

# ‘What doesn’t kill you. . .’: A qualitative analysis of factors impacting the quality of life of people living with HIV

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## Abstract

Despite viral suppression, people living with HIV (PLHIV) report lower quality of life (QoL) than the general population, negatively impacting treatment adherence and wellbeing. This qualitative study explored factors influencing QoL of PLHIV. Participants completed a QoL questionnaire, with cut-off scores used to allocate participants into Low-Moderate QoL ( $n=11$ ) or High-Very High QoL ( $n=10$ ) focus groups. Thematic analysis indicated convergence across factors perceived to impact QoL, with some notable discrepancies. Socioeconomic stability, social connection and support, maintaining good health, adaptive attitudes and reduced impact of stigma were perceived to improve QoL, while obstacles to connection, ageing and poor HIV literacy in the general population were perceived to worsen QoL in both groups. The Low-Moderate QoL group alone identified socioeconomic stressors and ongoing burden of negative life experiences worsened their QoL. Results are presented in the context of local and global HIV health strategies, with implications for clinical management noted.

## Keywords

Covid, HIV, psychosocial, qualitative, quality of life

## Introduction

HIV has radically evolved from an acute threat to a manageable, albeit chronic, condition (Moss, 2013; UNAIDS, 2014). The World Health Organization’s (WHO) aims ‘to end the HIV epidemic as a public health threat by 2030’ is currently operationalised by the UNAIDS 95-95-95 targets such that 95% of people living with HIV (PLHIV) should be aware of their diagnosis; of those 95% should be taking antiretroviral therapy (ART); and of those 95%

should achieve viral suppression by 2030 (Heath et al., 2021; UNAIDS, 2014). Guided by these targets, modern testing and treatment

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regimens have successfully reduced community transmission rates, suppressed viral load, and slowed disease progression, improving medical outcomes for PLHIV in many countries. Today, PLHIV who adhere to their treatment regimen have a similar life expectancy to that of the general population (Samji et al., 2013). However, without a cure the lifelong impact of HIV, such as the side effects of long-term medications, and living with a stigmatised disease, continue to affect 38 million people worldwide, with 1.7 million under 15-years-old (UNAIDS, 2021). While UNAIDS targets serve to ensure PLHIV live longer, they stop short of operationalising WHO's full strategic vision of achieving 'health', defined as a 'state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity' (Lazarus et al., 2016; WHO, 2020: 1).

HIV is a multifaceted condition with broad implications for quality of life (QoL) across physical, social, financial and mental wellbeing (Karkashadze et al., 2017; Power et al., 2019; Zeluf-Andersson et al., 2019). The presence and severity of treatment side-effects and highly prevalent physiological comorbidities, often occurring at younger ages compared to the general population, are associated with lower QoL (Degroote et al., 2014; Guaraldi et al., 2011; Outcomes, 2021a, 2021b). Psychosocial factors have been shown to negatively impact QoL more than physiological or medical determinants of health in PLHIV (Mendonca et al., 2022; Mikołajczak et al., 2022). HIV is a highly stigmatised condition, disproportionately affecting individuals already managing the stress of multiple marginalised identities, including men who have sex with men (MSM), those who engaged in sex work, injecting drug users, individuals that have been incarcerated and people from culturally and linguistically diverse backgrounds (Centre for Population Health, 2020; Skinta et al., 2014; UNAIDS, 2021). Within the PLHIV community is a high prevalence of mental health issues, socioeconomic pressure and social disconnection, each independently associated with lower QoL

(Lazarus et al., 2016; Zeluf-Andersson et al., 2019). Long-term implications of HIV infection and management incur additional physiological and psychosocial difficulties, compounding the natural challenges of ageing (Balderson et al., 2013). Ageing PLHIV have higher risk of social isolation, loneliness, stigma, mental illness and neurocognitive impairment compared to the general population (Rueda et al., 2014). More research is required to understand the unique experiences and needs of this cohort, to define 'healthy ageing' with HIV, and to guide client-centred integrative care to achieve this (Guaraldi et al., 2019).

Factors linked to poor QoL often negatively influence HIV treatment adherence; understanding QoL in PLHIV is vital to maintaining and improving medical outcomes and working towards health and wellbeing (Bulsara et al., 2018). Currently PLHIV report lower QoL compared to the general population (Hutton et al., 2013; Miners et al., 2014; Nazik et al., 2013) and this discrepancy remains regardless of viral suppression (Miners et al., 2014). Recognising the importance of QoL a fourth target is proposed, that virally suppressed PLHIV should also report good health-related quality of life (HRQoL). Expanding treatment outcomes to appropriately reflect WHO's strategic vision from simply living longer with HIV to *living well* with HIV (Lazarus et al., 2016). In developed nations with universal healthcare and surpassing UNAIDS targets, the subjective wellbeing of PLHIV appears to be declining over time with over one third reporting 'poor' QoL in Australia (Power et al., 2019). This study sought to understand and explore this alarming trend further.

