



Psychosocial, mental health, and behavioral issues of aging with HIV

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Purpose of review

People with HIV continue to live with the health consequences of an episodic illness that limits their ability to fully participate in society, particularly for the growing number of older people living with HIV. The present review describes the recent evidence exploring the psychosocial challenges facing older adults living with HIV.

Recent findings

Aging for people with HIV may be more challenging than for the general population because of HIV-related stigma, loss of friends and social networks, and the detrimental effects that HIV and antiretroviral treatment have on normal aging processes. Older people with HIV are more likely to experience mental health and neurocognitive impairment than their HIV-negative counterparts, as well as more social isolation as a result of decreased social participation and engagement. People develop different approaches for coping with the challenges associated with aging with HIV.

Summary

As this field of research evolves, many research gaps need to be addressed, including a better conceptualization and measurement of successful aging and the development of high-quality integrated care, programs, and services tailored to the needs of older people with HIV. A more integrated policy response is needed to improve the psychosocial and economic well being of older people with HIV.

Keywords

aging with HIV, coping with HIV, mental health, neurocognitive functioning, social isolation and support

INTRODUCTION

Despite the progress in treatments, people living with HIV – particularly the growing number age 50 and older – continue to live with the health consequences of an episodic illness that limits their ability to fully participate in society [1^{••},2]. In both the USA and Canada, the prevalence of HIV disease among older adults is growing because of longevity (i.e., more people with HIV living into their 60s and 70s) and new HIV diagnoses among older adults [3,4]. In high-income countries, approximately 30% of all adults living with HIV are aged 50 years and over [5].

HIV infection among older adults is an emerging issue in high-income, middle-income, and low-income countries, and research in this area is evolving rapidly. We recently conducted a scoping review of the peer-reviewed and grey literature exploring the health of older people living with HIV (i.e., 50 years of age or older) [1^{••}], which located and catalogued 209 studies published since 1996 until March 2011. The main domains included physical health (comorbidities, HIV-related symptoms,

mortality and survival, and opportunistic infections), mental health (mental health conditions, neurocognitive function or impairment, and psychological well being), social participation (social support, stigma, and disclosure), antiretroviral therapy (adherence, antiretroviral response, and alternative treatments), health services (healthcare utilization, healthcare access, and hospitalizations), and sexual health (sexual risk behaviors, sexuality, and sexually transmitted infections) [1^{••}].

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KEY POINTS

- Older people with HIV face unique psychosocial challenges in dealing with multifactorial comorbidities that affect their mental health, neurocognitive functioning, access to social support, and use of coping strategies to aging successfully with HIV.
- Research efforts should be dedicated to further develop the concept of *successful aging* with HIV, including what constitute complete response to combination antiretroviral therapy, how to measure it, and its implications for clinical management.
- Novel intervention research needs to address the issues surrounding disclosure, social support, and coping strategies to improve the psychosocial well being of older people living with HIV.
- There is a need to develop cognitive rehabilitation and behavioral interventions to improve brain health, and address the neurocognitive impairments associated with aging with HIV and, in particular, in the context of multiple comorbidities.
- Healthcare providers, front-line workers, and policy-makers need to have a greater understanding of the experience of aging with HIV to offer better programs and services dedicated to mitigate the psychosocial challenges facing older people with HIV.

The present review focuses on the recent evidence exploring the psychosocial challenges facing older adults living with HIV. We conducted a series of electronic searches to capture the peer-reviewed literature from January 2013 until February 2014 related to mental health and quality of life, neurocognitive functioning, social isolation and support, and coping with HIV. The 13 electronic databases covered the national and international literature (restricted to English language) in medical and health sciences, psychology, social sciences and social work, including AgeLine, CINAHL, Cochrane Library, Embase, MEDLINE, PsycINFO, Social Sciences Abstracts, Social Work Abstracts, and Sociological Abstracts (search strategy available upon request). We considered studies for inclusion if they met the following criteria: provided results from empirical research (quantitative, qualitative or mixed methods studies); study population included people with HIV age 50 or older, or people identified as older, middle-aged, seniors, aged, aging or elderly; and addressed one or more psychosocial domains. Given the broad focus of the review, we focused on the most salient literature. We also found three recent reviews that summarize the public health challenges of growing old with HIV [6[■]]; challenges nurses face when caring for older people with HIV in

non-HIV healthcare settings [7]; and the clinical management of older people with HIV, including comorbidities [8[■]].

