

HIV, how do I know thee, let me count the ways

By R. Woods

Still more to learn

You hear about it for the first time, the tone is equal measures concerned, sensational, self-righteous: 'Young gays in America are getting sick and dying from an unknown disease'. The story grows, the first Australian cases are reported, and you realise you'll need to start paying attention to this. Friends test positive, there's safe sex, friends get very ill, you fall in love with a positive guy, HIV-related prejudices and stigma increase, there's loss, grief and mourning, organisations form, the health care system adapts – you're living the plague. You test regularly and it remains negative, but one day a test comes back positive and a retest confirms it – you're getting to know HIV quite well by now.

You deal with the bureaucracy, relocate, reorganise your life, find new ways of living your sexuality, get on and off the dole, relocate again, fall in love with a negative guy, take on a new career path, venture overseas – you're learning to live with HIV. Things go awry, you pick yourself up and dust yourself off, the CD4 count dips below the threshold, you begin treatmentⁱ, share side-effects stories with peers,

focus on diet and exercise, revel in U=Uⁱⁱ – you're beginning to feel in control.

The years go by and niggling little things crop up: agility and stamina issues, your mind failing you in mysterious ways, previously unimagined topics of conversation with friends – you're realising that, despite years of living with the virus, there's still more to learn. With poetic licence you mutter: HIV. How do I know thee? Let me count the ways.ⁱⁱⁱ

You're not alone. Modelling from the Kirby Institute [8] suggests that by 2027, the highest proportion of people living with HIV (PLHIV) in Australia will be in the 55-59 age group, and the average age will be 52 years. A lot can be learned from what's already out there. Let's take a look.

Growing older with HIV

Much is happening in Australia and elsewhere regarding HIV and ageing. PLHIV organisations have advocated for the wellbeing of peers since the 1980s, are applying and adapting their methods – peer mentoring, support and navigation, advocacy, community engagement and events, research and more – to better understand and

address the needs of peers growing older with HIV. From a service point of view, models and approaches are being developed that would help PLHIV better navigate the aged care system when they are ready to do so [10] and to benefit from appropriately-tailored support services. Providers are addressing issues such as workforce development and responding to concerns about stigma and discrimination [5].

Much is being written, and summaries or reviews of the current state of knowledge are available^{iv} and updated. There are conferences, workshops, videos, demonstration and research projects, and interest groups. Australian research has traced the experiences of older PLHIV [16][24] and studies have identified multimorbidity, polypharmacy and quality of life as key considerations [24][5]. There is a range of problems linked to chronic inflammation that affect some older PLHIV [20]; and susceptibility to frailty for long-term survivors in particular [30].

As participants in research, older PLHIV have expressed concerns around loneliness and social isolation, maintaining independence in light of

ⁱ People living with HIV are now recommended to start treatment as soon as possible after diagnosis.

ⁱⁱ Undetectability = Untransmissibility

ⁱⁱⁱ With honour, respect and apologies to Elizabeth Barrett Browning; from Sonnet 43

^{iv} for example, Woods (2019)

comorbidities and functional decline, accessing services when needed, and the potential impact of unpreparedness and HIV-related stigma on the quality of mainstream service provision [29]. International research confirms and extends these findings [14]. Qualitative research from the UK [25] has found that the experience of ageing for PLHIV is shaped by HIV as well as by gender, sexual orientation, culture, income, migration status, and age at diagnosis.

A consistent research outcome is that vulnerability increases for those who have been living with HIV for many years [23][17]. Mental health problems are commonly reported among older PLHIV [26][25], and cognitive declines may occur earlier in comparison to HIV-negative counterparts [20]. There is also some evidence that the severity of the symptoms of depression and anxiety may **decrease** with age [23][26]. Studies of the lived experiences of older PLHIV often report high levels of self-rated health, active engagement with life, and optimism about the future [23]. A finding that is consistent across several studies is that, as the years go by, happiness increases and self-stigma decreases. PLHIV have reported that the complexities of their lived experiences generate wisdom that could be applied to the process of ageing.

At the same time, older PLHIV are more likely than younger peers and HIV-negative peers to be dealing with concurrent health conditions (multimorbidity) [15], and also more likely to report limitations in their capacity to undertake daily tasks due to poor health. A recent large-scale San Francisco study found that 59% of older PLHIV had trouble with at least one activity of daily living (ADL) [1]. While a few participants in this study felt confident that care would be available to them if they became sick or injured, many were uncertain and afraid of what would happen if they were no longer able to care for themselves. Several expressed reluctance or fear at the prospect of having to rely on

mainstream care services [1]. In similar vein, Australian research points to the underutilisation of aged care services by PLHIV aged 65 years and older [16]. All of this suggests that more could be done to better integrate HIV care and aged care.

Integrating aged care and HIV care

While there is always room for improvement to Australia's aged care system, there have been positive developments in recent years. The age profile of the country is changing and policy makers and service providers have placed more decision-making power in the hands of consumers and their carers (consumer-directed care).

Reforms have streamlined service gateways and transitions to ensure better continuity of care, and have addressed the breaking down of silos among the health, disability and aged care sectors [3], although it is worth noting that the *Royal Commission into Aged Care Quality and Safety* received many submission saying that the reform process was too slow and not properly resourced. Features such as a single-entry point to the aged care system, better recognition and resourcing of carers, strong use of online technology, and national standards and complaints procedures all have the potential to help break down traditional distinctions between home care, residential care and hospital care; and between the care that is provided by informal unpaid carers and formal service providers.