There is little research into how concurrent factors impact the QoL of PLHIV. Quantitative studies of HIV and QoL often rely on retrospective analyses of data routinely captured in research or clinical settings, therefore limited to the exploration of variables included in standard assessments (Ghiasvand et al., 2019; Oguntibeju, 2012). Its possible key factors influencing QoL from the perception of PLHIV have been overlooked, particularly in

an Australian context. Additionally, much of the quantitative research to date has assessed the influence of factors on QoL in isolation, while PLHIV likely experience multiple interacting, factors concurrently. A deeper understanding of interrelated and concurrent factors impacting QoL would likely support both policy and practitioners in achieving QoL targets.

To address these issues, this study aims to qualitatively explore factors improving or worsening QoL for PLHIV, and whether factors identified differ between those currently reporting higher versus lower QoL. Additionally, the study examines how the experience of living with HIV influenced coping during the COVID-19 pandemic.

## Method

### Participants

The present study was part of a larger data collection exercise requiring participants to complete a 25-minute battery of questionnaires online (Mendonca et al., 2022). Participants were engaged in regular HIV medical care with the Albion Centre (Albion), an interdisciplinary HIV specialist healthcare facility in Sydney Australia. Those over 18-years and proficient in English were invited to participate and reimbursed for their time. Recruitment posters were displayed in the clinic, social media posts and SMS detailing the study, directing interested clients to register via a QR Code or URL. All participants completed consent forms confirming the confidential and voluntary nature of the study, and willingness to participate in qualitative focus groups. To minimise QoL variability in the context of multiple COVID-19 lockdowns, only those who completed questionnaires after lockdowns ended in NSW were invited to join the focus groups. Twenty-one participants between 35 and 74 years-old ( $\mu=52$ -years) took part in one of eight focus groups conducted over a 4-month period between April and July 2022. Focus groups were scheduled until there were no

further participant enquiries. Consistent with the profile of the Australian HIV epidemic, most participants were male ( $n=20$ ) and identified as gay ( $n=15$ ). Just over half were born in Australia, with one participant identifying as Indigenous Australian.

Included in the questionnaire battery was the PozQoL, a 13-item measure developed and validated within the Australian PLHIV population. The PozQoL demonstrates excellent construct validity and very good reliability assessing QoL in PLHIV across four domains; Health concerns, Psychological, Social and Functionality (Brown et al., 2018; PozQoL Project, 2020). Participants were allocated to one of two groups using PozQoL cut-off scores (PozQoL Project, 2020), to optimise homogeneity within focus groups thus enabling detailed exploration of key themes, and whether perspectives of individuals reporting lower QoL might differ to those reporting higher QoL (PozQoL Project, 2020). Scores  $\leq 45$  were allocated to Low-Moderate QoL (L-M) focus group ( $n=11$ ), while scores  $\geq 46$  were allocated to High-Very High QoL (H-VH) focus group ( $n=10$ ). Participants were not made aware of individual PozQoL results, nor categorical difference between focus groups.

Eight 90-minute focus group sessions were conducted via telehealth, to mitigate risk of COVID-19 infection and conversational interference of facemasks. Confidentiality was discussed at the beginning of each focus group, with an emphasis on respectful communication during the process if disagreements were to arise. All participants agreed to ensure the discussion during the group remained confidential. Computers at Albion were offered to reduce access limitations and two participants requested this option. Participants were compensated for their time with a \$25 supermarket voucher for completing the original online questionnaires, and an additional \$20 supermarket voucher following focus groups. Ethics approval was received from South Eastern Sydney Local Health District (SESLHD; HREC 2020/ETH01434) and University of Technology Sydney (UTS; HREC ETH21-5827).

## Focus group questions and data analysis

Each focus group followed a series of semi-structured open-ended questions, used flexibly and adapted as required to promote discussion and elaboration of ideas.

1. Can you describe factors which improve your QoL?
2. Can you describe factors that worsen your QoL?
3. Does either the experience, or anticipation of stigma impact your QoL?
4. Did your experience of living with HIV help or hinder your capacity to cope with the COVID-19 pandemic?

