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Leading the community response to HIV

Submission to the Royal Commission into Aged Care Quality and Safety

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Australian Federation of AIDS Organisations

The Australian Federation of AIDS Organisations (AFAO) is the national federation for the HIV community response in Australia. AFAO works to end HIV transmission and reduce its impact on communities in Australia, Asia and the Pacific. AFAO's members are the AIDS Councils in each state and territory; the National Association of People with HIV Australia (NAPWHA); the Australian Injecting & Illicit Drug Users League (AIVL); Anwernekenhe National HIV Alliance (ANA); and Scarlet Alliance, Australian Sex Workers Association. AFAO's affiliate member organisations – spanning community, research and clinical workforce – share AFAO's values and support the work we do.

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National Association of People with HIV Australia

Founded in 1989, The National Association of People with HIV Australia (NAPWHA) is Australia's peak non-government organisation representing community-based groups of people living with HIV (PLHIV). NAPWHA's membership of national networks and state-based organisations reflects the diverse make-up of the HIV-positive community and enables NAPWHA to confidently represent the positive voice in Australia. NAPWHA provides advocacy, policy, health promotion, effective representation, and outreach on a national level. Its work includes a range of health and education initiatives that promote the highest quality standard of care for HIV-positive people. NAPWHA also contributes to clinical and social research into the incidence, impact and management of HIV.

Introduction

AFAO and NAPWHA welcome the opportunity to provide a submission to the Royal Commission into Aged Care Quality and Safety.

Recommendations

1. Aged care service providers should provide mandatory education and awareness training to staff about blood borne viruses and sexually transmissible infections. This should include training about HIV so that staff are informed on issues such as HIV treatment, actual risk of HIV infection in occupational settings and the effect of HIV stigma and discrimination on the quality of life of people living with HIV (PLHIV).

2. As the population of PLHIV grows in Australia, aged care providers must recognise that the coexistence of HIV and ageing will present unique health challenges for older people accessing services. Service providers should make arrangements to ensure that they provide optimal care and support, including the provision of specialised HIV medical and support services.

3. Aged care service providers should promote a healthy sex life for older people accessing services inclusive of sexual health promotion and education and HIV and STI screening for those who are sexually active.

4. HIV community organisations should be resourced with the capacity to provide peer-based support, advice and appropriate referral pathways to support and advocate for PLHIV as they age, and to create settings that address the needs of sexually active older people.

5. Service providers should have clear policies and procedures in order to give transparent, professional parameters for staff, clients and sex workers about their rights and responsibilities in relation to sex work.

Summary

HIV and Ageing in Australia

According to the most recent data, there are 27,545 people currently living with HIV in Australia[1]. The first reported cases of HIV occurred in Australia in the early 1980s and today 11,361 PLHIV in Australia are aged 50 years or older[2].

Because of the availability of subsidised effective treatment through the Pharmaceutical Benefits Scheme (PBS), HIV is now regarded by healthcare workers and researchers as a chronic but manageable medical condition[3]. As a result of the advances in HIV antiretroviral therapy (ART), the proportion of PLHIV in Australia aged 50 years or older will continue to grow. As a corollary there will be an increasing number of individuals who are ageing with HIV and who need higher levels of care, including in residential aged care[4].

Many PLHIV will lead long and healthy lives as they age. However, there is a growing body of evidence to suggest that HIV can have adverse effects on the ageing process. Ageing (whether in tandem with HIV infection or not) can impact the immune system in a variety of ways, including decreasing CD4 count, decreased CD4/CD8 ratio, decreased thymic output, and other signs of immune system decline. The same trends in immune function can also be seen in those living with HIV[5].

