

## Quality of life in people living with HIV in Aotearoa New Zealand: an exploratory cross-sectional study

Susan McAllister, Ella Iosua, Brooke Hollingshead, Jane Bruning, Mark Fisher, Rodrigo Olin, Judith Mukakayange, Carl Greenwood, Ashleigh de Gouw & Patricia Priest

To cite this article: Susan McAllister, Ella Iosua, Brooke Hollingshead, Jane Bruning, Mark Fisher, Rodrigo Olin, Judith Mukakayange, Carl Greenwood, Ashleigh de Gouw & Patricia Priest (2022): Quality of life in people living with HIV in Aotearoa New Zealand: an exploratory cross-sectional study, *AIDS Care*, DOI: [10.1080/09540121.2022.2082359](https://doi.org/10.1080/09540121.2022.2082359)

To link to this article: <https://doi.org/10.1080/09540121.2022.2082359>



Published online: 30 May 2022.



Submit your article to this journal [↗](#)



View related articles [↗](#)



View Crossmark data [↗](#)



## Quality of life in people living with HIV in Aotearoa New Zealand: an exploratory cross-sectional study

Susan McAllister<sup>a</sup>, Ella Iosua<sup>b</sup>, Brooke Hollingshead<sup>c</sup>, Jane Bruning<sup>d</sup>, Mark Fisher<sup>e</sup>, Rodrigo Olin<sup>c</sup>, Judith Mukakayange<sup>c</sup>, Carl Greenwood<sup>f</sup>, Ashleigh de Gouw<sup>a</sup> and Patricia Priest<sup>a</sup>

<sup>a</sup>AIDS Epidemiology Group, Department of Preventive and Social Medicine, University of Otago, Dunedin, New Zealand; <sup>b</sup>Biostatistics Centre, Division of Health Sciences, University of Otago, Dunedin, New Zealand; <sup>c</sup>New Zealand AIDS Foundation, Auckland, New Zealand; <sup>d</sup>Positive Women Inc., Auckland, New Zealand; <sup>e</sup>Body Positive Inc., Auckland, New Zealand; <sup>f</sup>New Zealand Needle Exchange Programme, Wellington, New Zealand

### ABSTRACT

Quality of life (QoL) in people living with HIV (PLHIV) is reportedly worse than in people without HIV, with many factors impacting on this. We aimed to investigate QoL in PLHIV in New Zealand (NZ). In-person interviews were conducted including socio-demographic, health, social connectedness, and stigma-related questions. QoL was measured using the 13-question PozQoL Scale – summed to give a score between 13 and 65. Univariate linear regression was used to investigate factors associated with differences in PozQoL scores. PLHIV ( $n = 188$ ) of different ethnicities from throughout NZ participated. The mean age was 47 years; 65% were men; 61% were men who have sex with men; 61% had been living with HIV for  $\geq 10$  years. The mean summary PozQoL score was 47.16. Factors associated with a lower mean PozQoL included no sex in the last 12 months ( $-9.03$ ), inability to meet basic needs ( $-7.47$ ), ever ( $-6.49$ ) or recently ( $-5.03$ ), experiencing stigma or discrimination, mental health condition ( $-5.74$ ), HIV diagnosis  $< 5$  years ( $-5.48$ ), poor health ( $-5.43$ ), being unemployed ( $-5.02$ ), not having support ( $-4.71$ ), and greater internalised stigma ( $-2.81$ ). Improving QoL will require investment in peer support and community welfare programmes to better support PLHIV, and stigma reduction campaigns targeting the broader community.

### ARTICLE HISTORY

Received 8 November 2021  
Accepted 20 May 2022

### KEYWORDS

Quality of life; HIV; New Zealand

## Background

HIV is now considered a chronic and manageable condition due to effective antiretroviral treatment (ART). People living with HIV have a life expectancy almost equivalent to people without HIV (Nakagawa et al., 2012) and are able to lead long and productive lives, yet their quality of life (QoL) has been reported to be worse compared to people without HIV (Miners et al., 2014; Pedersen et al., 2015).

The World Health Organization (WHO) Global Health Strategy on HIV includes the goal “To end the AIDS epidemic as a public health threat by 2030, within the context of ensuring healthy lives and promoting wellbeing for all, at all ages” (World Health Organization, 2016). People living with HIV continue to experience stigma and discrimination (Grierson et al., 2008; Mundt & Briggs, 2016), and a range of other factors have been reported to impact on QoL, including financial stress, depression, anxiety, hopelessness, negative self image, sexual dissatisfaction, smoking and alcohol consumption (Andersson et al., 2020; Degroote et al.,

2014; Grierson, et al., 2004; Herrmann et al., 2013; Miners et al., 2014; Rueda et al., 2016; Skevington et al., 2010; Zeluf-Andersson et al., 2019). To meet the WHO goal of promoting wellbeing requires consideration of each of these factors.

