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SEXUAL HEALTH

'It's like I have this weird superpower': experiences of detectable and undetectable viral load among a cohort of recently diagnosed people living with HIV

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ABSTRACT

Background. By reducing HIV viral load to undetectable levels, HIV treatment slows disease progression and eliminates the possibility of sexual transmission. The promotion of undetectable viral load has also been accompanied by expectations of reducing HIV-related stigma, including self-stigma. Drawing on accounts of people recently diagnosed with HIV, we explored experiences of both detectable and undetectable viral load. **Methods.** Between January 2019 and November 2021, semi-structured interviews were conducted with 35 people living with HIV (PLHIV) who had received an HIV diagnosis in Australia from 2016 onward. Of these participants, 24 completed follow-up interviews approximately 12 months later. Interviews were transcribed verbatim, entered into NVivo (software v12), and thematically analysed. **Results.** Reflecting on the period in which their viral load was detectable, some participants described feeling 'dirty,' 'viral,' and 'a risk' to sexual partners. During this period, some participants minimised or ceased having sex, sometimes despite being in ongoing romantic relationships. Reaching undetectable viral load was commonly characterised as an important goal in HIV care and signalled a marker of good health and enabled a return to sexual relationships. However, the psychosocial benefits of undetectable viral load were not universally experienced, with some participants highlighting ongoing challenges of living with HIV long term. **Conclusions.** Increasing awareness of the benefits of undetectable viral load is an important and powerful tool for improving the health and wellbeing of PLHIV; however, the period in which one's HIV viral load is detectable can be challenging, particularly as feelings of being 'unclean' and 'a risk' may be internalised. Ensuring PLHIV are appropriately supported during periods of viral detectability is necessary.

Keywords: HIV, people living with HIV, PLHIV, TasP, treatment as prevention, undetectable equals untransmissible, undetectable viral load, U=U.

Introduction

HIV treatment is a key aspect in managing the health of people living with HIV (PLHIV), and a core public health strategy to reduce rates of HIV transmission.[1,2] By reducing viral load to undetectable levels, slowing disease progression and preventing the onset of AIDS-defining illnesses, HIV treatments have led to a reframing of HIV from a fatal illness to that of a chronic, manageable condition.[3–5] For PLHIV who maintain an undetectable viral load, HIV treatment also eliminates the risk of sexual transmission of HIV.[6,7] Within public health discourses, reaching community-level undetectable viral load is framed as an imperative to keep the broader, HIV-negative population protected from HIV.[8] Within this framework, the focus of reaching an undetectable viral load risks emphasising the health and wellbeing of those who are HIV-negative as a priority, with the health benefits for PLHIV secondary.[9] In this paper, we focus on how both detectable and undetectable viral load are experienced by PLHIV.

The scientific consensus that sustained, undetectable viral load eliminates the risk of HIV sexual transmission underpins the global 'Undetectable equals Untransmissible' (U=U) movement. Established in 2016, advocates behind the U=U campaign aim to raise awareness of undetectable viral load as an effective HIV prevention strategy.[10] Advocates of U=U have also promoted undetectable viral load as 'a highly effective tool for destigmatising HIV among the general population and reducing associated discrimination'.[11] Recognising the protective benefits of an undetectable viral load, the state of Victoria became the first Australian jurisdiction to publicly endorse U=U as an effective HIV prevention strategy in 2017. Since then, recommendations have been made that all healthcare providers inform PLHIV about the benefits of a sustained, undetectable viral load to both empower individuals and minimise the impact of internalised HIV-related stigma.[12]

Reducing HIV-related stigma and improving the quality of life among PLHIV is a key aspect of Australia's National HIV Strategy.[1] Increasing awareness of undetectable viral load as preventing HIV sexual transmission can reduce HIV-related stigma and improve quality of life for PLHIV. Some PLHIV, for example, have reported a decrease in experiences of HIV-related stigma as awareness of undetectable viral load has expanded and become more widespread among the broader, HIV-negative population.[13,14] In a global survey of PLHIV, an association was also found between improved self-reported physical and mental health outcomes among participants who had been informed about the benefits of undetectable viral load.[15] This same survey also found an association between awareness of undetectable viral load and diminished anxieties about HIV disclosure.[15]