PLHIV are also at increased risk of cardiovascular disease due to traditional risk factors (increased lipids, high blood pressure, diabetes, and smoking), ART-related factors (due to lipid, glucose and/or insulin abnormalities),

[1] The Kirby Institute (2018) HIV in Australia: Annual Surveillance Short Report 2018, UNSW, Sydney, Australia.
[2] Ibid.
[3] Gallant, J. (2000) Strategies for long-term success in the treatment of HIV infection, *The Journal of the American Medical Association*, 283 (10): 1329-1334.
[4] Murray, K. et al (2014) Developing a protocol for people living with HIV entering aged care facilities, *Australian Nursing and Midwifery Journal*, 21 (1): 34-36.
[5] Henry, K. (2009) What are the standards of care for HIV-positive patients aged 50 years and older?, *HIV/AIDS Reports*, 6 (1): 153-161

neurological issues (HIV-associated neurocognitive disorder) and other factors possibly related to HIV (decrease in high-density lipoprotein, decrease in bone density, increase in triglycerides, immune activation, increased thrombosis and fibrinolysis, and endothelial dysfunction)[6].

In response to the Royal Commission into Aged Care Quality and Safety, AFAO and NAPWHA conducted a joint community consultation at the Bobby Goldsmith Foundation with older PLHIV who access or have accessed aged care services. One participant at the joint community consultation noted:

> *"I've got absolutely no bone structure left in my body, because of the drugs and the low immune and everything else that affects you, so I'm literally left a cripple. And I blame a lot of that on the treatment"* – David, aged 57[7].

As PLHIV age, the complexity of their health problems may increase, which could place additional demands on the health care system[8]. It is important that the aged care sector is well positioned to deal with this reality, especially as the population of PLHIV grows older and begins accessing aged care services at a higher rate. The coexistence of ageing, HIV infection, and a wide range of both HIV-related and unrelated comorbidities will likely result in more complex treatment situations[9].

The progression of HIV in the body can cause people living long term with HIV to experience a higher prevalence of co-morbidities than their HIV negative counterparts[10]. While the risk of experiencing adverse effects on the aging process can be managed by using effective ART, some people may not tolerate this treatment or cannot take treatment as prescribed. This cohort of people are at high risk of experiencing HIV-related illnesses and may need earlier access to residential aged care facilities and home-based care. Similarly, people who took HIV medications before the availability of effective ART are at increased risk of experiencing co-morbidities and may also require earlier access to care in residential aged care facilities or through home-based packages. Another participant at the community consultation explained:

> *"I want to live at home as long as I possibly can, because I like being involved with the community around me and so on. But the reality is, my heart is extremely poor. I've got a couple of nasty HIV diseases which can flare up and knock everything out of place"* – Roger, aged 62[11].

This submission will demonstrate that, despite the effectiveness of current HIV treatment and care, discrimination, stigma and mistreatment of PLHIV in aged care settings persists[12]. The situation exists because of an inadequately supported workforce that has insufficient knowledge of HIV treatment, medical and social support services and inaccurate perceptions of HIV transmission. Additionally, PLHIV can present with additional needs in the form of social and cultural concerns in relation to the intersection between living with HIV and sexuality, particularly for gay and bisexual men.

Stigma and Discrimination

PLHIV are at constant risk of stigma and discrimination based on HIV status and/or sexuality[13]. PLHIV are likely to have different experiences of stigma, however these experiences can have a major impact on esteem and overall health and wellbeing[14]. Stigma and discrimination based on HIV status is usually a result of misinformation and unsubstantiated fears of HIV transmission. Therefore, the opportunity exists to educate aged-care service providers about HIV in a way that addresses fears of infection and promotes the wellbeing of HIV-positive people[15]. The effect

[6] Henry, K. (2009) What are the standards of care for HIV-positive patients aged 50 years and older?, *HIV/AIDS Reports*, 6 (1): 153-161
[7] AFAO and NAPWHA Aged Care Community Consultation, Held at Bobby Goldsmith Foundation, Sydney, 16 July 2019
[8] Henry, K. (2009) What are the standards of care for HIV-positive patients aged 50 years and older?, *HIV/AIDS Reports*, 6 (1): 153-161
[9] Ibid.
[10] Petoumenos, K, et al. (2017) Prevalence of self-reported comorbidities in HIV positive and HIV negative men who have sex with men over 55 years—The Australian Positive & Peers Longevity Evaluation Study (APPLES), PLOS ONE 12(9)
[11] AFAO and NAPWHA Aged Care Community Consultation, Held at the Bobby Goldsmith Foundation, Sydney, 16 July 2019
[12] Murray, K. et al (2014) Developing a protocol for people living with HIV entering aged care facilities, *Australian Nursing and Midwifery Journal*, 21 (1): 34-36.
[13] Grierson, J. et al (2013) HIV Futures Seven: The Health and Wellbeing of HIV Positive People in Australia.
[14] Alzheimer's Australia (2014) Living with HIV Associated Neurocognitive Disorder (HAND)
[15] Barrett C. et al (2008) Ready or not: addressing stigma and promoting wellbeing of people living with HIV in aged-care, *HIV Australia*, 8 (3): 35-37

of stigma and the role of education was noted by a number of community consultation participants:

