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**Ready or not: addressing stigma and promoting wellbeing of people living with HIV in aged-care**

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Given the increasing number of people ageing with HIV, it is important that aged-care services are ready to meet their care needs.

The aged-care sector currently supports a large number of older Australians to remain in their own homes, with residential services provided to about 5% of people over 65 years. These supports need to take into account particular issues faced by older people living with HIV.

However, recent studies indicate that aged-care services do not understand the needs of older HIV-positive people and discriminate against this cohort because of fear of HIV. These findings are of particular concern in the context of a recent study of the health and psychological wellbeing of HIV-positive, older gay men. The study found that:

‘… the strongest predictor of subjective wellbeing was men’s reported history of discrimination from medical service providers around their HIV status, therefore highlighting perceived stigma as a crucial element in overall wellbeing.’ [1](http://www.afao.org.au/view_articles.asp?pxa=ve&pxs=103&pxsc=127&pxsgc=138&id=900#n1)

This article looks at the readiness of aged-care services to meet the needs of people living with HIV from the perspective of older HIV-positive people (and those assumed to be HIV-positive), and from the perspective of people working in aged-care. We then examine these perspectives in the current context of aged-care service provision, to illustrate the need for a person centred strategy to educate aged-care service providers.

**Client experiences of aged-care**

In 2008, a study was undertaken in Victoria to explore the experiences of older gay, lesbian, bisexual, transgender and intersex (GLBTI) people in aged-care. [2](http://www.afao.org.au/view_articles.asp?pxa=ve&pxs=103&pxsc=127&pxsgc=138&id=900" \l "n2) The My People study included interviews with eight gay or bisexual men, one of whom disclosed being HIV-positive. Most of the men raised concerns about the readiness of aged-care services to care for people who are HIV-positive, or assumed to be so. Several described how carers assumed that they were HIV-positive because they were gay. For example, Andrew described having a home care provider from his local council visit his home daily to shower his partner Bill. Andrew described inadvertently revealing that he and Bill were in a relationship and noted that in response

“The carer wouldn’t really shower Bill after that. Bill was blind, deaf, full of arthritis and needed all the help going. I think the carer was concerned that we were gay. The guy thought: he’s gay and has he got something else wrong with him? He was worried about HIV/AIDS. That’s what I think. I phoned the council and told them. They were very good. I told them I didn’t want him back.” [3](http://www.afao.org.au/view_articles.asp?pxa=ve&pxs=103&pxsc=127&pxsgc=138&id=900" \l "n3)

Other interviewees described aged-care service staff refusing to physically touch them or ‘double gloving’ for all physical contact with them when it was revealed that they were gay. As a consequence all the interviewees reported that they were reluctant to access aged-care services and that they hid their sexual identity when accessing services to avoid being assumed to be HIV-positive.

The study was small and limited to the experiences of gay men in Victoria. However, the findings indicate that some aged-care service providers do not understand HIV, with the result that their responses are discriminatory. This is concerning given the finding that discriminatory responses are a crucial element affecting overall wellbeing.

**Staff perspectives**

The views of aged-care service providers on caring for HIV-positive people were described in a 2008 study exploring their perspectives on the care of GLBTI clients. [4](http://www.afao.org.au/view_articles.asp?pxa=ve&pxs=103&pxsc=127&pxsgc=138&id=900" \l "n4) The study included three focus groups and 16 interviews with aged-care service providers. Participants were given a scenario of a newly admitted HIV-positive client, and they were asked to describe how staff in their service would respond to this client. Most of the study participants reiterated the misinformation and fear of contagion identified in the My People study. One interviewee reported that her colleagues:

“ … would over-glove; there are always staff who go too far; I don’t think staff have nursed enough HIV, so they would freak out.” [5](http://www.afao.org.au/view_articles.asp?pxa=ve&pxs=103&pxsc=127&pxsgc=138&id=900" \l "n5)

Another reported that:

“ … some staff might steer away, not go near him, and avoid nursing him. They need the facts of how HIV is transmitted and whether there going to be any dangers for them.” [6](http://www.afao.org.au/view_articles.asp?pxa=ve&pxs=103&pxsc=127&pxsgc=138&id=900" \l "n6)

These responses were fairly typical of the views expressed by other interviewees. The fear of the contagion of HIV, and the assumption that all gay men are HIV-positive, was also identified in the focus groups. One focus group was held in a high-care facility where staff had recently identified that a resident was gay. In reference to this resident, one of the focus group participants reported that:

“We don’t have the information on whether he has AIDS. I feel sorry for the poor personal care attendants that go in there and don’t wear gloves to protect themselves. If they get AIDS who are they going to sue?” [7](http://www.afao.org.au/view_articles.asp?pxa=ve&pxs=103&pxsc=127&pxsgc=138&id=900" \l "n7)

These views demonstrate the fear of contagion that is associated with ignorance about HIV and its transmission. Many of the study participants reported that they had not received any education around HIV since the ‘Grim Reaper’ Australian national television campaign of the 1980s. Perhaps then it is not surprising that they fear HIV-positive clients.

