Increased uptake of cervical screening by women with HIV infection in Auckland regardless of ethnicity, requirement for an interpreter or level of education

Michele Lowe, Rupert Handy, Joan Ingram, Mitzi Nisbet, Stephen Ritchie, Mark Thomas, Simon Briggs

**ABSTRACT**

**BACKGROUND:** Current guidelines recommend that women with HIV infection receive annual cervical smears.

**METHODS:** We evaluated the uptake of annual cervical smears by women with HIV infection under the care of the Infectious Disease Service at Auckland City Hospital. In an attempt to identify potential barriers to regularly receiving an annual cervical smear, we invited the women to complete a questionnaire. The responses from women who had regularly received an annual cervical smear were compared with those who had not.

**RESULTS:** The proportion of women who had received a cervical smear increased from 44% in 2001, to 73% in 2010 (p=0.001). Ninety-three women (76%) completed the study questionnaire. No statistically significant differences were found in the questionnaire responses between the women who had regularly received an annual cervical smear and those who had not.

**CONCLUSION:** The proportion of women in this cohort who received a cervical smear in 2010 is comparable with other studies of women with HIV infection in New Zealand and overseas. We have not been able to identify barriers that prevent women with HIV infection in Auckland regularly receiving an annual cervical smear. We plan to encourage women who have not received a cervical smear in the previous 2-year period to have a cervical smear performed when they attend the Infectious Disease Clinic, and will continue to notify the National Cervical Screening Programme that all women who are newly diagnosed with HIV infection should have an annual recall code attached to future cervical smear reports. We expect that these interventions will further increase the proportion of women with HIV infection in Auckland who receive an annual cervical smear.

Women with HIV infection have an increased risk of cervical cytologic abnormalities and cervical cancer compared to women without HIV infection. The current New Zealand and American recommendations are that women with HIV infection receive cervical screening when their HIV infection is diagnosed, 6 months later if the initial screen is normal, and then annually if the second screen is normal.

The Infectious Disease Service at Auckland City Hospital cares for the majority of adults with HIV infection in the Auckland and Northland regions of New Zealand; regions that contain a population of approximately 1.3 million adults.
An audit of women with HIV infection under the care of the Infectious Disease and Sexual Health Services at Auckland City Hospital showed that as of 31 December 2007, only 69 (56%) of 123 women met our definition for regularly receiving an annual cervical smear.

Following this audit, we introduced a number of interventions intended to increase the regular uptake of annual cervical smears by women with HIV infection under our care. These interventions included sending a letter documenting the importance of annual cervical smears for women with HIV infection to all general practitioners (GPs) caring for women with HIV infection in the Auckland area, documenting this issue in the first clinic letter for women with HIV infection who were newly referred to the Infectious Disease Service, and sending a list of all women with HIV infection seen by the Infectious Disease Service to the National Cervical Screening Programme (NCSP) stating that these women were immunocompromised. This notification resulted in an annual recall code being attached to the woman's future cervical smear reports that were sent to the woman's cervical smear taker.

The aims of this study were to assess the current uptake of annual cervical smears by women with HIV infection under our care, and to attempt to identify potential barriers to regularly receiving an annual cervical smear with a questionnaire-based survey.

**Methods**

We evaluated the uptake of annual cervical smears between 2001 and 2010 in the cohort of women with HIV infection aged 20 to 69 years who had received at least 2 years of active follow-up from the Infectious Disease Service at Auckland City Hospital as of 31 December 2010. This age range was used as the NCSP does not recommend cervical screening for women younger than 20 or older than 69 years. Women were included in the yearly assessments from the first full year that they had received follow-up by an HIV care provider in New Zealand.

In order to measure the proportion of women who had received annual cervical smears, each woman's cervical smear history dating back to 2001 was obtained from the NCSP. To allow for some variation in the interval between each cervical smear, we defined an annual cervical smear using the ratio between the number of cervical smears received and the number of years since HIV diagnosis, or since January 2001, for those diagnosed with HIV infection prior to 2001. A woman was considered to have regularly received an annual cervical smear if this ratio was 0.8 or above, provided there were no intervals between two cervical smears of more than 2 years. For those women who were diagnosed with HIV infection before their arrival in New Zealand, we used the number of years they had resided in New Zealand, instead of the number of years since the diagnosis of their HIV infection.

We invited the women in our study cohort to complete a questionnaire (Appendix A) when they attended their usual outpatient Infectious Disease Clinic appointment. Women were given the opportunity to answer the questionnaire at the time of their appointment or at a suitable later time. Women were offered access to an interpreter, if required, to help them answer the questionnaire.

Women were divided into two groups depending on whether, or not, they met our definition for regularly receiving an annual cervical smear. We compared the questionnaire answers from both groups in an attempt to identify barriers to regularly receiving an annual cervical smear.

