

ORIGINAL ARTICLES

Women's acceptability of screening for HIV in pregnancy

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Abstract

Aims. To elicit acceptability of HIV screening during pregnancy in women of reproductive age in Christchurch.

Methods. In-depth face-to-face interviews were conducted with women of reproductive age recruited from seven different service sites in Christchurch.

Results. Women wanted to know about treatment that significantly reduces the risk of mother-to-child transmission. They wanted to know about other antenatal

screening and were prepared to provide general consent, rather than specific consent for HIV testing. All study participants favoured routine offer of HIV testing during pregnancy for all women and most would agree to be tested, if the test was offered and recommended.

Conclusions. The results of this study indicate the need to develop and test a user-friendly approach for offering routine HIV testing during standard antenatal care in New Zealand.

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It is now possible to significantly reduce the risk of HIV transmission from mother to child, provided the woman's HIV status is known. Most OECD countries now offer some form of routine antenatal screening.¹ The Ministry of Health (MOH) in New Zealand circulated provisional guidelines for routine HIV risk assessment in 1997. However, as presented in the companion article, in this issue of the Journal, recent evidence shows that antenatal women are not routinely assessed for HIV risk or offered HIV testing, at least not in the South Island, nor are they informed of the effective treatment to prevent mother-to-child transmission. As of 31 December 2000, twelve children in New Zealand were known to be infected with HIV by perinatal transmission.² International studies suggest that the probability an HIV-positive woman will transmit the virus to her baby during pregnancy, labour, delivery, or breastfeeding ranges from 15-25% in an industrialised country, with no intervention.^{3,4} Since 1992, the number of women living with diagnosed HIV infection in New Zealand has nearly tripled.⁵

In February 1994, the Pediatric AIDS Clinical Trials Group (PACTG) Protocol 076 demonstrated that zidovudine (or AZT), could reduce the risk for mother-to-child HIV-1 transmission by nearly 70%.⁶ In early 1998, the results of shorter regimens of zidovudine in three developing countries showed a 50% reduction in the risk of mother-to-infant HIV transmission at a cost of only US\$50.⁷ A team of researchers from Johns Hopkins University in Kampala demonstrated that a single dose of nevirapene to a woman in labour and to her baby within three days of birth, cut the transmission rate by 47%, for only US\$4.⁸ By June 1999, the relative risk of vertical transmission was reduced to around 1-2% when elective caesarean-section delivery was combined with zidovudine in a randomised clinical trial conducted by the European Collaborative Study.⁹ These findings have prompted important changes to the standards of screening practice for maternity carers in all OECD countries.¹

A US Centers for Disease Control and Prevention (CDC) literature review of women's acceptance of HIV testing, concluded that client-directed counselling, routine offer of the HIV test, and understanding the medical and social benefits of testing were factors found to most likely result in

acceptance.¹⁰ The uptake of HIV testing among antenatal women shows different results where strategies have varied from universal offer, to selective offer, to opt-out offer, to testing only women who request it or opt-in.¹¹⁻¹³ The results of a randomised controlled trial in Edinburgh recently concluded that the universal offer of HIV testing is acceptable to pregnant women and when offered in a routine manner, resulted in higher uptake, without increased anxiety or dissatisfaction.¹¹ Regardless of the strategy, it has been repeatedly demonstrated that when women are aware of their HIV status, they want to manage their pregnancies to reduce the risk of infection to their babies.¹³

The first acceptability study among antenatal women conducted in New Zealand was commissioned by the MOH and conducted by Fursman in Wellington just prior to the release of the circular letter in 1997. This study found that knowledge of HIV in general and of HIV and pregnancy in particular was high, but there was little awareness of the reductions in vertical transmission associated with AZT.¹⁴ Once informed of the effective treatment, respondents felt that having an HIV test would be 'useful' and that the benefits outweighed any drawbacks. In contrast, women's acceptability of HIV testing was perceived as a significant barrier by most maternity care providers, as shown in the results of two provider surveys conducted in Otago in 1998 and in Canterbury-West Coast in 1999.^{15,16}

In response to these study results, the availability of an effective treatment, and the provisional MOH guidelines which called for further research, the Women's Acceptability of Screening HIV (WASH) study was funded in September 1999. The purpose of WASH was to investigate the acceptability of HIV testing among women of reproductive age in Christchurch.

