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## Living with HIV in New Zealand: balancing health and quality of life

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### Abstract

**Aim** This paper characterises the health and wellbeing of HIV-positive people in New Zealand.

**Methods** The HIV Futures New Zealand Survey is a self-complete anonymous questionnaire distributed in a variety of ways. Data were collected on health, clinical, and social variables.

**Results** There were 226 responses, estimated to be approximately 25% of the HIV positive population. Respondents were aged between 18 and 68, and 56% were homosexual men. Most (68%) reported a viral load on most recent test of below 500 copies/mL and 59% had a CD4 lymphocyte count on most recent test of over 250 cells/ $\mu$ L. However, 28% reported a major health condition in addition to HIV and 21% had a mental health condition. Most respondents (64%) were currently using antiretroviral therapy. Many (84%) knew other people with HIV and had contact with an HIV/AIDS organisation (77%). Forty-two percent of respondents had stopped working because of HIV, and 47% reported their main source of income as a Government benefit.

**Conclusions** This research has demonstrated that, while the HIV-positive population of New Zealand generally has improved health as a result of antiretroviral therapy, there are still significant social and economic barriers to their quality of life.

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This is the first large-scale, comprehensive examination of the health and social experiences of HIV-positive people to be carried out in New Zealand. To date, there has been little comprehensive information on the social and clinical experience of HIV positivity in New Zealand. Community based research such as the *HIV Positive Campaign Survey*<sup>1</sup> has suggested that there are substantial differences among People Living with HIV/AIDS (PLWHA) in terms of their informational needs and service experiences. The clinical and social aspects of living with HIV/AIDS change quickly.

In the past five years there have been dramatic advances in the effectiveness of HIV/AIDS treatment, particularly the introduction of antiretroviral combination therapy. Understanding the long-term consequences of living with HIV/AIDS and the effectiveness of treatment is increasingly important. While advances in treatment may give hope to many PLWHA, issues such as social isolation, personal relationships, employment, housing, and finances are also important. This survey provides an overview of the personal, social and clinical aspects of living with HIV in New Zealand.

## Methods

Recruitment occurred from November 2001 until February 2002. The sample was obtained through HIV/AIDS service organisations, medical centres, and hospitals; mailing lists of HIV-related publications; and a targeted advertising campaign.<sup>2</sup> As many surveys were distributed through third parties, it was not possible to calculate a response rate for the survey. Respondents completed an anonymous, self-administered, mail-back questionnaire that assessed the personal and social impacts of HIV/AIDS. The questionnaire for the study was based on that used for the HIV Futures 3 study of Australian PLWHA,<sup>3</sup> with suitable alterations to suit the national context.

226 HIV-positive men and women across the country completed the HIV Futures New Zealand Survey. Based on estimates of the HIV-positive population of New Zealand,<sup>4,5</sup> this sample represents approximately 25%–28% of the total population of PLWHA in New Zealand.

**Demographics**—Table 1 shows the demographic characteristics of the sample. The sample comprised mainly men (of whom the majority were homosexual) and ranged in age from 18 to 68 years. The sample was well educated, with 40% having some kind of post-secondary qualification. Sexual transmission was the most common source of the respondents' HIV infection, although a large number of respondents did not know how they were infected (79% of these being refugees from Africa). The sample was predominantly European/Pakeha, but also contained significant numbers of Maori and Africans. The gender, age, ethnicity, and presumed mode of transmission of the sample is very similar to that reported in an audit of New Zealand's HIV-infected population who were under active follow-up in 2000.<sup>4</sup>

**Table 1. Demographic characteristics of respondents (including refugee respondents)**

<b>Mean age in years (SD)</b>	40.5 (10.9)
<b>Gender</b>	<b>N (%)</b>
Male	171 (76%)
Female	54 (24%)
Transgender	1 (<0.5%)
<b>Ethnicity*</b>	
Maori	25 (11%)
European/Pakeha	151 (68%)
Pacific Islander	5 (2%)
African	34 (15%)
Asian	6 (3%)
Missing	5
<b>Highest completed level of education</b>	
No school qualification	47 (21%)
5 <sup>th</sup> Form Certificate	42 (19%)
6 <sup>th</sup> Form Certificate or university entrance	19 (9%)
High School Certificate/bursary	24 (11%)
Professional/technical/trades certificate/diploma	52 (24%)
Bachelors or undergraduate degree	19 (9%)
Graduate or postgraduate degree	18 (8%)
Missing	5
<b>Sexual identity</b>	
Male homosexual	121 (56%)
Female homosexual	3 (1%)
Male heterosexual	32 (15%)
Female heterosexual	45 (21%)
Male bisexual	13 (6%)
Don't know	2 (1%)
Missing	10

