

EXPLORING UNDERSTANDINGS OF CHRONIC ILLNESS AMONG PEOPLE RECENTLY DIAGNOSED WITH HIV IN AUSTRALIA.

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ACKNOWLEDGEMENT OF COUNTRY

La Trobe University acknowledges our campuses are located on the lands of many Traditional Custodians in Victoria and New South Wales. We recognise their ongoing connection to the land and value their unique contribution to the University and wider Australian society.

La Trobe University is committed to providing opportunities for Aboriginal and Torres Strait Islander people, both as individuals and communities, through teaching, learning, research and partnerships across all our campuses.



PROJECT ACKNOWLEDGEMENTS

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CHRONIC MANAGEABLE ILLNESS

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- Chronic diseases are long lasting, have persistent effects, with their management reliant on medications and various forms of social and health care.
- The sociology of health and illness has produced a large body of work that explore the time/temporality in relation to chronic illnesses
- In this paper we explore newly diagnosed peoples:
 - understandings of HIV as a manageable chronic illness
 - whether it is meaningful way to frame the contemporary experience of HIV disease for this group/generation
 - highlight the way a concept of 'normal, life, health, time is used to make sense of living with HIV for newly diagnosed people

DEMOGRAPHIC PROFILE

Gender and sexuality: 30 participants identified as gay/queer men, 5 bisexual men, 4 heterosexual men, and 5 heterosexual women.

The median age of the sample was 39 years (range 24–67)

Only one participant was not taking HIV treatment at the time of interview

Country of birth:

16 Australia/New Zealand born (16)

United Kingdom (3)

Southern Africa (3)

Middle-East (1)

South-east Asia (12)

South America (6)

Oceania (2)

Caribbean (1)

APPROACH

- Data collected via 44 semi-structured interviews with people newly diagnosed with HIV (within the past 12 months).
- The interviews were conducted between December 2023 – August 2025 (recruitment is ongoing)
- The interview schedule included a specific question about the meaningfulness of describing HIV as a chronic illness. We analysed the responses to this question as well as narratives related to how people imagined their future as a person with HIV at time of diagnosis or the period shortly after.

CHRONIC ILLNESS

*I think that's a good thing. It's like a chronic condition. It can be treated, but it cannot be cured. I think it's better for people to look in that way rather **than in a taboo way**. I think that's a better way to put it, that positive way to see, I think that's how people should see the HIV as a recent diagnosed person. (Ravi, 26 gay man)*

*Yeah, I mean I think it's very on the nose. It's right though. Hey, I don't think with anything [...] that is a medical thing, I always feel like you need to be honest about what it is. It's a chronic condition. **I could have liver problems in the future**. I know there's potential neuro problems that can happen as well, but for the most part it is manageable, chronic disease, incurable, **but you just pop a pill once a day** and it's generally you're good. (Branko, 30 gay man)*

CHRONIC ILLNESS

I don't think so. I think a chronic illness is something that has a symptomatic challenge to it, but there's two ways to look at that, and it's all about perception. I don't consider it a chronic illness because the medication renders it inactive. So, the only time it would be a chronic situation is if I stopped taking my tablet. (Pierce, 57 gay man)

I don't really feel like it's an illness. It's just something that my body isn't necessarily able to fight off entirely. And by taking a tablet a day, it's going to mean that I don't feel like, from the research that I have done is that with having an undetectable viral load, I'm just like a normal person. It's not an illness, it's not an autoimmune disease. [...] it's not going to develop into AIDS if I keep up with the medication. And by the sounds of it that there's probably going to be medication that I will probably have to take maybe once every three months, and potentially there's going to be a cure as well. But yeah, I don't feel like it's an illness as such that I have to live with. (Elijah, 40 bisexual man)

NORMAL LIFE, TIME, HEALTH

LIFETIMES ARE NOT WHAT THEY USED TO BE (McDiarmid, 1994)

Well, I'm still no expert on it, and I still have a lot to learn. [...] but I understand that it's no longer a death sentence, **what it was like say in the 1980s** or in that period of time, that the medication has advanced so much, thankfully. And the treatment and care that people are receiving [mean] that I can live a **normal, healthy lifestyle**. I know you're still vulnerable to certain diseases like diabetes, strokes, heart attacks, and increased risk of cancer [...] But I still know that because the medication is more effective, that by and large people are able **to live a normal life** and have a **normal life expectancy**, which is great news, which at the start that wasn't aware of. (Ned, 34 heterosexual man).

For me, undetectable is about getting to undetectable, which means whilst I will always test positive to HIV, but being undetectable means that that virus is hiding in the reservoirs in my body, wherever it chooses to hide. [...] it just sits there effectively dormant. And as long as I keep taking my medication, that's what it will do. So being undetectable means that the virus is effectively, I guess dormant is probably not the word, but I see it as being dormant, just sitting there. It's not going to harm me [...] I should live to a **normal lifespan**, whatever that would be for me, and that I should just die comfortably of old age (Lazlo 58 bisexual man)

SUMMARY SLIDE

- Chronic illness is a medical concept that is meaningful for some and not others
- How newly positive people think about their present and future is strongly associated with treatment and in some cases specifically undetectability
- Narratives around normality reference time in a range of ways (measured against normal life expectancy, or different chronological moments in the epidemic i.e. and era before treatment)
- This analysis is part of a broader interest we have in HIV generations and specifically the ways in which different generations of treatment shape the ways that people living with HIV experience and understand HIV disease.
- Are new ways needed to articulate the long-lasting and persistent effects of HIV disease.

THANK YOU