MENTAL HEALTH AND QUALITY OF LIFE

The process of aging may be more challenging for people living with HIV than for the general population. This is because of the detrimental effects that HIV and its treatment have on normal aging processes as well as other factors, such as HIV-related stigma, loss of friends and social networks [9[■]]. According to a case-controlled study comparing HIV⁺ and HIV⁻ older people, people with HIV are less happy, less resilient, and have poorer attitudes toward their aging [10[■]]. They also report lower physical and mental health, and experience more negative life-events, anxiety, and perceived stress. On the other hand, both groups reported similar levels of optimism, mastery, and social support.

The more medical comorbidities someone experiences, the poorer their quality of life [11,12]. In a United States multistate study, 94% of people with HIV aged 50 years or older ($n = 452$) had at least one other chronic illness, with an average of three comorbid conditions (including depression) [13]. Commonly reported chronic illnesses included high blood pressure (46%), chronic pain other than headache and back pain (45%), hepatitis (39%), arthritis (35%), diabetes (21%), and major depression (14% reported symptoms consistent with major depression). The presence of more chronic conditions was also associated with decreased functioning [11,12]. Another United States study of 262 people with HIV found that older people with HIV had significantly higher medical comorbidity burden (as measured with the Charlson Co-morbidity Index): almost half had at least one major medical comorbidity, including diabetes (18%), neurocognitive impairment (15%), and malignancy (12%) [11]. In a cohort study of 1230 injection drug users (IDUs), HIV⁺ participants had an increased risk of frailty (odds ratio = 1.66; 95% confidence interval, CI 1.24–2.21) [14], and depressive symptoms were independently associated with frailty.

The prevalence of depression among older adults with HIV differs according to subpopulations and geographical settings. In a Brazilian study of people with HIV over age 60, 28% experienced major depression, and women had 10.65 times higher odds of being diagnosed with major depression (95% CI 8.96–12.33) than men [15]. An Ontario study of 1129 older adults with HIV found that, compared with heterosexual, bisexual, and gay men, women had the highest mean scores for

depressive symptoms (using the Center for Epidemiologic Studies Depression Scale) [16]. However, in a study of older adults with HIV in the USA ($n = 904$), similar proportions of men and women experienced depressive symptoms (61% for both groups) and loneliness (34 and 28%, respectively) [17]. Differences across the studies may be because of different sample compositions and different measures or cutoffs to evaluate depression and depressive symptoms.

In terms of sex differences, Storholm *et al.* [17] found that men were significantly more likely than women to report a lack of positive relations with others (50 vs. 39%), purpose in life (51 vs. 39%), self-acceptance (51 vs. 42%), and environmental mastery (53 vs. 35%). Mediation analyses showed that individuals with greater minority burden (i.e., the number of minority statuses, including being gay or bisexual, nonwhite, disabled, low-income, foreign-born, and speaking English as a second language) experienced greater HIV-related stigma, which was associated with greater mental health burden. Another study, however, found that gay and bisexual men reported higher mental health-related quality of life than heterosexual men and women [16], and gay men reported less HIV-related stigma than women or heterosexual and bisexual men, which may be associated with the supportive networking within the gay community, better programs and services from AIDS service organizations, and the experience of having lived with HIV for many years.

In qualitative studies exploring the experiences of older adults with HIV, the main theme is uncertainty about the future and the unpredictability of the aging process [9^a,18,19]. Older people with HIV often compare themselves to their HIV⁻peers and report experiencing an earlier and more rapid decline in health, which increases anxiety about the future [18,19]. Other uncertainties include concerns regarding the ability of healthcare providers to provide high-quality care at the intersection of aging and HIV; the financial situation and transition to retirement, including adequate pension; the availability of appropriate long-term housing; and the decreasing ability to care for themselves [20^a]. In addition, older adults with HIV often need to negotiate multiple identities and the resulting stigma(s) attached to those identities, including ageism, homophobia, and HIV-related stigma [12,18]. Although ageism plays a role in the overall stigma experienced by older adults with HIV, some also report experiencing stigma and rejection from their HIV⁻ contemporaries [19]. Many express concerns about being discriminated against by other older people if they have to move into old-age care

facilities [18,20^a]. Whereas disclosure is important for people with HIV to receive social support, perceived and internalized stigma affects disclosure among older adults living with HIV [21,22].