Ethical approval was granted by the Northern X Regional Ethics Committee.

The Fisher's exact test, Chi-square test and Mann-Whitney U-test were used to compare demographic and questionnaire variables.

**Results**

As of 31 December 2010, the Infectious Disease Service at Auckland City Hospital cared for 723 adult patients with HIV infection, of whom 146 (20%) were women. The 123 women who were aged 20 to 69 years and had been under our care for at least 2 years prior to 31 December 2010 comprised the study cohort.

The median age of the 123 women was 40 (range 24 to 61) years. Their self-reported ethnicity was African (n=64), New
Zealand European (n=20), Asian (n=18), European (n=9), Pacific person (n=7), Māori (n=4) and Middle Eastern (n=1). They had been diagnosed with HIV infection for a median of 7 (range 2 to 24) years, and had been under follow-up by a New Zealand HIV care provider for a median of 6 (range 2 to 18) years.

The proportion of this cohort of 123 women who received a cervical smear during each year between 2001 and 2010 is shown in Figure 1. Twenty of 45 (44%) women had received a cervical smear in 2001, compared to 90 of 123 (73%) women in 2010 (p=0.001). Eleven (9%) of the 123 women had not received a cervical smear in either 2009 or 2010.

Sixty-six (54%) women met our definition for regularly receiving an annual cervical smear during the study period. The median age for those women who met and who did not meet our definition for regularly receiving an annual cervical smear was 38 (range 24 to 61) years and 41 (range 27 to 58) years, respectively (p=0.09). The proportion of women who regularly received and who did not regularly receive an annual cervical smear with regard to their demographic and clinical characteristics is shown in Table 1. No statistically
significant difference was found for any of these characteristics.

Ninety-three of the 123 (76%) women completed the study questionnaire. Questionnaires were not completed for the following reasons: declined to participate (n=5); consented to participate but did not return the questionnaire despite repeated reminders (n=11); or were not asked to participate/did not attend clinic during the 12-month enrolment period (n=14).

Fifty-four of the 93 (58%) women who completed the questionnaire, and 12 of the 30 (40%) women who did not complete the questionnaire, met our definition for regularly receiving an annual cervical smear during the study period. These proportions were not statistically significantly different (p=0.10).

The median age of the 93 women who answered the questionnaire was 40 (range 24 to 58) years. Their self-reported ethnicity was African (n=46), Asian (n=17), New Zealand European (n=12), Pacific person (n=7), European (n=6), Māori (n=4) and Middle Eastern (n=1). Some of the following data are incomplete, as not all women answered every question in the questionnaire. Fifty-five (60%) of 92 women reported that English was not their first language. Seventeen (20%) of 84 women required an interpreter (9 a medical interpreter, and 8 a non-medical interpreter) when completing this questionnaire, 14 (17%) of 82 women required an interpreter when attending Infectious Disease Clinic, and 15 (18%) of 83 women reported that they could not read English. The highest level of education for 88 women was reported as no formal education (n=10), primary/secondary education (n=38), or university degree or diploma (n=40). Six (6%) women had been circumcised and 3 (3%) were uncertain as to whether they had been circumcised. The proportion of women answering the questionnaire who regularly received and who did not regularly receive an annual cervical smear for different patient characteristics is shown in Table 2. No statistically significant difference was found for any of these characteristics.

The responses (agree or disagree) to the questions grouped under the headings of smear knowledge, family views/support,
and barriers to obtaining a cervical smear were analysed for the proportion of women who met or did not meet our definition for regularly receiving an annual cervical smear. No statistically significant difference was found in any of these responses. Ninety-seven percent, 96%, 95% and 88% of women, respectively, agreed with the following statements: I know what a cervical smear is; I understand why I need to have cervical smears; women with HIV infection need yearly cervical smears; and women with HIV infection have an increased risk of abnormal smears.

**Discussion**

We found that the proportion of women with HIV infection under active follow-up from the Infectious Disease Service at Auckland City Hospital who received a cervical smear during each year between 2001 and 2010 increased significantly, from 44% in 2001, to 73% in 2010 (p=0.001).

The regular uptake of an annual cervical smear was not significantly lower for women who had demographic features that may be expected to be associated with decreased adherence to screening recommendations. The regular uptake was not significantly lower in non-New Zealand European women, in women for whom English was not their first language, in women with a low level of formal education, or in women who required an interpreter at clinic. We acknowledge the relatively small number of women in some of these categories in our study population.

