

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

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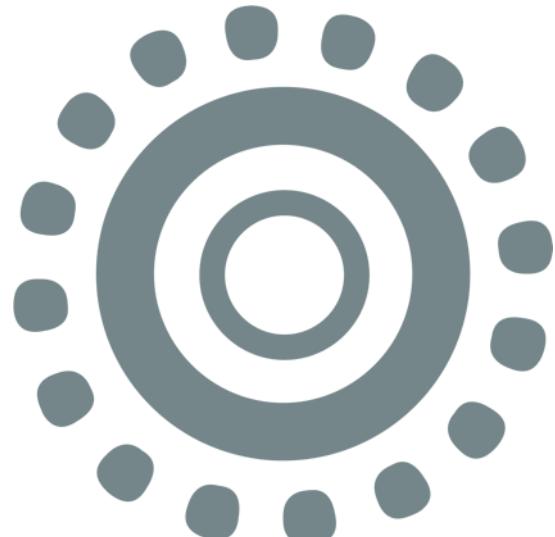
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ACKNOWLEDGEMENT OF COUNTRY

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PROJECT ACKNOWLEDGEMENTS

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The Investigator team is Dr Dean Murphy, Dr Jeanne Ellard, Professor Adam Bourne and Dr Dion Kagan

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CHRONIC MANAGEABLE ILLNESS

- HIV 'manageable chronic illness.'
- 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)	South-east Asia (12)
United Kingdom (3)	South America (6)
Southern Africa (3)	Oceania (2)
Middle-East (1)	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