



# Ageism: the -ism affecting the lives of older people living with HIV

Giovanni Guaraldi, Jovana Milic, Mario Cascio, Cristina Mussini, Esteban Martinez, Jules Levin, Daniele Calzavara, Rebecca Mbeve, Julian Falutz, Chloe Orkin, Matteo Cesari, Jeffrey V Lazarus

Lancet HIV 2024; 11: e52–59

Published Online

November 28, 2023

[https://doi.org/10.1016/S2352-3018\(23\)00226-6](https://doi.org/10.1016/S2352-3018(23)00226-6)

Surgical, Medical and Dental Department of Morphological Sciences related to Transplant, Oncology and Regenerative Medicine, University of Modena and Reggio Emilia, Modena, Italy

(Prof G Guaraldi MD, J Milic MD, Prof C Mussini MD); European AIDS Treatment Group, Brussels, Belgium (M Cascio);

Infectious Diseases Unit, Hospital Clinic, Barcelona, Spain (Prof E Martinez MD);

Department of Medicine (Prof E Martinez), and Barcelona Institute for Global Health (ISGlobal), Hospital Clinic (Prof J V Lazarus PhD),

University of Barcelona, Barcelona, Spain; National AIDS Treatment Advocacy Project, New York, NY, USA

(J Levin); Milano Check Point, Milan, Italy (D Calzavara); Positively UK, London, UK

(R Mbeve); McGill University Health Centre, Montreal, QC, Canada (J Falutz MD); SHARE Collaborative and Department of Immunobiology, Blizard Institute, Queen Mary

University of London, London, UK (Prof C Orkin MBChB FRCP);

Department of Clinical Sciences and Community Health, University of Milan, Milan, Italy

(M Cesari MD); The City University of New York Graduate School of Public Health and Health Policy (CUNY SPH), City University of New York, New York, NY, USA

(Prof J V Lazarus)

Correspondence to:

Prof Giovanni Guaraldi, Surgical, Medical and Dental Department of Morphological Sciences related to Transplant, Oncology and Regenerative Medicine, University of Modena and Reggio Emilia, Modena 41124, Italy

[giovanni.guaraldi@unimore.it](mailto:giovanni.guaraldi@unimore.it)

WHO defines ageism as stereotypes, prejudice, and discrimination based on age. Ageism is a multidimensional concept that encompasses multiple components related to the individual, the social group, and the institution in different cultural and environmental settings. In people ageing with HIV these elements include self-stigma, discrimination in society, and experiences in care, many of which are unique to older people. In this Position Paper, we use experience of people with HIV and clinicians taking care of them to explore these issues in high-income countries. The intersectionality of multiple -isms, which affect the lives of older people living with HIV, and ageism enhance several HIV-related issues, including self-inflicted stigma, and loneliness. Research is needed to explore how ageism contributes to worse physical, mental, and social wellbeing outcomes for people with HIV. The model of care for older people living with HIV needs to go beyond virological success by adopting a geriatric mindset, which is attentive to the challenge of ageism and is proactive in promoting a comprehensive approach for the ageing population. All stakeholders and the community should work together to co-create institutional strategies and educational programmes and enable respectful intergenerational dialogue to foster a stigma-free future for older people living with HIV.

## Introduction

At the AIDS 2022 conference in Montreal (QC, Canada), and more recently at the International AIDS Society 2023 conference in Brisbane (QLD, Australia), older people living with HIV expressed dismay and a growing concern about ageism. The Silver Zone at the 2022 conference was the first ever networking space at an international meeting for older people with HIV; and soon after that pioneering educational experience, older and younger people living with HIV and HIV researchers and clinicians realised the urgency to address stigma and discrimination associated with ageism.

The rationale for this Position Paper was to retrace the nature of ageism in HIV, as described in WHO's Global Report on Ageism.<sup>1</sup> First, the authors who are living with HIV shared their personal and peers' experiences of ageism. Second, the authors who are health-care workers presented case reports and unstructured interviews done during routine clinical, proactive care. We selected vignettes to provide anecdotal evidence that best describes the scale, effect, and determinants of ageism. With real stories, we highlight the struggles of older people living with HIV and provide insights that could guide meaningful interventions and recommendations. We examine the nature and determinants of ageism in people living with HIV in high-income countries and outline the effect of ageism on health. Finally, we provide strategies to reduce discrimination.

We hope that this Position Paper will also encourage a broad discussion of ageing and ageism in people living with HIV in low-income and middle-income countries and their needs, which is largely unexplored.

## Ageism: nature and determinants

The WHO definition of ageism includes stereotypes (how we think), prejudice (how we feel), and discrimination (how we act) because of age.<sup>1</sup> Ageism is

a multidimensional concept that encompasses multiple components related to the individual, the social group, and the institution in different cultural and environmental settings.<sup>2</sup> The clinical vignette presents an older person living with HIV, Bruno (panel 1), who was among the 14% of patients who disengaged from care at his centre during the COVID-19 pandemic.<sup>3</sup> This case illustrates some examples of the WHO ageism definition and depicts the pernicious role that loneliness can play in exacerbating the scenario of the case individual.

Institutional ageism, as experienced by Bruno in the relationship with his new general practitioner, refers to the laws, rules, social norms, policies, and practices of institutions that place individuals at a disadvantage because of their age. This facet of ageism can manifest itself across different settings, such as those providing health and social care, in the workplace, the media, and the legal system.<sup>1</sup> Interpersonal ageism arises from interactions with other groups of people in a community.

