



Diversity, stigma, and social integration among older adults with HIV

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Abstract

The population of people with HIV is aging globally as access to anti-retroviral therapy becomes more widely available. The diversity of older population with HIV has an impact on their experiences of stigma. HIV stigma may be enacted or felt. Enacted stigma is the prejudice, discrimination, and mistreatment that individuals and societies use to sanction people with HIV. Felt stigma refers to the internalized feelings of shame, guilt, and fear that arise from enacted stigma. Nondisclosure is rooted in the fear of negative consequences of revealing one's HIV status, such as losing a job, or being rejected by one's social network. Stigma may also affect social integration through self-protective withdrawal to avoid anticipated stigma. In addition to facing HIV stigma, people with HIV may possess multiple discredited identities due to their race, ethnicity, gender identity, etc., which is described as intersectionality. Older age represents an additional intersectional identity that affects people with HIV through the experience of ageism. Stigma and discrimination from HIV or any discredited identity are linked to poorer physical and mental health outcomes. Given the pervasiveness of stigma, it is not surprising that many older adults with HIV are socially isolated and report greater self-perceived stigma compared to those who are more socially integrated. While there is evidence that HIV stigma has declined compared to previous eras, more research is needed on HIV stigma among older adults in low- and middle-income countries to design policies and programs to combat HIV stigma globally.

Keywords Intersectionality · Ageism · Social isolation · Physical health · Mental health

Diversity of the older population with HIV

People with HIV (PWH) engaged in care and virally suppressed are achieving life expectancies similar to non-infected peers [1]. As a result, people 50 and older are now estimated to comprise the majority of PWH in the United States [2], as well as other places where access to anti-retroviral therapy (ART) has become widespread. This trend is being observed globally as access to ART improves in low- and middle-income countries [3]. The most current estimate using 2013 data is that among PWH worldwide, 4.2 million are age 50 and older [3] with the highest burden (2.5 million) in sub-Saharan Africa.

Due to differences in HIV transmission and risk factors, the population of older PWH is diverse in many ways. In the US, HIV was first identified among gay and bisexual men,

later spreading to intravenous drug users, then to heterosexuals, and became increasingly concentrated in communities of color over time [4, 5]. Rates of HIV infection in the US are disproportionately high among transgender and gender non-conforming individuals, which are related to the high proportion of sex workers in this population [6, 7].

In sub-Saharan Africa, the HIV epidemic largely impacts heterosexuals [5]. In Eastern Europe and China, intravenous drug use was the initial vector for HIV transmission, but infections have spread to the largely heterosexual sex partners of these drug users [5]. There is also diversity of populations affected by HIV within regions. For example, in the Eastern Mediterranean region, HIV predominantly affects sex workers, gay and bisexual men, and intravenous drug users [8]. But transmission by injection drug use is highest in Pakistan, Iran, Libya, Afghanistan, and Egypt; transmission through same-sex contact is rising in Egypt and Tunisia, while female sex workers in Morocco, Djibouti, and Somalia are increasingly at risk for HIV [8]. These population characteristics are important to keep in mind when we consider the impact of stigma on people with HIV.

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HIV stigma

Efforts to understand HIV stigma are rooted in the theoretical work of Erving Goffman which dates to 1963 [9]. Goffman defined stigma as a discredited or spoiled identity. In the Greek culture, stigma was an outwardly visible sign or mark indicating a moral failure that should be avoided that has evolved into evidence of an ignominy itself rather than an outward sign [10]. For example, historically blindness has been highly stigmatized because it has been associated in writings and scriptures with punishment for sin or moral failings levied by a supernatural power [11], such as the Oedipus story in Greek mythology.

Emler, who has done extensive research on HIV stigma among older adults, posits that HIV stigma is manifested in two ways: enacted or felt [12]. Enacted stigma is described as the prejudice, discrimination, and mistreatment that individuals and societies use to sanction people with HIV. Felt stigma refers to the internalized feelings of shame, guilt, and fear that arise from the experience of enacted stigma. In his research, Emler has documented extensive enacted stigma among older adults with HIV in the US, including rejection by family, friends, clergy, and service providers [12, 13]. A study of Indian adults with HIV by Steward and colleagues revealed a third manifestation of stigma—vicarious stigma [14]. In this research, people with HIV in India perceived high levels of discrimination based on stories they had heard about other people with HIV, leading them to not disclose their serostatus.

