and fragile, later research found that there were three types of social networks in this population that are

roughly equally prevalent (Brennan-Ing, Seidel, & Karpiak, 2017). The first group was characterized by integrated social networks with a variety of interactive relationships involving children, other family members, and friends along with involvement in religious congregations. The second group had more friend-centered networks, having frequent interaction with friends but little contact with family members or religious congregations. This group was dominated by gay and bisexual men, who are likely to have friend-centered networks (sometimes called families of choice) regardless of HIV status (Brennan-Ing, Larson, Seidel, & Karpiak, 2017; Dewaele, Cox, Van den Berghe, & Vincke, 2011). Those in the third group were isolated, having intermittent contact with family members but without friends. And while many studies of older PWH find relatively high levels of unmet needs for assistance with activities of daily living and emotional support (Brennan-Ing, Larson, et al., 2017; Brennan-Ing et al., 2016; Cantor et al., 2009), those who were socially isolated reported the lowest levels of perceived social support, in line with the low level of assistance they received from family and friends compared to those with integrated and friend-centered networks (Brennan-Ing, Seidel, et al., 2017). Further, while older PWH with friend-centered networks were more advantaged in terms of support received from the social network compared with those who were isolated, the assistance they received from friends was not able to compensate for the lack of support from family members in comparison to those with integrated networks (Brennan-Ing, Seidel, et al., 2017). However, there is evidence that an HIV diagnosis may activate family social support resources among older gay and bisexual men as family members engage with these older PWH when they perceive a need to provide support (Brennan-Ing, Larson, et al., 2017).

Because of the relation between social supports and physical and mental health, the issue of social isolation is critical to older PWH. Among people in general, social isolation has strong associations with poor health, and may be as detrimental to health as smoking, obesity, and high blood pressure (Cornwell & Waite, 2009; Holt-Lunstad, Smith, Baker, Harris, & Stephenson, 2015; Holt-Lunstad, Smith, & Layton, 2010). Among middle-age and older military veterans with HIV, research finds that social isolation is related to greater likelihood of hospitalization and risk for mortality (Greysen et al., 2013). Inadequate social supports are associated with non-adherence to ART, which interferes with viral suppression and may lead to poor clinical outcomes such as multimorbidity (Edwards, 2006). Social isolation also impacts mental health and psychological well-being in older PWH, and is associated with greater levels of perceived HIV stigma, depressive symptoms, and loneliness (Brennan-Ing, Seidel, et al., 2017).

Loneliness

Loneliness and social isolation are related, but are different indicators of social connectedness. Social isolation refers to the objective characteristics of the presence of and interaction with other people in one's social network, while loneliness is a psychological state related to the discrepancy between a person's desires and expectations for social interactions (including intimacy) and their perceptions of such interactions (Gale, Westbury, & Cooper, 2018; Gardiner, Geldenhuys, & Gott, 2018; Gierveld, Van Tilburg, & Dykstra, 2018). Loneliness has effects similar to those of social isolation in terms of physical health and well-being in older adults (Gale et al., 2018; Ong, Uchino, & Wethington, 2016). Loneliness may impact health through health behaviors as well as direct effects on physiological processes (Ong et al., 2016). Among older PWH, loneliness is associated with functional impairment, lower health-related

quality of life, and severe levels of depressive symptoms (Greene et al., 2018; Grov, Golub, Parsons, Brennan, & Karpiak, 2010). Older PWH report high levels of loneliness (nearly two-thirds report being lonely) (Erenrich et al., 2018; Greene et al., 2018), and experience greater loneliness on average compared with older adults in general (Brennan & Applebaum, 2009). In addition to impacting the health of older PWH, the high levels of loneliness in this population represent an additional challenge to secondary HIV prevention since loneliness is linked to greater sexual risk and drug-use behaviors that may result in HIV transmission (Greene et al., 2018; Leigh-Hunt et al., 2017; Mergenova et al., 2017; Valdes, Gattamorta, Jones, Fenkl, & De Santis, 2019).