Methods

65 women from different socio-demographic and ethnic backgrounds were recruited and referred by staff from seven community service and clinic sites in Christchurch using a recruitment check list prepared by the WASH research team. In the clinic sites, consecutive attenders were approached within the designated three-week recruitment period. The study team was reliant on staff members in the different services to remember to approach women. This did not occur as efficiently in some

sites as in others. The Maori, Pacific Island, Cambodian, and Ethiopian women were approached by health workers from their own communities in the same time period when they attended regular meetings and training programmes. Women were eligible if they were nulliparous, antenatal, one to two years postpartum, and/or considering pregnancy. Women with no immediate or long-term plans for pregnancy were screened out.

The specific service sites that were deliberately engaged in this study represented the team's best opportunity to recruit as wide a socio-economic and ethnic variety of women of reproductive age in Christchurch as possible. Budget constraints precluded a larger sample. While other ethnic groups are represented in the refugee community, limited resources restricted recruitment. The research team made its selection by prioritising one group from the African continent where the HIV/AIDS epidemic has raged for two decades and one group from Southeast Asia, where the epidemic is more recent but equally volatile.

Fourteen of the 65 referrals were either unable to be scheduled or withdrew. 51 women were interviewed (Table 1). Two interviews were lost due to failure of taping equipment, leaving a total of 49 participants. Each participant completed an in-depth semi-structured interview in September-October 1999 to assess general HIV knowledge, knowledge related to pregnancy and breast feeding, perceptions of personal risk, and preferences for HIV screening techniques and provider practices. The interview schedule included dichotomous, Likert scale, forced choice, and limited choice style questions conducive to quantitative analysis. The versatility of the interview method allows qualitative and quantitative analysis methods to be combined in a complementary fashion, especially where the assessment of complex issues such as HIV/AIDS is undertaken. The results from the quantitative questions were further validated and enriched with the qualitative analysis of responses from the more open-ended questions. All interview data were coded and entered into an ACCESS database that accommodated both quantitative and qualitative data entry fields. The interview method was chosen because it offers the flexibility to explore reasons for personal preferences and to respond to any concerns or questions in a private and personal data-gathering situation about a subject that is still considered sensitive and potentially stigmatising.

Table 1. WASH recruitment sites, women approached, referred, and interviewed.

Service Site	Approached	Referred	Interviewed
1. Christchurch Women's Hosp.	11	9	7 (13%)
2. '198' Youth Health Centre	8	6	3 (6%)
3. Ngai Tahu Development Corp.	17	9	9 (18%)
4. Methadone Programme	3	2	2 (4%)
5. Family Planning Assoc.	72	17	11 (21%)
6. Crown Public Health, Ltd.	12	12	9 (18%)
7. Refugee & Migrant Centre	10	10	10 (20%)
Totals	133	65	51*

*Two interviews lost due to faulty audio equipment. Table shows % of total number of women interviewed to illustrate variety of participants.

The 51 interviews were completed in less than five weeks by three female interviewers, including two of the co-investigators and one Senior Research Officer whose skills helped establish rapport and an environment of trust and disclosure. The decision to use three interviewers was based on time and resource constraints as well as respect for cultural appropriateness, ie the Maori Co-Investigator interviewed all Maori participants. All interviews were conducted in the participant's home, at Te Waipounamu Centre, or at 45 Cambridge Terrace (Department of Public Health & General Practice) and lasted 100 minutes on average. All interviews were tape recorded and transcribed.