Four clinicians facilitated focus groups in pairs. Author KLB transcribed and reviewed data upon completion to develop the codebook, which was then reviewed with a second author SB to ensure reliability. A relativist constructionist approach informed thematic analysis of each data set following protocols outlined by Braun and Clarke (2006, 2014), using NVivo v12 software to systematically code and organise key themes. Analyses were integrated by comparing commonalities and differences between and within overarching themes across groups.

Firstly, themes associated with improved QoL are presented, beginning with common sub-themes identified across both groups. Next, unique sub-theme variations are reported, where groups expressed the same theme but with a different emphasis or perspective. The reporting process is then repeated to report themes and subthemes associated with worsened QoL.

## Results

### Demographics

Demographic profiles were similar across both groups, except for the presence of one female, a heterosexual identifying male, and one

Indigenous Australian within the L-M groups (Table 1). Confirming the appropriateness of the group categorisations (Power et al., 2019), the L-M group described greater socioeconomic difficulties, reporting lower income, higher rates of underemployment and greater dependence on government welfare and housing than the H-VH group (Table 1). In contrast, the H-VH group reported higher rates of retirement.

*Factors improving QoL.* Thematic analyses of factors improving QoL revealed five themes common to both L-M and H-VH groups: *Attainment of basic needs, Attitude about HIV, Reduced impact of stigma, Connection and support* and *Capacity to maintain good health* (Table 2). While there was considerable overlap between groups there were also notable variations.

*Attainment of basic need.* Both groups identified *attainment of basic needs*, such as employment, adequate housing and the financial security to pay bills and access a healthy diet, improved their QoL:

*Having a clean environment in where I live, having money to get good meals*

(50-year-old female, L -M).

Additionally, access to affordable and good quality healthcare reportedly improved QoL:

*We are very lucky in this country that we do have all these services for HIV people, and Medicare*

(74-year-old male, H-VH).

While the L-M group focused on immediate needs, H-VH participants identified that long-term financial stability enhanced QoL, such as home ownership, adequate superannuation/pension and the option to retire:

*Rents are so high everywhere as well, so if you're (retired and) on a limited income, well, things can*

**Table 1.** Summary of demographic characteristics.

Demographic	Low–mod QoL (n = 11)	High–very high QoL (n = 10)
<i>PozQoL</i> scores		
Range	19–44	46–56
Mean	37	50
Sex	91% male	100% male
Age	40–70 (m = 52)	35–74 (m = 53)
Country of birth		
Australia	55%	60%
Overseas	45%	40%
Education		
Post grad	1	1
Undergrad	3	1
TAFE/college	4	6
Year 12	1	1
Year 10	2	–
Less than year 10	–	1
Sexual orientation		
Gay	7	8
Bi-sexual	1	–
Queer	2	1
Heterosexual	–	1
Undisclosed	1	–
Duration of illness		
<5 years	1	–
5–9 years	2	1
10–19 years	3	5
20–29 years	3	1
30–39 years	2	3
Physical comorbidity		
	4	4
Employment		
Full time	3	5
Part time	1	–
Unemployed	4	1
Retired	3	5
Student	–	1
Income		
\$0–18,200	3	–
\$18,201–\$37,000	5	2
\$37,001–\$90,000	2	5
\$90,001–\$180,000	–	3
\$180,001+	1	–
Income methods		
Centrelink	6	2
Family/friends	–	1

(continued)

**Table 1.** (continued)

Demographic	Low–mod QoL (n = 11)	High–very high QoL (n = 10)
Employment/self employed	5	6
Superannuation/dividends	1	3
Housing		
Own	3	5
Rent	3	5
Govt. Housing	5	0

*be tough. I haven't had that problem, which I think is quite an asset*

74-year-old male (H-VH).

**Attitudes about HIV.** A range of attitudes regarding HIV were credited as improving QoL across both groups, such as ‘HIV has helped me’:

*I think things come to you in life and they challenge you . . . in a strange sort of a way (they) are a blessing*

60-year-old male, L-M.

Specifically, increasing physical and mental health awareness, literacy and agency were associated with improved QoL:

*(HIV) also helped me to . . . look after myself better so I was more aware of my health*

60-year-old male, H-VH.

