

Mate Araikore A Muri Ake Nei: Experiences of Maori New Zealanders living with HIV

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ABSTRACT. *Background:* This paper is drawn from the first comprehensive study in New Zealand of the health and social experiences of HIV positive people and specifically addresses the experiences of HIV positive Maori. *Methods:* A total of 226 HIV positive men and women completed an anonymous, self-administered HIV Futures New Zealand questionnaire. Twenty-five Maori completed the survey (17 male, 7 female, 1 transgendered). The majority identified as takataapui (Maori and homosexual) five were heterosexual women, and four identified with other sexualities. *Results:* Seven respondents indicated that they had received pre-test counselling, and 18 that they had received post-test counselling. The mean CD4 count at most recent test was 462.4 cells/ μ L. The mean HIV viral load result at most recent test was 558.1 copies/mL. Two-thirds of respondents were currently using antiretroviral treatments, and half had taken a break from them. The most commonly cited source of social support was their doctor. Eight respondents were in full-time work; most received benefits or a pension as their main income source; five were living below the poverty line. Only two respondents did not personally know another person with HIV. All had disclosed their status to someone; fifteen said that unwanted disclosure had occurred. Eight reported experiencing discrimination concerning accommodation, nine in a medical setting and seven in relation to employment. *Conclusions:* Maori people in New Zealand have access to a comprehensive health care system, nonetheless it is of concern that a number report discrimination and unwanted disclosure of their HIV status, most particularly within health care settings.

Introduction

This paper is drawn from the first comprehensive study of the health and social experiences of HIV positive people to be carried out in New Zealand. Specifically, this paper addresses the personal, social and clinical aspects of living with HIV in New Zealand for the HIV positive Maori sub-sample. While there has been limited empirical investigation in New Zealand into the lived experience of HIV infection, there has been almost no investigation of the particularities of HIV positivity for the indigenous population. Broughton¹ argues that the Maori experience of HIV/AIDS sits within an historical experience, common to many indigenous populations, of illnesses that arrive with colonisation and decimate communities, a view supported by others.² It is in part as a response to this cultural history of marginalisation and the devastating impact of disease that the Maori community response to HIV/AIDS prevention

was both rapid and involved broad community action. In particular, in 1987 a takataapui (an indigenous term used by those identifying as both Maori and homosexual)³ support group Te Roopu Tautoko quickly established itself shortly after HIV/AIDS was identified in New Zealand. This was followed in the early 1990s by the New Zealand AIDS Foundation's Maori Youth Project, and regional takataapui support groups Te Waka Awhina in Auckland, and He Manu Ano in Wellington.

In 2000, the New Zealand AIDS Foundation re-branded its Maori-specific services by establishing its Hau Ora Takataapui health promotion unit. Up to date, clear and precise HIV/AIDS information coupled with Ai Haumaru (safe sex) messages set within a Maori health and sexuality framework ensured Maori gay men had access to HIV prevention resources that were both effective and culturally appropriate. The Tapa Wha Maori perspective of health

highlights interaction between spiritual aspects, thoughts and feelings, physical health and the extended family.⁴ These early and self-determined HIV prevention efforts among Maori may well have limited infection rates among Maori.

Unlike many other indigenous populations, available evidence does not indicate that Maori are over represented in HIV infections or AIDS diagnoses.⁵ According to the 2001 New Zealand Census of Population and Dwellings, Maori represented 14.1% of the total resident population and 11.4% of the total population aged 15 and over.⁶ A recent audit of New Zealand's HIV-infected population under active follow-up identified 8% as being of Maori ethnicity,⁷ and Maori constituted 7.7% of those who were reported to have had a viral load test to the end of 2002.⁸ This under representation in HIV notifications, in itself, is a significant difference to the experience of the HIV epidemic among many indigenous communities internationally.^{9–11} The Health Research Council of New Zealand, however, has identified that overall, the gaps between Maori and non-Maori mortality have widened over the last 2 decades, and morbidity across several key health outcomes are still higher for Maori than for other population groups.¹² This paper offers, for the first time, a detailed examination of the health and wellbeing of those Maori who are HIV positive and offers the opportunity to reflect on the social and health consequences of HIV for Maori New Zealanders.