New Zealand has a low prevalence of HIV ( $< 0.1\%$ ) (UNAIDS, 2019) with approximately 3500 people living with HIV throughout the country – mostly in the main urban centres. Men who have sex with men (MSM) and heterosexual people from sub-Saharan Africa and parts of Asia are the main population groups affected by HIV (Dickson et al., 2015). There is no specific HIV strategy but the overall Aotearoa New Zealand Health Strategy 2016–2026 has the goal that “All New Zealanders live well, stay well, get well” (Minister of Health, 2016) to ensure that people lead not only a long life, but also have quality of life, living well for as many years as possible. Very little, however, is known about the QoL of people living with HIV in New Zealand. Only two online surveys have been conducted in 2001 and 2007, in which approximately 75% rated their general

wellbeing as excellent or good (Grierson, et al., 2004, 2008). The aim of this paper is therefore to measure QoL and examine factors associated with QoL in people living with HIV in Aotearoa New Zealand.

## Methods

### Overview of the study

The QoL study was part of the Aotearoa New Zealand Stigma Index which sought to identify stigma and discrimination experienced by people living with HIV using “The People Living with HIV Stigma Index” tool (Stigma Index Working Group, 2020). The study was run by, for and with people living with HIV thereby incorporating the principle of meaningful involvement of people living with HIV and AIDS (MIPA principle). A Working Group was established to guide and manage the study, with diverse representation of people living with HIV alongside allies and people affected by HIV.

### Study population and sample size

Eligible participants were people living with HIV aged 16 years and over, recruited from throughout New Zealand between July 2019 and September 2020. Recruitment was a convenience sample through community organisations for people living with HIV (websites, email and newsletters), notices placed in HIV specialist clinics, pharmacies commonly used by people living with HIV to collect their prescriptions, word-of-mouth, and the employment of a Māori recruiter to implement focused recruitment of Māori living with HIV. We aimed to recruit a sample of 200 people and to have similar numbers of men and women from each main ethnic group (Māori, African, Asian and European/Other).

### Interview and data collection

Twelve people living with HIV were trained as peer interviewers. People living with HIV registered their interest in participating through the study website. The Study Coordinator then allocated each participant an interviewer and interviews were arranged in a location mutually agreed upon where privacy was ensured. All participants went through an informed consent process and provided written consent before proceeding with the interview. The side-by-side in-person interviewing technique was used whereby the participant and interviewer were sitting next to each other, able to see each question, and record each answer together.

Answers to all questions were written onto a paper copy of the questionnaire and sent to the Study Coordinator who entered the information into the REDCap 10.1.2 (Harris et al., 2009) secure database. Data were cross-checked by a separate member of the research team.

### Study variables

The 13 question PozQoL scale, a QoL tool specific to people living with HIV, was used to measure QoL (Brown et al., 2017, 2018). Participants could indicate their response to each of the 13 questions on a scale from 1 “Not at all” to 5 “Extremely”. Responses were re-coded so that higher scores for all items indicated better QoL. Results were summed to give a total PozQoL score of between 13 and 65 – categorised as low ( $\leq 36$ ), moderate (37–45), high (46–53) or very high ( $\geq 54$ ). Within each sub-scale, summary scores could range from 3–15 for health concerns, social, and functional sub-scales, and from 4–16 for the psychological sub-scale (Brown et al., 2019).

In recognition of the many factors that affect QoL we identified four main categories of variables to investigate: socio-demographic, health-related, social connectedness, and stigma and discrimination.

Socio-demographic factors included age, gender categorised to women (including trans women (whaka-wahine in Māori)), men (including trans men), and non-binary. The latter were excluded from quantitative analysis due to small numbers. Sexual identity was categorised to MSM, heterosexual men or women, and bisexual women (the latter three combined for analysis). Ethnicity allowed for multiple responses that were categorised to Māori, European, and other ethnicities (African, Asian, Pacific peoples, Middle Eastern, Latin American combined due to small numbers), with Māori and other ethnicities prioritised above European. Employment was categorised as employed (full or part-time), unemployed/receiving a government benefit, or retired/homemaker. Area of residence was combined to major urban (population  $\geq 100,000$ ) and medium urban/rural (population  $< 100,000$ ) (Statistics New Zealand, 2020). Participants were asked how often in the last 12 months they were able to meet basic needs, such as for food, shelter and clothing. Responses were “always”, “some of the time” or “almost none of the time” – with the latter two combined for analysis. Identifying as a person who uses or used drugs (such as heroin, cocaine or methamphetamines) or identifying as a sex worker were both dichotomous questions (yes/no).

Health-related factors included the length of time living with HIV (dichotomised to  $< 5$  years and  $5+$  years), currently being on ART, having an undetectable viral

load, any other medical condition not related to HIV, and whether they had been diagnosed in the past 12 months with a mental health condition such as anxiety, depression or insomnia (yes/no). Health status was reported as good, fair or poor – with the latter two combined for analysis.

To identify the level of people's support and social connectedness, participants were asked whether they were in an intimate or sexual relationship, in a network or support group of people living with HIV, if they had decided not to have sex in the past 12 months because they have HIV, and whether people close to them had been supportive on disclosure of their HIV (yes/no).