The following factors have been associated with women with HIV infection not receiving a cervical smear in other studies: older age, non-Caucasian ethnicity, non-English speaking, lower levels of formal education, unemployment, drug use including smoking, depressive symptoms, being sexually inactive, women who obtain their gynaecological care at a location other than their usual source of HIV care, CD4 count <200 cells/mm³ and HIV viral load >50 copies/mL or in one study HIV viral load <400 copies/mL.⁷⁻¹⁰ Although we did not find that women for whom English was their second language were less likely to regularly receive an annual cervical smear, given that this has been identified in other studies, GPs in Auckland should be aware that they are able to access telephone interpreters through their District Health Board Interpreting Service free of charge.

We were encouraged by the finding that almost all of the women in this study appeared to have a good understanding of cervical smears and the reasons why yearly cervical smears are recommended. Many of the women in this study have had a number of targeted interactions in an attempt to increase their cervical smear knowledge. These have included discussions with their Infectious Disease physician, HIV nurse specialist, or HIV social worker, as well as being given written information carefully explaining the benefits of receiving a yearly cervical smear.

In their answers to our questionnaire, women did not consistently identify barriers to regularly receiving an annual cervical smear. We were surprised that women who agreed with questionnaire statements regarding potential barriers to regularly receiving a cervical smear did not have a significantly lower regular uptake of annual cervical smears, but again acknowledge the relatively small number of women who agreed with a number of these questionnaire statements.

In our previous audit of cervical screening in women with HIV infection in Auckland,⁴ the only factor that was associated with not regularly receiving an annual cervical smear was women who received their cervical smears from their GP. We postulated that not all GPs may have been aware of the need for an annual cervical smear in women with HIV infection, and introduced interventions aimed at increasing this awareness. We are encouraged that in this study there was no association between receiving a cervical smear from a GP and lower rates of receiving annual cervical smears. We postulate that our interventions have contributed to this improvement.

Although only 54% of the women in our cohort met our criteria for regularly receiving an annual cervical smear, it was encouraging to note that the proportion of the 123 women who received a cervical smear each year increased during the 10-year study period from 44 to 73%.
The proportion of women in this cohort who received a cervical smear in 2010 is comparable to other studies of women with HIV infection with self-reported, or medical record confirmed, yearly cervical smear rates of 77 and 78%. The NCSP does not provide data on the proportion of immunocompromised women in New Zealand who receive yearly cervical smears; the only other available New Zealand data is a study from Waikato Hospital which showed that for the period March 2008 to March 2009, 68% of women with HIV infection, and 40% of women with a renal transplant, had received a cervical smear within the previous year. The NCSP aimed to increase cervical screening coverage to at least 80% in all population groups by 2014. Although the NCSP strategic plan does not comment specifically on a coverage target for immunocompromised women, our current cervical screening coverage remains below the NCSP general target of 80%.

Although we have not been able to identify barriers that can be targeted to increase the proportion of women regularly receiving an annual cervical smear, targeting the relatively small number of women who had not received a cervical smear in the most recent 2-year period would be an option; only 11 (9%) of the 123 women in this cohort had not received a cervical smear in 2009 or 2010. These women could be offered a cervical smear at the time of their next Infectious Disease Clinic visit that would be performed by one of our HIV nurse specialists; this opportunistic approach to cervical screening is supported by the NCSP as a way of increasing cervical smear uptake, as long as the woman is advised that she will need to return to her usual smear taker for her next cervical smear at the appropriate time interval, and both the woman and her GP are provided with the results of the cervical smear.

The strengths of this study include the very good response rate to our questionnaire and that we were able to obtain accurate cervical smear history data from the NCSP. Accurate cervical smear history data is important, as studies have shown that women may over report cervical smear uptake by as much as one quarter to one third. This study has a number of limitations. The relatively small sample size contributed to a lack of statistical power. A number of women, for whom English was not their first language and/or who had difficulty reading English, choose to answer the questionnaire without an interpreter or with a family member or friend interpreting, which may have resulted in less accurate responses. The strong relationship that many of the women in this study have with the Infectious Disease Service may have influenced the way that some women answered the questionnaire; some women may have consciously or subconsciously answered questions in a way that they felt would be pleasing to the study investigators. We did not attempt to address the complex issues of HIV stigma and discrimination or sexual violence in this study; these are areas that require further research.

While it can be argued that our definition of what constituted the regular receipt of an annual cervical smear was somewhat lax, we felt that this definition reflected the real world where there may be a delay between notification of the need for a cervical smear and having this test performed.