Methods

Recruitment occurred from November 2001 until February 2002. The sample was recruited through HIV/AIDS service organisations, medical centres and hospitals, mailing lists of HIV-related publications and a targeted advertising campaign. Because 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 questionnaire that assessed the personal and social impacts of HIV/AIDS. This omnibus survey instrument consisted of 250 items in eight sections: demographics, accommodation, health and treatments, services and organisations, sex and relationships, employment, recreational drug use and finances. The instrument was designed to give a comprehensive overview of the aspects of living with HIV that are critical for social and health planning and policy. Full details can be found in the project report.¹³

The completed surveys were mailed back to the principal investigators at La Trobe University. The appropriateness of the survey to Maori respondents, the distribution of the survey to specific Maori sites and the dissemination of Maori-specific analyses in this study was overseen by a Maori reference group. In all, 226 HIV positive men and women completed the HIV Futures New Zealand Survey across the country. Based on estimates of the HIV positive population of New Zealand,^{7,8} this sample represents ~25% of people living with HIV/AIDS (PLWHA) in New Zealand. Twenty-five Maori respondents completed the survey of whom 17 were male, seven were female and one was a transgendered person. As with epidemiological and New Zealand Census classification, Maori ethnicity was determined by self-definition and included those who identified solely as Maori and those who identified as Maori and another ethnicity. The proportion of our study sample identifying as Maori (11%) is therefore consistent with available estimates of the population with diagnosed HIV infection described above and constitutes ~34% of the population of HIV positive

Maori under active follow-up. Maori respondents ranged in age from 21 to 52 years with the average being 36.4. The majority of the respondents (13) identified as Takataapui, with five being heterosexual women, two bisexual men, one heterosexual woman, one lesbian and three who did not give their sexuality (one male, one female and one transgendered person).

While the sample represents a significant proportion of the population of HIV positive Maori, the small absolute number makes meaningful statistical comparison with the remainder of the sample problematic. Given these limitations, there appear to be few differences in the demographic profile of the Maori and non-Maori respondents. Maori respondents were somewhat younger than the remainder of the sample (36.4 v. 41.0, $P = 0.046$, $f = 4.011$, $df = 1,217$) and were more likely to be male (Chi-square = 8.457, $P = 0.015$, $df = 2$)* No difference was found in: diagnosis with an AIDS defining illness (Chi-square = 0.898, $P = 0.258$, $df = 1$)* number of years since infection (6.44 v. 6.42, $P = 0.985$, $f = 0.000$, $df = 1, 221$), income (\$345 p/w v. \$408 p/w, $P = 0.371$, $f = 0.805$, $df = 1, 201$), employment status (Chi-square = 5.712, $P = 0.574$, $df = 7$)*, education (Chi-square = 3.940, $P = 0.685$, $df = 6$)* relationship status (Chi-square = 1.826, $P = 0.131$, $df = 1$), and sexuality (Chi-square = 1.259, $P = 0.739$, $df = 3$)*.

Due to the sample size, results in this paper are given as numbers rather than proportions and additional information is provided where incomplete data affected the denominator.

Results

In order to describe the experience of living with HIV for Maori, we present findings that broadly cover their engagement with health services, health status, social support and socio-economic status.

Pre- and post-test counselling

We asked respondents if they had received pre- and/or post-test HIV counselling at the time they tested HIV positive, and how satisfied they were with the information and support they had received at that time. Seven of the 25 respondents indicated that they had received pre-test counselling, with four of those seven indicating they were satisfied with the information and the support they received. Eighteen of the 25 respondents indicated that they had received post-test counselling. Of those, 16/17 who received post-test counselling said they were satisfied with the information they had received and thirteen were happy with the support they had received. These findings are consistent with the experiences of other HIV positive New Zealanders, where a discussion with the physician which is understood as pre-test counselling has not been consistently provided, particularly among repeat testers.