The promotion of U=U as a strategy to reduce HIV-related stigma relies on the hope that increasing awareness of, and belief in, undetectable viral load as preventing HIV will minimise concerns about HIV transmission among those who are both HIV-positive and HIV-negative. Holt *et al*. compared attitudes about undetectable viral load among Australian gay, bisexual, and other men who have sex with men (GBM).[16] They found that there had been an increase in the number of GBM willing to rely on undetectable viral load to prevent HIV transmission (from 2.6% of survey respondents in 2013 to 34.6% in 2019). However, almost two-thirds of respondents overall expressed hesitancy or refusal to rely on viral load as an HIV prevention strategy. Moreover, only half of those using HIV pre-exposure prophylaxis reported that they trusted that undetectable viral load prevented HIV, despite using the same class of drugs themselves to prevent HIV infection (see also[14,16]).

Significant attention has been given to how undetectable viral load is experienced by PLHIV. Previous research has shown that undetectable viral load is an important goal for PLHIV and can provide a sense of returning to good health.[17,18] Camlin *et al*.[19] also highlight that reaching viral undetectability enables PLHIV to reclaim a 'spoiled identity' and sexual citizenship;[20] that is, by eliminating any risk of HIV sexual transmission, reaching and maintaining an undetectable viral load can enable some PLHIV to reclaim themselves as 'responsible' sexual citizens who pose no threat to the sexual health and wellbeing of others. To date, however, little attention has been given to how detectable viral load is experienced by people who have recently received an HIV-positive diagnosis. To address this gap, we contrasted experiences of *both* viral detectability and undetectability among PLHIV who had recently received an HIV diagnosis in Australia. In this analysis, we are not seeking to explore the totality of the benefits associated with reaching undetectable viral load; rather, we are seeking to contrast accounts of how both undetectable and detectable viral loads are experienced.

Methods

Study setting

This study is an ongoing qualitative study exploring the experiences of people recently diagnosed with HIV in Australia. Participants were invited to complete follow-up interviews approximately 12 months after their initial interview. This article is based on data from interviews conducted between January 2019 and August 2021.

Eligibility and recruitment

To be eligible, participants had to be aged ≥16 years, permanent or temporary Australian residents, and diagnosed in 2016 or later. Participants were recruited through sexual health centres, high caseload HIV clinics, community-based HIV organisations, and/or self-referral. After being forwarded to the research team, potential participants were contacted by a member of the research team by telephone or email and invited to be interviewed.

Data collection

Semi-structured interviews were conducted face-to-face, via telephone, or through video conferencing software by members of the research team. Interviews lasted between 1 and 2 h and with participants' consent were audio recorded, transcribed by a professional transcription service, and de-identified. Pseudonyms are used in reporting of data to ensure participants' confidentiality. Interviews explored: the diagnosis experience; HIV treatment and clinical care; engagement with HIV support services; sex and relationships; and the impact of HIV on participants' lives. Participants were also asked about who they had told about their HIV status, and factors influencing decisions around (non-)disclosure, and where relevant, their participation in HIV and gay/bisexual communities. Follow-up interviews examined any shifts in participants' experiences of living with HIV.

Analysis

Interview transcripts were transcribed verbatim, entered into NVivo (software v. 12; Lumivero, Denver, CO, USA) and thematically analysed.[21] An initial codebook was developed based on the interview schedule and a close reading of a small sample of transcripts. Using an inductive approach[22] and drawing on empirical literature, the codebook was revised as the remaining transcripts were analysed. Follow-up interviews were conducted to explore any shifts in participants' experiences of living with HIV. As part of follow-up interviews, participants were asked to reflect on their hypothetical reaction to receiving news of their viral load returning to detectable levels. Although comparing attitudes to viral (un)detectability was not the primary focus of this paper, second-round interviews were included in this analysis as participants were asked to consider what returning to viral detectability might mean. The research team met regularly to discuss findings and ensure data reliability.