Both groups noted that facing an HIV diagnosis facilitated finding purpose or passion in life:

*I became empowered through my diagnosis. . . to force myself to find the reason to live in some ways, I've had to face my mortality. . . its driven more passion for life . . . [and] forced me to go well, 'Holy fuck', excuse my French, I'm gonna live now. . . whereas before that, I was just letting life go by*

**Table 2.** Summary of factors improving and worsening QoL.

	Themes	Common	Low–mod QoL only	High–very high QoL only
<i>Improve QoL</i>	<i>Attainment of basic needs</i>	<ul style="list-style-type: none"> <li>- Employment</li> <li>- Adequate housing</li> <li>- Affordable and quality healthcare</li> <li>- Financial stability</li> </ul>	<ul style="list-style-type: none"> <li>- Immediate needs (food, bills, shelter)</li> </ul>	<ul style="list-style-type: none"> <li>- Long-term financial security (retirement)</li> </ul>
	<i>Attitudes</i>	<ul style="list-style-type: none"> <li>- HIV has helped me</li> <li>- Health awareness</li> <li>- Find purpose in life</li> </ul>	<ul style="list-style-type: none"> <li>- Cultural acceptance of HIV</li> </ul>	<ul style="list-style-type: none"> <li>- HIV resilience</li> <li>- I feel lucky/grateful</li> </ul>
	<i>Reduced impact of stigma</i>	<ul style="list-style-type: none"> <li>- Rejecting shame (MSM)</li> </ul>		<ul style="list-style-type: none"> <li>- Still present but improved overtime</li> <li>- Encountering stigma is disappointing</li> </ul>
	<i>Connection and support</i>	<ul style="list-style-type: none"> <li>- Personal relationships</li> <li>- Community connection (MSM)</li> <li>- Volunteer work</li> <li>- Reciprocal exchange of information</li> <li>- LGBTQI+ and HIV 'Safe Spaces'</li> </ul>	<ul style="list-style-type: none"> <li>- Cultural connection (Indigenous Australian)</li> </ul>	
	<i>Capacity to maintain good health (mental and physical)</i>	<ul style="list-style-type: none"> <li>- Overcoming past mental illness</li> <li>- Established relationships with mental health professionals and services</li> <li>- Motivation and literacy to maintain Physical Health</li> </ul>	<ul style="list-style-type: none"> <li>- Cultural safety in healthcare settings</li> </ul>	<ul style="list-style-type: none"> <li>- Positive relationships with healthcare workers</li> <li>- Absence of illness</li> </ul>
<i>Worsen QoL</i>	<i>Socioeconomic stressors</i>		<ul style="list-style-type: none"> <li>- Rising cost of living</li> <li>- Inadequate public housing</li> <li>- Addiction</li> <li>- Difficulty navigating financial support services</li> </ul>	
	<i>Obstacles to connection</i>	<ul style="list-style-type: none"> <li>- Anticipation of stigma</li> <li>- Outside the gay community (self/ others)</li> </ul>	<ul style="list-style-type: none"> <li>- Location (rural, suburban)</li> <li>- Financial restraints</li> </ul>	
	<i>Poor HIV literacy</i>	<ul style="list-style-type: none"> <li>- Experience or anticipation of stigma</li> <li>- Outside the gay PLHIV community</li> <li>- Negative self-stigma</li> </ul>		
	<i>Ageing</i>	<ul style="list-style-type: none"> <li>- Transition to retirement</li> <li>- Loss of purpose and/or identity</li> <li>- Loss of libido</li> </ul>		<ul style="list-style-type: none"> <li>- Uncertainty about future (reduced mental/physical health and social support)</li> </ul>
	<i>Burden of the past</i>		<ul style="list-style-type: none"> <li>- Personal and intergenerational difficulties weighing heavily on present (illness, trauma, injustice, intersectional stigma and discrimination)</li> </ul>	

39-year-old male, H-VH.

The H-VH group uniquely identified that living with HIV fostered resilience that continues to serve them throughout their lives:

*It has been, it's been a bit of a badge of honour. . . what doesn't kill you, you know, brings you out stronger.*

60-year-old male, H-VH.

The H-VH group also strongly endorsed feeling lucky compared to other individuals (i.e. enjoying good mental and physical health, and ample social support), and other social contexts (i.e. improvements in healthcare, stigma and discrimination compared to the 1980s or other countries):

*Basically, if you kind of feel as though you're lucky in life, you are. It's your attitude that drives you through all of your ups and down so. . . it's got a lot to do with your personality*

69-year-old male, H-VH.

Within the L-M group one Indigenous Australian male reported cultural acceptance of HIV improved his QoL:

*I have a different relationship with HIV than Western people do. HIV as a virus, as a living thing, has a right on earth mother, so I view HIV as a companion, and my relationship with HIV exists and that has a lot to do with my quality of life.*

61-year-old male (L-M).

**Reduced impact of stigma.** While both groups reported HIV stigma still occurs, participants in the H-VH group felt an improvement in recent decades. For H-VH participants there was a common view that encountering stigma is disappointing, but attributed to the perpetrator's ignorance:

*I don't have too much anticipation of the stigma. I get disappointed when I do come up against it. Especially on the [dating] apps, for the most part,*

*I'd say, look, I'm happy to answer your questions but I would recommend that you educate yourself and get on the [local HIV information organisation] website directly*

40-year-old male, H-VH.