Vicarious stigma is related to the phenomenon of anticipated stigma, namely behaviors aimed at mitigating the experience of enacted stigma, such as self-protective withdrawal, social isolation, and fear of disclosing one's serostatus [12, 15]. For example, one study of older adults with HIV found that nearly half had not disclosed their HIV status to anyone in their religious congregation, although they still attended services [16]. In a US study, older adults with HIV reported a variety of reasons for not disclosing their serostatus, including not wanting to worry others, not wanting to burden others, or fear that others would disclose the person's HIV status [17]. In an examination of HIV disclosure patterns, older adults with HIV were most likely to have disclosed to at least one health care provider (96%), followed by friends and family (89% and 86%, respectively), sex partners (84%), social or political organizations (70%), drug buddies (57%), and lastly people in the workplace (49%) [17]. Often, nondisclosure is rooted in the fear of negative consequences of revealing their HIV status, such as losing a job, rejection, angry reactions, physical violence, and even death [17]. Similar themes emerged among people with HIV in Kenya and Uganda, such as fear of spousal abandonment, blaming and accusations, and violence [18].

Unfortunately, enacted stigma is often manifested by those in positions of power and trust, such as health care providers [12, 19–21]. HIV stigma has multiple impacts on public health, including reluctance to be tested for HIV, to disclose to others such as sexual partners, and to disclose being HIV positive to healthcare providers [22–25]. A report by UNAIDS [25] underscores that HIV stigma is a global issue that represents a major impediment to reaching goals of testing, engagement in care, and reducing new HIV infections.

The origins of HIV stigma

What are the characteristics of HIV that result in a discredited identity and subsequent experiences of stigma? Although treatments like ART are able to successfully manage HIV infection, HIV remains a chronic, incurable, and communicable disease. Despite being in the fourth decade of the epidemic, HIV risk and modes of transmission are still poorly understood [17]. Moral judgements around vectors for HIV transmission including sexual behavior (same-sex behavior, sex work, extramarital sex, and having multiple partners) and intravenous drug use contribute to HIV stigma [17, 22]. Thus, HIV infection is often viewed as a moral failure or punishment for sin [26–28].

Intersectionality and layering of stigma

In addition to facing prejudice, discrimination, and mistreatment for being HIV positive, people with HIV may possess multiple discredited identities due to their race, ethnicity, gender identity and expression, sexual orientation, socioeconomic position, or substance use behaviors, which is described as intersectionality or layering of stigma [22, 29]. Meyer considered the intersection of multiple stigmatized identities in his Minority Stress Model [30, 31]. For example, Meyer notes that lesbians not only encounter stigma due to their sexual orientation, but are also challenged by sexism as cisgender women. Meyer also discusses the experience of sexual minorities who are people of color facing racism within the lesbian, gay, and bisexual community, and experiencing concomitant homophobia within communities of color. Porter and Brennan-Ing further expanded this concept in the case of older transgender and gender non-conforming people with HIV in their Five Corners model [32]. The Five Corners model is composed of the intersection of race, class, gender identity, sexual orientation, age, and HIV stigma that shapes the experience of transgender older adults living with HIV and illustrates how health inequities associated with stigmatized identities are manifested in this population.

In a qualitative study of older adults with HIV, Johnson Shen and colleagues found that the experiences of intersectional stigma in this population were not uniform [33].

Gay and bisexual men were most impacted by the confluence of HIV stigma and ageism. Among heterosexual men, stigma concerns were related to HIV as well as perceptions that they may have contracted HIV through sexual relations with another man or through intravenous drug use. For Spanish-speaking older adults with HIV, stigma experiences pertained to HIV and ethnicity (Hispanic origin). In contrast, women did not appear to be impacted by experiences of intersectional stigmas. Storholm and colleagues investigated the relationship between multiple minority status, HIV stigma, and psychosocial distress among older adults with HIV [34]. This research found that multiple minority status was related to greater levels of HIV stigma and psychosocial distress. Further, greater HIV stigma was related to greater distress among older adults with multiple minority identities. That is, the experience of prejudice and discrimination due to other minority identities (e.g., race, ethnicity) intensified the experience of HIV stigma. These findings were in line with Meyer's Minority Stress Model [30, 31].

As described by Turan and colleagues [29], intersectional stigma for people with HIV represents a juncture of identities at the micro-level of society (e.g., HIV status, race, gender identity) with macro-level factors that may or may not be expressed at the individual level (e.g., HIV stigma, racism, transphobia). This intersection may result in health inequalities through mechanisms such as inequitable resource allocation and opportunities. At the meso-level, stigma is manifested as community norms which may be context dependent (e.g., cultural, geographical) [29]. Consider the case of a Black gay male with HIV. In the US, this individual may experience enacted stigma due to race, sexual orientation, and HIV status. However, considering that the US has relatively liberal views on homosexuality compared to sub-Saharan Africa, this individual would encounter even more harsh sanctions due to sexual orientation in places such as Uganda where homosexuality is routinely punished [35], but he would not have the same experiences of racism in that region compared with the US.