Eleven questions were asked about stigma and discrimination experienced because of HIV. Answers were combined to two dichotomous variables of "stigma ever" and "stigma in the last 12 months". Internalised

stigma, or the way a person thinks about themselves, was investigated through six separate statements about feeling dirty, guilty, ashamed or worthless, or whether they found it difficult to tell people about, or hid, their HIV. Participants could agree (coded as 1) or disagree (coded as 0) with each statement. Answers were summed and combined into a single variable that ranged from 0–6. To identify people's sense of resilience they were asked if they had taken any action in response to stigma or discrimination in the past 12 months, such as challenging someone or participating in an educational campaign (yes/no).

### Statistical analysis

Variables identified from the literature as potentially being associated with QoL in people living with HIV

**Table 1.** Socio-demographic characteristics of participants ( $n = 188$ ).

Characteristics	$n$ (%)
<b>Age</b>	
<30	19 (10.1)
30–49	85 (45.2)
50+	84 (44.7)
<b>Gender identity</b>	
Women	61 (32.4)
Men	122 (64.9)
Non-binary	5 (2.7)
<b>Sexual identity</b>	
Men who have sex with men (MSM) <sup>a</sup>	115 (61.2)
Heterosexual women	53 (28.2)
Heterosexual men	11 (5.9)
Bisexual women or sexual identity not stated	9 (4.8)
<b>Ethnicity</b>	
Māori	37 (19.7)
New Zealand European	93 (49.5)
Other European	13 (6.9)
Pacific peoples	6 (3.2)
Asian	15 (8.0)
African	17 (9.0)
Middle Eastern and Latin American	7 (3.7)
<b>Residential location</b>	
Major urban area	141 (75.0)
Medium urban or rural area	47 (25.0)
<b>Education</b>	
Secondary school	39 (20.7)
Trade/vocational education	27 (14.4)
Tertiary education	122 (64.9)
<b>Employment</b>	
Employed (full or part-time)	119 (63.3)
Unemployed or on a government benefit	50 (26.6)
Retired or homemaker	19 (10.1)
<b>Able to meet basic needs</b>	
Always	127 (67.6)
Some of the time	40 (21.3)
Almost none of the time	21 (11.2)
<b>Identifies as a person who uses (or used) drugs</b>	
No	129 (68.7)
Yes	59 (31.4)
<b>Identifies as a sex worker</b>	
No	183 (97.3)
Yes	4 (2.1)
No answer	1 (0.5)

<sup>a</sup>Includes Gay, bisexual men and MSM.

**Table 2.** Health-related characteristics, social connectness, stigma and discrimination ( $n = 188$ ).

Characteristics	$n$ (%)
<b>Health-related:</b>	
<b>Length of time living with HIV</b>	
<5 years	31 (16.5)
5–10 years	42 (22.3)
10+ years	115 (61.2)
<b>On anti-retroviral therapy</b>	188 (100.0)
<b>Viral load undetectable</b>	178 (94.7)
<b>Current health status</b>	
Good	144 (76.6)
Fair	34 (18.1)
Poor	10 (5.3)
<b>Mental health condition</b> (anxiety, depression, insomnia)	61 (32.5)
<b>Other medical condition</b> (not related to HIV)	106 (56.4)
<b>Social connectedness:</b>	
<b>Currently in an intimate/sexual relationship</b>	
No	107 (56.9)
Yes	81 (43.1)
<b>Member of a network or support group of people living with HIV</b>	
No	54 (28.7)
Yes	134 (71.3)
<b>Decided to not have sex in past 12 months</b>	
No	105 (55.9)
Yes	72 (38.3)
Not applicable	11 (5.9)
<b>People close had been supportive on disclosure of HIV</b>	
Agree	122 (64.9)
Somewhat agree	45 (23.9)
Disagree	14 (7.5)
Not applicable	7 (3.7)
<b>Stigma and discrimination:</b>	
<b>Stigma or discrimination ever</b>	142 (75.5)
<b>Stigma or discrimination in the last 12 months</b>	66 (35.1)
<b>Taken action against any stigma or discrimination in past 12 months</b>	
No	56 (29.8)
Yes	132 (70.2)
<b>Internalised stigma (number and % who agreed with each statement)</b>	
Difficult to tell people I have HIV	132 (70.2)
I hide that I have HIV from others	130 (69.2)
Having HIV makes me feel dirty	53 (28.2)
I feel guilty that I have HIV	63 (33.5)
I am ashamed that I have HIV	67 (35.6)
I sometimes feel worthless because I have HIV	57 (30.3)

were investigated using linear regression. All analyses were undertaken using Stata software version 16.0. QoL responses were available for all study participants therefore summary PozQoL scores were used (Brown et al., 2017, 2018, 2019).

## Results

### Study population

A total of 188 people living with HIV participated in the study. Table 1 details the socio-demographic characteristics of participants. The mean age was 47 years (range 20–75). The majority were men (65%) and identified as being gay, bisexual or MSM (61%). Three quarters resided in a major urban area (75%). Approximately two-thirds had a tertiary education (65%), were employed either full or part-time (63%), and were always able to meet basic needs (68%). Just over half were of European ethnicity (56%), with the remainder being Māori (20%), African (9%), Asian (8%), Middle Eastern and Latin American (4%) or Pacific Peoples (3%).