A recurrent sub-theme of MSM across both groups was consciously rejecting shame traditionally derived from stigma or discrimination:

*I'm not giving you the power to make me feel that way. . . I would be very upfront, because I just want to save myself the time and the disappointment. . . and all those negative feelings*

39-year-old male, H-VH.

**Connection and support.** Across both groups, personal relationships (i.e. friends, biological and chosen family, partner and pets) were reported to buffer stigma and mental health concerns, improving QoL:

*We need people, we need to know that we're needed. We need to be liked (and) we need to like other people (it's a) huge part of. . . just basic human emotions*

57-year-old male, L-M.

A strong sub-theme of community connection through LGBTQI+ and HIV friendly organisations emerged among MSM across both groups. Regardless of sexual orientation, volunteer work and the reciprocal exchange of HIV information through organisations was endorsed as improving QoL:

*I went to [multiple local HIV information organisations], I did [HIV organisation] Workshop, I did all these things which gave me information. . . and I even became a speaker for [HIV organisation] for a couple of years. . . I'd go out and speak to healthcare workers, hospitals, and nurses about my experience*

44-year-old male, H-VH

Both groups associated, access to safe spaces with improved QoL, including HIV and queer-friendly medical care (i.e. clinics and chemists), or social opportunities (i.e. events or locations):

*Our community spaces are . . . vitally important. Queer bars and night club [are] not just a place for recreation . . . it's not just about hedonistic pleasure. It's a place of connection and relating to people that have a similar experience. I'm fortunate that I have a large family and I have good friend connections, that's all great, but take me to my local queer bar with my 'queer-dos' any day. That's the place where I feel most comfortable.*

39-year-old male, H-VH

**Capacity to maintain good mental and physical health.** Both groups reported maintaining good mental and physical health as central to improved QoL. Overcoming past mental illness was perceived to be beneficial to QoL as it increased health literacy (i.e. noticing warning signs, and adjusting unhelpful behaviours), and help-seeking behaviour:

*It took me getting to a certain crisis point, to recognise that I need to reach out for help. That is a lesson that I did learn from my diagnosis*

39-year-old male, H-VH.

However, only the H-VH group reported the absence of illness as positively influencing QoL:

*By the sound of it, none of us have gone through a period where we've had extended illness because of HIV, so we've lived a life that's relatively normal health wise.*

69-year-old male, H-VH.

The H-VH group identified positive relationships with healthcare workers as important to improved QoL:

*It gives you the reassurance that you know, you're cared for and you're going to be fine, that you have the support.*

35-year-old male, H-VH.

Cultural safety in healthcare settings was key to maintaining physical and mental health for the Indigenous Australian participant.

*My way of engaging with psychologists, particularly getting them to read on decolonising [their] thinking, so they understand how I'd like to construct or integrate Indigenous knowledges into the treatment that I receive.*

61-year-old male, L-M.

**Factors worsening QoL.** Five key themes were identified that were associated with depleted QoL: *Socioeconomic stressors, Obstacles to connection, Poor HIV literacy, Ageing and Burden of the Past* (Table 2). Notable variations between groups were evident.

**Socioeconomic stressors.** The L-M group reported that socio-economic stressors worsened their QoL, specifically inadequate public housing and financial instability. It was also identified that negotiating the rising cost of living negatively impacted QoL:

*The rising cost of living is also such a heavy aspect for quality of life. . . It's impossible to live on (welfare) if you are living in a big city like Sydney or Melbourne.*

60-year-old male, L-M

The cost of living was reportedly further exacerbated by addiction:

*I personally make the decision 'do I eat, or do I get some cigarettes?' . . . and I'm an addict so what do you think the answer's going to be?*

57-year-old male, L-M.



**Obstacles to connection.** Members of both groups identified limited physical and/or emotional intimacy due to anticipation or experience of HIV stigma, negatively impacted QoL:

*You sort of sometimes run the risk of being treated like a leper and it does make you a bit cautious of how you disclose that information. I feel like it is a barrier to having more close relationships and more open relationships*

39-year-old male, H-VH.

Participants seeking connection outside of the gay community (i.e. bisexual or heterosexual PLHIV) appeared to be more acutely impacted:

*All these years I have stayed without a partner and without having any relationships because I do not know how to bring up the topic with anyone. I do not know if people would even understand my situation. . .*

50-year-old-female, L-M

Participants in the L-M group also identified living in outer-suburban or rural areas resulted in geographical and financial constraints on social connection:

*I'd like to find some more gay groups or gay events. . . my counsellor's recommended a gay walk every Tuesday morning in Hyde Park, I've got to drive from the 'burbs. . . they're all centred in Darlington.*

70-year-old male, L-M.

