Received: 8 November 2023 | Accepted: 9 November 2023

DOI: 10.1111/hiv.13589

EDITORIAL COMMENT

Tackling ageism in the healthcare system: A community perspective

INTRODUCTION

The UNAIDS political declaration of June 2021 [1] calls for transformative action to end inequalities and end HIV transmission by 2030, and explicitly recognizes that ageing people with HIV face stigma and discrimination across multiple aspects of their lives. UNAIDS is unambiguous in its call to reinforce responses to HIV across the age spectrum, to ensure that the needs of ageing people with HIV are met and that their lives are free from stigma and discrimination. Research into ageing people with HIV that examines the intersectionality of stigmas will play a part in advancing the United Nations 2030 Agenda.

This contribution frames ageism as one of the last remaining pillars of stigma and one of the main barriers hindering the ability of ageing people living with HIV to achieve and sustain a good health-related quality of life (HRQOL). For people living with HIV, sexual health and intimate partner relationships are important components of HRQOL and emotional well-being across the life span [2, 3]. Although their importance has been increasingly recognized in the literature [4, 5], the sexuality of ageing people living with HIV is often considered of little importance when assessing HRQOL, despite evidence that older adults continue to desire romantic relationships, intimacy and sexual activity [6, 7]. This would suggest that sexuality, sexual health and sexual desires need to be considered in the assessment of HRQOL.

CARING FOR AGEING PEOPLE LIVING WITH HIV

The general care of ageing people living with HIV should consider both HIV-related and age-related conditions. A patient-centred care [8] approach should be considered as the main strategy, as it addresses access to care, emotional support, physical comfort and respect for patient's preferences, among other principles. This model of care requires collaboration between the patient and an interdisciplinary team to facilitate active patient involvement in decision-making [9]. To offer appropriate management, care providers need to be able to predict the demands of an ageing population living with HIV and change both their approach and the goals of their offered care as necessary [10]. Needs change, not only between different individuals but also within the same person over time, and therefore the appropriate use of patient-reported outcomes (PROs) and the multidisciplinary geriatric assessment of patients are of pivotal importance. Ageing people living with HIV require functional, psychological and emotional support, with age-specific information, education and counselling programmes to support optimal physical and mental health [11]. This is critical for improving HRQOL and patients' satisfaction. Care interventions also need to be mindful of gender, ethnicity and the socio-economic environment, and to be free from discrimination and ageism.

AGEISM

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 [12]. The WHO definition of 'ageism' includes stereotypes (how we think), prejudice (how we feel) and discrimination (how we act) on the basis of age [13]. According to WHO, the effects of aegism are manifested as far as the denial of people's human rights, thus hindering their ability to reach their full potential [14]. Ageism is prevalent and ubiquitous, yet it remains largely unrecognized and unchallenged in our society and in healthcare settings. Research on ageism across contexts reveals ambiguous definitions [15] incorporating intolerant knowledge, values, attitudes and behaviours towards older people or, more generally, people of a certain age [16].

One common manifestation of ageism is age discrimination, usually used in the context of labour market research to describe the manifest preference for younger employees. However, ageism manifests in many other ways, depending on the context in which it is observed. For instance, when it comes to HIV prevention and sexual health, targeted efforts are very often geared

towards young people, the assumption being that aeging people are not engaging, nor have the desire to engage, in sexual activity. For many ageing people living with HIV, the intersection between stigma, self-stigma and ageism can lead to a self-protecting withdrawal from social, affective and sexual life. This can result in decreased intrinsic capacity, depression, loneliness and poor engagement with the healthcare system and poor health outcomes.

Ageism is not only a social construct. It has an important impact on the physical and mental health of the individual [17], being associated with a variety of outcomes such as mortality and physical and/or functional health, including frailty [18]. Ageism also has an impact on the way in which sexual activities, sexual desires and sexual expressions [19] are depicted and understood in relation to ageing people living with HIV. Within (but not exclusive to) the heteronormative construction of sex and sexuality, the aged body is naturalized, denied desire, or, where there is acknowledgement that sexual desire is still present, medical, sexological and cultural discourses are constructed with pathological representations. Ageing bodies are subject to sexual dysfunction, frailty, fragility and impaired performance, or fetishized notions of sexual relations, such as 'old with young'. Ageing bodies are seen in a range of positions from being incapable of physically engaging in sexual activity, to being sexualized in only fetishized form, to being characterised as grotesque, ugly, unattractive and sexually undesirable. Only where the body can be re-made young in its appearance, whether by cosmetic surgery or other soma technics, is there even the semblance of extending the 'shelf life' of desirability.