Health services

When asked who they saw for their HIV-specific treatment, 14 respondents reported a HIV specialist at an outpatient clinic, three a GP, three a doctor at a sexual health centre, two a HIV specialist in a ward at a hospital and one a GP with a high HIV caseload (see Table 1). Similarly, when asked who they saw for general health care, 10 respondents reported seeing a GP, seven seeing a HIV specialist at an outpatient

clinic, four saw a doctor at a sexual health centre, two saw a HIV specialist in a ward at a hospital and one saw a GP with a high HIV caseload. Eight out of 23 respondents said that the doctor they saw for general medical services was the same doctor they saw for HIV-related treatment. Of the 15 respondents who saw a different doctor, 14 said that the doctor knew their HIV status.

We presented respondents with a list of services, both clinical and ancillary, and asked which they had used in the last 6 months. Clinical services were the most utilised in the list with 17 (out of 24) respondents using a GP and 17 an HIV outpatient specialist, however, significant numbers also used support services (12 an AIDS Foundation support group, 10 an HIV peer support group). Respondents were also asked if they currently used a range of specific services either at an HIV/AIDS organisation, or at another organisation. Treatments advice was the service used most by Maori PLWHA at AIDS organisations (13 of 23 respondents), while counselling (11 respondents) and peer support groups (nine respondents) were also used extensively. At non-HIV/AIDS organisations, pharmacy services, library services and transport were the most utilised (10 out of 23 respondents).

CD4 and viral load

Almost all Maori respondents had had their CD4 lymphocyte count (24) and their HIV viral load (23) measured at some time. Most respondents had their CD4 lymphocyte count measured within the last 6 months (20/23) and 13 in the last 3 months; and their HIV viral load measured within the last 6 months (17/19) and 11 in the last 3 months. On average, participants had undergone 3.1 viral load tests in the preceding 12 months. Among those who had undergone a CD4 lymphocyte count, 16 out of 17 reported that they had at some time had a CD4 lymphocyte count of less than 500 cells/ μ L and 11 reported a count of less than 250 cells/ μ L. Results for the most recent CD4 lymphocyte count ranged from 16 to 1100 cells/ μ L with a mean of 462.4 cells/ μ L and a median of 418 cells/ μ L (see Table 2). Among those who had undergone an HIV viral load test, all reported that at some point they had had a result of over 50,000 copies/mL. Results for the most recent HIV viral load test ranged from

Table 1. Primary physician for HIV specific and general medical care

Physician	For HIV specific care	For general health care
HIV specialist at outpatient clinic	14	7
General Practitioner	3	10
Doctor at sexual health service	3	2
HIV specialist at inpatient clinic	2	2
General practitioner with high HIV caseload	1	1

Table 2. Health status and treatments

	Number of respondents
Current health	
Poor	4
Fair	4
Good	14
Excellent	3
Missing	0
Current well-being	
Poor	5
Fair	4
Good	13
Excellent	3
Missing	0
Most recent viral load test results	
<500 copies/mL (below detection)	9
501–50,000	2
>50,000 copies/mL	3
Missing	11
Most recent CD4 test result	
<250 cells/ μ L (severe damage)	4
250–499 cells/ μ L (mild damage)	12
>500 cells/ μ L (little damage)	5
Missing	5
Antiretroviral (ARV) drug use	
Currently using	16
Have used in the past	1
Have never used	7
Missing	1

below detectable levels to 2500,000 copies/mL with a mean viral load of 558.1 copies/mL with the median being a result below detectable levels (less than 500 copies/mL).

Antiretroviral therapy

Two thirds (16/24) of respondents were currently using antiretrovirals, one respondent had used them in the past, and seven had never used them. All respondents who were using antiretrovirals were on combination therapy. Seven of the 16 respondents currently using antiretrovirals reported side effects. The majority of participants (12 out of 16) were on a combination of three antiretroviral drugs, with two on more than three antiretroviral drugs and two on two. Eight of the 16 who were on antiretrovirals had taken a break from them at some stage. Over half (14 out of 24) of the respondents felt antiretroviral therapy meant better prospects for people with HIV infection, six thought it was too soon to tell and three reported that they didn't know. When asked about their friends' opinions on this issue, 10 reported that their friends felt antiretroviral therapy had lead to better prospects, one that it was too soon to tell and 12 did not know their friends' opinions. The opinion of the respondents with regard to medical care indicated that 16 (64%) agreed with the

statement: 'My doctor knows more about the treatment of HIV than I do', and 15/23 (65%) agreed with the statement: 'My doctor and I work together to find the best treatment for me'. Almost two-thirds (15/24) of respondents were using complementary therapies. Respondents were asked the number of times they took a range of medication per day. Overall, PLWHA were taking medication 2.4 times per day (range 0 to 6, median = 2).