**Poor HIV literacy.** Both groups identified low HIV literacy in the general population worsened QoL leading to experience or anticipation of HIV stigma. This was particularly evident outside of the gay community and outer suburban/rural areas with a lower density of PLHIV:

*(People) are still living with information from the early 90's and late 80s . . . [which] can be quite frustrating.*

39-year-old male, H-VH.

*The first thing they ask is 'have you been with a guy?'. . . it's just like 'no, it was actually my ex-girlfriend she passed it to me'*

37-year-old male, H-VH

Additionally, participants in both groups reported the lack of HIV literacy in the general population fostered negative self-stigma:

*I was also uneducated myself. . . I didn't realise there was another closet to come out of. I'm part of the gay community here and so. . . well there was still a little bit of stigma, but mainly it was self-stigma*

44-year-old male, H-VH

**Ageing.** Those in the H-VH group identified elements of ageing negatively impacted QoL, specifically uncertainty about the future (i.e. declining mental or physical health, loss of social support, not wanting to be a burden):

*But now that you do get old, yeah certainly, I do think about that and what would I do if I need. . . (if) I get dementia and I'm on my own*

59-year-old male, H-VH.

Both groups endorsed loss of libido worsened QoL:

*I'm not sure whether or not this is just me getting older, or the long-term effects of medications, or just a whole lot of psychological things going on. . . but certainly diminishing libido over the years.*

69-year-old male, H-VH.

Both groups also discussed the transition to retirement as an important subtheme in relation to the loss of purpose and identity

*It's hard for me to stay positive and stay engaged with the world when suddenly it's like, well, that's it. You're done.*

70-year-old male, L-M.

**Burden of the past.** In contrast to the H-VH group, participants in the L-M group responses featured rumination on personal and intergenerational difficulties (i.e. negative life events, injustice, intersectional stigma and discrimination of race and sexuality). While the H-VH group discussed past difficulties through the perspective of learned resilience or gratitude things have improved, comments in the L-M group suggested historical burdens continue to weigh heavily on their current lives:

*I spent many a year beating myself up over this. . . and then I find out its the result of damage done in childhood so not much I can do about that.*

57-year-old male, L-M.

**HIV and coping with COVID-19.** Participants were asked to consider how living with HIV impacted their coping during the Covid-19 pandemic. Two broad themes of HIV assisting coping, and HIV hindering coping, were generated.

**Experience of HIV assisted coping.** Both groups identified HIV resilience improved coping during the COVID-19 pandemic and associated restrictions. Compared to the L-M group, the H-VH participants could readily identify multiple personal and communal benefits and opportunities of lockdowns and perceived challenges as a temporary inconvenience. Again, the H-VH group reported attitudes of gratefulness:

*I have a hell of a lot of privilege living in a city and living in this country that we do. And I just try and make it a point of just checking that privilege all the time*

60-year-old male, H-VH.

Both groups identified health awareness from living with HIV enabled them to notice and counteract unhelpful behaviours impacting mental and physical health:

*. . . you find that you're more conscious of how to look after your mental health, because we've probably both felt at times, when that end of our lives slipped a little bit, and we um had to try and pull ourselves out of that*

39-year-old male, H-VH.

Participants in the L-M groups acknowledged being socially disconnected prior to lockdowns, due to geographic distance or feeling excluded from a predominantly LGBTIQ+ HIV community, assisted their coping:

*I didn't find COVID made that much [difference], I was a bit isolated prior to COVID*

57-year-old male, L-M.

**Experience of HIV hindered coping with Covid-19.** Across both groups isolation due to Covid-19 restrictions negatively impacted QoL, as did the loss of LGBTIQ+ and HIV safe spaces. One participant noted he felt re-traumatised as elements of COVID-19 that paralleled his HIV diagnosis.

*I felt re-traumatized during COVID-19, severely. I put this around being 'toxic' and the ability to pass on a contagious disease. Intellectually, I knew that they were very different things. . . (but) there was a lot of shame. Bringing back the trauma of knowing that I probably was, but not getting diagnosed, and then getting diagnosed, but keeping it secret. . . it was really bad*

39-year-old male, H-VH.

