Women who decline antenatal screening for HIV infection in the era of universal testing: results of an audit of uptake in three London hospitals


Abstract

Universal screening for HIV in early pregnancy is strongly promoted policy in the United Kingdom with a target of 90 per cent uptake. We identified characteristics of women declining screening by conducting an audit at three hospitals in inner north London. In early 2002 midwives were asked to complete an audit form following first antenatal appointment. Of 2,710 women attending 401 (15 per cent) declined an HIV test. Of women who declined 38 per cent reported they had been tested for HIV in the past; 65 per cent accepted every other antenatal test. In multivariable analysis parity (OR: 1.19; 95 per cent CI 1.10–1.29 per additional child), declining other tests (OR: 3.10; 95 per cent CI 2.44–3.93 per test declined) and previous HIV testing (OR: 1.70; 95 per cent CI 1.30–2.23) were predictors of declining an HIV test. Women declining screening were not obviously from high-risk demographic groups: women from sub-Saharan Africa were not at greater risk of declining an HIV test than women from other regions.

Keywords: HIV infections, diagnosis, prenatal care, pregnancy complications, infectious

Introduction

HIV infection in pregnant women continues to be a major problem especially in London. In 2001 anonymous testing indicated that 1 in 286 women giving birth in London were infected with HIV.1 Over half of the mothers of HIV infected children are from Black African ethnic groups.2

Detection of HIV infection in the antenatal period is valuable both for identification and treatment of the mother and prevention of transmission to her child. In 1999 a UK Government paper recommended that maternity units in the United Kingdom make HIV testing available to all women and ensure satisfactory uptake.3 The current policy in the United Kingdom is a variant of ‘opt-in’ policy. All women are briefly but specifically offered and recommended an HIV test at the same time as other tests.4 This usually occurs at their first midwife-run booking clinic.5 Discussion of all tests and investigations typically takes around 10 min. All women have the option to refuse.6

Understanding groups who decline screening for HIV in the antenatal period is important. If women from high-risk groups choose not to be tested the value of universal screening is undermined. This was the conclusion of the experience with universal screening at the Kaiser Permanente health maintenance organization in California.7,8 This has implications for the way in which screening is offered, informed consent, counselling and overall benefit of a screening programme.

In inner north London there are three obstetric units serving typically diverse multi-ethnic inner city populations. In 1999, before inception of new targets, uptake of HIV testing was 56–68 per cent. We planned an audit of antenatal HIV testing with the aim of gauging progress towards the NHS target of 90 per cent uptake9 and characterising women who declined HIV screening.

Methods

The audit was conducted within three maternity units (Whittington Hospital, Royal Free Hospital and University College Hospital) in inner north London from January to April 2002. Midwives completed an audit form immediately after first antenatal (booking) appointment for each new woman (hospital or community) collecting routine demographic information, information about the offer of an HIV test and whether the offer was accepted or declined. We obtained information on total numbers booking from either antenatal clinics or where

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this information was unavailable from numbers of rubella screening tests. The audit was overseen by the HIV testing group of Camden and Islington Health Authority.

Risk factors for declining an HIV test were examined using logistic regression. Variables investigated through single variable analysis included hospital, religion, region of birth, marital status, previous HIV testing, age, parity, time of first appointment and whether other tests had been declined. Significant variables ($p < 0.05$) were included in a multivariable model and retained if they were still significant after adjustments. Because opportunity of HIV testing increases with parity we decided to investigate interactions between age, parity, and previous testing for HIV.

## Results

Over the 4 month audit period midwives completed 2710 forms (estimated 76 per cent of births). Half (47.5 per cent) of the women were born in a country other than the United Kingdom and 42.3 per cent were from non-white ethnic groups including Black African (19.0 per cent) and groups from the Indian sub-continent (10.7 per cent). The median age of women booking was 31 years. Half (49.4 per cent) were having their first child, 29.1 per cent their second, 12.5 per cent their third and 8.9 per cent their fourth or more. Ten per cent were single, separated or divorced. The median week of pregnancy for first antenatal visit was 14, and 86.0 per cent of women had their first antenatal clinic visit before 20 weeks. One quarter (24.7 per cent) of women had been tested for HIV in the past.

Overall 2309 (85 per cent) of women accepted an HIV test at first antenatal clinic appointment. After adjustment, declining an HIV test was associated with the hospital attended, religious affiliation, parity, time of booking, declining other screening tests and previous HIV testing (Table 1). Neither region of origin or age were independent risk factors for declining an HIV test. Women attending hospital B were 1.56 times more likely to decline an HIV test compared with women attending hospital A (95 per cent CI 1.16–2.11). Jewish women were 2.93 times more likely to decline an HIV test than women of Roman Catholic affiliation (95 per cent CI: 1.84–4.64). The odds of declining an HIV test increased three-fold for each additional screening test declined. For each additional child the odds of declining an HIV test increased by 1.19 (95 per cent CI: 1.10–1.25). Women who had been tested for HIV before were 1.70 times more likely to decline than those who had not (95 per cent CI: 1.30–2.23). There was a significant interaction ($p < 0.0001$) between parity and previous testing for HIV. If women had not been tested before there was no relationship between increasing parity and declining an HIV test, but if women had been tested for HIV