Most participants had been living with HIV for 10 or more years (61%). All were on ART, and 95% said their viral load was undetectable. Despite just over half (56%) having another medical condition not related to HIV, most (77%) described their current health status as good. A third had been diagnosed with a mental health condition (33%) (Table 2).

Having ever encountered stigma or discrimination in their lifetime was reported by 76% of participants. Stigma or discrimination within the last 12 month was reported by 35%. Almost three-quarters agreed that it was difficult to tell people about their HIV (70%) or that they hide that they have HIV (69%). Feeling dirty (28%), guilty (34%), ashamed (36%) or worthless (30%), and deciding not to have sex because of their HIV (38%) were commonly reported (Table 2).

### Quality of life (PozQoL) score

The mean summary PozQoL score was 47.16 with a range from 15 to 65. Categorising this score showed 33 (18%) had a low score, 41 (23%) moderate, 49 (26%) high, and 65 (35%) very high (Table 3).

### Associations between participant characteristics and quality of life (PozQoL) score

Several characteristics were found to have a mean PozQoL score that was significantly lower than those in their comparison group (Table 4). Socio-demographic

characteristics included the inability to meet basic needs (−7.47; 95% CI −10.56, −4.38) and being unemployed (−5.02; 95% CI −8.48, −1.55). Health-related characteristics included having a mental health condition (−5.74; 95% CI −8.92, −2.56), being diagnosed with HIV within the past 5 years (−5.48; 95% CI −9.54, −1.43), and self-reported poor health (−5.43; 95% CI −8.96, −1.90). Social connectedness factors included deciding not to have sex in the last 12 months (−9.03; 95% CI −11.98, −6.09) and not having the support of close people on disclosure of HIV (−4.71; 95% CI −8.00, −1.42). Ever experiencing stigma or discrimination (−6.49; 95% CI −9.93, −3.06), stigma or discrimination within the last 12 months (−5.03; 95% CI −8.16, −1.91), and greater internalised stigma (−2.81; 95% CI −3.49, −2.12) were also factors associated with a lower mean PozQoL score.

## Discussion

Our study of people living with HIV in Aotearoa New Zealand using the PozQoL Scale showed that despite being a relatively well educated, employed and connected group of people, more than a third reported having a low to moderate QoL. A range of factors in the different domains of socio-demographic, health-related, social connectedness, and stigma and discrimination were found to be associated with poorer QoL.

This is the first time QoL has been measured in people living with HIV in New Zealand using the PozQoL Scale. The HIV Futures Study of 226 men and women with HIV in 2001, and 261 people in 2007, used a question about wellbeing with about three-quarters in each study stating their wellbeing was good or excellent (Grierson et al., 2004, 2008). Sixty-one percent of people in our study had a high or very high PozQoL. While it is difficult to compare between different measures, the more specific set of questions to generate the PozQoL score, which is a well validated tool, is likely to give a more accurate measure of QoL than a generic wellbeing question. It was also interesting to note that while the self-reported physical health status was similar in both HIV Futures, and in our study, the proportion reporting a mental health condition increased from 21% in 2001–2, to 29% in 2007 in the HIV Futures studies, and then in our study was 33%. A similar rising trend for people diagnosed with a mood and/or anxiety disorder has also been noted in the New Zealand general population from 12.7% in 2006/07 to 19.8% in 2019/20 (Ministry of Health, 2020).

Compared to people without HIV, a survey in 2020 asked 6930 adults resident in eight New Zealand cities to rate their QoL on a 7-point scale from extremely



**Table 3.** Quality of life (PozQoL) summary scores.

	Health n (%)	Psychological n (%)	Social n (%)	Functional n (%)	Total n (%)
Low	25 (13.3)	27 (14.4)	25 (13.3)	48 (25.5)	33 (17.6)
Moderate	54 (28.7)	27 (14.4)	44 (23.4)	21 (11.2)	41 (21.8)
High	72 (38.3)	76 (40.4)	56 (29.8)	71 (37.8)	49 (26.1)
Very high	37 (19.7)	58 (30.9)	63 (33.5)	48 (25.5)	65 (34.6)
	Mean (SD; range)	Mean (SD; range)	Mean (SD; range)	Mean (SD; range)	Mean (SD; range)
Summary score	10.00 (2.97; 3–15)	14.94 (3.62; 4–20)	10.57 (3.40; 3–15)	11.65 (3.29; 3–15)	47.16 (10.62; 15–65)

Note: SD: standard deviation.

poor to extremely good, with 87% rating their overall QoL positively (Nielsen, 2020). This is considerably higher than the 61% with a high or very high QoL score in our study, although again the use of different QoL measures makes for difficult comparison.