The prevalence of ageist attitudes differs among countries and cultures. The highest prevalence of ageism has been reported in low-income and middle-income countries (eg, India, Nigeria, and Yemen) where up to 39% of survey participants reported ageist attitudes.<sup>4</sup> Interpersonal ageism might also differ within countries and intersect with socioeconomic status. For example, a wealthy person might be able to afford better care in older age, whereas a person with low income might be forced to seek care in a setting with inadequate resources to serve older people, which could result in an overall worse experience.

Institutional and interpersonal ageism might influence and enhance a more personal form of ageism (ie, self-ageism). Bruno was undervaluing himself. Unlike his treatment for HIV, he did not interrupt treatment for other comorbidities (eg, hypertension or hypothyroidism). In addition, Bruno seemed to self-

perceive as an old and socially isolated person living in a nursing home and consequently preferred death to loneliness. HIV status clearly had an effect on this feeling.

Other aspects of identity also intersect to affect the experience of ageism. In the case of Bruno, his sexual orientation might have contributed with his age to create a greater sense of isolation. In an Australian survey including 752 lesbian and gay adults aged 60 years and older, only 51% of lesbian women and 64% of gay men felt comfortable disclosing their sexual orientation to health-care providers. Individuals who disclosed their status were less likely to experience self-directed homophobia or discrimination.<sup>5</sup> In another survey including 613 gay men and lesbian women, gay men with concerns regarding acceptance of their sexuality by others reported higher psychological distress and lower resilience, especially when they experienced greater levels of surrounding ageism.<sup>6</sup>

Self-ageism in people living with HIV is complex and sometimes individuals can face unique challenges not experienced by people living without HIV, such as survivor guilt. Panel 2 depicts personal insights shared by older people living with HIV in different regions. Many people living with HIV have not had the opportunity to build a professional career due to their short-term future perspectives and, as a result, live in conditions of economic hardship. This adverse situation has had a strong effect on their futures. Furthermore, many have lost most of their loved ones (family and friends) and, as such, survivor guilt and social isolation are frequent among older people living with HIV. The burden of stigma, including self-stigma and loneliness, has become challenging for many people living with HIV.

The factors that contribute to ageism in people living with HIV and the interventions that might contribute to fighting ageism are manifold (figure 1).<sup>1</sup> The vignettes we present (panels 2 and 3) underline that there might be sex and gender identity-based differences in how people living with HIV transition to older age. This process might also differ by geographical context. Ageism is prevalent and ubiquitous, but it remains largely unrecognised and unchallenged in society and in health care. According to WHO, ageism “damages health and dignity as well as economies. It denies people’s human rights and their ability to reach their full potential. Addressing ageism is critical for creating a more equal world in which the dignity and rights of every human being are respected and protected.”<sup>11</sup>

### Effects of ageism in people living with HIV

For many older people living with HIV, the intersection of stigma, self-stigma, and ageism can lead to self-protecting withdrawal from social life and sexuality. This withdrawal can result in frailty, depression, loneliness, and poor engagement with the health-care system. Ageism is not only a social construct; it has an important effect on the physical and mental health of

#### Panel 1: Multifaceted nature and consequences of ageism

##### Clinician’s account

Bruno is a White gay man, aged 85 years, from a small village in northern Italy, who has been living with HIV for 28 years. He has no relatives and lives alone. He has developed severe lipodystrophy. Clinical efforts initially focused on prevention of comorbidities and frailty but have shifted to their treatment. In 2021, he was among the 14% of patients who disengaged from care during the COVID-19 pandemic. When the clinic was able finally to speak to him by telephone, he explained that he was discharged to a nursing home after a long stay in hospital with COVID-19-related pneumonia. His general practitioner (whom he did not find welcoming) had retired. Bruno was assigned to a new general practitioner, whom he had never met. The choice to be admitted to the nursing home was partly due to his perceived loss of support from younger people from his village as most of his peers had died or avoided any social activities because of COVID-19. When Bruno entered the nursing home, he did not notify his health-care providers nor other nursing home residents that he lived with HIV, and consequently decided to stop antiretroviral therapy. Bruno did, however, continue treatments for other age-related conditions. In the past, Bruno spent a lot of time at the public house in the village; however, fewer older people interact with him nowadays, and when they do, they sometimes make derogatory remarks about him being slow and having a big stomach. He is aware that antiretroviral therapy is lifesaving, but he consciously refuses it. He admits that he would prefer death to feeling lonely. He says that in comparison with other residents in the nursing home, being alone with no children or nephews or nieces makes him feel as though his life is less valuable.

##### From a peer case worker from the UK

A Black woman of African heritage aged 67 years presented several times at different intervals to primary care with various ongoing health concerns. These concerns included weight loss, fatigue, and a loss of appetite. Among the more serious of health concerns, she presented deteriorating eyesight, which was unexplainable. Due to her age, and supposedly the assumption that she had not been sexually active, she was not offered, nor did she undergo testing for any sexually transmitted infections, including HIV. It is possible that she might have acquired the virus several years before while still married to her husband who had since died. Her health continued to deteriorate until she presented with late-stage HIV and required hospitalisation. It was then that she was diagnosed with HIV. However, by this time she had completely lost her sight as a consequence of cytomegalovirus. At this point, nothing could be done to correct her sight.