LOSS OF POWER

With older age inevitably comes a loss of power, which is reflected in the relationship between clinicians, heathcare providers and ageing people living with HIV. Old people lose authority and autonomy. Anecdotal evidence suggests that HIV care providers treat their ageing patients differently from the way they treat younger patients, more often avoiding discussions around sexuality and sexual desire [20]. Clinicians may take the complaints of ageing people living with HIV with regard to sexual performance and sexual desire less seriously than those of younger patients, attributing the complaints to 'old age' [21], as is seen in the general ageing population. By contrast, old age has been bio-medicalized, with the outcomes of social factors being defined as medical or personal problems to be alleviated by medical intervention. Old people lose their ability to make decisions about their bodies [22] because of the ways in which healthcare systems are organized [23] so that sexual health is relevant only if it is in relation to HIV and prevention of sexually transmitted diseases.

When ageing people living with HIV discussor attempt to discuss, aspects of their sexuality with healthcare providers, they may be met with the belief that older people are not and should not be sexually active [24]. Fear of discrimination and stigma could result in self-imposed restrictions on expressions of sexuality, further compromising sexual health in this population [25].

Research on sexual health among people living with HIV most often assesses the likelihood of sexual risk-taking or tests the efficacy of different risk reduction strategies rather than examining interventions that target intimacy, satisfaction or pleasure [26]. While certainly relevant, risk reduction strategies for older people with HIV should be discussed with healthcare providers in combination with interventions to maintain intimacy and increase sexual well-being, so as to increase engagement in HIV-related care and maintain and improve good HRQOL. To date, there are no published reviews that examine other aspects of sexual health that are important to ageing people living with HIV, such as desire, satisfaction and intimacy. Examining the literature on the sexual well-being of this group is a crucial first step in developing comprehensive, generationally specific HIV-related interventions that attend to both risk reduction and sexual pleasure.

PATHOLOGIZING SEXUAL DYSFUNCTIONS

Many ageing people living with HIV enjoy an active sex life, although they might experience problems. The environment of care does not lend itself to discussions about sex, and many patients find it difficult and embarrassing to talk about sexual problems, particularly in the context of ageism. To address this, specific training targeted at healthcare providers who work with ageing people living with HIV should be provided to impart knowledge of elderly sexuality and the skills required to discuss it sensitively.

Sexual problems in older people should be managed sensitively with respect to individual differences in sexual interest and activity. As with other systems of inequality, an exploration of age relations must begin by listening to those disadvantaged by them. At the same time, care must be taken not to over-sexualize the ageing process or to over-medicalize declining sexual function and interest. For example, the heavy involvement of drug companies

in the definition of male and female sexual dysfunction as a medical diagnosis is potentially worrying [27]. Moynihan describes how 'the potential risks, in a process so heavily sponsored by drug companies, is that the complex social, personal, and physical causes of sexual difficulties—and the range of solutions to them—will be swept away in the rush to diagnose, label, and prescribe' [28]. Katz and Marshall [29] describe the changing attitudes towards sexual decline in older age, with it now being seen primarily as a 'modifiable para-ageing phenomenon' rather than an inevitable consequence of ageing. We should be vigilant to the rebranding of normal processes as 'dysfunctional' with the consequent pathologizing of any aspect of normal ageing whether or not it causes a problem to the person themselves.

SUMMARY

When framing the care for ageing people living with HIV, we need to recognize that just as gender, race, class and sexual orientation serve as organizing principles of power, so too do stigma and ageism. A stronger theoretical grounding that recognizes the inherent complexities of the phenomenon of ageism as experienced by ageing people living with HIV should go hand in hand with the application of a more comprehensive and, ideally, unified definition of ageism that can reflect the multiplicity and complexity of its manifestations. For example, by applying a comprehensive definition of ageism, we can allow for the comparison of results between studies and across fields, enhancing the validity of the evidence. If this is not done, we will continue to have an incomplete picture of the prevalence of ageism in healthcare without fully comprehending the impact on HRQOL. We need to provide further evidence and greater clarity on the conceptualization and measurement/assessment of ageism in healthcare, specifically in relation to intimacy, sexual health and sexual needs for ageing people living with HIV.