Studies in other countries have reported mixed results about QoL with some indicating that people living with HIV are resilient and have similar levels of QoL to those without HIV (Degroote et al., 2013). However,

**Table 4.** Factors associated with quality of life summary PozQoL score, with 95% confidence intervals (CI).

Characteristic ( <i>Reference category</i> )	Co-efficient	95% Confidence Interval
<b>Socio-demographic:</b>		
Age – years (<30)		
30–49	–4.12	–9.43, 1.20
50+	–2.90	–8.22, 2.42
Gender ( <i>Women</i> )	–0.87	–4.18, 2.44
Sexual identity ( <i>Gay, bisexual, MSM</i> )		
Heterosexual men, women, other	–0.01	–3.16, 3.13
Ethnicity ( <i>European</i> )		
Māori	–0.22	–4.25, 3.80
Other ethnicities	–0.65	–4.39, 3.10
Region of residence ( <i>Major urban</i> )	–0.55	–4.09, 2.98
Education ( <i>Less than tertiary</i> )	1.88	–1.31, 5.08
Employment ( <i>Employed</i> )		
Unemployed or on a government benefit	<b>–5.02</b>	<b>–8.48, –1.55</b>
Retired or homemaker	1.15	–3.93, 6.23
Able to meet basic needs ( <i>Always</i> )	<b>–7.47</b>	<b>–10.56, –4.38</b>
Identifies as a person who uses or used drugs ( <i>No</i> )	–0.55	–3.85, 2.75
<b>Health-related:</b>		
Length of time living with HIV ( <i>5+ years</i> )	<b>–5.48</b>	<b>–9.54, –1.43</b>
Current health status ( <i>Good</i> )	<b>–5.43</b>	<b>–8.96, –1.90</b>
Mental health condition ( <i>No</i> )	<b>–5.74</b>	<b>–8.92, –2.56</b>
Other medical condition ( <i>No</i> )	–2.77	–5.83, 0.30
<b>Social connectedness:</b>		
In an intimate/sexual relationship ( <i>No</i> )	2.67	–0.40, 5.74
In a network/support group for PLHIV ( <i>No</i> )	1.13	–2.27, 4.52
Decided not to have sex in past 12 months ( <i>No</i> )	<b>–9.03</b>	<b>–11.98, –6.09</b>
People close had been supportive on disclosure ( <i>Agree</i> )	<b>–4.71</b>	<b>–8.00, –1.42</b>
<b>Stigma and discrimination:</b>		
Stigma or discrimination ever ( <i>No</i> )	<b>–6.49</b>	<b>–9.93, –3.06</b>
Stigma or discrimination in past 12 months ( <i>No</i> )	<b>–5.03</b>	<b>–8.16, –1.91</b>
Taken action against stigma or discrimination in past 12 months ( <i>No</i> )	–2.54	–5.88, 0.79
Internalised stigma	<b>–2.81</b>	<b>–3.49, –2.12</b>

a large study in the United Kingdom, which used the same measure of health-related QoL in people living with HIV and in the general population found the QoL significantly lower in people with HIV (Miners et al., 2014). The only other study we are aware of that has used the PozQoL Scale was an online survey in Australia, mostly in adult gay men, in which the mean summary score (44.62) was similar to our study (47.16) (Brown et al., 2019).

Finding a range of characteristics associated with poor QoL, across the different domains of socio-demographic, health-related, and social connectedness factors, and stigma and discrimination, is in keeping with studies in other countries, and shows the many factors at play in the often layered stigma experienced by people living with HIV (Degroote et al., 2013, 2014; Lambert et al., 2020; Logie et al., 2017; Nobre et al., 2017; Scofield & Moseholm, 2021). It is likely that there will be a considerable correlation between characteristics (Logie et al., 2017; Skevington et al., 2010) but a larger study sample would be required to tease out and investigate the pathways and connections in more detail (Logie et al., 2018; Oetzel et al., 2014; Skevington et al., 2010).

Unemployment and the inability to meet basic needs, found in our study, have been reported in other studies to be a strong predictor of lower QoL scores (Nobre et al., 2017; Rueda et al., 2011; Worthington & Krentz, 2005). Employment not only provides income, but also social connection, structure, and meaning to everyday life and is intrinsic to feelings of self-worth (Degroote et al., 2014). Both socio-economic status and employment are related to physical and mental health which in turn impacts on QoL (Catalan et al., 2017; Degroote et al., 2014; Nobre et al., 2017; Worthington & Krentz, 2005). Despite considerable improvements made to HIV treatments over the last couple of decades, about a quarter of participants in our study reported only fair or poor health. Moreover, a large number of participants reported a mental health condition. Both physical and mental health were associated with lower QoL, as have been reported in other

studies (Degroote et al., 2013, 2014; Nobre et al., 2017), particularly anxiety and depression which impacts on daily life (Degroote et al., 2014; Miners et al., 2014). The lower QoL in those more recently diagnosed with HIV is possibly related to less social support and a greater sense of vulnerability in the early months and years after their diagnosis (Lambert et al., 2020). Having good social support, for those newly diagnosed and living with HIV long-term, can be a buffer for reducing the impact of many stresses and therefore has an indirect role on QoL (Degroote et al., 2014; Lambert et al., 2020; Skevington et al., 2010). In our study, being in a relationship or a support group for people living with HIV were not significantly associated with increased QoL but having the support of people close on disclosure of their HIV was, indicating the importance of close family and friends. Deciding not to have sex was associated with lower QoL (Zeluf-Andersson et al., 2019). People living with HIV continue to face high levels of stigma and discrimination (Degroote et al., 2014; Hibbert et al., 2018; Lambert et al., 2020; Scofield & Moseholm, 2021). This stigma and discrimination can be due to attitudes within the society and in turn how people living with HIV view themselves (internalised stigma). Experience of stigma and discrimination negatively impacts on QoL directly and possibly indirectly via stigma affecting higher rates of depression and lower social support (Logie et al., 2018; Rueda et al., 2016; Scofield & Moseholm, 2021).