an individual. Ageism is associated with a variety of outcomes, such as mortality and physical or functional poor health, including frailty.<sup>7</sup> Frailty is a relevant clinical outcome as it is considered a construct to address the complexity of ageing. Frailty is a well known negative driver that affects health trajectories marked by reduced strength, endurance, and physiological function that leads to an increased risk of disabilities or other unfavourable health outcomes.<sup>8</sup> In an HIV setting, a longitudinal study including more than 1000 people living with HIV and people who were HIV-negative showed that negative self-perception of ageing (ie, older subjective age and low ageing satisfaction) was associated with frailty transitions (from either a non-frail to frail, frail to non-frail, pre-frail to frail, or frail to pre-frail) when compared with non-frail people.<sup>9</sup> Loneliness worsens cardiovascular risk and is associated with a higher risk of death in some studies.<sup>10,11</sup>

**Panel 2: Why is ageing with HIV difficult?**

**An older man living with HIV in Europe**

“You know, sometimes you even feel guilty about complaining about your health: people would think what the hell, you’re still alive unlike so many others, what’s there to complain about?” Many people who have been living with HIV for over 20 years have gone through significant psychological trauma. Research finds that a high percentage of people living with HIV experience depression and strong levels of anxiety, which is understandable for a condition that is serious, life-threatening, and surrounded by so much stigma and discrimination.

Living long term with HIV is often accompanied by a feeling of being suspended in time with a low perception of the natural lifecycle of time passing. We were doomed to die, spending and wasting all our money and not investing in the future. Becoming older is a physiological process and throughout life, we all experience, in a non-linear fashion, the progressive decline of our intrinsic capacity. For many people living with HIV who were diagnosed before 1996, the time of their diagnosis marked a date beyond which time stopped. These individuals were told they were going to die at a young age and, thus, planning ahead for projects, such as professional or economic engagements and relationships, was worth nothing. Even in the era of antiretroviral therapy, this distorted vision of time has somehow remained in many older individuals.

**An older man living with HIV in the USA**

“There is a misperception that stigma has improved significantly, at least in Western countries. That is far from the truth. I feel no one wants to start a long-term relationship with a person living with HIV. You can hear both older and younger people living with HIV say ‘we are doing great’. This reflects the fact that they don’t fully understand the potential impact of premature ageing. They think undetectable viral load is everything and the stigma is solved by U=U (ie, undetectable=untransmittable). But when you are 65 and live with multiple comorbidities and mental and physical disabilities, U=U is meaningless. We are self-stigmatized

as different and no one wants to help us, not even our own community.”

**A young transgender woman living with HIV in Latin America**

“I am 37 years old, and I feel distressed about aging more rapidly and fear that my body will progressively become more masculine. When I was a 13-year-old girl all what I wanted was to become a woman taking gender-affirming hormone therapy at any cost. Now I know I will be taking hormone therapy lifelong; however, I am concerned of the long-term impact it may have in my physical and mental health.”

**From an older man living with HIV in Europe**

“Since my 40s, I have felt more vulnerable to adverse health problems, leading to a perception of feeling old rather than actually being old. Nevertheless, I sometimes have the impression of feeling younger than I actually am, as I experience difficulties in accepting the changes related to the advent of older age. At the same time, though, I also have the feeling of being vulnerable and frail, and older than I actually am. The uncertainties of the early days emerge once again today because we don’t know what the future reserves for us.”

**From an older man living with HIV in the USA**

“Ordinary activities that healthier people living without HIV can perform without difficulty are overwhelming for older people living with HIV, including making telephone connections with their HIV clinics, transportation, shopping, preparing food and dressing. Many older people living with HIV feel shame for being physically or mentally impaired or, in fact, disabled. We need to teach our HIV system, including doctors, government leaders, and people living with HIV advocates, to not be ageist and to understand the problem and improve the situation. In low- and middle-income countries there are inadequate infrastructure to provide care and services for older people living with HIV. In the high-income countries these are not prioritised or provided adequately in most HIV clinics.”

In developing a public health response to ageing, WHO has built a conceptual framework to consider health status in ageing individuals. The term healthy ageing has been issued to promote a positive approach to ageing that relies on the reserves and capacities of an individual rather than on the accumulation of deficits and impairments. In 2015, the World Report on Aging and Health attempted to combine clinical and public health outcomes for ageing by defining healthy ageing as the process of developing and maintaining the functional ability that enables wellbeing in older age.<sup>12</sup> The functional ability construct stems from the interaction of two entities: intrinsic capacity, which is the composite of all cognitive and physical functioning of the individual, and the environment (figure 2). In particular, the intrinsic capacity construct might be perceived as an evolution of the frailty concept that takes into special consideration

the need of worldwide implementation of prevention, the continuum of the ageing process, and the opportunities offered by novel (and next-to-come) technologies.<sup>13</sup>

In people with HIV, the course of intrinsic capacity trajectory might be lower than in the general population due to the higher burden of comorbidities and frailty. More importantly, an observation can be made regarding the gap between intrinsic capacity and functional ability, underscoring that the effect of the environment relies on multiple factors such as welfare, health system, community support, HIV stigma, and ageism. We argue that in people with HIV (and in other marginalised populations), this gap is wider than what has been observed in the general population. This gap might diverge starting from the high-capacity period due to, among other factors, the intersection of HIV stigma and ageism.