> *"It [stigma] can be very hurtful, someone is supposed to be looking after you. And again, it's the old principle of education. We all know how hard it is. You're not going to get through to everyone with education because there is not enough money for it. But … I certainly expect that the staff … should know"* – Roger, aged 62[16].

The opportunity also exists to educate other aged-care facility residents on these issues as well. It is important that education and training on HIV is engaging, culturally appropriate and mandatory. Unless carers and other residents are educated about HIV and PLHIV's needs, there is a risk that their responses will be influenced by misinformation and unfounded fears, and there will be missed opportunities to promote the health and wellbeing of PLHIV[17]. Should the Royal Commission adopt the proposal to implement registration of aged care workers, training should be inclusive of HIV and STIs.

PLHIV are acutely aware that HIV stigma exists, which can impact their desire or willingness to access services – including aged care services. In one study[18], 61% of participants were apprehensive about future placement into a residential aged care facility (RACF), 54% of respondents were concerned about lack of HIV knowledge of staff, 48% were worried about HIV related discrimination, and 42% of aged care workers lacked experience caring for PLHIV. Those respondents who identified as gay were also anxious that aged care facilities were not gay friendly.

> *"I would hate for somebody like myself, who is an out male, or somebody who is a fabulous drag queen to be shoved into a nursing home. That would be like shoving them back into the closet. Most aged care facilities are full of nothing but negative people. They are run by negative staff. Uneducated staff who do not understand HIV"* – Phil, aged 59[19].

In another study that included a survey of aged-care providers in Sydney, 55% said they were worried about acquiring HIV from an HIV-positive resident, and 62% said that they were worried about passing HIV onto their families after caring for a resident living with HIV[20]. This survey illustrates the lack of knowledge among aged care providers of contemporary HIV science and, in particular, concepts like Undetectable equals Untransmissible (U=U). An HIV positive person who has an undetectable viral load, sustained for six months or more, cannot transmit HIV to sexual partners[21]. This reinforces the importance of educating aged-care service providers about HIV transmission and treatment as prevention, to ensure older PLHIV are cared for properly and consistently.

> *"I was really upset at the way some people were being treated…it wasn't consistent. The level of knowledge [about HIV] was not as good as it should have been"* – Roger, aged 62[22].

It has been reported that some aged care service-providers consider being gay and HIV-positive mutually inclusive[23]. This can result in potential dual stigma and discrimination, in which aged-care service providers assume an individual's HIV status or sexuality and may care for an older person differently or use unnecessary and degrading HIV prevention strategies upon learning that the individual is gay. In another study[24], a participant reflected on his experience:

> *"The carer wouldn't really shower Bill after that…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".*

[16] AFAO and NAPWHA Aged Care Community Consultation, Held at the Bobby Goldsmith Foundation, Sydney, 16 July 2019
[17] Barrett C. et al (2008) Ready or not: addressing stigma and promoting wellbeing of people living with HIV in aged-care, *HIV Australia*, 8 (3): 35-37
[18] Cummins, D. & Trotter, G. (2008) Ageing and HIV disease – a client's perspective, *Australian Journal of Advanced Nursing*, 25 (3): 58-64.
[19] AFAO and NAPWHA Aged Care Community Consultation, Held at the Bobby Goldsmith Foundation, Sydney, 16 July 2019
[20] Cummins, D. & Trotter, G. (2008) Ageing and HIV disease – a client's perspective, *Australian Journal of Advanced Nursing*, 25 (3): 58-64.
[21] https://ashm.org.au/about/what-we-do/position-statements/U-equals-U/
[22] AFAO and NAPWHA Aged Care Community Consultation, Held at the Bobby Goldsmith Foundation, Sydney, 16 July 2019
[23] Barrett, C (2008) My people: A project exploring the experiences of Gay, Lesbian, Bisexual, Transgender and Intersex seniors in aged-care services, Matrix Guild Victoria and Vintage Men
[24] Barrett, C (2008) My people: A project exploring the experiences of Gay, Lesbian, Bisexual, Transgender and Intersex seniors in aged-care services, Matrix Guild Victoria and Vintage Men