Ethical approval

All authors approved the article for submission. All procedures involving human participants were in accordance with the ethical standards of the institutional research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. Ethics approval was provided by the UNSW Human Research Ethics Committee (HC161712).

Results

Of the 35 participants who completed first-round interviews, 24 completed follow-up interviews, providing 69 interviews in total for analysis. Most[21] participants identified as gay male (n = 22), seven as bisexual men, four as heterosexual men, and two heterosexual women. Participants were born in Australia (n = 23),[22] Asia (n = 6),[6] Western Europe (n = 3),[3] South America (n = 2)[2] and Southern Africa (n = 1).[1] Participant characteristics are described in Table 1.

Australia is a setting with high HIV treatment coverage and with the exception of one, all participants were engaged in HIV care, had access to treatment under Australia's universal healthcare system, and had a sustained undetectable viral load. Nearly all participants had initiated treatment immediately or very soon after diagnosis and reaching undetectable viral load was generally characterised as relatively straightforward and unproblematic. Moreover, all participants except the one not on treatment had maintained an undetectable viral load between first- and second-round interviews. Our analysis highlights three overarching themes: (1) undetectable viral load as providing a sense of control over HIV; (2) undetectable viral load removing anxieties about HIV sexual transmission; and (3) the limitations of an undetectable viral load.

Table 1. Participant characteristics.

	N
Age (years)	
20–29	13
30–39	11
40–49	6
50–59	5
Gender	
Male	33
Female	2
Sexuality	
Gay male	22
Bisexual male	7
Heterosexual male	4
Heterosexual female	2
Region of birth	
Australia/New Zealand	23
Asia	6
Western Europe	3
South America	2
Africa	1
Year of HIV diagnosis	
2016	7
2017	9
2018	7
2019	8
2020	3
2021	0
2022	1

Undetectable viral load as regaining control

Reflecting on the period between receiving an HIV diagnosis and learning their viral load was undetectable, a period in which their viral load was believed to be detectable, some participants described feeling 'dirty,' 'viral,' and 'a risk' to others. Flynn (bisexual male, 27 years) recalled feeling:

> imperfect. [I] felt dangerous, dirty. I felt in the process of becoming healthy, but not healthy ... and I certainly felt alienated although I was also reassured that I would reach that point [of undetectable].

Flynn had a history of working in HIV advocacy and prior to his diagnosis had high levels of knowledge about the role HIV treatments played in managing HIV and preventing onward transmission. Despite this history, Flynn drew on longstanding, stigmatising tropes of PLHIV as 'dangerous' and 'dirty' when describing his own feelings after receiving an HIV diagnosis and the period in which his viral load was detectable.

For some participants, even the unlikely possibility of receiving a detectable viral load result engendered a sense of loss of control and self-worth. Percy (gay male, 27 years) explained: '[I would] definitely feel a loss of control ... I wouldn't say 'dirty' because I hate that word, but I would definitely value myself a little bit less.' Although Percy stopped short of describing feeling 'dirty,' the association of detectable viral load with notions of uncleanliness was present in his account. Contrasting with this account, participants regularly spoke of reaching an undetectable viral load as a prized stated of being. Percy continued: '[undetectability is] my security blanket. Just having that – an undetectable viral load – makes you feel normal and validated.' Viral undetectability not only provided Percy with a sense of bodily control, but also underpinned notions of self-worth. Like Flynn, Percy also drew on notions of cleanliness when contrasting his experiences of detectable and undetectable viral load.