Ageism and HIV

Age, specifically older age, represents an additional intersectional identity that affects the stigma experiences of people with HIV. Prejudice due to age, or ageism, may be multidirectional, but ageism generally refers to bias and discrimination towards older people [36–38]. Emlet explored the intersection of ageism and HIV stigma among older adults with HIV in an article aptly titled, “You're Awfully Old to Have this Disease” [12]. Approximately, two thirds of the older adults in Emlet's study reported experiencing both HIV stigma and ageism. Experiences of ageism were related to employment and dealing with financial institutions. A number of Emlet's respondents exhibited forms of

internalized ageism, joking about memory loss as “senior moments” or relating the expectation of age-related health issues. In a sample of older gay and bisexual men with HIV, Slater and colleagues reported a confluence of HIV stigma, homonegativity, and ageism [39]. Wight and colleagues examined internalized ageism among older gay and bisexual men, many of whom were HIV positive, and described a phenomenon of psychological “accelerated aging” due to pervasive ageism in the gay community [38]. Internalized ageism may have a negative impact on physical and mental health. Levy and colleagues found that attitudes toward aging are related to physical function, with those having more positive self-perceptions of aging having better functional health over time [40].

Levy proposed that ageism has a negative impact on health through psychological, behavioral, and physiological pathways [41]. The psychological pathway represents expectations around aging, with evidence that those holding more negative age stereotypes perform more poorly on cognitive tests. The behavioral pathway involves healthy practices that may be curtailed due to beliefs that aging leads to inevitable health problems and physical decline. The physiological pathway involves the autonomic nervous system and environmental stress; those with internalized negative age stereotypes demonstrate a heightened response to stress that can result in health issues such as cardiac disease. These mechanisms may be responsible for empirical findings that internalized ageism is related to both chronic disease and longevity [41, 42]. Thus, for older adults with HIV, ageism may represent both a threat to health as well as an additional layer of stigmatization [43].

HIV stigma and psychological well-being

HIV-related stigma has been found to have a profound negative impact on the psychological well-being among older adults. Researchers have found a positive relationship between stigma and greater levels of depressive symptoms among older HIV-positive adults in the US [9, 44, 45]. Steward and colleagues observed that stigma-driven depression among people with HIV in India was mediated by coping strategies related to avoiding serostatus disclosure. Disclosure avoidance strategies included hiding medications, describing their HIV disease as another condition (e.g., tuberculosis), and accessing care outside of their home village to avoid being identified as an HIV patient [14].

In addition to depression, a meta-analysis by Rueda and colleagues found that HIV stigma was positively related to anxiety and emotional distress among people with HIV [46]. With regard to positive psychological functioning, Slater et al. found HIV stigma to be negatively related to quality of life [39, 47]. Porter and colleagues reported that HIV stigma was negatively related to psychological well-being in

older adults along dimensions of autonomy, purpose in life, positive relations with others, environmental mastery, self-acceptance, and personal growth [48]. Higher HIV stigma has also been found to be negatively related to quality of life in older gay men with HIV. The self-deprecation that would result from internalized HIV stigma explains in part the relationship between stigma and psychological well-being [49, 50]. Additionally, Meyer's Minority Stress Model would posit that the stress from HIV stigma would result in poorer mental health outcomes [30, 31].

There are a number of psychosocial factors that may mediate the experience of stigma among older adults with HIV. Stigma management may be more difficult for people with HIV who are not members of groups traditionally associated with high HIV risk [51]. Women with HIV may experience stigma more keenly due to beliefs that HIV "... is a dirty disease contracted through dirty needles and dirty sex," that sharply contrasts with social ideals of women being "clean and wholesome" [17]. Sexual minority older adults with HIV report lower levels of perceived stigma in comparison to heterosexuals [17, 52]. Older age may help to blunt the experience of HIV stigma [39]. In a study of older Canadian adults with HIV, Emler and colleagues found that people 55 and older reported significantly lower stigma than younger adults after controlling for gender and sexual orientation [53]. Personal resources, such as a sense of mastery, are related to lower HIV stigma in older adults [52, 53]. Dimensions of spirituality, such as purpose in life, transcendence, inner resources, and inter-connectedness, also appear to buffer the impact of spirituality on psychological well-being [48]. In fact, spirituality appears to have a stronger mediating effect on the relationship between HIV stigma and well-being among gay and bisexual men as compared with their heterosexual peers [54]. Greater social support, as assessed by emotional/informational support, affection, tangible support, and positive interactions, is also associated with lower levels of stigma among older men with HIV [47].