Ageism also has a worldwide economic impact primarily affecting disadvantaged groups. The loss of financial security and subsequent poverty can lead to a rapid decline in health, early mortality, and reliance on state welfare systems.<sup>14,15</sup> Yet, there is a scarcity of studies exploring how ageism contributes to poverty in people living with HIV. Researchers should undertake more studies analysing the intersection of HIV stigma and ageism across high-income, middle-income, and low-income countries. At the institutional level, awareness about the increased life expectancy of people living with HIV is still low. This lack of awareness might further limit their social and economic perspective, for example the possibility to obtain bank loans or insurance, and lower self-esteem as it relates to embarking on future life plans.

Sexuality is another important aspect of older people's relationships, which ageism could affect. Little is known about HIV knowledge and sexual practices in older adults across the world, and physicians often do not explore this health domain.<sup>16</sup> Conversely, older adults are often not seen as sexually active. This misconception means physicians can ignore the sexual health needs of older adults, and care providers are less likely to associate HIV-related symptoms to HIV acquisition. Prevalence of late HIV presentation (CD4 count below 350 cells per  $\mu\text{L}$ ) increases with age, ranging from 33% among people aged 15–19 years at diagnosis to 65% among people aged 50 years or older.<sup>17</sup>

Women living with HIV face various challenges in addition to their age (panel 3). Their sex, race, and cultural and faith beliefs often compound their negative experiences of living with HIV.

From a public health perspective, sexual health needs of older people living with HIV should be addressed if we are to achieve the ambitious UNAIDS 95-95-95 strategy (ie, 95% of all people living with HIV to know their HIV status, 95% of all people with diagnosed HIV infection to receive sustained antiretroviral therapy, and 95% of all people receiving antiretroviral therapy to have viral suppression by 2025). Older individuals might not perceive risk of sexually transmitted infections.<sup>18–20</sup> Reports from Botswana, the country with the second highest HIV prevalence in the world, indicate that sexually transmitted infection rates have increased in older men (age 50–64 years) from 17.2% (2004) to 27.8% (2013), and in older women from 16.3% (2004) to 21.9% (2013).<sup>21</sup> Moreover, current pre-exposure prophylaxis regimens based on tenofovir disoproxil fumarate could cause higher bone and kidney toxicities in older people. Nevertheless, specific studies have not been conducted in this age group.<sup>22</sup>

## Strategies to reduce ageism

### Policy and law

Despite all the effects of ageism on older people living with HIV, specific legal instruments to end prejudice and discrimination are not present in all countries or

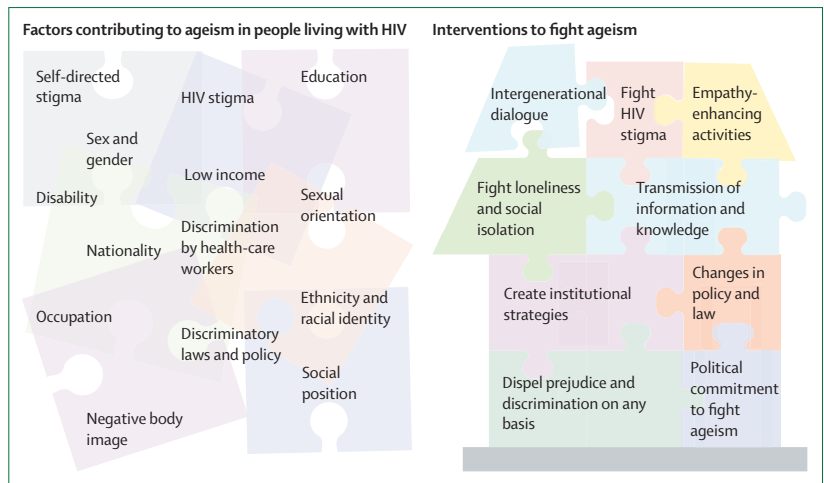


Figure 1: Factors contributing to ageism in people living with HIV and interventions that might contribute to fighting ageism

### Panel 3: The lost motherhood

#### From a menopausal woman living with HIV

“When my period stopped 2 years ago, I initially didn't care that much. I discussed it with my infectious diseases doctor during my routine HIV visit, and a lot of anger came out when he told me I was obviously in menopause, given my age (52 years old). In my twenties I got pregnant, and I had an abortion. I was afraid of mother-to-child transmission of HIV. But now I am aware that any women living with HIV can have a healthy child. It was too late for me. I realized my motherhood had been stolen from me.”

#### From a peer case-worker

“For women, the possibility of mother-to-child transmission of HIV meant that women avoided pregnancy and thus often missed the window of opportunity to have children. Fast forward to now, these women are menopausal and suffer the trauma of the fact that they will never have children of their own in which this was something they would have wanted.”

universally well applied. Most international human rights instruments do not explicitly list age as a prohibited ground for discrimination. In the HIV field, strong changes in policy and laws have led to free access to HIV care and recognition of the rights of people living with HIV. This occurred when Italian law 135/90 was enacted, guaranteeing the right to health and the dignity of people living with HIV, and making it possible for a high level of quality of care to be achieved.<sup>23</sup> Another example is Uganda, which was one of the first countries to reach the UNAIDS 90-90-90 goals for 2020 in Africa. Active government involvement played a major role in reducing HIV transmission and scaling antiretroviral therapy coverage, even in remote areas.<sup>24</sup> This success was based on the development of national strategies to manage the HIV epidemic and the personal commitment of major