Psychosocial well being – which includes perceived positive relationships and a purpose in life, as well as environmental mastery – is important for older adults to age successfully. It can also have a positive impact on HIV prevention. For example, in one study, better psychological well being was associated with sustained safer sex practices, including the consistent use of condoms [23].

NEUROCOGNITIVE FUNCTIONING

About 50% of people living with HIV will develop HIV-associated neurocognitive impairments and disorders (HAND) [24,25]. Combination antiretroviral therapy (cART) is allowing people with HIV to live longer, but it is not sufficient on its own to prevent neurocognitive problems in those with the milder forms of HAND – asymptomatic neuropsychological impairment (ANI) and HIV-associated neurocognitive disorder (MND) [26]. Important research work is necessary in the context of aging, as MND can significantly affect people's ability to work, adherence to medication and function in their daily lives.

Cognitive function in HIV is associated with a host of medical and psychiatric factors [24,25,27], including demographics, HIV disease severity, substance use, and comorbid conditions [24,25,28–31]. A recent study examined the interaction between aging and HIV on neurocognitive impairment and everyday functioning by comparing younger and older adults, with and without HIV [29]. Although the study failed to find interaction effects, older people with HIV consistently performed worse on eight of nine neuropsychological and everyday functioning tests. Another study of people living with HIV ($n = 106$) found that older age was associated with about a five-fold higher odds of developing memory deficits: about half of those over age 50 had measurable memory impairment [32]. In one study, the driving performance of older people with HIV was less efficient and slower than their younger counterparts [33]. In a qualitative study that used a disability framework to examine the subjective experiences of older men with HIV [34], participants described how HAND resulted in difficulties with work and social relationships. The study suggests that managing HAND should focus on triggers that worsen the condition, not just on the impairments themselves. In addition to affecting function, HAND can have damaging effects on older adults' psychosocial well being.

As people age, there is a need to emphasize psychosocial and cognitive rehabilitation specifically for HAND [35²²] and the associated comorbidities [36–38]; particular attention is warranted as well on the primary and secondary prevention efforts to address the medical, mental health, and addiction complications which can contribute to the development of cognitive impairments in HIV. Although several studies have looked at the risk factors for neurocognitive impairment, we were only able to identify two that examined potential interventions to help older people with HIV improve their cognitive abilities. Kaur *et al.* [39] – following on a previous report [40²²] – conducted a pilot study to determine the predictors of neurocognitive and everyday function improvement following speed of processing training. The study found that participants who presented with worse outcomes at baseline (i.e., worse performance on neurocognitive and everyday function, higher viral load, poorer medication adherence, and longer time since HIV diagnosis) benefitted most from the intervention. In a randomized, double-blind, placebo-controlled crossover pilot study with 17 HIV⁺ patients with HAND to examine the efficacy of receiving oral rivastigmine (up to 12 mg/day for 20 weeks) in improving neuropsychological functioning, researchers found that the drug improved processing speed but had nonsignificant effects on the primary outcome (Alzheimer's Disease Assessment Scale-Cognitive subscale) and other neurocognitive functions [41].

SOCIAL ISOLATION AND SUPPORT

Older adults living with HIV are at an increased risk of social isolation because of less social participation and shrinking social networks. As people with HIV age, they may lose friends and find it increasingly difficult to make new social connections [19,42,43]. In some cases, they may find it easier to be alone to avoid stigma or discrimination, or they may not have the energy to be socially engaged.