The original WASH research design proposed Focus Group Discussions (FGDs) with all participants following the interviews in order to further investigate women's preferences for the delivery of information about HIV. Most women initially gave their consent to participate in both the interview and the FGD. However, many were ambivalent about joining a focus group following the interview, expressing that they had little more to add. Scheduling for the focus groups ran into the school holidays, which added to the unanticipated difficulty. The results of the few focus group discussions that did occur will be reported in another publication.

Results

Recruitment data are shown in Table 1. Figures 1 and 2 show that the women who participated in WASH were very much like all women from the seven service sites who were offered the opportunity to participate, in terms of employment status, studying, having had an HIV test and age range. The

interviewed women were slightly more likely to have children and a long-term partner.

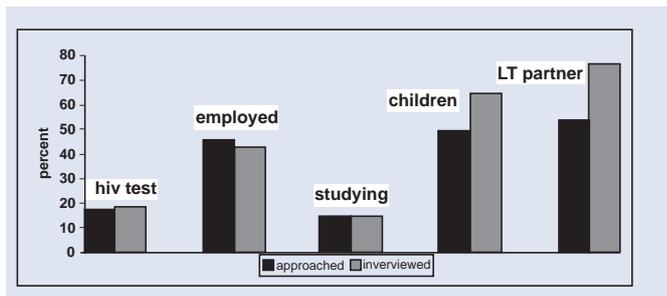


Figure 1. Women approached compared to women interviewed.

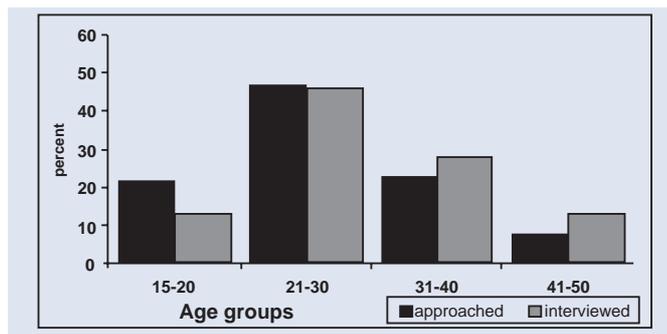


Figure 2. Age groupings for women approached compared to women interviewed.

Of the 49 WASH participants; 19 (59%) were New Zealand European, 11 (22%) were Maori, 9 (18%) were Pacific Islanders, 5 (10%) were Cambodian, and 5 (10%) were Ethiopian. Maori, Pacific Island, Cambodian and Ethiopian women were over-sampled in response to the funding agency's request and in order to access the unique cultural perspectives of these groups of women. Nationally, the respective proportions of Maori and Pacific Island peoples to the total population are 14 and 5%. In the territorial authority of Christchurch these proportions are 7 and 2% respectively, based on 1996 census data. Fifteen (33%) of participants voluntarily disclosed they were pregnant during the interview.

Participants were asked if they had heard about HIV or AIDS. Over half said they had and most had received their information from a variety of 'other' sources such as magazines, school sexual health programmes, workshops, office, friends and the movies, and not from the main media such as television or newspapers. Responses from the ten refugee women were incomplete for this question and were not included in this analysis.

WASH participants were asked 25 knowledge questions regarding the transmission and prevention of HIV/AIDS. These questions included nine 'true/false' statements, fourteen 'high risk/low risk/no risk' activities, and two 'yes/no' questions regarding methods of transmission and prevention. Knowledge scores were calculated based on the number of correct responses. Figure 3 presents the distribution of correct knowledge scores. Most scores were in the 80th and 90th percentiles, about the same level of HIV/AIDS knowledge demonstrated in other parts of the world among the general public.¹⁷ 30 participants, or 61%, answered more than half of the general knowledge questions correctly. There were no measurable ethnic differences in general knowledge. Study participants were also asked six questions about the HIV test. Knowledge about the HIV test was not as high as general HIV knowledge, however,

Maori women were slightly better informed about the HIV test than the other women.