We have found that an increased proportion of women with HIV infection under active follow-up from our service received a cervical smear in 2010 compared to 2001, and that only a small number of women had not received a cervical smear in the last 2 years of the study period. We have not been able to identify barriers that prevent women with HIV infection in Auckland regularly receiving an annual cervical smear. We plan to target women who have not received a cervical smear in the previous 2-year period with the opportunistic offer of a cervical smear when they are seen at the Infectious Disease Clinic, and will continue to notify the NCSP that all women who are newly diagnosed with HIV infection are immunocompromised, so that these women have an annual recall code attached to future cervical smear reports. We expect that these interventions will further increase the proportion of women with HIV infection in Auckland who receive an annual cervical smear.
Appendix A: Questionnaire

Participant study number _____
Participant NHI _______

Please circle the correct answer
Age: 20-29   30-39   40-49   50-59   60-69
Ethnicity: __________________________

English is my first language
I required an interpreter to complete this questionnaire
I require an interpreter for clinic visits
I can read written English

Highest level of Education:
No formal schooling
Attended primary/secondary school
University degree or diploma

I am enrolled with a Family Doctor (GP)
I have seen my Family Doctor in the past 12 months
I received the influenza vaccination in the past year

Method of contraception:
Not required   Condoms   IUD   Hysterectomy or tubal ligation
Hormonal contraception such as pills, implants or injection
Hysterectomy or tubal ligation
Other, please state ____________

My last smear taker was:      Male  Female

I had my last cervical smear at:
Family Doctor         Hospital        Family Planning        WONS        Sexual Health        Other

I had had a cervical smear before I came to New Zealand
My smear taker sent me a letter to remind me to get my smear
My smear taker phoned me to remind me to get my smear
I have had my womb/uterus removed
I have been circumcised/pharonic

Smear knowledge:
The following statements are some ideas about cervical smears. Please indicate with a cross in the appropriate column the answer that best describes your belief about each of the sentences. There are no right or wrong answers. If a question does not apply to you please leave it out and move on to the next question.
<table>
<thead>
<tr>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
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</thead>
<tbody>
<tr>
<td>I know what a cervical smear is</td>
<td></td>
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<tr>
<td>I understand why I need to have cervical smears</td>
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<tr>
<td>Getting a regular cervical smear can prevent cervical cancer</td>
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<tr>
<td>Women with HIV infection need yearly cervical smears</td>
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<tr>
<td>Women with HIV infection have an increased risk of abnormal cervical smears</td>
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<tr>
<td>There is treatment available for abnormal cervical smear results</td>
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**Family views/support:**

It is important in many cultures that families/whanau understand and support women to have medical procedures. Please indicate with a cross in the appropriate column the answer that best describes your belief about each of the sentences. There are no right or wrong answers.

If a question does not apply to you please leave it out and move on to the next question.

| My husband/partner knows I have cervical smears |       |          |                  |
| My family/whanau knows I have cervical smears |       |          |                  |
| My husband/partner encourages me to have a cervical smear |       |          |                  |
| My family/whanau encourage me to have a cervical smear |       |          |                  |
| My husband/partner doesn’t want me to have a cervical smear |       |          |                  |
| My family/whanau don’t want me to have a cervical smear |       |          |                  |
| My husband/partner understands the importance of cervical smear tests |       |          |                  |
| My family/whanau understand the importance of cervical smear tests |       |          |                  |
| I am afraid someone from my family/church/community will find out I have cervical smear tests |       |          |                  |
**Barriers:**

The following sentences are some reasons why women may have or may not have cervical smears. Please indicate with a cross in the appropriate column the answer that best describes the reason you would or would not get a cervical smear test. There are no right or wrong answers.

If a question does not apply to you please leave it out and move on to the next question.

<table>
<thead>
<tr>
<th>Reason</th>
<th>Strongly agree</th>
<th>Agree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
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<tr>
<td>Last time I had a cervical smear it was uncomfortable</td>
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<td>I have previously had a bad experience when visiting my Family Doctor</td>
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<tr>
<td>Due to my circumcision, cervical smear examinations are difficult</td>
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<tr>
<td>Due to my circumcision, cervical smear examinations are not possible</td>
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<td>I get embarrassed when I have a cervical smear</td>
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<td>I do not have time to get a cervical smear</td>
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<tr>
<td>I get cervical smears because I like to look after myself</td>
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<td>It is too difficult to arrange transport to get to a cervical smear appointment</td>
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<td>It is too expensive to have a cervical smear</td>
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<td>The health centre where I have my cervical smear is not open at times that suit me to get a cervical smear</td>
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<td>I have not had a cervical smear because I am afraid to find out I have cancer</td>
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<td>I do not have any problems or symptoms so I do not need a cervical smear</td>
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<td>I do not have sex so I do not need a cervical smear</td>
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<td>I have nobody to look after my children while I have a cervical smear</td>
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<td>I would be more likely to have a cervical smear if there was an interpreter available</td>
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<td>My cervical smear taker is aware that I have HIV infection</td>
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<td>I find it easy to talk with my cervical smear taker about my HIV infection</td>
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We would value any further comments you may have on why you would or would not have a cervical smear test.
Competing interests:
Nil

Acknowledgments:
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