Social integration and stigma

As stated earlier, ostracism or rejection by members of one's social network [13, 16, 55] and self-protective withdrawal [12, 15] are just some of the ways that HIV-related stigma can impact social integration among older people with HIV. Social integration and social support resources are critical for people with HIV due to their relationship with physical and mental health. There is a large body of literature that supports the link between social isolation and poor health in the general population. In a meta-analysis of 148 studies on social support and mortality, Holt-Lunstad and colleagues found that those with strong social relationships had a 50%

greater likelihood of increased survival when controlling for other factors and that social supports have a similar effect size compared to other recognized predictors of mortality such as tobacco use or hypertension [56]. Cornwell and Waite examined multi-dimensional indicators of social integration (e.g., network size, social participation) and found that social disconnectedness and perceived social isolation were independent covariates of poor self-rated health [57]. Social isolation has been associated with poor ratings of mental health among HIV-positive adults as well [58]. In a study of middle-aged and older veterans with HIV, social isolation increased the risk for hospitalization and mortality [59]. Poor social support has been linked to poor ART medication adherence that increases the risk of poor clinical outcomes such as viremia and multimorbidity [60].

Haile and colleagues examined the effects of stigma on social integration in a qualitative study of older men with HIV [61]. The men in this study were stigmatized not only for their HIV serostatus, but because of their race (Black), sexual orientation (gay and bisexual), and socio-economic position (poor). The first theme that emerged was that in medical and institutional settings, these men felt dehumanized, feeling like they were, "...just another body," and that medical staff wanted to keep interactions as brief as possible. Another respondent described his experience in religious congregations as being accepting of HIV, but not of his being a sexual minority person. Another complained about homophobic treatment in an educational institution, but authorities did nothing to ameliorate the situation when they were notified. Secondly, these men described having to "know their place" within existing social structures. For example, that they occupied the lowest rung in the gay/bisexual community because of their race. Some spoke of being excluded from certain social spaces by law enforcement because they were poor. Another spoke of the need to conceal his gay identity in public places to avoid harassment. The last theme concerned the myriad structural constraints these men faced due to the poverty, race, sexuality, and HIV status, which was aptly characterized as, "...stuck in the quagmire of an HIV ghetto," limiting opportunities for social interaction and integration [61].

An examination of the social networks of older people with HIV finds different levels of social integration that are unsurprisingly related to self-reported HIV stigma. Brennan-Ing and colleagues used cluster analysis to develop a typology of social networks among older people with HIV [62]. Their analysis identified three network types that were nearly evenly distributed among their sample. One group had integrated networks with a broad spectrum of interactive relationships with children, family, and friends with high levels of religious participation (Integrated group). The second group was characterized by Friend-centered networks, reporting frequent interaction with friends, but little contact

with family. Not surprisingly, this group was dominated by gay and bisexual men that tend to have friend-centered social supports, also known as families of choice, regardless of HIV status [63]. Similar social network characteristics have been observed among older sexual minority men with HIV in Finland [64]. The last group was composed of older people with HIV who were socially isolated, having intermittent contact with a few family members, but not having friends. The lack of social integration in the isolated group was manifested by the lowest levels of tangible and perceived social support. The isolated group reported the highest levels of loneliness, depression, and HIV stigma. While the friend-centered group did nearly as well as the integrated group with regard to psychosocial functioning, the lack of family interaction in their social networks is evidence of ongoing stigma with regard to sexual orientation, HIV status, or both.

Aging itself may be related to lower levels of social integration and greater isolation among people with HIV. In a comparison of younger and older adults with HIV in the Pacific Northwest, Emler found that older adults were significantly more likely to live alone (48%) compared with those less than 50 years-of-age (18%) [55]. An even greater proportion of adults 50 and older living with HIV in New York City were found to live alone (71%), significantly greater than the 35% of New Yorkers 65 and older who were living alone [65]. When Emler compared the older and younger respondents in his study, younger individuals were significantly more likely to report the presence of relatives, friends, and neighbors in their social networks compared with younger adults [55]. As in the Brennan-Ing study [62], Emler also reported that among gay and bisexual men with HIV, regardless of age, friends tended to dominate the social networks, and stigma was related to fewer social support resources [55]. The role of age in reduced social support resources for people with HIV deserves further study as there are a number of possible explanations, including the tendency for social networks to decrease with age [64], loss of social network members due to HIV/AIDS before effective treatments became available in the mid-1990s, and the tendency to constrain emotional investment in social contacts in later life [66].