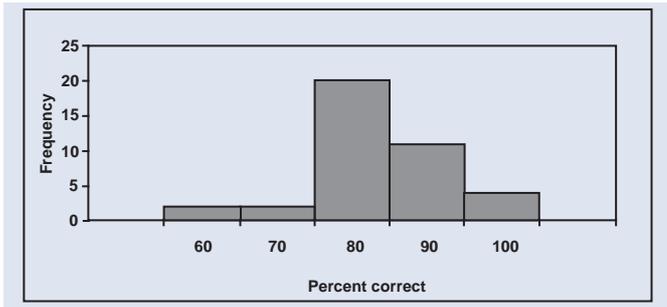


Figure 3. Distribution of HIV/AIDS knowledge scores for 25 questions.

The relatively high general knowledge about HIV transmission also contrasted with lower levels of knowledge regarding effective treatment during pregnancy and risk attributed to breast feeding. Almost all women, 47 (98%) knew that 'a mother who is HIV positive can pass the virus on to her baby', but only 20 women (41%) knew that not all babies get the virus. Only 33% (16 women) were aware that HIV can be transmitted through breast milk.

Women's perceptions of their own risk of being exposed to HIV in the past five years and currently or 'tomorrow' were assessed on a five point scale where 1 was 'no chance' and 5 was a 'very high chance'. Three women rated their risk of exposure to HIV in the past as 'very high'. However, none of the women rated their current risk as 'very high' and approximately 75% (38 women) perceived that they had 'no chance' of currently being exposed to HIV.

WASH participants were asked a number of attitudinal questions about HIV screening as part of antenatal care. Most (86%) said they would have the test if it was offered and more than half (68%) thought that knowing one's HIV status would help the baby. 82% said they would have the test if they knew it was part of the antenatal 'routine' and that all other pregnant women were having it too. Almost half, (42%) said they thought they would have the test even if it wasn't part of the routine, and even if they thought that they were the only one being offered the test.

The interviewers also explained that the doctor could be required to ask a woman for specific permission for the test during antenatal care, or the woman's consent could be provided when general permission for all antenatal screening was given. 34 women (69%) said they preferred to give general permission and only eleven (22%) said they wanted specific consent for the HIV test. One woman was 'unsure' and data from three women were missing.

Midway through each interview and after responding to the knowledge and attitudinal questions discussed above, all participants were informed about the effective treatment for minimising mother to child transmission of HIV. Each participant was then shown a card listing seven different screening options (Table 2). Figure 4 shows that 96% of participants expressed a preference for routine screening during pregnancy, whether Option A, 'routine compulsory' selected by 16 (33%) participants, or Option B, 'routine offer and recommended' selected by 31 (63%) participants. Most Ethiopian and Cambodian women preferred the option of compulsory screening, whereas most Maori, Pacific Islands, and European participants preferred routine and recommended offer of HIV testing, with women being able to opt out. Only one participant chose option C (the same as the current MOH provisional guideline) and another chose Option F, 'No set policy or practice on testing pregnant women for HIV.'

Table 2. Seven different screening options.

- A. Routine compulsory testing for all women.
- B. Offered an HIV test and recommended to have it, but a woman can turn the offer down.
- C. All women assessed for their risk of exposure to HIV and those at risk are offered an HIV test.
- D. All women in high HIV risk areas are offered an HIV test. Women in other areas are offered the test if they are assessed as being at high risk of exposure to the virus.
- E. HIV testing is available but women have to ask for it.
- F. No set policy or practice on testing pregnant women for HIV.
- G. Other approach?

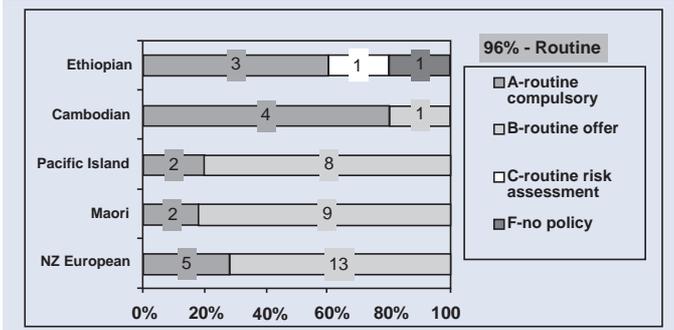


Figure 4. Women's preferences for HIV testing option based on interviews.