## Discussion

This study sought to identify factors influencing QoL for PLHIV, exploring similarities and variations across those currently reporting higher versus lower QoL. Unsurprisingly factors

improving QoL across both groups included sufficient social connection; support and capacity to maintain good mental and physical health; and socioeconomic stability (Degroote et al., 2014; Mendonca et al., 2022; Mikołajczak et al., 2022; Zeluf-Andersson et al., 2019). Additionally, both groups reported the reduced impact of stigma and adaptive attitudes towards HIV improved QoL. Congruent with the literature, both groups reported social disconnection (Mendonca et al., 2022) and ageing (Rueda et al., 2014) worsened their QoL. Both groups also identified that poor HIV literacy in the broader population was perceived to worsen QoL. Only those in the lower QoL group reported socioeconomic stressors and unresolved past trauma were associated with worsened QoL.

### **Good health**

Few physiological comorbidities were reported in this sample and those reporting higher QoL attributed a lack of health concerns with improved QoL. Access to quality, affordable healthcare bolstered capacity to maintain health and was collectively perceived to improve QoL. Several participants disclosed mental health comorbidities; however, in contrast to the literature (Carvalho, 2010; Outcomes, 2021b; Power et al., 2019), these weren't perceived as worsening QoL for either group. Instead, the successful management of current or historical mental illness was described as improving QoL through strengthened agency, health literacy and relationships with healthcare providers. It is likely results are reflective of individuals receiving regular treatment from a well-resourced, multi-disciplinary HIV-specialist clinic.

Ensuring respectful inclusion of cultural and social perspectives in healthcare enhanced QoL for one Indigenous Australian participant. However, this was inconsequential for other culturally diverse participants, reinforcing the importance of centring the individual needs in HIV health care (Ferreira, 2008; Kagawa-Singer et al., 2010; Ward et al., 2021).

### **Socioeconomic status**

Consistent with the literature, this study highlights the negative impact of concurrent socioeconomic stressors on QoL in PLHIV (Power et al., 2019). Concerningly, those reporting lower QoL and more financial stress also indicated their HIV status impeded accessibility and navigation of financial supports and services (i.e. purchasing life insurance, and accessing disability welfare for children). Community-based cost-of-living initiatives, originally introduced to support severely ill PLHIV, have undergone substantial restructuring in recent decades following advanced medical outcomes in PLHIV (Power et al., 2019). The results of this study suggest strengthening financial support initiatives or increasing awareness and accessibility to existing services may be advantageous in reaching QoL targets.

### **Adaptive attitudes and burden of the past**

Although both groups reported attitudes that enhanced their coping with Covid-19 restrictions, they were more prevalent and varied in the higher QoL group. These adaptive attitudes may be expressions of cognitive flexibility, essential to adapt to challenging contexts, manage negative thoughts and emotions, switching attention and generating efficacious coping strategies. Cognitive flexibility is a key component in psychotherapy interventions as it improves coping with life stressors (Gabrys et al., 2018), and has been associated with improved resilience and QoL (Airdrie et al., 2022; Dajani and Uddin, 2015; Davis et al., 2010). Difficulty overcoming the past negative life events, as evident in those reporting lower QoL, may suggest some degree of cognitive inflexibility. However, the capacity to think flexibly is likely facilitated by certain privileges, such as the absence of illness, complex trauma or socioeconomic stressors, a profile consistent with participants reporting higher QoL.

### **Connection, stigma and HIV literacy**

Consistent with current literature, social connection facilitated greater QoL while disconnection was thought to worsen QoL across both groups (Mendonca et al., 2022; Power et al., 2019). Those with lower QoL emphasised that financial and geographical restraints limited opportunities for connection. Despite advances in HIV treatment, stigma continues to impede connection and QoL for many PLHIV (Turan et al., 2017). Both groups endorsed limited quality and quantity of social connections due to anticipation of HIV-related stigma when engaging with people outside the MSM community. Further, only MSM endorsed consciously rejecting shame and subsequently a reduced impact of stigma on their QoL. These findings likely demonstrate protective effects of group identity on internalised and enacted stigma (Fuster-Ruizdeapodaca et al., 2014), which may be less accessible for isolated or minority PLHIV due to location, culture, gender or sexuality (Andersson et al., 2020). Participants credited poor HIV literacy in the general population for fuelling stigma and limiting social connection. Findings emphasise a need for affordable and accessible opportunities for connection, particularly targeting PLHIV under financial stress, living outside main cities and those who do not identify with the MSM community. Additionally, efforts to raise general HIV literacy may contribute to reducing stigma and positively influence the QoL of PLHIV.