This echoed experiences of a participant in our community consultation:

> *"These people are generally straight, that don't have HIV or anything like that. You're treated like a leper, they treat your friends like lepers. They automatically assume they're the same" – David, aged 57.*

Another participant in the study[25] spoke of choosing not to disclose his HIV status due to fear of discrimination:

> *"I didn't tell them at first I had HIV, but they were giving out my medications. They worked out I was gay".*

Similar sentiments were expressed in our own community consultation:

> *I would not disclose my status, because the minute someone knows your status it can be used as a weapon against you* – Phil, aged 59[26].

While the National LGBTI Ageing and Aged Care Strategy references PLHIV, more needs to be done to ensure that PLHIV can readily and easily access services, care and treatment without fear of discrimination and stigma.

First recommendation

Aged care service providers should provide mandatory education and awareness training to staff about blood borne viruses and sexually transmissible infections, as well as anti-discrimination laws. This should include training about HIV so that staff are informed on issues such as HIV treatment, actual risk of HIV infection in occupational settings and the effect of HIV stigma and discrimination on the quality of life of people living with HIV (PLHIV).

HIV-Associated Neurocognitive Disorders

PLHIV may also experience a higher prevalence of dementia at a younger age compared to the general community[27]. HIV may result in damage to the brain, leading to a range of medical conditions known as HIV-associated neurocognitive disorders (HAND). Symptoms of HAND vary from person to person. In most people, symptoms are mild, or may only be picked up through medical testing[28]. With the population of PLHIV ageing due to improved life expectancy, the prevalence of HAND may increase in the future[29]. One community consultation participant described the effect HIV and treatment has had on his neurocognitive function:

> *"The brain has had a sheer kicking, memory's going and I'm a bit paranoid…the dodgy memory I see as my biggest [HIV related] problem"* – Frank, aged 75[30].

HAND can be mild to severe, depending on the seriousness of symptoms and their impact on daily life[31]. HAND can affect cognitive functions such as memory, language, attention, concentration, planning and judgement. As a result, HAND can reduce a person's independence and quality of life[32]. HAND affects people differently, and the support needs of someone living with HAND vary over time. HAND may pose a substantial personal, societal and economic burden, with studies suggesting between 20-52% of PLHIV may be affected at some point[33,34]. This has serious implications for the ability of people with HAND to navigate complex application and assessment processes independently to access the care and support services they need.

[25] Barrett, C (2008) My people: A project exploring the experiences of Gay, Lesbian, Bisexual, Transgender and Intersex seniors in aged-care services, Matrix Guild Victoria and Vintage Men
[26] AFAO and NAPWHA Aged Care Community Consultation, Held at the Bobby Goldsmith Foundation, Sydney, 16 July 2019
[27] Murray, K. et al (2014) Developing a protocol for people living with HIV entering aged care facilities, *Australian Nursing and Midwifery Journal*, 21 (1): 34-36.
[28] Alzheimer's Australia (2014) Living with HIV Associated Neurocognitive Disorder (HAND)
[29] Buchanan, R. J. et al (2001) Analyses of nursing home residents with HIV and dementia using the minimum data set, *Journal of Acquired Immune Deficiency Syndromes*, 26 (1): 246-255.
[30] AFAO and NAPWHA Aged Care Community Consultation, Held at the Bobby Goldsmith Foundation, Sydney, 16 July 2019
[31] Alzheimer's Australia (2014) Living with HIV Associated Neurocognitive Disorder (HAND)
[32] Ibid.
[33] Ibid.
[34] Heaton, R. et al (2010) HIV-associated neurocognitive disorders persist in the era of potent antiretroviral therapy: CHARTER Study, *Neurology,* 75 (23): 2087-96.