The sense of undetectable viral load as an end goal that offered a sense of control over HIV was captured by Sherwood (gay male, 47 years) who described a:

> Sense of achievement. I know sounds really weird [but] I'm like: 'Yeah, fuck you! I've beaten you.' ... I remember these are the words, I remember them: 'I'm going to control the virus. The virus isn't going to control me.'

Sherwood's account of reaching undetectability was imbued with a sense of triumph at having 'beaten' HIV and having reclaimed control over his body. As with other participants, Sherwood characterised reaching undetectable viral load as an 'achievement,' a regaining of control such that his life trajectory was no longer dictated by the threat of HIV. Importantly, however, any sense of control offered by an undetectable viral load was contingent on adherence to a daily treatment regimen which, if was to be stopped, could see viral load return to detectable levels, increase the health impacts of HIV, and raise the possibility of HIV transmission to sexual partners. Nonetheless, HIV treatment enabled Sherwood and other participants to feel healthier such that they were able to imagine a life not overshadowed by potential health complications arising from HIV if left untreated.

The sense of victory at having reached undetectable viral load was also expressed by Jasmin (heterosexual female, 26 years). Unlike other participants who emphasised the health benefits, Jasmin described undetectable viral load as providing a sense of empowerment in the face of HIV-related stigma she had experienced from her brother:

> For me, it was being able to go, 'After what you've said to me and after all the things you've said' ... I was able to turn around and go, 'Well hang on a minute. I might be positive but there's also this that you don't understand. I can't give [HIV] to anybody ... I don't understand what your problem is.'

Although having an undetectable viral load did not necessarily shield Jasmin from the experience of HIV-related stigma, her knowledge of it did provide a sense of resiliency against negative comments from her brother. Just her awareness of undetectable viral load enabled Jasmin to reframe the stigmatising reactions of her brother. Rather than HIV as a deficiency within herself, her brother's *lack* of awareness was framed as ignorance and, in turn, a deficiency within him.

Undetectable viral load removing anxieties about HIV transmission

When reflecting on the period in which their viral load was detectable, participants commonly recalled limiting or ceasing sex completely, sometimes even when they were in ongoing romantic relationships. Reflecting on the period in which his viral load was detectable, Oskar (bisexual male, 23 years) stated: 'If I'd infected someone else, I would have been suicidally depressed ... I would feel so awful if my negligence put someone else through what I went through.' Oskar's account was reflected in that of Rhys (gay male, 35 years) who also stated: 'I didn't want to put anyone at risk in any way. It's not even about using protection ... I just wanted to be absolutely sure I can't make anyone sick.' The accounts of both Oskar and Rhys articulate concerns about potentially putting their sexual partners at risk of HIV. For Rhys, the concern over potential onward transmission of HIV was so great that, even with strategies such as the use of condoms or pre-exposure prophylaxis, the risk was considered so great that he ultimately disengaged from sex.

In contrast to the period in which their viral load was detectable, reaching an undetectable viral load was commonly experienced as reopening the possibility of engaging in sexual relationships. Jasper (gay male, 32 years) commented: 'Very soon after I found out I was undetectable my sex drive came back, so that was nice ... Basically ever since diagnosis I'd had zero sex drive.' Importantly, Jasper's HIV diagnosis coincided with a return to Australia after living abroad and moving into a new share house. Occurring at a time of already heightened anxiety, Jasper's diagnosis 'just seemed to be adding one more layer of anxiety onto any kind of sexual engagement.' In contrast, Jasper described receiving an undetectable viral load results as taking:

> a lot of the stress out of both the diagnosis and the idea of having sex. ... Even if a condom breaks or not using a condom, it's just, HIV is not in the picture.

Although HIV viral detectability was not the sole reason Jasper's desire for sex diminished, by removing any risk of HIV transmission, undetectable viral load enabled Jasper to feel more comfortable reengaging with sexual partners. Regardless of what other HIV prevention strategies were used, undetectable viral load effectively removed any thought of HIV from Jasper's experience of sex.