### **Ageing**

Consistent with existing literature, ageing was commonly perceived as detrimental to QoL, due in part to the negative impact of loss of libido and intimacy (Zeluf-Andersson et al., 2019). Additionally, the transition to retirement was perceived to worsen QoL through disruptions to identity, and purpose. Congruent with the literature there was a prominent concern for the future, specifically with respect to declining physical and mental health, and adequate social support (Rueda et al., 2014). Interestingly this was only evident in those reporting higher QoL. An Australian longitudinal study found a unique

decrease in QoL scores for PLHIV aged 50–64 years (Power et al., 2019). It is hypothesised that approaching retirement age heightens awareness of future uncertainty, which may be one facet negatively influencing QoL of PLHIV in this age group.

### **HIV and coping with COVID-19**

As expected, many aspects perceived to facilitate or impede coping with Covid lockdowns paralleled factors influencing QoL. Acknowledging the importance of connection for QoL in PLHIV, it remains unsurprising both groups identified isolation and closing of communal ‘safe spaces’ as detrimental to coping throughout the Covid-19 pandemic. Adaptive attitudes, or cognitive flexibility as previously discussed, were perceived to be highly beneficial in coping with the Covid-19 pandemic for those with higher QoL. Both groups identified that their experience of resilience, and the capacity to maintain mental and physical health from living with HIV, as well as having survived the HIV epidemic, enhanced their capacity to cope throughout the pandemic.

### **Clinical implications**

The results discussed here provide insight into the important role of psychologists and other mental health practitioners in supporting PLHIV to improve their QoL. Specifically, psychotherapy can play an important role in the development of cognitive flexibility to process and understand previous negative life events and adjust how they impact individuals currently. This might include processing trauma and treating associated mental health sequelae to limit its impact currently. Likewise, assisting PLHIV to develop connections, build resilience and adjust to the effects of ageing might also be beneficial.

### **Limitations and future directions**

Qualitative findings lack generalisability as data was attained from a small sample size, and vulnerable to inextricable biases of the tertiary

educated, straight, Caucasian, female researcher facilitating and coding focus groups (Braun and Clarke, 2006). This small but culturally and socio-economically diverse sample, were self-selected and sourced from a single, well-resourced urban HIV-specialist clinic. The sample was reflective of the largely MSM PLHIV community in Sydney, and few outside this demographic were represented. Some unique challenges of minority groups within the PLHIV community, in terms of gender, sexual orientation and ethnicity were explored, however these perspectives require closer consideration.

## Conclusion

QoL plays a vital role in improving and maintaining physiological outcomes, as well as more broadly defined health and wellbeing of PLHIV. This study enhances the current understanding of factors perceived to improve and worsen QoL for PLHIV. In addition to considerable convergence among broad themes, key variations were identified and explored between those currently reporting higher versus lower QoL. Additionally, discrepancies were noted across factors influencing QoL for minority groups (based on sexuality, gender, culture, age and geographic location) within the broader, predominately gay, male PLHIV community.

Findings suggest socioeconomic pressure, confusion navigating support services and poor HIV literacy amongst the broader population appear to be barriers to QoL for PLHIV. Challenges to maintaining QoL appear to evolve across the lifespan, particularly around significant transitional periods such as approaching retirement age. In addition, other factors appeared to positively influence QoL, such as increasing opportunities for social connection and HIV safe spaces for all PLHIV and being mindful of vulnerable and often overlooked minority groups. Further, the experience of cultural safety in health-care settings was perceived to improve QoL of those from minority groups. Finally, the cognitive flexibility or capacity to integrate positive perceptions, attitudes or meaning from one's own challenging

experiences of living HIV was thought to enhance QoL in PLHIV. This study broadly confirms and extends upon existing literature, and may prove useful in guiding future research, policy and clinical intervention efforts to reduce barriers and enhance positive influences on QoL for PLHIV across the lifespan.

## Author contributions

The authors confirm contribution to the paper as follows: KLB: Conceptualisation (equal); formal analysis (lead); writing – original draft (lead); review and editing (equal). TNJ: Conceptualisation (equal); Writing – review and editing (equal). RH: Data collection (supporting); Methodology (lead); writing – review and editing (equal). DA: Data collection (supporting); Writing – review and editing (equal). KB: Writing – review and editing (equal). SB: Conceptualisation (equal); data collection (supporting); formal analysis (supporting); writing – review and editing (equal).

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## Data sharing statement

The data generated and analysed during the current study are not publicly available nor are they available on request due to privacy concerns, as stipulated by ethics approval.

## Declaration of conflicting interests

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## Ethics approval

Ethics approval was received from South Eastern Sydney Local Health District (SESLHD; HREC 2020/ETH01434) and University of Technology Sydney (UTS; HREC ETH21-5827).

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