The importance of educating aged-care service providers was reiterated in a study conducted in aged-care across Sydney, in which service providers were invited to complete a survey about their knowledge of HIV and their concerns. Of the 106 respondents, 55% said they worried about catching HIV from a resident, and 62% said that they worried about passing on HIV to their families after caring for the resident. [8](http://www.afao.org.au/view_articles.asp?pxa=ve&pxs=103&pxsc=127&pxsgc=138&id=900" \l "n8) This study reinforces the importance of educating aged-care service providers to ensure the wellbeing of older HIV-positive people.

**A framework for education to promote wellbeing**

The opportunity exists to educate aged-care service providers about HIV in a way that addresses fears of contagion and promotes the wellbeing of HIV-positive clients. This can be achieved by focusing on person-centred care. A person-centred approach is generally accepted in aged-care and has been identified by the Department of Health in Victoria (2004) as a strategy to improve care for older people. [9](http://www.afao.org.au/view_articles.asp?pxa=ve&pxs=103&pxsc=127&pxsgc=138&id=900" \l "fn9)

The person-centred approach adopted in our training, which is co-ordinated by Gay and Lesbian Health Victoria, sets out to improve outcomes for the care of people living with HIV by addressing the needs of both staff and clients. The education begins by inviting staff to describe their fears, assumptions and beliefs. This provides the opportunity to challenge myths and provide factual information, including reinforcing universal precautions. Staff can then understand the experience of aged-care from the perspective of the HIV-positive client. To achieve this we use narratives from older HIV-positive people, these providing humanising accounts of the experience of living with HIV. This encourages service providers to look beyond the virus to the experience of the person living with the virus. The narratives also demonstrate for staff how a discriminatory response can impact on client wellbeing.

This educational framework needs to take into account the current context of aged-care services. For the past decade, the aged-care section of the Victorian Department of Health has experienced a number of challenges. In 2004, concerns about care and staff recruitment led to a Senate inquiry into the aged-care workforce. [10](http://www.afao.org.au/view_articles.asp?pxa=ve&pxs=103&pxsc=127&pxsgc=138&id=900" \l "n10) The inquiry found that although the numbers of older people requiring aged-care services has increased, the aged-care workforce has decreased. Furthermore, the inquiry recognised that poor pay and increasing bureaucratisation of aged-care made it difficult to recruit and retain staff. While the inquiry noted a shortage of appropriately qualified staff in all health sectors, it reported that this was most notable in the aged-care sector. The inquiry also uncovered that the effects of an inappropriate skills mix included increased stress and a potential decrease in the quality of care.

Education of aged-care service providers also needs to take into account high turnover of staff, low literacy, low morale and significant workloads. There is also a need to recognise that many who work in aged-care services are motivated by good intent – that they would provide a higher standard of care if the education were provided to show them what was required. For example, in the study described earlier by Cummins et al., [11](http://www.afao.org.au/view_articles.asp?pxa=ve&pxs=103&pxsc=127&pxsgc=138&id=900" \l "n11) aged-care service providers indicated that they were concerned about HIV contagion but were more worried (60% of respondents) about not knowing how to care for a resident with HIV. Aged-care service providers deserve to be given the information they require to do their job well.

**Conclusions**

Until aged-care service providers are educated about the needs of people in their care living with HIV, their responses will continue to be driven by misinformation and misplaced fears, and they will continue to miss the opportunity to promote the wellbeing of this client group. The educational model described in this article involves exploring staff and client narratives as a way of addressing staff fears and meeting client needs. The narratives told by older HIV-positive people provide aged-care services providers with the opportunity to understand their clients’ journeys, including challenges encountered and overcome, and their experience of co-morbidities. This model needs to be considered by those providing services to older people in residential care, home care, community care, rehabilitation and acute care.

**References**

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[7.](http://www.afao.org.au/view_articles.asp?pxa=ve&pxs=103&pxsc=127&pxsgc=138&id=900" \l "fn7" \o "7.) Ibid.

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