

“Is it HIV or just old age?” How Australia’s first generation of PLHIV are experiencing ageing

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Around half of all people living with HIV (PLHIV) in Australia are now over 50 [1] with this number projected to rise [2]. A substantial proportion of older PLHIV are living in rural and regional areas [3]. Older PLHIV are likely to require particular care and support, with important implications for Australia’s health and aged care services across regional, rural and urban areas.

Most PLHIV are ‘ageing well’, but increasing comorbidities, side effects of long-term treatment and uncertainties about future care are evident. We know from the research literature that biological ageing processes often occur earlier for PLHIV, and multi-morbidity and polypharmacy are common [4, 5]. As PLHIV live longer they are at risk of increased disability and poorer physical and mental health-related outcomes compared with the general population [6, 7]. *HIV Futures 8* found older PLHIV reported poorer physical health and limitations in their capacity to do daily tasks [8]. Uncertainties surrounding future care, including concerns related to health providers’ knowledge of HIV and ageing, and management of complex comorbidities are also common in older PLHIV [9, 10].

Australia’s current population of PLHIV is the first to reach older age. As such, they are the focus of a growing body of research designed to understand current and future health and social care needs. Their life expectancy is now close to that of the general population [11, 12], but they face unique challenges related to HIV and ageing, further complicated by intersections with social determinants of health. Understanding how social factors [13, 14] influence PLHIV’s ability to self-manage and age ‘well’ is a critical question for researchers and policy makers.

Living Positive in Queensland

Living Positive in Queensland (LPQ) is a qualitative longitudinal study that considered ageing, locality and support for people living long term with HIV. Between 2013 and 2017, 73 participants completed more than 200 interviews. LPQ was conceived, designed and conducted in partnership with HIV related community organisations including Queensland Positive People (QPP) and the Queensland AIDS Council (QuAC). It has operated in accordance with MIPA

(Meaningful Involvement of PLHIV and Affected Communities) principles.

Two-thirds (49) of LPQ participants were 50 plus. The majority have lived with HIV for 15 years or more and many had moved to regional and rural Queensland following diagnosis. Four older participants were women and 45 were men; 39 participants identified as gay. Most were living with co-morbidities including mental health and cognitive issues, cancers, heart disease, diabetes and premature menopause. Participants have experienced transformations in the social, biomedical and policy contexts of HIV in Australia. They provide valuable insights into the intertwining of long-term and new complex health and social issues situated within a rapidly changing policy environment in Queensland. To protect the identities of participants, pseudonyms are used in this essay.

Living with uncertainty

Ambivalence and uncertainty have been features of positive peoples’ lives across the history of the epidemic associated with changing understandings of HIV [15]. Most LPQ participants described uncertainty about ageing, expressing ambivalence in the face of debates

surrounding adverse HIV ageing discourses and unknown futures.

Warren described himself as 'medically inclined' given his history with HIV, yet was unsure whether emerging health issues were 'normal' or a consequence of 'accelerated/accentuated' ageing:

Is it my HIV having worn out my body early or am I just suffering from old age? ... I've always had a belief that I'd probably wear out sooner because of the HIV and what it's doing to the immune system. So when I noticed these old men signs, if I can call them that, it does sort of freak me out a little bit and hypervigilance is probably not the – they're not necessarily real yet but they're certainly alarming me.

Female participants expressed concern about the lack of knowledge among healthcare providers about health issues facing older women living with HIV, particularly associated with menopause and 'how ageing and HIV are going to go together' (Madeline).

Alongside uncertainties about health and increasing comorbidities, participants described uncertainty about social determinants of 'successful ageing' including income, housing and access to care. A small number of older PLHIV, mostly diagnosed more recently, were well resourced (e.g. they had partners, secure employment, their own home, superannuation) and actively 'planning' for ageing. However, most LPQ participants lived alone and received government pensions and about a third lived in public/community housing. Older participants, particularly those from the Pre-HAART era, experienced financial disadvantage related to disrupted employment trajectories, limited resources and/or being long-term welfare recipients. This, combined with limited support, generated worries about living in disadvantage as they got older, as Warren explained:

... even if I lived to 70 ... it's a long time to live if you've just got enough income to pay for basic groceries and rent and nothing else.

Declining physical health and additional co-morbidities shook participants' self-perceptions and raised concerns about

the effects of long-term medication and the intersections of HIV and ageing.

Ageism and lost opportunities

Many LPQ participants experienced ageism, in both gay and PLHIV cultures. Some of the oldest participants, who had been active in the HIV/AIDS community, felt their experiences were ignored or not appreciated by the 'new generation' of PLHIV. As Hugh reflected, older PLHIV felt their experiences of health, poverty, stigma and discrimination were dismissed:

Your voice as an older long-term is not acceptable to talk about that lived horrific experience. ... [In an increasingly biomedicalised context] what for me as a much broader and nuanced view of the way I experience my HIV is no longer being listened to, that it's being separated from a gay agenda.