Consumer-directed principles underpin the Australian aged care system. International best practice suggests that organisations and their frontline staff should ideally put these principles into practice in networked, multi-dimensional and multidisciplinary ways [15]. Approaches to care that address medical, psycho-social and functional capabilities and limitations in a coordinated way can help clients, and their informal carers and formal providers, to better manage the ageing process as a whole. To this end,

frameworks for integrated HIV and geriatric care are being developed [28][26].

Evidence-based, multi-faceted models of care for older people with HIV are also emerging [2][27]. Many of these begin with the offer of a Comprehensive Geriatric Assessment (CGA) to an individual who feels ready to seek help in the context of ageing [19]. In an integrated way, the CGA seeks to understand the impacts of HIV (including comorbidities and polypharmacy) and ageing (including medical and functional aspects). It also considers broader socio-economic factors such as living arrangements and availability of informal supports. Updated on a regular basis, the levels of care and interventions proposed as the outcome of assessments are designed to contribute to improved health and wellbeing outcomes for older PLHIV.

There are promising models that can be looked at, for example:

- Care in the home: A model of nurse-led community care developed in the Netherlands starts from the client perspective and works outwards to assemble solutions that bring independence and improved quality of life [9].
- Residential care: The Silver Clinic is a combined HIV and geriatrics clinic for older people living with HIV in Brighton UK, with a recent evaluation finding that its approach is acceptable to both service users and referrers within HIV medicine [21].
- End-of-life care: In Canada, Compassionate Communities is an approach to ageing, end-of-life care and grieving that respectfully responds to the needs of diverse communities [18].

In keeping with the principle – expressed again in the *Eighth National HIV Strategy* [4] – of meaningful participation of people living with HIV in programs and policies, the provision of peer support within aged care teams could promote a better integration of

HIV and aged care. Let's see what this might look like.

Peer support within aged care teams

There is concrete evidence that peer support is effective in helping people as they move through the HIV continuum of care [6]. The provision of peer support has:

- A **direct effect** - influencing health outcomes through, for example, assisting peers to better navigate support systems and helping them improve their health literacy
- A **buffering effect** – protecting against the influence of stress on health through, for example, discussion of coping strategies and problem-solving techniques
- A **mediating effect** – indirectly influencing health through, for example, providing peers with observational learning through role modelling [12].

A task for HIV organisations, especially those that already have established programs of peer support, peer navigation and/or community advocacy, is to work with service providers to develop insights into where – on the aged care support spectrum – peer support can best be targeted. The National Association of People with HIV Australia (NAPWA) is developing a national training program for HIV peer navigators. The model could possibly be extended, or alternatively be more inclusive of specific supports for those ageing with HIV.

Put differently, nodes within community-based, clinical, residential, and end-of-life care settings could be identified where HIV peer support would best complement health and aged care service provision. The work would include mapping of the organisational networks; partnership

^v The increased vulnerability of long term survivors reflects the impacts of a diagnosis in the earlier period of HIV, when prognosis was poor, treatments were less effective, and HIV-related

and coalition building; shared professional development; and establishing protocols for teamwork.

Systems need to be set into place to recruit, train, support and manage peer helpers as they take on such roles within professional service teams. The Home Care Packages Program, Integrated Carer Support Service, Primary Health Networks and others would be important partners for HIV community organisations to work with as more PLHIV access and transition between medical, community, disability and aged care services. PLHIV organisations and the AIDS Councils have a long history of working with PLHIV at all stages of the epidemic, and would be essential partners.

The presence of factors such as loneliness, poverty, cognitive decline, frailty, multimorbidity and polypharmacy could indicate the need for priority outreach and care [17], with long term survivors being particularly at risk^v. Peer presence and support may help vulnerable PLHIV and their informal carers to be more open to engage with the aged care system, while aged care providers themselves would benefit from the insights provided by peers and the HIV and community-based organisations [16]. These community organisations would work with others in health promotion initiatives, discussed in conclusion next.

Promoting successful, resilient aging

At this early stage in the ageing trend, outreach and health literacy campaigns focusing on 'successful ageing' or 'resilient ageing' for PLHIV would have long-term benefits. In doing health promotional work of this nature, peer-based and other community organisations could draw on synergies with initiatives and the experiences of

trauma and stigma were more pronounced; as well as a longer period of living with a chronic disease, including a younger age at HIV diagnosis, and the effects of prolonged HIV treatment, or

people living with other blood borne viruses such as Hepatitis C [22]. A focus on resilient ageing would encourage the development of person-centred services in which providers harness existing strengths and resources and are open to addressing stigma and marginalisation.

Pathways to successful ageing include:

- Avoiding disease, disease-related disability, and the risk factors for morbidity [14];
- Focusing on 'quality of life, autonomy and self-rated health' [23];
- Addressing with support those life issues – difficulty in making ends meet, isolation, relationship problems etc. – that impact negatively on health and wellbeing [17]
- Active engagement with life [14]; and
- Recognising that 'giving back is receiving' and, for example, helping others to 'navigate the landscape of aging with HIV' [13].

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