Social isolation decreases social support, which can have a negative impact on mental and physical well being. Older adults living with HIV enrolled in the United States Veterans Aging Cohort Study (VACS) had significantly greater social isolation than their HIV⁻ counterparts [9²²]. Using a composite social isolation score – based on the frequency of visits by close friends or family, number of close friends and family, use of self-help groups, volunteer work or involvement with a community organization, attendance at religious events, relationship status, and living alone – this study found that being HIV⁺ increased the odds of social isolation

by 1.0–6.8 times, with an increasing trend by age. Social isolation was associated with a higher risk of hospitalization and death among both HIV⁺ and HIV⁻ participants. Given the higher overall prevalence of social isolation among people with HIV, the population level effect of social isolation on hospitalization and death is likely greater among those who are aging.

Both employment and volunteering can provide social support. However, HIV-associated neurocognitive impairments greatly reduce older HIV⁺ adults' ability to stay employed. With less ability to focus on or remember tasks, multitask and solve problems, and more fatigue, older adults with HIV often find it difficult to maintain satisfactory job performance [9²²,22] and may retire early. As a result, they are less likely to get social support through employment and are at risk of deteriorating financial situations and living conditions [19]. Lack of employment can exacerbate feelings of social isolation, whereas the inability to be a productive member of the workforce limits social engagement. On the other hand, volunteering can empower older people with HIV by allowing them to contribute to their communities. Some view volunteering as an opportunity to be productive [9²²] and find it fulfilling [22]. However, volunteering, like paid employment, comes with challenges, including lack of organizations' flexibility to accommodate HIV⁺ older adults.

In terms of interventions to enhance the quality of life, emotional or informational support, including people with whom to express and share feelings and to obtain advice, information and guidance, has the greatest positive influence [11,44]. On the other hand, limited activities, lifetime victimization, decreased self-efficacy, and low levels of social support are significantly associated with poorer mental health-related quality of life [45].

COPING WITH HIV

A growing body of research is exploring coping strategies to minimize the negative impact of aging with HIV. According to a recent qualitative study of long-term survivors, coping strategies can be grouped in three categories: disease coping, practical coping, and emotional coping [46²²]. For disease coping, older adults with HIV find that being well educated on the effects of HIV medications, being able to manage treatment requirements within their daily lives, and having good physician–patient communication helps. Although disease coping is important, recent research has found that practical and emotional coping mechanisms seem to have the greatest positive effect on psychosocial well

being [12,21,46[¶],47]. Practical coping strategies, including seeking social support and solution-focused coping, are associated with lower reports of depression and loneliness [12,47]. They help older adults with HIV find meaning in new activities, such as primary caregiver for a child or a grandchild [19,46[¶]]. Caregiving can also be a motivator to live well and remain socially engaged [22]. The wisdom that comes with age can be a practical coping strategy: older people with HIV experience lower overall and internalized stigma than their younger counterparts, probably related to increased self-acceptance, positive self-concept, and self-compassion (C. Emler, personal communication). Social interactions with spouses or partners, family, close friends (and even pets) as well as meaningful employment were important to maintain an optimistic outlook and nurture positive traits and relationships [46[¶]].

Emotional coping includes identifying strategies to stay positive and to manage negative emotion. The most common type of emotional coping was through spirituality and religion [18,21,46[¶],47]. In a study that examined a new measure to evaluate coping in older adults, participants who were depressed or lonely were significantly less likely to use spiritual coping techniques, whereas those who were experiencing anxiety were more likely to use spirituality as a coping mechanism [47]. Given the cross-sectional nature of this study, it is not clear whether anxiety prompted the use of spirituality as a way to search for inner peace or the use of spirituality increased anxiety as a result of an augmented sense of personal responsibility. In a phenomenological study, older adults with HIV often reported beneficial effects from newly acquired spirituality, which helped them develop a more positive outlook and empower them in life [18]. Emotional coping strategies appear to be population and context specific. For example, in a study of spirituality and religiousness among HIV⁺ gay, bisexual, and other men who have sex with men, men of color were more likely to report higher levels of existential well being as well as spirituality and religiousness [48].

Spiritual and faith-based connections can also enable social engagement and participation [21]. Spiritual explorations within self and disease can help ground individuals, and could guide them away from fears and anxiety about their disease and future [18]. As an intervention, guidance for spiritual coping may help reduce depressive symptoms, improve the quality of life, and reduce the need to seek refuge in more harmful habits, such as illicit drug use or excessive alcohol consumption [49].