Experience of health and general well being

We asked respondents to indicate on a four point scale their current state of physical health, and their overall sense of well being. Around half the sample (14) rated their physical health as *good*. A further eight rated their health as *fair* or *poor*, and three as *excellent*. Thirteen respondents rated their well-being as *good*. A further nine rated their well-being as *fair* or *poor*, and three as *excellent*. Three respondents had been diagnosed with an AIDS defining illness at some point. Six out of 23 respondents were currently taking prophylaxis for opportunistic infections.

Four respondents had at some point had hepatitis A infection, and nine had been vaccinated against this virus. Twelve respondents reported that they had neither been infected nor vaccinated and therefore may not be protected against hepatitis A infection. Three respondents had at some time been diagnosed with hepatitis B infection and a further 12 had been vaccinated; nine respondents reported that they had neither been infected nor vaccinated and therefore may not be protected against hepatitis B infection.

Almost one half (9/20) of respondents reported that they had had no test to determine their hepatitis C status. Four respondents had had an antibody test, four had had a diagnostic PCR test and five reported some sort of test for hepatitis C, but were unsure what. We used a series of items from the survey including test results, year of diagnosis with hepatitis C, and designation of hepatitis C as a major health condition to determine that two respondents had hepatitis C infection.

Contact with other PLWHA

Only two respondents did not personally know anyone else with HIV infection. Most had a HIV positive friend (18) or acquaintance (14) and eight had either an HIV positive partner or ex-partner. Five respondents had been involved in the nursing or care of another HIV positive person at some time in the last 2 years, and 17 had had someone close to them die from HIV/AIDS. When asked how much time they spent with other HIV positive people eight respondents said none, eight said a little, seven said some and one said a lot, and one respondent did not answer this question.

Disclosure

Respondents were asked to whom they had disclosed their HIV status (see Table 3). All had disclosed their status to

Table 3. Disclosure of HIV status by category of those to whom status was disclosed (multiple responses possible, N = 24)

Category of those disclosing status	Number of respondents
No-one	0
Partner/spouse	18
Close friends	18
Brothers or sisters	16
Other family/whanau members ^A	16
Parents	15
Positive friends	14
Other friends	9
Work colleagues	9
People from own ethnic community	8
Neighbours	5
Son/daughter	3

^AWhanau is a term referring to extended family.

someone; most had disclosed to close friends, and all of the respondents in relationships had disclosed to their partner.

Respondents were asked if their HIV status had ever been disclosed without their permission. Fifteen (out of 23) respondents said that unwanted disclosure had occurred, and seven that it had occurred in the last 2 years. When asked who had disclosed their status, six (out of 15) respondents said acquaintances, five work colleagues, four community organisation staff and volunteers and four health care workers.

Social support

We asked participants about the amount of social support they received from a range of sources including household members, social contacts and service providers (see Table 4). Participants cited multiple sources of social support. For all participants, the source most likely to be cited as 'a lot' of support was the participant's doctor (13 respondents), followed by partner/spouse and pets (11 respondents each). Not all categories are relevant to all participants, for example not all participants have siblings, and when these data are examined using adjusted denominators the source that participants were most likely to rate as one from whom they receive 'a lot' of social support was the participant's partner or spouse (85% of those with partners).

Employment and financial status

Eight respondents were in full-time work, seven were unemployed, three were students, and two were working part-time. Most (12/23) received benefits or a pension as the main source of their income, however the main income source for eight was a salary, one received support from his (or her) partner and two had other sources of income. Five respondents were living below the poverty line.