Our study was the first to explore QoL in people living with HIV in Aotearoa New Zealand using the PozQoL Scale, however, there were several limitations. First, the study was cross-sectional and it is therefore not possible to establish causal relationships. Second, the small sample size meant that we were only able to undertake an initial exploratory analysis. Third, having no national sampling frame for recruitment meant that the sample may not be representative of people living with HIV in New Zealand. Fourth, due to the convenience sampling approach, the results are vulnerable to self-selection bias. Fifth, the measures were limited to the instruments and questions used in the parent study (i.e. Stigma Index study). Moreover, we chose to use the PozQoL Scale which, despite being a well validated measure of QoL developed in partnership with people living with HIV (Brown et al., 2018), may not capture Māori understandings of QoL, for example, connection to whenua tīpuna (the ancestral land), connection to marae (significant space of collective identity and belonging), and the importance of whakapapa (lines of descent from and to one's ancestors). Any future study of QoL in New Zealand would need to be customised to better capture Māori realities in order for

results to be meaningful for them. Different measures of QoL used in studies also makes comparison between studies difficult. Nevertheless, many of the factors associated with QoL continue to be the same (Cooper et al., 2017).

Despite considerable improvements in care and treatment for people living with HIV and the social environment in which they live, QoL appears to remain low, not only in our study population, but also in other jurisdictions throughout the world (Miners et al., 2014). It is a basic human right of people living with HIV to live meaningful lives. Their QoL is important. This initial exploratory study of factors associated with QoL has shown that more can be done to address issues to improve QoL. As the factors influencing QoL are broad and multifactorial, so the responses must also be multi-dimensional through cross-sector collaboration. Stigma reduction campaigns targeting the broader community must be scaled up to prevent further experiences of stigma and discrimination felt by people living with HIV. Greater investment in peer support, and social and community welfare programmes to better support people living with HIV, particularly those that have poorer health and are unable to work are needed.

## Acknowledgements

The authors would like to acknowledge the study participants who gave of their time and shared their personal experiences of living with HIV with us. We also thank the interviewers whose dedication and commitment to this study made it possible.

## Funding

The study was funded by the University of Otago, the Ministry of Health, New Zealand AIDS Foundation, Glaxo Smith Kline, Positive Women Inc., Te Whāriki Takapou, Air New Zealand, and Foundation North, Merk Sharp Dhome, MAC AIDS Fund and Lottery Grants via Positive Women Inc.

## Ethical approval

Ethical approval was obtained from the University of Otago Human Ethics Committee (Health) (H18/135).

## ORCID

Susan McAllister  <http://orcid.org/0000-0001-7881-6622>

## References

- Andersson, G. Z., Reinius, M., Eriksson, L. E., Svedhem, V., Esfahani, F. M., Deuba, K., Rao, D., Lyatuu, G. W., Giovenco, D., & Ekström, A. M. (2020). Stigma reduction