The association between undetectable viral load and removing anxieties about onward HIV transmission was powerfully captured in the account of Zaid (gay male, 40 years). Zaid had deliberately chosen to not engage in sex while his viral load was detectable. Explaining his reasoning, Zaid stated: 'if I'm a hazard, well then it's just Russian Roulette and its just stupid.' Since learning of his undetectable viral load, however, Zaid once again felt comfortable participating in sexual relationships. Reflecting on the experience of living with HIV in the current context of treatment and undetectable viral load, Zaid commented:

> You will have the best possible life because you know that you are no longer a risk to others. And that is phenomenal because if [they're] on PrEP or not ... I know right now that I can't infect anyone else.

Zaid continued, characterising the knowledge of his undetectable viral load as being:

> Like I have a weird superpower. That is, the superpower not to ever give anyone HIV. But it's also the weird superpower in my own head: now, I'm free of all those cultural things that were put in my head about what I should and shouldn't do.

Zaid's description of undetectable viral load as being like 'a weird superpower' went beyond simply knowing that, even in the absence of other HIV prevention strategies, there was no possibility of onward HIV transmission to his sexual partners. For Zaid, undetectable viral load also removed an internalised feeling of being 'a hazard' and, echoing previous accounts, a heightened sense of responsibility in ensuring his sexual partners remained HIV negative.

The limitations of undetectable viral load

For nearly all participants, reaching and sustaining an undetectable viral load was an important aspect of their HIV care. For some participants, however, reaching viral undetectability had not necessarily produced improved psychosocial wellbeing. Levi (gay male, 23 years) recounted:

> I [thought] in my mind being undetectable meant my life could be back to normal ... [but] it didn't make any difference really. I wasn't feeling anything different ... From that point on I was just [thinking to] myself: 'Now this is the hard part. When can I go back to dating? Can I go back to dating? Can I go back to having casual hook-ups? Am I going to tell anyone?'

Despite Levi's initial expectations that an undetectable viral load might enable a return to so-called 'normality,' the sense of liberation Levi had anticipated ultimately did not materialise. Despite eliminating the potential of sexual transmission and minimising the health impacts of HIV, reaching undetectable viral load had not *cured* HIV. Levi was therefore left to navigate many of the social challenges associated with HIV and even characterised the period after reaching an undetectable viral load as 'the hard part.' Although treatment enabled Levi to sustain an undetectable viral load relatively unproblematically, it had not resolved his feelings of uncertainty about disclosing his HIV status to sexual partners.

In Sherwood's account earlier, the use of treatment to reach undetectability was characterised as engendering a sense of control over HIV and his own health. For Lonnie, however, that same treatment was experienced as a daily reminder of aspects of his life prior to receiving an HIV diagnosis, despite its role in helping to sustain an undetectable viral load:

> [Medication] reminds me of the fact that I fucked my life up. Every time I take the medication, it's a constant, daily reminder that my life has just gone off the rails.

As stated previously, the ability to sustain an undetectable viral load is contingent on PLHIV adhering to a daily treatment regimen. Most participants did not experience adhering to daily treatment as problematic. For Lonnie, however, the same treatment needed to sustain his viral load at undetectable levels was experienced more ambivalently, particularly as prior to receiving an HIV diagnosis he had been experiencing mental ill-health: '[treatment] makes me feel depressed. Maybe that's because I'm already depressed, who knows.' Although it was not specifically HIV that had caused Lonnie to experience adverse mental health outcomes, treatment nonetheless functioned as a daily reminder of negative aspects of his past prior to receiving an HIV diagnosis.