Table 4. Number of respondents receiving social support from different sources

Degree of social support	A lot	Some	A little	None	Not Applicable
Doctor	13	8	1	1	2
Partner/spouse	11	1	0	1	12
Pets	11	1	2	1	10
Close friends	9	6	1	4	5
Parents	7	3	1	5	9
HIV positive friends	6	3	5	3	7
Brothers and sisters	5	4	4	3	9
Other family/whanau ^A	5	3	2	7	8
Counsellor	3	5	5	3	9
Health care workers	3	5	5	4	8
Volunteer counsellor	3	2	1	3	16
Other friends	2	6	4	6	7
Children	2	0	1	1	21
PLWHA groups	2	4	5	4	10
Religious or spiritual adviser	0	2	1	4	18

^AWhanau is a term referring to extended family.

Experience of discrimination

Almost a third (8/25) of respondents reported receiving less favourable treatment in regard to accommodation as a result of their HIV status at some stage; for four this was within the last 2 years. Nine reported less favourable treatment at a medical service due to their HIV status, five within the last 2 years. Discrimination most commonly took the form of avoidance, additional infection control or confidentiality problems. Seven out of 22 respondents reported that they had received less favourable treatment in relation to employment due to their HIV status, four in the last 2 years. When asked about discrimination in the area of insurance, seven out of 19 respondents felt that they had received less favourable treatment due to their HIV status.

Discussion

The purpose of this paper is to review the experiences of Maori living with HIV in New Zealand, rather than identify inequalities in HIV prevalence, health care, social support or discrimination compared to non-Maori. As this is the first time that data on the experience of Maori living with HIV have been available, it will provide a baseline against which developments in the New Zealand HIV epidemic can be measured.

At the beginning of the AIDS epidemic, Maori experienced an initial presence of risk factors that are associated with HIV infection such as higher prevalence of

sexually transmitted diseases, needle sharing, incarceration and lower socio-economic status,^{4,14} and continue to do so.¹² Nearly 2 decades after the introduction of HIV into New Zealand surveillance figures do not indicate that Maori have higher levels of diagnosed HIV infection than non-Maori New Zealanders.⁵ This appears to hold true even when one examines the number of Maori diagnosed as a proportion of the New Zealand born HIV population⁷ and therefore, this under representation cannot be attributed to the increased number of immigrant and refugee cases.

The data presented in this paper give the first systematic insight into the experience of living with HIV for Maori in New Zealand. While there are clear challenges to the health and well being of this population, as there are for all people living with HIV, there is little evidence of the severe disadvantage experienced by other indigenous populations around the world.^{6,9-11} The health and support systems available to all New Zealanders have provided to HIV positive Maori a level of care and support that is comparable with Pakeha and other non-Maori populations.

Early, culturally appropriate and, crucially, self-determined intervention may have had a profound effect on limiting infections within the Maori gay male population, and the responsiveness of the affected communities may have acted to reduce the disadvantage that one would expect in this population, given other social and health factors. It is apparent that these early interventions have reduced the incidence and the impact of HIV for Maori people. Many of those living with HIV in New Zealand have not been tested for hepatitis A, B or C. This is important for health consequences, since we know that co-infection, and particularly with hepatitis C has significant implications for HIV treatment and well-being.

Maori people in New Zealand have access to a comprehensive health care system; nonetheless it is of concern that a number report discrimination and unwanted disclosure of their HIV status, most particularly within health care settings.

Limitations of the study

This is a small study, but offers a unique perspective on a group of HIV positive people who have not previously been the subject of social research. As such, results here much been treated with caution and the need for further research with this population is evident. The most striking finding is that Maori do not experience the systematic discrimination identified in other indigenous HIV positive populations.

Due to the inescapable difficulties gathering comprehensive information about individuals with diagnosed HIV infection, this study did not use probability sampling and therefore is open to greater potential for participation bias. However, the total sample represented around 25% of New Zealand's estimated population of individuals with diagnosed HIV infection and the Maori sample represents

34% of the HIV positive Maori population, which we believe is the highest proportion of any country's PLWHA population to have been investigated to date. If this study is repeated, similar biases will presumably operate and thus the ability to measure change will be retained.

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