- interventions in people living with HIV to improve health-related quality of life. *The Lancet HIV*, 7(2), e129–e140. [https://doi.org/10.1016/S2352-3018\(19\)30343-1](https://doi.org/10.1016/S2352-3018(19)30343-1)
- Brown, G., Mikolajczak, G., Lyons, A., Power, J., Drummond, F., Cogle, A., Allan, B., Cooper, C., & O'Connor, S. (2018). Development and validation of PozQoL: A scale to assess quality of life of PLHIV. *BMC Public Health*, 18(1), 527. <https://doi.org/10.1186/s12889-018-5433-6>
- Brown, G., Mikolajczak, G., Lyons, A., Power, J., Drummond, F., Coogle, A., Allan, B., Cooper, C., & O'Connor, S. (2017). PozQoL: Valuing quality of life among people with HIV, ARCSHS Broadsheet Series Number 2. Australian Research Centre in Sex, Health and Society, La Trobe University. [https://www.latrobe.edu.au/\\_\\_data/assets/pdf\\_file/0010/843373/PozQoL-Broadsheet.pdf](https://www.latrobe.edu.au/__data/assets/pdf_file/0010/843373/PozQoL-Broadsheet.pdf)
- Brown, G., Mikolajczak, G., Lyons, A., Power, J., Drummond, F., Coogle, A., Allan, B., Cooper, C., & O'Connor, S. (2019). *PozQoL Scale Implementation Kit June 2018 (Revised Sept 2019)*. La Trobe University. <https://pozqolhome.files.wordpress.com/2019/09/pozqol-implementation-kit-june-2018-revsept2019.pdf>
- Catalan, J., Tuffrey, V., Ridge, D., & Rosenfeld, D. (2017). What influences quality of life in older people living with HIV? *AIDS Research and Therapy*, 14(22), 1–10. <https://doi.org/10.1186/s12981-017-0148-9>
- Cooper, V., Clatworthy, J., Harding, R., & Whetham, J. (2017). Measuring quality of life among people living with HIV: A systematic review of reviews. *Health and Quality of Life Outcomes*, 15(1), 220. <https://doi.org/10.1186/s12955-017-0778-6>
- Degroote, S., Vogelaers, D., & Vandijck, D. M. (2014). What determines health-related quality of life among people living with HIV: An updated review of the literature. *Archives of Public Health*, 72(40), 1–10. <https://doi.org/10.1186/2049-3258-72-40>
- Degroote, S., Vogelaers, D. P., Vermeir, P., Mariman, A., De Rick, A., Van Der Gucht, B., Pelgrom, J., Van Wanzele, F., Verhofstede, C., & Vandijck, D. M. (2013). Socio-economic, behavioural, (neuro)psychological and clinical determinants of HRQoL in people living with HIV in Belgium: A pilot study. *Journal of the International AIDS Society*, 16(1), 18643. <https://doi.org/10.7448/IAS.16.1.18643>
- Dickson, N., Lee, B., Foster, T., & Saxton, P. J. (2015). The first 30 years of HIV in New Zealand: Review of the epidemiology. *New Zealand Medical Journal*, 128(1426), [www.nzma.org.nz/journal/read-the-journal/all-issues/2010-2019/2015/vol-128-no-1426-4-december-2015/6745](http://www.nzma.org.nz/journal/read-the-journal/all-issues/2010-2019/2015/vol-128-no-1426-4-december-2015/6745)
- Grierson, J., Pitts, M., Whyte, M., Misson, S., Hughes, A., Saxton, P., & Thomas, M. (2004). Living with HIV in New Zealand: Balancing health and quality of life. *The New Zealand Medical Journal*, 117(1200), 1–9.
- Grierson, J., Thorpe, R., Pitts, M., Hughes, A., Saxton, P., Smith, J., Smyth, E., & Thomas, M. (2008). *HIV Futures New Zealand 2 [Mate āraikore a muri ake nei (Tuarua)]*, monograph series number 66. The Australian Research Centre in Sex, Health and Society, La Trobe University.
- Harris, P. A., Taylor, R., Thielke, R., Payne, J., Gonzalez, N., & Conde, J. G. (2009). Research electronic data capture (REDCap)—a metadata-driven methodology and workflow process for providing translational research informatics support. *Journal of Biomedical Informatics*, 42(2), 377–381. <https://doi.org/10.1016/j.jbi.2008.08.010>
- Herrmann, S., McKinnon, E., Hyland, N. B., Lalanne, C., Mallal, S., Nolan, D., Chassany, O., & Duracinsky, M. (2013). HIV-related stigma and physical symptoms have a persistent influence on health-related quality of life in Australians with HIV infection. *Health and Quality of Life Outcomes*, 11(56), 1–13. <https://doi.org/10.1186/1477-7525-11-56>
- Hibbert, M., Crenna-Jennings, W., Kirwan, P., Benton, L., Lut, I., Okala, S., Asboe, D., Jeffries, J., Kunda, C., Mbewe, R., Morris, S., Morton, J., Nelson, M., Thorley, L., Paterson, H., Ross, M., Reeves, I., Sharp, L., Sseruma, W., ... Delpech, V. (2018). The people living with HIV stigma survey UK 2015: HIV-related sexual rejection and other experiences of stigma and discrimination among gay and heterosexual men. *AIDS Care*, 30(9), 1189–1196. <https://doi.org/10.1080/09540121.2018.1479027>
- Lambert, C. C., Westfall, A., Modi, R., Amico, R. K., Golin, C., Keruly, J., Quinlivan, E. B., Crane, H. M., Zinski, A., Turan, B., Turan, J. M., & Mugavero, M. J. (2020). HIV-related stigma, depression, and social support are associated with health-related quality of life among patients newly entering HIV care. *AIDS Care*, 32(6), 681–688. <https://doi.org/10.1080/09540121.2019.1622635>
- Logie, C. H., Ahmed, U., Tharao, W., & Loutfy, M. R. (2017). A structural equation model of factors contributing to quality of life among African and Caribbean women living with HIV in Ontario, Canada. *AIDS Research and Human Retroviruses*, 33(3), 290–297. <https://doi.org/10.1089/aid.2016.0013>
- Logie, C. H., Wang, Y., Lacombe-Duncan, A., Wagner, A. C., Kaida, A., Conway, T., Webster, K., de Pokomandy, A., & Loutfy, M. R. (2018). HIV-related stigma, racial discrimination, and gender discrimination: Pathways to physical and mental health-related quality of life among a national cohort of women living with HIV. *Preventive Medicine*, 107, 36–44. <https://doi.org/10.1016/j.ypmed.2017.12.018>
- Miners, A., Phillips, A., Kreif, N., Rodger, A., Speakman, A., Fisher, M., Anderson, J., Collins, S., Hart, G., & Sherr, L. (2014). Health-related quality-of-life of people with HIV in the era of combination antiretroviral treatment: A cross-sectional comparison with the general population. *The Lancet HIV*, 1(1), e32–e40. [http://doi.org/10.1016/S2352-3018\(14\)70018-9](http://doi.org/10.1016/S2352-3018(14)70018-9)
- Minister of Health. (2016). *New Zealand Health Strategy: Future direction*. Ministry of Health. <https://www.health.govt.nz/system/files/documents/publications/new-zealand-health-strategy-futuredirection-2016-apr16.pdf>
- Ministry of Health, New Zealand. (2020). *Annual update of key results 2019/20: New Zealand Health Survey*. <https://www.health.govt.nz/publication/annual-update-key-results-2019-20-new-zealand-health-survey>
- Mundt, S., & Briggs, S. (2016). HIV-related stigma and discrimination in the New Zealand healthcare setting: A mixed-methods study. *Sexual Health*, 13(6), 582–588. <https://doi.org/10.1071/sh16063>
- Nakagawa, F., Lodwick, R. K., Smith, C. J., Smith, R., Cambiano, V., Lundgren, J. D., Delpech, V., & Phillips, A. N. (2012). Projected life expectancy of people with HIV according to timing of diagnosis. *AIDS*, 26(3), 335–343. <https://doi.org/10.1097/QAD.0b013e32834dccc9>
- Nielsen. (2020). *Quality of Life survey 2020: Technical report*. A report prepared on behalf of Auckland Council,