Resilience

Given the myriad challenges faced by older PWH due to HIV infection and aging, there is growing attention to how resilience in this population may help them in facing these issues more successfully. Resilience among older PWH in terms of being proactive about one's health has been identified as a critical resource enabling long-term survival and coping with HIV and aging (Halkitis, Krause, & Vieira, 2017). However, there is no consistent definition of resilience in the HIV or larger scientific literature, and resilience may be understood as both a personality trait and a process of coping with life's adversities (Emlet, Shiu, Kim, & Fredriksen-Goldsen, 2017; Halkitis et al., 2017). In terms of a trait, resilience has features of hardiness, grit, determination, and strength of character; inherent qualities that help a person cope with challenging situations. But resilience can also be viewed as a process involving coping mechanisms and the impact of these ways of coping in adapting to life's challenges (Halkitis et al., 2017). Halkitis and colleagues have unified these two aspects of resilience in considering it a trait that enables older PWH to engage in these adaptive processes resulting in more favorable outcomes (Halkitis et al., 2017). These resilience processes are hypothesized as being multifaceted, and may involve factors such as self-acceptance, optimism, purpose in life, spiritual transcendence, positive connections with others, active coping, autonomy, and generativity (Dulin et al., 2018; Emlet, Harris, Pierpaoli, & Furlotte, 2018; Emlet et al., 2017; Furlotte & Schwartz, 2017; Halkitis et al., 2017; McGowan et al., 2018; Porter et al., 2017).

Among older gay and bisexual men with HIV, resilience was associated with higher levels of education, not having a history of depression, greater perceived mastery (sense of control), and greater social support and community engagement (Emlet et al., 2017). Among older women with HIV, resilience was related to self-perceived successful aging (Rubtsova et al., 2019). There are numerous studies that report resilience is related to more positive outcomes among older PWH, including ART adherence, CD-4 count, and viral suppression, although these positive associations were not universal in all studies (Dulin et al., 2018). Resilience in PWH has also been related to lower depression and anxiety and better functional ability (activities of daily living) (McGowan et al., 2018). Resilience, in the form of spirituality and active coping through complementary and integrative health practices (CIH), was found to significantly mediate the negative impact of HIV stigma on psychological well-being among older PWH (Porter et al., 2017). Interestingly, the effects of spirituality in buffering psychological well-being from stigma were stronger in gay and bisexual men as compared with heterosexual men in this study (Porter et al., 2017). This finding was explained in terms of gay and bisexual men developing stronger coping

mechanisms to deal with homophobia in addition to HIV relative to their heterosexual male peers (Kimmel, 1978; Porter et al., 2017). Thus, research on resilience among older PWH has the potential to identify important targets for intervention that will support the ability of these individuals to maintain optimal health and psychological well-being as they grow older (Emlet et al., 2017; High et al., 2012).

Accessing Critical Medical and Social Services

Older PWH are likely to turn to government and community-based services due to high rates of multimorbidity and behavioral health issues and having limited social support resources to provide assistance during times of need (Cantor, 1979; Cantor & Brennan, 2000). Unfortunately, available information about service utilization and barriers to service among older PWH is fairly limited to date. One study examined service use patterns among older PWH who were clients at a large AIDS service organization (ASO) in New York City (NYC) (Brennan-Ing, Seidel, London, Cahill, & Karpiak, 2014). In this sample, heterosexual men and women were the most likely to be enrolled in Medicaid, while gay and bisexual men were more likely to have Medicare or private insurance coverage. The most frequently expressed service needs were opportunities for socialization (54%), personal or family counseling (42%), help with accessing entitlements (41%), someone to call or visit regularly (31%), an escort to a health care provider (31%), or help finding a job (28%). Approximately one-quarter of these older PWH needed help with instrumental and personal care tasks (meals brought to the home, housekeeping/personal care, care after hospital stays, and home repairs). Gay men were the most likely to need counseling (53%), while heterosexual women were the most likely to need meals brought to the home (38%) (Brennan-Ing et al., 2014). Recent data on older PWH in San Francisco found similar patterns of need, but greater proportions needing these services such as socialization opportunities (79%), counseling (73%), help with home repairs (67%), and help with entitlements (64%) (Erenrich et al., 2018).

Service questions in the NYC study pertained to use in the past year and were grouped into four domains: government agencies and offices, HIV/AIDS services, health and long-term care services, and other older adult services. The most frequently used government services were the NYC Human Resources Administration (66%) and the Social Security office (62%). Among HIV/AIDS services nearly all reported using one or more ASOs (88%), while 70% used the NYC HIV/AIDS Services Administration. The most frequently used health services were dental services (61%), outpatient hospital and behavioral health services (44% each), and the emergency room (40%). Meal and nutrition services were the most frequent type of other service (59%). On average, older PWH used 9.9 services. Using a list of 15 services that did not include HIV/AIDS agencies, for comparison purposes, older PWH used significantly more services on average (3.6) than older New Yorkers in general (1.0). Significant factors involved in overall service use included being a heterosexual male, using case management services (which serve as a bridge to other services), higher levels of depressive symptoms, and the number of self-reported service needs (Brennan-Ing et al., 2014).