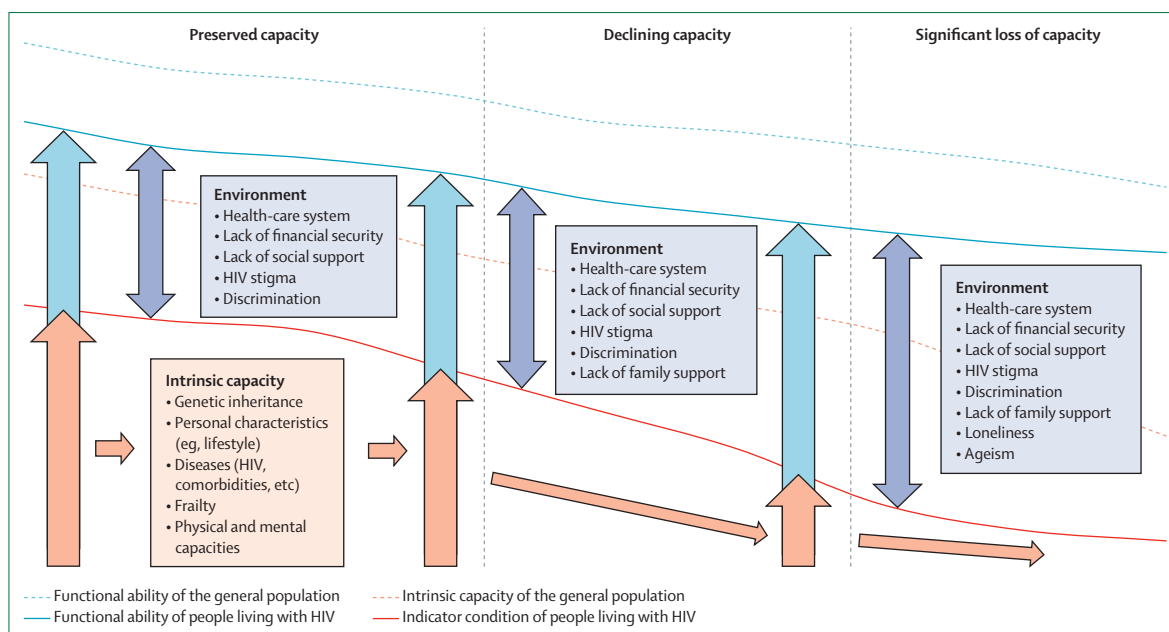


Figure 2: A public health framework for healthy ageing

policy makers to discuss HIV as a public health priority. Uganda was a pioneer in opening voluntary HIV testing centres in sub-Saharan Africa, despite the prevalent discrimination against the LGBT+ community.<sup>25</sup>

In 2019, the HIV Outcomes initiative in the EU, promoted by a group of HIV experts and people living with HIV, launched a call to action. European policy makers were asked to take concrete actions to ensure that the long-term health outcomes and quality of life of people living with HIV are high on the political agenda. The call to action highlights the value of promoting wellbeing, preventing comorbidities, and eliminating stigma and discrimination to improve people's lives. These actions will, in turn, help reduce future public expenditure, increase productivity, and extend the working lives of people living with HIV.<sup>26</sup>

Political commitment to fighting HIV stigma is also included in the Paris declaration, which supports the Fast-Track Cities initiative. This is a global partnership between cities and municipalities around the world that focuses on reaching zero new HIV infections and zero AIDS-related deaths. Among other initiatives, it provides financial backing for the Growing Older Wiser and Stronger (GROWS) project, which is a collaboration between The Sophia Forum, Positively UK, National AIDS Map, and University College London, to develop a sustainable support programme for women older than 40 years living with HIV and ageing in the UK. To extract the main themes about the concerns of ageing with HIV among women, evidence was gathered from existing research studies, the PRIME study, and We Are Still Here, and research done specifically for the GROWS project. These themes included both professional and personal

(peer) support, stigma, social issues, financial concerns, and physical and psychological concerns. Policy strategy to reduce ageism might be perceived differently according to geographical, sociocultural, and economic context.<sup>27</sup>

An interesting example of policy making recommendations is seen within the Situating the Preferences and Needs for Aging Care among HIV-positive Elderly people in Ontario within the UN Principles for Older Persons project.<sup>28</sup> Its objectives are to make recommendations to policy makers, health-care leaders, and organisational decision makers that prompt changes that would improve the quality of life of older adults with HIV. This improvement in quality of life could be via increased access to existing services or advising the development of new programmes.<sup>28</sup>

Although no systematic reviews are available about the effects of policies and laws on addressing ageism in the general population, evidence on the effectiveness of laws in tackling ageism and other -isms supports the use of this strategy to reduce or to eliminate it. By 2030, modelling suggests that 75% of people living with HIV will be older than 60 years, and 40% older than 75 years. Older people living with HIV will be the largest part of the entire population with HIV. In this setting, there should be a focus on antidiscrimination laws and policies aiming to eliminate ageism. It will be equally important to assess contributing factors to effectiveness.<sup>29</sup>

#### Educational and research interventions

Research shows that educational interventions are among the most effective strategies for reducing ageism against older people. Educational interventions seek primarily to transmit information and knowledge. They

For the Fast-Track Cities initiative see <https://www.fast-trackcities.org/>

operate on the assumption that stereotypes, prejudices, and discrimination are the result of ignorance, mistaken information, misconceptions, and simplistic thinking. Teaching more complex thinking skills will allow people living with HIV to consciously reconsider and update their beliefs, feelings, and behaviours, thereby leading to a decrease in ageism. In addition to new educational methodologies, psychology or social psychology could play an important role by offering more complex emotional reasoning skills in addition to critical thinking skills. Empathy refers to the ability to sense other people's emotions and imagine what someone else might be thinking or feeling.<sup>30</sup> Empathy-enhancing activities aim to generate identification with, and awareness of, another person or group's suffering, generally through perspective-taking exercises used to counter stereotypes, prejudice, and discrimination.