Social integration with regard to intimate relationships and sexual expression is also a challenge for older adults with HIV given that the virus is frequently contracted through sexual contact. In a US study, only 15% of these older adults, were married or partnered and only half were sexually active [65, 67]. The low rates of this sample being married/partnered were due in part because approximately one third were lesbian, gay, and bisexual in an era prior to legalization of same-sex marriage in the US. But rates of marriage and partnership were also low among primarily heterosexual older adults with HIV in Uganda (33%), with only one-quarter being sexually active [68]. However, in

the Uganda sample there were sharp differences by gender; among men, 60% were married and nearly one-half were sexually active, while among women 14% were married and the same proportion was sexually active.

For older adults with HIV, risk management during sex can be accomplished using barrier protection like condoms or dental dams, serosorting (only having unprotected sex with others who are HIV-positive), and strategic positioning by being the receptive partner with someone who is HIV-negative [67]. In a study of older women with HIV, Taylor and colleagues found that many no longer employed safe-sex practices with long-term HIV-negative partners because they perceived the risk to be low as the receptive partner, and because the partner did not contract HIV despite repeated exposure [69]. Older men with erectile dysfunction having penetrative intercourse in the context of HIV infection may find condom use to be problematic. Until fairly recently, mitigating the risk of HIV infection after unprotected sex could only be accomplished through post-exposure prophylaxis (nPEP). Currently, pre-exposure prophylaxis (PrEP) is available that employs one of the medications in ART and is highly effective in preventing infection among HIV-negative partners in serodiscordant couples when taken at recommended doses [70]. While PrEP does not prevent other sexually transmitted infections, it is a useful alternative for those unable or unwilling to use barrier protection to prevent HIV infection.

Addressing stigma and enhancing social integration

Given the widespread issues around HIV-related stigma and its impact on social integration, it is not surprising that the most prominently expressed need among older adults with HIV is more opportunities for socialization [71]. While socialization programs may be developed within AIDS Service Organizations and other community service providers, these run the risk of only expanding the “quagmire of the HIV ghetto” [61] and failing to present opportunities for social integration in with the larger community.

Numerous stigma reduction interventions have been suggested to improve the quality of life for people with HIV. In healthcare settings, Nyblade and colleagues proposed that stigma reduction must be a multilevel effort, targeting individual, environmental, and policy levels [21]. These authors suggest educating health care workers about the nature of stigma, improving knowledge of HIV transmission to reduce fears of casual contact, and breaking down the association of HIV with immoral behavior. Other stigma reduction efforts have been aimed at reducing HIV stigma among the general population or improving the coping skills of people living with HIV to deal with enacted stigma [72]. But as noted by

Brown and colleagues [72], the long-term sustainability and impact of such interventions are questionable.

However, there is evidence that reducing stigma is possible. Identifying a cure for HIV would certainly reduce stigma around this incurable condition. Social attitudes may be changing as well. In a survey of physicians on attitudes, Marlin and colleagues found that 13% would have discomfort treating a patient with HIV, 7% would be uncomfortable with homosexual patients, and 22% would have discomfort with patients who are transgender [73]. Earlier year of medical school graduation, male gender, and heterosexual orientation were related to a greater tendency to have stigmatizing attitudes. While these data point to significant pockets of stigma among these healthcare providers, Marlin et al. report that stigma in this population has decreased significantly compared to earlier surveys conducted in 1982 and 1999 [73].

HIV stigma remains a toxic aspect of living with this virus and compounds the challenges of living with what is at present a treatable, but incurable, chronic condition. At present, most of our knowledge on the impact of HIV stigma on older adults is limited since it is derived from research conducted in high income countries. Thus, this body of work likely does not accurately describe the stigma experiences of older adults with HIV in low- and middle-income countries. Such information is vital if we are to design policies and programs to combat HIV stigma globally given the nuanced ways that stigma is enacted and experienced. But one powerful and potentially game-changing phenomenon is research finding that people with HIV having sustained undetectable viral loads are not infectious and have little chance of passing the virus on to others [74]. This evidence has been the foundation of the U = U movement (Undetectable = Uninfectious), which has reduced fear among the public about contracting HIV and served to reduce the experience of stigma among those living with the virus [75]. U = U has the potential to substantially reduce stigma around HIV infection by rendering it more like other chronic conditions and may eventually serve to open more opportunities for social integration among older adults with HIV.

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Compliance with ethical standards

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