

Resilient Ageing and End-of-Life with a blood borne virus (BBV-RAEL) – HIV focus

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Study rationale

The aim of this project is to explore the landscape of ageing, health and social service needs of older people living with blood borne viruses (BBVs).

Today, we focus on findings related to HIV in Australia:

1. What are the ageing, health and social service needs of older people living with HIV?
2. How are existing service arrangements and models equipped to meet these needs into the future?
3. How do care and illness contexts shape experiences of ageing and the end of life?

Study methods

1. **Scoping the literature:** on what is known about the care and support provided for an aging cohort of people with lived experience of chronic viral hepatitis as they near end-of-life.
2. **Qualitative interviews:** in-depth exploration of the views of key stakeholders working within organisations that support people living with BBVs or who work in the ageing and end-of-life sectors.
3. **Online modified Delphi survey:** a process of consensus building in iterative survey stages of the participants who can provide workforce perspectives into the policy, programmes and practices associated with ageing and end-of-life in a range of contexts.

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Study methods

Qualitative, semi-structured interview study; online interviews using zoom (n=20)

Interviews with key national and state stakeholders, including those working in the fields of:

- LGBTIQ community health
- Blood borne virus prevention and treatment
- Culturally and linguistically diverse communities
- Social work
- Harm reduction
- Palliative nursing and
- Aged care.

Study findings

Our analysis identified three key related themes among participants:

1. resilience and/in coping with ageing, BBVs and comorbidities;
2. barriers to talking about or preparing for death, dying and bereavement; and
3. making sense of the *transition* from ageing well to dying well.

We talk a lot about **resilience** in HIV and that as being the element that keeps us going and has kept us going and is something to be proud of.

I agree with you about the resilience, it's certainly true, it kind of goes back to what we were saying before about that, you know, when these people were first diagnosed, it was a death sentence. They weren't going to live past a certain age, and I guess that certainly would build resilience in a lot of people and I suppose then also when death does stare you in the face, who knows how you're going to react to that.

No, we more talk about end of life in the terms of the retiring, what does that mean and all that sort of stuff. When people are ill and we're supporting them through the hospital system, they're so used to bouncing back now, that end of life sometimes is not talked about until real end of life, you know, somebody who's in, you know, palliative care and stuff like that.

You go to a doctor, and you are given a diagnosis and then that becomes an emergency type thing. So, I think for a lot of people, it's because they're so used to getting over hurdles and they think that "this is another one I'll get over".

As people with HIV, often people are living quite a challenged lives in terms of you know the number of comorbidities and number of pills and you know living with mental health conditions exacerbated often by alcohol and other drugs and yet there is still this sort of determination to keep going and reluctance to face [end-of-life].

Okay, other challenges that even though we are aging, even though people might be heading towards that end-of-life thing, life goes on. So, if someone is still wanting to work and contribute, and do that sort of stuff, why not? You know, the end-of-life stuff for me is a bit of a grey area, because there's end of life which is immediate, okay, there's end of life, which, for some people we know is coming and is purely because of age and there's end of life, yeah, that we've done everything we can and you might have another 3, 4 or 5 years, you know?

Implications

- Historical legacies associated with short term planning continue to underpin expectations related to resilient ageing.
- Enduring discourses of resilience and living well may obscure opportunities to discuss and plan for the dying process, even in contexts of old age.
- The *transition* from ageing to dying presents opportunities to consider the value of resilience in end-of-life planning.