The high levels of service use among older PWH belies the fact that many experience barriers to accessing services. Looking at NYC and San Francisco, two cities that are considered “resource rich” in terms of health and social service availability, significant proportions of older PWH face service barriers

in terms of access (not knowing where to go, an inability to afford services or access free services, a lack of locally available services, a long wait for services, a confusing or difficult service enrollment process, transportation difficulties), staff/organizational barriers (a perception that the staff dislikes “people like me,” unmotivated or unhelpful staff, difficulty in expressing needs to staff, staff that do not speak the client’s language), and personal barriers (trouble keeping appointments, fear that HIV status would be disclosed, caregiving interferes with getting services) (Brennan-Ing, 2012; Erenrich et al., 2018). In addition, older women with HIV are more likely to report barriers to services in all three domains (access, staff/organizational, personal) than their male peers (Brennan-Ing, 2012). In less service-rich environments, such as smaller cities and rural areas, barriers to service are similar in some respects (lack of transportation, long waits to obtain services), but other issues arise (Nguyen et al., 2020). For example, older PWH in these locations reported that the time or distance to get needed services was too long, locations to access services were limited, providers did not accept reimbursement through Medicaid or the AIDS Drug Assistance Program (ADAP), there was a shortage of behavioral health care providers, and providers lacked knowledge about hepatitis C treatment, a common comorbidity among PWH (Nguyen et al., 2020).

Policy Goals and Recommendations on Areas of Focus

Based on the data in this report, there are a number of areas where policy development to support older PWH is needed. This list is not exhaustive but suggests primary areas of focus.

- **A Healthcare System Prepared to Meet the Needs of an Aging Epidemic.** To date, we lack an agreed upon standard of care for older PWH, which is critical given the high level of physical and behavioral health comorbidities in this population. This standard of care can be informed by existing geriatric care models (Siegler & Brennan-Ing, 2017; Singh, Del Carmen, Freeman, Glesby, & Siegler, 2017). We need to critically examine how well current reimbursement mechanisms and clinical practice serve the older PWH who have complex needs, and who may require more time with a provider and/or different approaches to address the complex intersection of comorbid conditions. In addition, older PWH may require additional support in navigating a complex health care environment and accessing services given the high volume of health services needed, barriers to care, and personal factors that might make accessing needed services difficult (e.g., language, immigration status, cognitive difficulties). Recent rollbacks by the federal government in policies regarding equitable treatment of sexual and gender minorities in health care settings, who constitute a substantial proportion of older PWH, can only serve to exacerbate these barriers.
- **A Focus on Behavioral Healthcare.** Research consistently finds high levels of mental health problems (e.g., depression, anxiety, substance use) among older PWH, suggesting both a lack of attention to these issues in healthcare settings as well as a lack of capacity within the system to adequately provide needed services. Contextual factors that promote behavioral health care problems, such as HIV stigma, social isolation, and loneliness, need to be reduced through policy and program remedies.

- **Planning for Caregiving Needs and Other Forms of Assistance.** While some older PWH have robust social support networks that will be able to meet their needs for caregiving and other types of help as they face the challenges of aging, many, perhaps the majority, do not. Our current system of long-term care services and supports is expensive and does not have the capacity to meet current demands, much less the projected demands given population aging. When asked about plans for caregiving needs when they get older, many older PWH had not even considered being in this situation (Erenrich, Seidel, Karpiak, Brennan-Ing, & Luniewicz, 2017). Policies are needed to expand long-term services and supports to meet the needs of a growing aging population that includes older PWH.
- **Recalibrating Community-based Older Adult and Social Services.** Older PWH have many of the same service needs as other older adults, but with a median age of approximately 60, they are not eligible for age-restricted programs such as those funded through the Older Americans Act. Older PWH would benefit from being able to access mainstream services, and at the same time they express a need for community spaces to be with other people like themselves. These two options are not mutually exclusive, and policies are needed to make the services older PWH need available and accessible.
- **Ensuring that Health and Social Service Providers Deliver Competent Services.** Efforts to broaden health and social services for older PWH will fall short of their goals if providers are not knowledgeable and competent to work with this population, as well as the many subpopulations this group comprises, such as racial/ethnic minorities, sexual minorities, people who are gender diverse, sex workers, and people who use drugs.
- **Supporting Community Organizing and Advocacy.** A number of grassroots movements to organize HIV long-term survivors and older PWH have emerged in recent years (e.g., ACT-UP HIV & Aging Wellness Coalition, Let's Kick ASS [AIDS Survivor Syndrome], the Reunion Project). Policies that encourage and promote this type of community organizing are needed so that older PWH are equal partners in addressing the aging of the HIV epidemic.

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