<b>Presumed mode of infection</b>	
Male homo/bisexual contact	117 (53%)
Heterosexual contact	43 (20%)
Injecting drug use (IDU)	10 (5%)
Male homosexual/bisexual contact + IDU	1 (1%)
Haemophilia/coagulation disorder	1 (1%)
Blood products/healthcare setting	7 (3%)
Don't know	38 (17%)
Other	4 (2%)
Missing	5
<b>AIDS defining illness</b>	
Yes	42 (18%)
No	179 (82%)
Missing	5

\*Ethnicity was determined based on census definitions. Therefore, respondents categorised as 'Maori' included those who identify as 'Maori and another ethnicity'.

Specific issues concerning the experiences of HIV-positive refugees in New Zealand have previously been reported.<sup>6,7</sup> These include different experiences of testing, disclosure, stigma, social support, and healthcare access. Initial analysis of the data from this study suggested that the pattern of responses was systematically different for refugees.

For these reasons, we have decided to present the refugee data separately to allow us to:

- Reflect the refugee experience more accurately, and to
- Be able to consider the remainder of the responses independently.

Thirty-three refugee respondents completed the survey; these results are not reported in this paper but will be presented elsewhere.

## Results

**Health and treatments**—Table 2 shows the responses to a number of items relating to health and use of treatments. The majority of respondents rated both their health (76%) and wellbeing (73%) as either 'good' or 'excellent'. Respondents most commonly reported having a viral load below detectable levels, and reported an average CD4 lymphocyte count of 495 cells/ $\mu$ L. While these data on clinical markers are self-reported, we are confident that the results fall within the broad ranged given below.

**Table 2. Respondents' health and treatments**

<b>Current health</b>	<b>N (%)</b>
Poor	11 (6%)
Fair	35 (18%)
Good	85 (45%)
Excellent	60 (31%)
Missing	2
<b>Current wellbeing</b>	
Poor	12 (6%)
Fair	39 (21%)
Good	84 (44%)
Excellent	55 (29%)
Missing	3
<b>Most recent viral load test results</b>	
<500 copies/mL (or below detection)	97 (68%)
501–10,000 copies/mL	20 (14%)
10,001–50,000 copies/mL	12 (8%)

>50,000 copies/mL	14 (10%)
Missing / Not applicable*	50
<b>Most recent CD4 test result</b>	
<250 cells/μL (severe damage)	72 (42%)
250-499 cells/μL (mild damage)	74 (43%)
>500 cells/μL (little damage)	27 (16%)
Missing / Not applicable†	20
<b>Major physical health condition in addition to HIV/AIDS</b>	
Yes	52 (28%)
No	132 (72%)
Missing	9
<b>Mental health condition</b>	
Yes	40 (21%)
No	151 (79%)
Missing	2
<b>HIV-related illnesses</b>	
Lipodystrophy	41 (22%)
Weight loss	55 (29%)
Fatigue	123 (65%)
Sleep disorder	78 (41%)
Confusion/memory loss	59 (31%)
Missing	3
<b>Hepatitis C</b>	
Tested positive	14 (8%)
Tested negative	64 (38%)
Not tested	91 (54%)
Missing	24
<b>Antiretroviral (ARV) drug use</b>	
Currently using	120 (64%)
Have used in the past	26 (14%)
Have never used	41 (22%)
Missing	6
<b>Use of prescribed medication other than antiretrovirals</b>	
Yes	61 (36%)
No	109 (64%)
Missing / Not applicable	23
<b>Use of alternative therapies</b>	
Yes	98 (53%)
No	87 (47%)
Missing	8
<b>Health since starting antiretrovirals</b>	
Stayed the same	18 (14%)
Improved	81 (61%)
Fluctuated	28 (21%)
Deteriorated	5 (4%)
Missing / Not applicable‡	61
<b>Wellbeing since starting antiretrovirals</b>	
Stayed the same	13 (10%)
Improved	66 (51%)
Fluctuated	42 (32%)
Deteriorated	9 (7%)
Missing / Not applicable‡	63

\*Includes 4 respondents who did not receive a viral load test;

†Includes 4 respondents who did not receive a CD4 test;

‡Includes 55 respondents not currently taking antiretrovirals.