Screening preferences were then analysed in relation to self-perception of risk and perceived drawbacks in order to detect any patterns or influence. Most women who chose Option B felt they were at low risk and there were no drawbacks to having an HIV test.

Discussion

The sample in the study was not intended to be representative of women of reproductive age in New Zealand. However, because the results of the WASH study were almost identical to those in the 1996 Wellington study and very similar to the results of the randomised control trial conducted in Edinburgh, they may reflect the views of many New Zealand women.¹¹ Women interviewed were similar to all women approached for most socio-demographic variables. However, those interviewed were more likely to have children and a long-term partner. It is important to note that Maori and Pacific Island women are not known to be at increased risk for HIV infection. They are known, however, to seek and use health care services differently from Europeans and their exposure to other sexually transmitted infections (STIs) may be higher due to social and economic factors that impinge upon their health status in general.^{18,19}

The most difficult interviews and transcripts were those involving Cambodian and Ethiopian participants. Professional interpreters were recruited through the Refugee and Migrant Centre and oriented to the interview schedule by the Principal Investigator and lead-interviewer. The migrant women preferred to be interviewed at home. In almost all cases young children were present which often resulted in interruptions and poor taping quality. In some cases the interview could not be completed which accounts for some missing data.

By the conclusion of the interviews it was clear that almost all 49 women were in favour of routine HIV screening during antenatal care. Moreover, 86% said they would be willing to have an HIV test if it were offered, even before they learned about the effective treatment for preventing transmission from mother-to-child. The women were also much more apt

to identify benefits of routine HIV testing than drawbacks; for themselves, for all women and for the babies. These results contrast with results from the two providers' studies conducted in Dunedin and Canterbury and the upper South Island that showed maternity care providers tend to think that HIV screening is not acceptable for most antenatal clients.^{15,16} Contrary to the providers' perceptions, most women favoured 'general consent' for all antenatal screening, rather than 'specific consent' for HIV screening.

The WASH study results clearly document that women want to know about treatment aimed at reducing risk of mother-to-child infection. They wanted to be offered HIV screening as part of routine standard antenatal care. They wanted to be informed about all antenatal screening and they wanted to provide general consent for all antenatal screening. WASH results further indicate that all women, especially antenatal women, should be informed by their primary or maternity care providers about HIV, the treatment available for preventing mother to child infection, and the risks of breast feeding. Results from both the provider and women's studies in Canterbury suggest that the national guidelines for all antenatal screening deserve to be reviewed.

To reconcile the differences between the providers' preferences towards HIV screening during antenatal care and the preferences of women, the research team has developed several antenatal screening protocols and propose to test their acceptability and uptake in a multi-centre study. The primary intent will be to identify key factors that predict uptake (eg uptake of the protocol among providers and uptake of testing among clients) and to explore the importance of informed consent for all antenatal screening.

There is a unique blend of ethnic cultures in New Zealand, which makes it important to ensure that the most acceptable methods of screening are developed. The research team expects to work with professional bodies such as the Colleges of General Practitioners, Obstetricians and Gynaecologists, and Midwives to trial the antenatal screening protocols. Acceptable methods of identifying HIV infected women in

pregnancy are urgently required to bring New Zealand into line with other Western countries and to minimise perinatal transmission of a preventable infectious disease.

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Dr Stuart Brown, Meadowbank, Auckland was lightening his load of files and came across a cartoon by Minhinnick from just prior to World War II. It portrayed "Mick" Savage, Prime Minister of the day, at the time of the first Labour Government, and his approach to the New Zealand branch of the BMA. He wondered if there was a parallel in the attitude of recent governments toward the medical profession.