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REFERENCES

1. UNAIDS. Political Declaration on HIV and AIDS: Ending Inequalities and Getting on Track to End AIDS by 2030. https://www.unaids.org/en/resources/documents/2021/2021_political-declaration-on-hiv-and-aids
2. 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.
3. Hsieh E, Polo R, Qian HZ, Fuster-RuizdeApodaca MJ, Del Amo J. Intersectionality of stigmas and health-related quality of life in people ageing with HIV in China, Europe, and Latin America. *Lancet Healthy Longev*. 2022;3(3):e206-e215.
4. Emlet CA. "You're awfully old to have this disease": experiences of stigma and ageism in adults 50 years and older living with HIV/ AIDS. *Gerontologist*. 2006;46:781-790.
5. Meeks S. Sexuality and aging: let's keep talking about this, shall we? *Gerontologist*. 2023;63(2):205-209.
6. Grosso TM, Hernández-Sánchez D, Dragovic G, et al. Identifying the needs of older people living with HIV (≥ 50 years old) from multiple centres over the world: a descriptive analysis. *AIDS Res Ther*. 2023;20(1):1-10.
7. Wang B, Peng X, Fu L, et al. Correlates of sexual lifestyles among older adults living with HIV in China: findings from the sexual well-being (SWELL) study. *Infectious Microbes & Diseases*. 2023;5(3):145-151.
8. Lazarus JV, Janamnuaysook R, Caswell G. A people-centred health system must be the foundation for person-centred care in the HIV response. *J Int AIDS Soc*. 2023;26(Suppl 1):e26125.
9. Okezue OC, Agbo EC, John JN, John DO. Patient involvement in medical decisions: a survey of shared decision making during physical therapy consultations. *Physiother Theory Pract*. 2023;39(4):878-886.
10. Ahmed MH, Ahmed F, Abu-Median AB, et al. HIV and an ageing population—what are the medical, psychosocial, and palliative care challenges in healthcare provisions. *Microorganisms*. 2023;11(10):2426.
11. Frey E, Johnston CD, Siegler EL. Treatment regimens and care models for older patients living with HIV: are we doing enough? *HIV AIDS*. 2023;15:191-208.
12. Levy SR, Lytle A, Macdonald J. The worldwide ageism crisis. *J Soc Issues*. 2022;78(4):743-768.
13. WHO Ageing and health. 2022 https://www.who.int/news-room/fact-sheets/detail/ageing-and-health
14. Chang ES, Kannoth S, Levy S, Wang SY, Lee JE, Levy BR. Global reach of ageism on older persons' health: a systematic review. *PLoS One*. 2020;15(1):e0220857.
15. Iversen TN, Larsen L, Solem PE. A conceptual analysis of ageism. *Nord Psychol*. 2009;61(3):4-22.
16. Mikołajczyk B. International human rights law and the intangible face of ageism. *Equal Divers Incl*. 2023;42(3):434-448.
17. Yu S, Carmody J, Wolfe M, Snyder R. The intersection between aging and public health. *Public Policy Aging Rep*. 2023;33(3):75-79.

18. 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;20:1-11.
19. Flesia L, Monaro M, Jannini EA, Limoncin E. "I'm too old for that": the role of ageism and sexual dysfunctional beliefs in sexual health in a sample of heterosexual and LGB older adults: a pilot study. *Healthcare*. 2023;11(4):459.
20. Henrickson M, Charles C, Ganesh S, Giwa S, Kwok KD, Semigina T. *HIV, Sex and Sexuality in Later Life*. Policy Press; 2022.
21. Brennan-Ing M, Mattas E. Aging with HIV: working to ensure equity and inclusion. *Gerontology*. 2023;69(8):946-952.
22. Hooper SC, Kilpela LS, Ogubuike V, Becker CB. Fat talk, old talk, or both? association of negative body talk with mental health, body dissatisfaction, and quality of life in men and women. *J Eat Disord*. 2023;11(1):1-17.
23. Meng LC, Huang ST, Chen HM, Hashmi AZ, Hsiao FY, Chen LK. Health care utilization and potentially preventable adverse outcomes of high-need, high-cost middle-aged and older adults: needs for integrated care models with life-course approach. *Arch Gerontol Geriatr*. 2023;109:104956.
24. Soysal P, Avsar E. Sexual activity and physical health benefits in older adults. *Sexual Behaviour and Health in Older Adults*. Springer International Publishing; 2023:15-24.
25. Gewirtz-Meydan A, Ayalon L. Reasons people refrain from sex in later life. *J Sex Marital Ther*. 2023;49(2):189-207.
26. Kitonsa J, Kansiime S, Kusemererwa S, et al. Changes in self-reported risky sexual behaviour indicators among adults receiving regular risk reduction counselling and optional initiation of pre-exposure prophylaxis in an HIV vaccine preparedness study in Masaka. *Glob Health Action*. 2023;16(1):2242672.
27. Fishman JR, Mamo L. What's in a disorder: a cultural analysis of medical and pharmaceutical constructions of male and female sexual dysfunction. *Women Ther*. 2002;24(1–2):179-193.
28. Moynihan R. Who pays for the pizza? redefining the relationships between doctors and drug companies. 2: disentanglement. *BMJ*. 2003;326(7400):1193-1196.
29. Katz S, Marshall B. New sex for old: lifestyle, consumerism, and the ethics of aging well. *J Aging Stud*. 2003;17(1):3-16.