Twenty-eight percent of respondents reported having a physical health condition other than HIV/AIDS, and 21% reported having been diagnosed with a mental health condition at some stage. The most commonly reported major health conditions were hepatitis C (5%), asthma (3%), cardiovascular disease (2%), and hepatitis B (2%)—while the most common mental health condition was depression (16%).

When asked about some specific HIV-related symptoms, most respondents reported they suffered from fatigue—with smaller numbers reporting problems with lipodystrophy, weight loss, sleep disorder, confusion, or memory loss. The majority of respondents reported they had not been tested for hepatitis C, while 8% of the sample reported having been infected with the hepatitis C virus, most commonly through intravenous drug use (44% of hepatitis C-infected respondents).

Thirty-six percent of respondents reported taking prescribed medication other than antiretrovirals. In separate questions, 27% reported taking prophylaxis for opportunistic infections, 15% reported taking anti-anxiety medication, 23% reported taking antidepressants, and 6% reported taking antipsychotics. Just over half the sample (53%) indicated they were using alternative therapies; the most common were massage (67%), vitamin or mineral supplements (57%), meditation or visualisation (36%) and using marijuana medicinally (36%).

Sixty-four percent of the sample was using antiretroviral medication at the time of the survey, and a further 14% had used them in the past. Of those currently using antiretrovirals, 79% reported some difficulties; these were, most commonly, remembering to take the pills on time (44%), taking medication in public (27%), transporting medication (27%), and organising meals around medication (26%).

Twenty percent of respondents (currently taking antiretrovirals) reported having skipped an antiretroviral dose in the previous two days, while 34% reported that they had taken a break from antiretrovirals at some stage. Forty-four percent reported experiencing adverse effects from antiretrovirals, most commonly diarrhoea and nausea. In addition, 11.6% of those currently using antiretroviral treatments had taken a break from treatments due to the severity of side effects. Despite these problems, respondents most commonly reported that their health and wellbeing had improved on antiretroviral medication.

**Sources of support**—Table 3 shows the sources of support for respondents.

Respondents were asked to rate sources of support on a four-point scale, with 1 being '*a lot of support*' and 4 being '*very little*'; with a '*not applicable*' category being treated as missing data. Respondents ranked their partner as being most supportive (mean=1.44, SD=0.97), followed by their pets (mean=1.60, SD=0.97), their close friends (mean=1.75, SD=0.94) and their doctor (mean=1.84, SD=0.93).

Almost all respondents (97%) had disclosed their HIV status. Disclosure was most commonly to close friends (84%), siblings (62%), parents (55%), and partners or spouses (52%). Over half the respondents (54%) reported having had their HIV status disclosed by others unwillingly, and a third of respondents reported having had this happen in the last 2 years. The most common sources of this unwanted disclosure were close friends (29%), other friends (28%), and work colleagues (21%).

Most respondents knew other PLWHA; most commonly, friends (58%) and acquaintances or members of support groups (52%); however the majority spent little or no time with these people. When asked to rate the importance of HIV to their identity, most respondents rated it as being important, but not essential. Most were in contact with HIV/AIDS organisations, with these respondents reporting that they receive newsletters or mail-outs (85% of those in contact with these organisations), are clients (71%), members (44%), volunteers (12%), or employees (4%).

**Table 3. Support networks**

<b>Know other PLWHA*</b>	<b>N (%)</b>
Yes	156 (84%)
No	30 (16%)
Missing	7
<b>Amount of time spent with other PLWHA</b>	
None	73 (39%)
A little	69 (37%)
Some	31 (17%)
A lot	14 (8%)
Missing	6
<b>Importance of HIV to identity</b>	
Essential	32 (18%)
Important	97 (53%)
Not important	36 (20%)
Irrelevant	18 (10%)
Missing	10
<b>Contact with AIDS organisations</b>	
Yes	145 (77%)
No	44 (23%)
Missing	4
<b>Disclosure to other people</b>	
Yes	180 (97%)
No	6 (3%)
Missing	7
<b>Unwanted disclosure</b>	
Never	84 (46%)
In last 2 years	60 (33%)
Longer ago	38 (21%)
Missing	11

\*People living with HIV/AIDS

**Employment and finances**—Most respondents were not in paid employment at the time of the survey; 42% said they had stopped work due to HIV infection, and 11% (who were working) reported some time out of the workforce due to HIV infection. Eighteen percent reported having experienced discrimination in relation to employment due to their HIV status, with 9% reporting that this had happened in the last 2 years. Unsurprisingly, the most common source of income for PLWHA was a Government benefit (47%), followed by a salary (39%); other reported options were much smaller percentages.