HAND is different to more common types of cognitive issues such as dementia and Alzheimer's disease. Generally, other types of dementia result in a permanent decline in function, however this is not the case with HAND. If a person diagnosed with HAND receives the right HIV treatment, their cognitive ability can be stabilised and improve[35]. Therefore, it is important that aged care providers can recognise the symptoms of HAND and provide care and treatment as appropriate, and as quickly as possible.

HIV and dementia both carry a burden of stigma, with a risk of prejudice and discrimination. Both conditions can be misunderstood because of myths and misconceptions[36]. Fear of stigma and discrimination can make people with HIV less likely to discuss problems, including those that might be caused by HAND. Peer support and professional counselling by people experienced in this area may help manage such concerns[37].

It is of note that the annual cost for care in Australia related to HIV associated dementia is expected to increase from approximately $29 million in 2009 to $53 million in 2030[38].

Second recommendation

As the population of people living with HIV grows in Australia, aged care providers must recognise that the coexistence of HIV and ageing will present unique health challenges for older people accessing services. Service providers should make arrangements to ensure that they provide adequate care and support, including the provision of specialised HIV medical and support services.

Sexual Health, HIV and Ageing

There is a broad social myth that older people do not have a sexual identity, nor are interested in or engage in sex. This erroneous belief is sometimes reflected in aged care staff attitudes[39]. Yet growing evidence shows that sexual desire and behaviour continues as people age, with older people having sex and other forms of intimate relationships well into old age[40].

The sexual health and rights of older adults continue to be a 'blind spot in the policy architecture'[41]. This issue is often omitted from wider conversations around sexual health and is not usually included in targeted programs, which are often directed at young people of reproductive age and usually through the lens of maternal health[42]. Aged-care staff and other medical professionals are often inadequately trained on sexual health, including the sexual health of LGBTI people, and thus can be uncomfortable discussing sex and sexuality with older people, including those who identify as LGBTI[43].

Because sexuality education and HIV information almost exclusively targets young and middle aged people, HIV and STI testing and counselling programs sometimes deny or discourage older adults from HIV testing as a result of misconception about their risk[44]. As a result, older people often do not perceive themselves at risk for HIV or other STIs, use condoms less than younger people, and are tested for HIV and STIs less frequently[45].

Third recommendation

Aged care service providers should promote a healthy sex life for older people accessing services inclusive of sexual health promotion and education and HIV and STI screening for those who are sexually active.

[35] Alzheimer's Australia (2014) Living with HIV Associated Neurocognitive Disorder (HAND)
[36] Ibid.
[37] Ibid.
[38] Cystique, L. A. et al (2011) The burden of HIV associated neurocognitive impairment in Australia and its estimates for the future, *Sexual Health,* 8 (1): 541-550.
[39] Petrie, N. & Cook, P. S. (2019) Catering to sex, sexual, and gender diversity: An exploratory study on the effects of LGBTI awareness training on aged care staff in Tasmania, Australia, *Journal of Gay & Lesbian Social Services*, 31 (1): 1-16.
[40] Heidari, S. (2016) Sexuality and older people: a neglected issue, *Reproductive Health Matters*, 24 (48): 1-5
[41] Aboderin I. (2014) Sexual and reproductive health and rights of older men and women: Addressing a policy blind spot, *Reproductive Health Matters*, 22 (44): 185–190.
[42] Heidari, S. (2016) Sexuality and older people: a neglected issue, *Reproductive Health Matters*, 24 (48): 1-5
[43] Ibid.
[44] Heidari, S. (2016) Sexuality and older people: a neglected issue, *Reproductive Health Matters*, 24 (48): 1-5
[45] Henry, K. (2009) What are the standards of care for HIV-positive patients aged 50 years and older?, *HIV/AIDS Reports*, 6 (1): 153-161

Fourth recommendation

HIV community organisations should be resourced with the capacity to provide peer-based support, advice and appropriate referral pathways to support and advocate for PLHIV as they age, and to create settings that address the needs of sexually active older people.

Sex Workers

As has been established, sexual desire and behaviour continues as people age. While it is recognised by some that older people living in aged-care facilities or accessing home-based care packages engage in intimate relationships with partners, another area that needs to be addressed is older people's ability to access the service of sex workers.