Only one recent study explored interventions to help older adults with HIV cope with their disease and reduce depressive symptoms. Heckman *et al.* [50^{¶¶}] conducted a randomized controlled trial with 361 older adults with HIV across 24 States to test the effectiveness of two different telephone-administered interventions: supportive-expressive group therapy (tele-SEGT) and coping effectiveness training (tele-CET). Both interventions, which have been proven effective at reducing depressive symptoms in previous studies, were compared to a standard-of-care control arm. Participants in the tele-SEGT arm reported significantly fewer depressive symptoms than those who received the tele-CET or standard of care: there was a 2.5-fold increase in the proportion of participants who had more than a 50% reduction in depressive symptoms compared with the other two arms.

CONCLUSION

The intersection of HIV, aging, and health raises a host of issues that health research, policy, and practice need to address, including challenges related to mental health, quality of life, neurocognitive functioning, social isolation and support, and coping with aging and HIV. In our view, health-care providers, front-line workers, and policy makers should have a greater understanding of the experience of aging with HIV. As the first cohorts of people with HIV grow old, they have concerns about the ability of providers to deliver high-quality integrated care, programs and services that address their mental health, neurocognitive, and social needs. Interdisciplinary teams will need to find new ways to organize care and share the knowledge and skills required to address the complex mental health needs of older people with HIV in an environment in which no single discipline holds all the expertise. Front-line providers at AIDS service organizations will need to develop and integrate more programs and services that mitigate the social isolation and stigma experienced by many older people with HIV and help them cope with aging with HIV. As a substantial proportion of people with HIV approach retirement age, policy makers need to develop new policies or adapt the existing ones to improve their social and economic outlook. For example, reforming retirement benefit programs could allow people with HIV to remain in the workforce as long as possible, and providing better integrated housing models could remove some of the barriers to subsidized housing and ensure that retirement homes and long-term facilities become more welcoming places for older people with HIV.

Although there are no data on the potential impact of retirement on the health and economic security of people with HIV, a number of concerns have been raised in the general population by the unprecedented size of the baby boom generation, including an increased burden on public and private retirement systems that threatens the financial security of baby boomers themselves. In addition to the financial benefits of working, many older workers appreciate the opportunity to maintain social contacts and contribute to society. Even those planning to retire often do not view retirement as an end to their working life. For many, retirement is a transition from working full-time to new employment opportunities and work arrangements (e.g., part-time and contract work). However, concerns about baby boomers remaining in the workforce have also been raised, particularly about the mental capacity of aging workers and their ability to remain productive. Of particular concern is a subgroup of older people with HIV who have been out of the labor force for a long time (>10 years) and who have become increasingly detached from the labor market over time. This group is less likely than the average older person with HIV to re-enter the labor market in the traditional sense (i.e., full-time work) and will need a different set of accommodations (e.g., strengthening social assistance access or amounts and flexibility of allowances for part-time work).

We have identified key areas for future research in psychosocial well being and increasing age with HIV, including effective strategies and the healthcare resources (e.g., multidisciplinary clinics and teams including psychologists, social workers, and nurse practitioners) to help older people with HIV deal with the issues related to disclosure and negotiating safer sex, and studies to understand the reciprocal relationship between psychosocial well being and HIV prevention; effective cognitive rehabilitation and behavioral treatments for neurocognitive impairment associated with HIV, especially the milder forms of HAND; interventions tailored to the needs of older adults living with HIV that target modifiable factors such as emotional or information social support and self-efficacy, which can have a positive impact on quality of life; population and context-specific interventions to help older adults living with HIV develop and nurture their own coping strategies; the epidemiology of mental health and brain health in cohorts of older people with HIV, including the use of common measures to characterize their status and needs, and document and monitor other strength-based factors that may mitigate the health decline of older people with HIV (e.g., resilience); longitudinal studies exploring the

process of aging with HIV, which should result in causal inferences about the factors that could increase psychosocial well being; and qualitative research to explore in depth the subjective, lived experiences of older people with HIV, which will help health planners and policy makers address the contextual challenges of aging with HIV.

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Conflicts of interest

Disclosure: There are no conflicts of interest related to this article.

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- of special interest
- of outstanding interest

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