Unlike some countries, New Zealand does not currently have an officially recognised poverty line. However, we used a poverty line measurement that establishes a threshold at 60% of the population's net median income, and is further adjusted for an

individual if their arrangements include a partner and any dependent children <sup>8</sup>. We modified this measure by the Consumer Price Index <sup>9</sup> to match it to the period in which the data for this study was collected.

This analysis suggests that 19% of the sample were living below the poverty line. Additionally, over half the sample reported that paying for basic costs such as food, housing and utilities was either 'a little difficult' or 'very difficult'.

**Table 4. Employment and finances**

<b>Employment history</b>	<b>N (%)</b>
Working, never left work	52 (30%)
Working, after HIV-related break	19 (11%)
Stopped working because of HIV	74 (42%)
Not working, stopped for other reasons	30 (17%)
Missing	18
<b>Source of income</b>	
Government benefit	88 (47%)
Salary	73 (39%)
Savings/superannuation etc.	7 (4%)
Partner/family/friends	6 (3%)
Other	14 (7%)
Missing	5
<b>Income below poverty line</b>	
Yes	32 (19%)
No	138 (81%)
Missing / Not calculable	23
<b>Difficulty meeting housing costs</b>	
Not at all difficult	64 (41%)
A little difficult	71 (45%)
Very difficult	23 (15%)
Missing / Not applicable	35
<b>Difficulty meeting food costs</b>	
Not at all difficult	80 (46%)
A little difficult	69 (40%)
Very difficult	25 (14%)
Missing / Not applicable	19
<b>Difficulty meeting costs of utilities</b>	
Not at all difficult	63 (37%)
A little difficult	76 (45%)
Very difficult	31 (18%)
Missing / Not applicable	23

## Discussion

This research provides us with the first comprehensive overview of the health and wellbeing of HIV-positive New Zealanders. Moreover, these findings provide a sound basis for the continued development of clinical and social services that seek to maximise the quality of life for PLWHA.

It is clear that the introduction of combination antiretroviral therapy has dramatically improved life expectancy and overall health status of the PLWHA population as a whole.



This research has shown that the majority of New Zealand PLWHA consider their overall health to be good, something that is supported by the findings for the traditional clinical markers of viral replication and immune system damage. Much of this clinical benefit can be attributed to the treatment regimens currently available. These regimens of treatment have, however, been associated with a high incidence of debilitating side effects.

The incidence of HIV-related illnesses (including fatigue, sleep disorders, cognitive difficulties, and lipodystrophy) add to the burden of illness. Despite these adverse experiences, the fact that PLWHA generally consider their health and wellbeing to be good is testament to the resilience in this population. This also demonstrates that health is assessed relative to the range of possible health consequences of HIV infection.

The co-existence of mental health conditions (particularly the worryingly high levels of depression) provide additional challenges to the maintenance of an acceptable quality of life for this population. Clearly, stigma and discrimination are persistent significant social correlates of HIV infection. Unwanted disclosure of HIV status and less favourable treatment in a range of settings (including the workplace) remain common experiences. Social stigmatisation of those with HIV not only compromises their quality of life, it is also likely to constrain access to treatment, services and information.

With increased longevity, the cumulative impact of social disadvantage has become of critical import. This social and economic marginalisation of PLWHA is evidenced by the high rates of unemployment, reliance on Government benefits, and rates of poverty. With the fluctuating illness trajectory that now characterises life for many PLWHA, and the increasing evidence of treatment failure and resistance to antiretroviral drugs, this disadvantage is likely to increase.

To sustain an effective response to the HIV epidemic in New Zealand, physicians, service providers, community organisations, and the PLWHA community must work together to ensure an equitable and meaningful life for HIV-positive people.

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