A pioneering educational experience was The Silver Zone at the AIDS 2022 conference in Montreal, which was the first ever networking space for older people with HIV at an international AIDS conference.<sup>31</sup> The Silver Zone was a place to socialise and mobilise, where older people living with HIV could feel included and appreciated. People living with HIV could increase their visibility, promote awareness of their strengths, and share experiences, challenges, and strategies for ageing. The networking space featured live and recorded presentations and interactive workshops on topics of interest for ageing and older people living with HIV. The agenda included categories such as ageing and sexuality, mental health, quality of life, comorbidity, and community engagement. Intergenerational dialogue (panel 4) among people living with HIV from different age groups highlighted the specific needs of people with HIV from a lifecycle perspective and aimed to address ageism via a mutual understanding of the capacities and difficulties faced by people at different stages of their lives.<sup>31</sup> One of the objectives of The Silver Zone was to set the basis, via a call to action, for the creation of a global coalition of ageing and older people living with HIV to advocate for changes in policy and clinical practice that could improve the wellbeing of ageing and older people. A short-term result of this initiative was the launch of the International Coalition of Older People with HIV (iCOPE HIV), a worldwide consortium of more than 150 HIV associations that endorsed The Glasgow Manifesto to promote equitable health outcomes.<sup>32</sup> Of note, the iCOPE HIV acronym pays tribute to WHO's ICOPE (ie, Integrated care for older people) programme developed for the general population.<sup>13</sup> One of the key messages of these initiatives and educational activities is that ageing well and living with HIV is possible. A healthy ageing goal requires a patient-centred approach and warrants a reshaped HIV health-care model.<sup>33</sup>

Educational activities might also refer to co-produced community academic programmes and medical education, and education of the next generation of

HIV activists. Infectious disease specialists and general practitioners, nurses, and pharmacists who care for people with HIV might profit from educational activities including a toolkit already available online.<sup>34</sup> Educational and intergenerational contact interventions should be implemented among all age groups. Research activities are of paramount importance. Since 2012, the Office of AIDS Research of the National Institutes of Health commissioned a working group to develop an outline of the current state of knowledge and areas of crucial need for research in HIV and ageing.<sup>35</sup> This Position Paper highlights that research should also explore how ageism contributes to worse physical, mental, and social wellbeing outcomes and intersectionality with socioeconomic status, employment, sex, and education.

#### Panel 4: Intergenerational gap and dialogue

##### From an older person living with HIV from the USA

"I feel we have been completely left out from the discussion on ending the epidemic and this is only used to refer to PrEP [pre-exposure prophylaxis] or cure. This is in fact ageism by the HIV community. These movements have no idea they are stigmatizing older people living with HIV or younger people living long term with HIV, increasing self or internalized stigma."

##### From a clinician from Italy

"Sometimes I feel distressed in engaging junior medical doctors and scientists in HIV care and research. Junior colleagues appear to be more interested in antibiotic stewardship or antimicrobial resistance rather than HIV. New generation of colleagues live in a different historical context. They did not have to fight AIDS like we did, and they perceive HIV much like any other chronic condition. Nevertheless, I am still optimistic. In the past 3 years, due to COVID pandemic, I was at the forefront of COVID care together with my junior colleagues. Something magical happened. Intergenerational barriers were immediately broken. We supported each other and realised that it was incredibly important to transfer the success of HIV care to the fight against fears and stigma generated by COVID-19. I believe HIV will still represent a reference model and HIV medicine will continue to be an incubator for a new generation of doctors and scientists who are able to put the individual in the centre of care."

##### From an older person living with HIV in the USA

"I have been working for years with younger advocates and my feeling is that younger HIV activists have difficulties to grasp and understand or appreciate these aging issues. They think this aging problem will not happen to them...that it's only happening to us who had HIV for 30 years and took the early bad drugs. Of course, they and none of us know exactly how this will affect them, but there will be many of them suffering this premature aging and comorbidity problem, too."

##### From a younger person living with HIV in Europe

"An intergenerational exchange can address ageism among people with HIV, helping to potentiate knowledge, expertise, experience of older adults and, at the same time, a better understanding of younger adults living with HIV. It seems that the big difference between adults who lived through the 1980s and 1990s and younger people, with respect to the topic of HIV, is death. Grown-ups believe that young people don't give a damn about ageing and death, young people often come to terms with a different kind of death, made up more of social stigma and discrimination, than a confrontation with actual death. In intergenerational dialogue, I believe there is a need for openness on both sides: from accepting a different, more fluid and inclusive community, to understanding that social dynamics are different but not unapproachable."