Discussion

Achieving community-level viral suppression is a key target in efforts to reduce and 'virtually eliminate' new HIV infections both globally and in Australia.[1,2] In our analysis and aligning with previous research,[9,17–20] participants commonly characterised reaching and maintaining an undetectable viral load as an important goal in their HIV care. Reaching an undetectable viral load was frequently characterised as an 'achievement' and 'victory,' with viral undetectability engendering a sense of control over HIV and one marker, among others, of good health. Reaching viral undetectability also provided a sense of comfort that the risk of sexual transmission had been eliminated and, as reported previously, was important when considering whether to disclose a positive HIV status to sexual partners.[23]

The sense of achievement at having reached viral undetectability contrasted with participants' experiences of the period in which their viral load was detectable. When describing their experiences of viral detectability, some

participants drew on notions of dirt, virality, and as being a threat to the health of others. Mary Douglas[24] has argued that notions of dirt and uncleanliness function to separate out that which presents a threat to the cohesiveness of the social and moral order. In her conceptualisation, that which is considered a threat to the values of a particular group or society is marked as 'unclean' and separated out. For some participants, even the unlikely possibility of returning to a state of viral detectability engendered a sense of losing social capital. Conversely, and aligning with previous research, reaching *un*detectability enabled participants to lay claim to new forms of HIV and sexual citizenship.[19,25–27] That is, by eliminating any potential for HIV sexual transmission, some participants felt able to reengage in sexual relationships confident that they were not putting the health of their partners at risk.

PLHIV commonly report the potential for onward transmission to sexual partners as a source of significant anxiety.[28] For participants in this study, eliminating the risk of sexual transmission also reduced anxieties about sex and onward HIV transmission.[18] In this way, the benefits of undetectable viral load go beyond improving the physical health of PLHIV and eliminating the risk of sexual transmission. Undetectable viral load also has the potential to improve the sexual health of PLHIV. According to the World Health Organization, sexual health extends beyond *just* the prevention of STIs and encompasses 'physical, emotional, mental and social wellbeing in relation to sexuality'[29] (p.4), By reducing anxiety about HIV transmission, undetectable viral load may also enable PLHIV to experience more pleasurable sexual lives.[4,13,25]

HIV is both a medical and social condition.[3] As we have demonstrated, reaching and maintaining an undetectable viral load has the potential to not only minimise the physical impact of HIV, but can also improve the physical, mental, and sexual wellbeing of PLHIV.[14,17–19] However, reaching undetectable viral load does not necessarily guarantee improved psychosocial wellbeing. The focus on reaching undetectable viral load as an endpoint in HIV clinical care risks overlooking the challenging experiences PLHIV may experience during periods of viral detectability. For participants in our study, the period of viral detectability generally coincided with the period immediately following an HIV diagnosis, a period of significant adjustment and concern for their futures.[30] A greater focus on the needs of PLHIV during the period in which their viral load is detectable may help some PLHIV adjust to an HIV diagnosis and improve psychosocial wellbeing.

Limitations

Participants had received an HIV diagnosis from 2016 onward, a period in which awareness about the benefits of undetectable viral load was increasing. This meant that for most participants, the knowledge that undetectable viral load improves HIV-related health outcomes and prevents sexual transmission was almost always readily accepted. Australia is a setting with high treatment access and participants in this sample had access to treatment through Australia's universal healthcare system or compassionate access schemes. Globally, not all PLHIV have this kind of access and so the narratives presented here are contingent upon being able to access treatment. Participants in our sample were also predominantly gay or bisexual men, limiting opportunities to observe and contrast patterns of experience among different population groups (e.g. heterosexual women). Accounts presented in this paper may not be generalisable to other population groups.

Conclusion

Public advocacy about the role of undetectable viral load in managing and preventing HIV is a powerful tool in improving the health and wellbeing of PLHIV. Reaching undetectable viral load can provide PLHIV with a heightened sense of control over the virus and certainty that there is no risk of HIV sexual transmission. At the same time, however, it is necessary to be attentive to the challenges PLHIV might experience during periods in which their viral load is detectable. For some PLHIV, this period coincides with the period immediately following receiving an HIV diagnosis. Increasing awareness of the health benefits of an undetectable viral load is important and it is a message that deserves to be spread widely. At the same time, however, it is crucial that the needs of PLHIV whose viral load is detectable are not overlooked.

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