- Wellington City Council, Christchurch City Council, and Dunedin City Council. <http://www.qualityoflifeproject.govt.nz/survey.htm>
- Nobre, N., Pereira, M., Roine, R. P., Sintonen, H., & Sutinen, J. (2017). Factors associated with the quality of life of people living with HIV in Finland. *AIDS Care*, 29(8), 1074–1078. <https://doi.org/10.1080/09540121.2017.1281879>
- Oetzel, J., Wilcox, B., Archiopoli, A., Avila, M., Hell, C., Hill, R., & Muhammad, M. (2014). Social support and social undermining as explanatory factors for health-related quality of life in people living with HIV/AIDS. *Journal of Health Communication*, 19(6), 660–675. <https://doi.org/10.1080/10810730.2013.837555>
- Pedersen, K. K., Eiersted, M. R., Gaardbo, J. C., Pedersen, M., Gerstoft, J., Troseid, M., & Nielsen, S. D. (2015). Lower self-reported quality of life in HIV-infected patients on cART and with low comorbidity compared with healthy controls. *JAIDS Journal of Acquired Immune Deficiency Syndromes*, 70(1), 16–22. <https://doi.org/10.1097/QAI.0000000000000697>
- Rueda, S., Mitra, S., Chen, S., Gogolishvili, D., Globerman, J., Chambers, L., Wilson, M., Logie, C. H., Shi, Q., Morassaei, S., & Rourke, S. B. (2016). Examining the associations between HIV-related stigma and health outcomes in people living with HIV/AIDS: a series of meta-analyses. *BMJ Open*, 6(7), e011453. <http://doi.org/10.1136/bmjopen-2016-011453>
- Rueda, S., Raboud, J., Mustard, C., Bayoumi, A., Lavis, J. N., & Rourke, S. B. (2011). Employment status is associated with both physical and mental health quality of life in people living with HIV. *AIDS Care*, 23(4), 435–443. <https://doi.org/10.1080/09540121.2010.507952>
- Scofield, D., & Moseholm, E. (2021). HIV-related stigma and health-related quality of life in women living with HIV in developed countries: A systematic review. *AIDS Care*, <https://doi.org/10.1080/09540121.2021.1891193>
- Skevington, S. M., Norweg, S., Standage, M., & The WHOQOL HIV Group. (2010). Predicting quality of life for people living with HIV: International evidence from seven cultures. *AIDS Care*, 22(5), 614–622. <https://doi.org/10.1080/09540120903311466>
- Statistics New Zealand. (2020). *Urban accessibility – methodology and classification*. <https://www.stats.govt.nz/assets/Uploads/Methods/Urban-accessibility-methodology-and-classification/Download-document/Urban-accessibility-methodology-and-classification.pdf>
- Stigma Index Working Group. (2020). *The Aotearoa New Zealand people living with HIV stigma index participant report*. <https://www.stigmaindex.org/wp-content/uploads/2020/12/New-Zealand-Aotearoa-SI-Report-2020.pdf>
- UNAIDS. (2019). *HIV and AIDS estimates*. Retrieved April 13, 2021, from <https://www.unaids.org/en/regionscountries/countries/newzealand>
- World Health Organization. (2016). Global health sector strategy on HIV 2016–2021, towards ending AIDS. WHO/HIV/2016.05.
- Worthington, C., & Krentz, H. (2005). Socio-economic factors and health-related quality of life in adults living with HIV. *International Journal of STD & AIDS*, 16(9), 608–614. <https://doi.org/10.1258/0956462054944408>
- Zeluf-Andersson, G., Eriksson, L. E., Schönnesson, L. N., Höijer, J., Månehall, P., & Ekström, A. M. (2019). Beyond viral suppression: The quality of life of people living with HIV in Sweden. *AIDS Care*, 31(4), 403–412. <https://doi.org/10.1080/09540121.2018.1545990>