**Panel 5: Recommendations****Institutional ageism**

- Clinical care systems need to be reshaped to meet the needs of older people living with HIV, including geriatric syndrome screening, integrated care, and support and referral systems that include provision of adequate time for medical visits with a focus on improving wellness and functional status
- HIV doctors and clinicians should receive training on how to provide comprehensive care for older people living with HIV
- Government authorities and international HIV organisations need to provide the resources, support, and funding to implement these changes
- More and better research is needed to identify interventions for ageing-related immune deficits; people living with HIV should be involved in discussions around what research is needed
- Promote anti-ageism law and policy reform with advocacy activities
- Funding bodies and regulators to insist on the inclusion of older people in trials and not to provide, solicit, or approve drugs without data on older adults
- Conference organisers to include sessions on ageing with HIV

**Interpersonal ageism**

- Elaborate educational programmes and intergenerational dialogue
- Community co-produced educational activities to engage younger community members with older members and the scientific community, more generally

**Self-ageism**

- More research is needed to address the effects of social isolation and, specifically, loneliness on HIV outcomes

**Conclusion**

This Position Paper resulted from a dialogue between younger and older scientists and people with HIV. They all agreed that ageism is an under-addressed issue in the HIV setting. Therefore, the WHO campaign to fight ageism needs to raise awareness in the HIV setting to develop dedicated actions to combat it (panel 5).

We have described the intersectionality of multiple -isms, which affect the lives of older people living with HIV, and imply a multiplication effect of the many stigmas that people with HIV often experience, making ageism enhance several HIV-related issues, including self-inflicted stigma, and loneliness. At-risk communities are particularly susceptible to experiencing these aspects. Ageism can be considered the last pillar of this stigma cascade and the most important barrier to achieving healthy ageing in people living with HIV. The model of care for older people living with HIV needs to extend beyond virological success by adopting a geriatric

mindset, which is attentive to the challenge of ageism and is proactive in promoting a comprehensive approach for the ageing population. All stakeholders and the community should work together to co-create institutional strategies and educational programmes, and respectfully enable intergenerational dialogue to foster a HIV stigma-free future.

**Contributors**

GG, JM, MCA, JL, and CO conceptualised and drafted the manuscript. GG, JM, MCA, CM, EM, JL, DC, RM, JF, CO, MCE, and JVL wrote and revised the Position paper. All authors approved the final version of the manuscript.

**Declaration of interests**

GG received research grants and speaker honorarium from Gilead, ViiV, MERCK, and Jansen and attended advisory boards of Gilead, ViiV, and MERCK. JM received speaker honoraria from Gilead and ViiV. MCA attended advisory boards for ViiV and received speaker honoraria from Gilead. EM received research grants from Merck Sharp & Dohme and ViiV; attended advisory boards for Janssen, Gilead, Merck Sharp & Dohme, and ViiV; and received speaker honoraria from Gilead and ViiV. JF received speaker honorarium from ViiV. CO received research grants from Gilead, GSK, ViiV, Merck Sharp & Dohme, AstraZeneca, and Janssen; speaker honoraria from Gilead, GSK, ViiV, Merck Sharp & Dohme, and Janssen; and support for attending meetings from Gilead and ViiV. JVL reports grants to his institution from AbbVie, Gilead, Roche Diagnostics, and Merck Sharp & Dohme and speaker honoraria from AbbVie, Gilead, Intercept, Janssen, and Novo Nordisk. JL, DC, RM, MCE, and CM declare no competing interests.

**Acknowledgments**

JVL acknowledges support to ISGlobal from the grant CEX2018-000806-S funded by MCIN/AEI/ 10.13039/501100011033, and support from the Generalitat de Catalunya via the CERCA Program.

**References**

- 1 WHO. Global report on ageism, 2021. March 18, 2021. <https://www.who.int/teams/social-determinants-of-health/demographic-change-and-healthy-ageing/combating-ageism/global-report-on-ageism> (accessed Oct 16, 2022).
- 2 Hu RX, Luo M, Zhang A, Li LW. Associations of ageism and health: a systematic review of quantitative observational studies. *Res Aging* 2021; 43: 311–22.
- 3 Guaraldi G, Borghi V, Milic J, et al. The impact of COVID-19 on UNAIDS 90–90–90 targets: calls for new HIV care models. *Open Forum Infect Dis* 2021; 8: ofab283.
- 4 North MS, Fiske ST. Modern attitudes toward older adults in the aging world: a cross-cultural meta-analysis. *Psychol Bull* 2015; 141: 993–1021.
- 5 Lyons A, Alba B, Waling A, et al. Comfort among older lesbian and gay people in disclosing their sexual orientation to health and aged care services. *J Appl Gerontol* 2021; 40: 132–41.
- 6 Lyons A, Alba B, Waling A, et al. Assessing the combined effect of ageism and sexuality-related stigma on the mental health and well-being of older lesbian and gay adults. *Ageing Ment Health* 2022; 26: 1460–69.
- 7 Ye B, Gao J, Fu H, Chen H, Dong W, Gu M. How does ageism influence frailty? A preliminary study using a structural equation model. *BMC Geriatr* 2020; 20: 422.
- 8 Morley JE, Vellas B, van Kan GA, et al. Frailty consensus: a call to action. *J Am Med Dir Assoc* 2013; 14: 392–97.
- 9 Nieves-Lugo K, Ware D, Althoff K, et al. Negative perception of aging is associated with frailty transitions within a cohort of sexual minority men. *Innov Aging* 2021; 5: igab035.
- 10 Holt-Lunstad J, Smith TB, Baker M, Harris T, Stephenson D. Loneliness and social isolation as risk factors for mortality: a meta-analytic review. *Perspect Psychol Sci* 2015; 10: 227–37.
- 11 Hawkey LC. Loneliness and health. *Nat Rev Dis Primers* 2022; 8: 22.
- 12 WHO. World report on ageing and health. Sept 29, 2015. [https://apps.who.int/iris/bitstream/handle/10665/186463/9789240694811\\_eng.pdf?sequence=1](https://apps.who.int/iris/bitstream/handle/10665/186463/9789240694811_eng.pdf?sequence=1) (accessed Nov 8, 2023).