Sex work is already occurring in aged care facilities[46], however there is a lack of clarity for service providers, service users and sex workers on this issue. This is in part due to haphazard laws and regulations that differ across Australian states and territories. While sex work is decriminalised in New South Wales, other states have more punitive laws relating to sex work. This lack of clarity is also influenced by misconceptions about the services that sex workers provide and the physical, social and emotional value for some aged care residents and service users.

Sex workers provide an important service for some older people who seek out intimacy and connection. Sexual expression should be part of a holistic, person-centred approach to the wellbeing of people in aged care. Emma Arvo, a sex worker whose clients include those living in RACFs, reflected for this submission:

> *"Their needs are as varied as their backgrounds, but the bottom line is that they all require a degree of intimacy and connection that is not available to them otherwise. Some struggle to form conventional relationships which can be due to physical or intellectual disability or social anxiety and isolation, the need for increased or different types of sexual and intimate fulfilment at different times of their lives, loneliness, dementia and illness or death of a partner when sexual engagement is no longer possible."*

While engaging a sex worker is not inherently risky, older people should be given the 'dignity of risk' to access these services should the wish to. Service providers should be open and prepared to facilitate their client's requests in relation to sex workers and staff should be willing and able to provide support by outlining a resident's needs, such as issues around their mobility and cognitive capacity.

Sex workers are still a highly stigmatised group of people, so addressing stigma towards sex workers in aged care facilities and broader society is vital. There needs to be fewer barriers, shame and greater dialogue about the importance of sex workers to some older people accessing aged care services. Service providers should have clear policies and procedures in order to give transparent, professional parameters for staff, clients and sex workers about their rights and responsibilities in relation to sex work.

Fifth recommendation

Service providers should have clear policies and procedures in order to give transparent, professional parameters for staff, clients and sex workers about their rights and responsibilities in relation to sex work.

Conclusion

HIV is a chronic condition that still impacts a large number of older Australians, and the number of people living with HIV and growing older will continue to increase.

> *"Everyone sits there and says oh well, they've got the pills now, they'll be alright. I had an ex-partner who said to me, well at least you'll get 15-20 years more life and I said that's all very nice but what about the quality of*

[46] Tran, M. (2018) Sex work in aged care more than just physical, Aged Care Insite

that. That's really important to me that I get care and medical treatment when I need it, that I'm not shoved in a corner, and that I get accommodation and a future that is not a dive to live in and that if there is people having to look after me, that they are not discriminating – Roger, aged 62[47]."

As the population of people living with HIV ages, pertinent issues will need to be addressed to ensure that those ageing with HIV can do so with dignity and in good health. As has been discussed, people living with HIV may have additional needs in the form of social and cultural concerns, specialised HIV medical and social support services, access to treatment and perceptions of risk and misinformation about HIV transmission among some aged care workers, potentially leading to discrimination, stigma and mistreatment.

Two recently published reports provide extensive documentation and evidence about the increasing number of people aged 50 years and above, living with blood borne viruses and HIV; and the intersection of ageing, disease management and quality of life for those living longer with these health conditions[48,49]. These reports acknowledge the complex health and policy frameworks and practices that need to be aligned to ensure that the aged care sector delivers access to care for all Australians who need care.

Education and awareness training and the streamlining or creation of policies and procedures relating to HIV, blood borne viruses and sexual health should be a priority for the aged care sector. Training, policies and procedures should focus on removing the current barriers experienced by the populations that AFAO and NAPWHA represent – particularly people who are living with HIV and ageing. AFAO and NAPWHA encourage the Royal Commission into Aged Care Quality and Safety to address the specific recommendations outlined in this submission.

[47] AFAO and NAPWHA Aged Care Community Consultation, Held at the Bobby Goldsmith Foundation, Sydney, 16 July 2019

[48] Mao,L. et al (2019) Ageing among people with HIV or Chronic HBV/HCV in the ACT: a brief report. Canberra: The AIDS Action Council

[49] Woods, R (2019) HIV and Ageing in Australia – The New Frontier. National Association of People with HIV Australia