Several participants described the importance of generativity and sharing their hard-earned 'wisdom' and experiences of living with HIV:

Over time as you grow you look at things differently ... once you start to get to our age, you just look at things differently and you just have to accept things. You just have to because nothing is – especially with this, it's not going to be any different. So when you accept it, it's just so much easier ... And that's what I'd like to do with my Positive Speakers role, to be able to stand in front of people [with HIV] ... and give them hope. (Xavier)

Social and active engagement and generativity, particularly in the form of sharing experiences of living with HIV with other (younger) PLHIV, is health enhancing [16]. Opportunities for volunteering, socialisation and sharing of experiences were among the most important unmet needs for older participants, further impacted by service cuts and the corresponding fracturing of communities.

Resilience and maintaining control

Across the interviews, participants described the ways they contended with and managed complexities of

ageing, declining health and social and financial precarity. Their stories revealed strengths and resilience developed through long histories of coping with health and social challenges, and managing new and unanticipated issues. As Lewis reflected after treatment for cancer:

I just think find something to love and something to be passionate about and if you've got that in your life, then you will want to keep going. Some people are just so easy to give up or never change – "I can't do it", "I can't do it". "Yes, you can, you can – but you won't know until you try".

Of concern however, a small number of older participants – those with the most complex health issues, fragile social networks and limited support, feared loss of agency and control. Discussions of the future featured apprehensions about not wanting to be a 'burden' on others or the healthcare system, and retaining some control over life and death. Lacking confidence in aged care options, they discussed 'back up plans' of treatment refusal or non-adherence:

I don't want to get to a stage where people have got to wipe my bum and that's time to check out. I don't have a safety net...I know then if things become unbearable there's an exit ... if I can just stop a couple of pills. It's only an escape hatch if things become unbearable. (Arthur)

Apprehensions about aged care

Many participants were anxious about their capacity to live independently in the future. For most, care for older people was synonymous with residential aged care. Having experienced stigma and discrimination in healthcare settings, they were concerned about stigma and discrimination in aged care settings and worried that the aged care sector was not ready to respond to the needs of PLHIV and was unlikely to be accepting of LGBTI couples:

I'm still absolutely paranoid about the response to people when they know and I was actually thinking about that other thing, going into a nursing home, I'd want to pick it very carefully to know

that there was acceptance and understanding. Even saying that sounds scary. (Warren)

Few knew or talked about ageing in place using in-home care. Dean was aware of options, but stressed the need for care workers to be trained in HIV and LGBTI cultural competency:

You should be doing everything to keep people in their homes and it saves the government money and is most people's preference. I think the focus needs to be on training [care providers] and making them become aware because that's where the issues lie. ... I know that home and community care people need to be trained and any planning needs to take in the uniqueness of the LGBTI community's ageing needs which [are] quite different. (Dean)

Discussion

The LPQ study highlights particular needs of PLHIV for health and social support as they age. Consideration of the findings parallel Australia's eighth *National HIV Strategy*, which identifies Aged Care as a priority area, requiring action in relation to: exploring models of care to meet the needs of older PLHIV; improving integration of care across health and aged care services, particularly in rural locations; and increasing HIV awareness, capability and collaboration of service providers across health, aged care, disability and housing [17]. These action areas, along with the experiences and concerns of older LPQ participants, make it clear new models of aged care are needed. Many older PLHIV will require complex clinical care to manage multiple morbidities, poly-pharmacy and potential complications associated with living long-term with HIV. Those needing residential care will require support transitioning and maintaining links with support services; coordination to address social and cultural concerns, ensure confidentiality and prevent stigma; and streamlined access to ART [18].

Most importantly, ageing with HIV is biosocial, lived within diverse intersections of embodied experiences of HIV, and generational, social, and locational contexts. Current research focuses on 'successful ageing' for PLHIV,

emphasising individualised actions including resilience, self-care and generativity [16], but with limited acknowledgement of the broader social determinants of health. Self-care opportunities for many older PLHIV have been weakened with the increasing biomedicalisation of policy and services at the expense of the psychosocial. The individualised approach to funded services and care has seen the fracturing and dismantling of 'community' networks that have also served as a resource for care. This is particularly an issue for older PLHIV who have memory of past services as supports such as home care volunteers and support networks from peer-based services.

Cumulative impacts of disadvantage that featured in many older LPQ participants' narratives highlight the need for policy, service provision, and peer support that goes beyond a focus on biomedical and includes social aspects of ageing with HIV.

As we move through the fourth decade of HIV, it is clear uncertainty and ambivalence about ageing with HIV parallels uncertainties about HIV biomedicine that occurred in the early stages of the epidemic [15]. Fear and limited knowledge of the aged care sector demonstrate the need for better HIV and ageing literacy; quality and culturally competent aged care services for PLHIV; and coordination and partnership between the aged care sector and HIV community.

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