- 13 WHO. Integrated care for older people. Jan 1, 2017. <https://apps.who.int/iris/bitstream/handle/10665/258981/9789241550109-eng.pdf;jsessionid=05F0E68283FCFBBB5972AB52FF91D343?sequence=1> (accessed Oct 4, 2020).
- 14 Davies M, Gilhooly M, Harries PGK. Financial elder abuse: a review of the literature. London: Brunel University for Ageing Studies, 2011.
- 15 Kwan C, Walsh CA. Old age poverty: a scoping review of the literature. *Cogent Soc Sci* 2018; 4: 1478479.
- 16 Brown MJ, Adeagbo O. HIV and aging: double stigma. *Curr Epidemiol Rep* 2021; 8: 72–78.
- 17 WHO. HIV/AIDS surveillance in Europe 2021. Nov 30, 2021. [https://www.ecdc.europa.eu/sites/default/files/documents/2021-Annual\\_HIV\\_Report\\_0.pdf](https://www.ecdc.europa.eu/sites/default/files/documents/2021-Annual_HIV_Report_0.pdf) (accessed Oct 16, 2022).
- 18 Mills EJ, Bärnighausen T, Negin J. HIV and aging—preparing for the challenges ahead. *N Engl J Med* 2012; 366: 1270–73.
- 19 Siedner MJ. Aging, health, and quality of life for older people living with HIV in sub-Saharan Africa: a review and proposed conceptual framework. *J Aging Health* 2019; 31: 109–38.
- 20 Wing EJ. HIV and aging. *Int J Infect Dis* 2016; 53: 61–68.
- 21 Matlho K, Randell M, Lebelonyane R, Kefas J, Driscoll T, Negin J. HIV prevalence and related behaviours of older people in Botswana—secondary analysis of the Botswana AIDS Impact Survey (BAIS) IV. *Afr J AIDS Res* 2019; 18: 18–26.
- 22 Franconi I, Guaraldi G. Pre-exposure prophylaxis for HIV infection in the older patient: what can be recommended? *Drugs Aging* 2018; 35: 485–91.
- 23 D'Amato S, Pompa MG. Aspects of the Italian legislation related to HIV testing. *Ann Ist Super Sanita* 2010; 46: 51–56.
- 24 Jain V, Byonanebye DM, Liegler T, et al. Changes in population HIV RNA levels in Mbarara, Uganda, during scale-up of HIV antiretroviral therapy access. *J Acquir Immune Defic Syndr* 2014; 65: 327–32.
- 25 Kitara DL, Amone C, Okello C. Knowledge and misconceptions about HIV counseling and testing (HCT) among the post-conflict youths of Gulu, Northern Uganda. A prospective study design. *Pan Afr Med J* 2012; 12: 31.
- 26 HIV Outcomes. Beyond viral suppression. 2023. <https://hivoutcomes.eu/> (accessed Oct 30, 2023).
- 27 Positively UK. Women with HIV growing older wiser and stronger (GROWS). <https://positivelyuk.org/grows-growing-older-wiser-and-stronger/> (accessed Dec 22, 2022).
- 28 PANACHE. Principles and practicalities: situating the preferences and needs for aging care among HIV-positive elderly people in Ontario within the UN principles for older persons. August, 2021. <https://www.realizecanada.org/wp-content/uploads/PANACHE-ON-FINAL-AUG-2021.pdf> (accessed Nov 8, 2023).
- 29 Niessen J, Masselot A, Larizza M, Landman T, Wallace C. Comparative analysis of existing impact assessments of anti-discrimination legislation: mapping study on existing national legislative measures—and their impact in—tackling discrimination outside. December, 2006. <https://tandis.odihhr.pl/bitstream/20.500.12389/19830/1/03260.pdf> (accessed Nov 8, 2023).
- 30 Greater Good Magazine. What is empathy? 2020. <https://greatergood.berkeley.edu/topic/empathy/definition> (accessed Nov 8, 2023).
- 31 Canadian Association of Social Workers. The silver zone. A networking zone for older adults living with HIV. August, 2022. <https://www.casw-acts.ca/en/silver-zone-networking-zone-older-adults-living-hiv> (accessed Oct 30, 2022).
- 32 European AIDS Treatment Group. The Glasgow Manifesto by the International Coalition of Older People with HIV (iCOPE HIV). August, 2022. <https://www.eatg.org/press-releases-and-statements/the-glasgow-manifesto-by-the-international-coalition-of-older-people-with-hiv-icope-hiv/> (accessed Nov 8, 2023).
- 33 Lazarus JV, Safreed-Harmon K, Kamarulzaman A, et al. Consensus statement on the role of health systems in advancing the long-term well-being of people living with HIV. *Nat Commun* 2021; 12: 4450.
- 34 Prime. Practical toolkit for providing holistic care for aging people with HIV. 2023. <https://primeinc.org/resourcecenter/practical-toolkit-for-providing-holistic-care-for-aging-people-with-hiv> (accessed Feb 23, 2023).
- 35 High KP, Brennan-Ing M, Clifford DB, et al. HIV and aging: state of knowledge and areas of critical need for research. A report to the NIH Office of AIDS Research by the HIV and Aging Working Group. *J Acquir Immune Defic Syndr* 2012; 60 (suppl 1): S1–18.

Copyright © 2023 Elsevier Ltd. All rights reserved.