### Table 1 Independent predictors of women declining an antenatal HIV test*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Decliners N (per cent)</th>
<th>Acceptors N (per cent)</th>
<th>Odds ratio (95 per cent CI)</th>
<th>p-value§</th>
<th>Odds ratio (95 per cent CI)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A</td>
<td>98 (11)</td>
<td>794 (89)</td>
<td>Reference</td>
<td>&lt;0.0001</td>
<td>Reference</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>B</td>
<td>147 (15)</td>
<td>808 (85)</td>
<td>1.47 (1.12, 1.94)</td>
<td></td>
<td>1.56 (1.16, 2.11)</td>
<td></td>
</tr>
<tr>
<td>C</td>
<td>156 (18)</td>
<td>707 (82)</td>
<td>1.78 (1.36, 2.35)</td>
<td></td>
<td>2.05 (1.53, 2.76)</td>
<td></td>
</tr>
<tr>
<td>Religious group:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>RC†</td>
<td>47 (11)</td>
<td>391 (89)</td>
<td>Reference</td>
<td>&lt;0.0001</td>
<td>Reference</td>
<td>0.002</td>
</tr>
<tr>
<td>None</td>
<td>97 (13)</td>
<td>660 (87)</td>
<td>1.22 (0.84, 1.77)</td>
<td></td>
<td>1.31 (0.89, 1.94)</td>
<td></td>
</tr>
<tr>
<td>Christian</td>
<td>38 (13)</td>
<td>244 (87)</td>
<td>1.30 (0.82, 2.05)</td>
<td></td>
<td>1.38 (0.85, 2.24)</td>
<td></td>
</tr>
<tr>
<td>C.of E‡</td>
<td>45 (14)</td>
<td>287 (86)</td>
<td>1.30 (0.84, 2.02)</td>
<td></td>
<td>1.23 (0.78, 1.96)</td>
<td></td>
</tr>
<tr>
<td>Hindu</td>
<td>9 (15)</td>
<td>53 (85)</td>
<td>1.41 (0.66, 2.05)</td>
<td></td>
<td>1.73 (0.78, 3.82)</td>
<td></td>
</tr>
<tr>
<td>Muslim</td>
<td>80 (16)</td>
<td>408 (84)</td>
<td>1.63 (1.11, 2.40)</td>
<td></td>
<td>1.50 (1.00, 2.26)</td>
<td></td>
</tr>
<tr>
<td>Jewish</td>
<td>65 (33)</td>
<td>134 (67)</td>
<td>4.04 (2.64, 6.16)</td>
<td></td>
<td>2.93 (1.84, 4.64)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>20 (13)</td>
<td>132 (87)</td>
<td>1.26 (0.72, 2.20)</td>
<td></td>
<td>1.51 (0.84, 2.71)</td>
<td></td>
</tr>
<tr>
<td>Previous testing:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>149 (14)</td>
<td>935 (86)</td>
<td>Reference</td>
<td>&lt;0.0001</td>
<td>Reference</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>Yes</td>
<td>151 (22)</td>
<td>521 (78)</td>
<td>1.82 (1.42, 2.34)</td>
<td></td>
<td>1.70 (1.30, 2.23)</td>
<td></td>
</tr>
<tr>
<td>Missing</td>
<td>101 (11)</td>
<td>853 (89)</td>
<td>0.74 (0.57, 0.97)</td>
<td></td>
<td>0.72 (0.54, 0.96)</td>
<td></td>
</tr>
<tr>
<td>Parity (per additional child)</td>
<td>NA</td>
<td>NA</td>
<td>1.30 (1.21, 1.39)</td>
<td>&lt;0.0001</td>
<td>1.19 (1.10, 1.29)</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>Week (per 5 weeks later)</td>
<td>NA</td>
<td>NA</td>
<td>1.17 (1.07, 1.27)</td>
<td>0.001</td>
<td>1.13 (1.03, 1.25)</td>
<td>0.012</td>
</tr>
<tr>
<td>Declined other tests</td>
<td>NA</td>
<td>NA</td>
<td>3.27 (2.61, 4.10)</td>
<td>&lt;0.0001</td>
<td>3.10 (2.44, 3.93)</td>
<td>&lt;0.0001</td>
</tr>
</tbody>
</table>

*Non-significant variables in multivariable analysis not shown.
†Roman Catholic.
‡Church of England.
§p-values for variables over several levels are global p-values.
the odds of declining an HIV test increased with each child (OR: 1.50; 95 per cent CI 1.24–1.81).

**Discussion**

In this audit of screening for HIV in early pregnancy in inner north London we found high rates of acceptance of HIV testing, however there was an important minority of women (15 per cent) who chose to decline an HIV test. Two-thirds of these women who declined accepted every other antenatal screening test.

Audit forms were completed for only 76 per cent of women attending during the audit period. This was mainly because of low participation by midwives at some sites in the early stages. The possibility that audit forms were more likely to be completed (or not completed) because women either accepted or declined cannot be excluded. However, we obtained no evidence that midwives were behaving in this way.

The strongest risk factors for declining an HIV test were parity and previous testing. Seventy-eight percent of the 401 women who declined an HIV test had either been tested for HIV in the past or had a child previously. Only 87 (22 per cent) had neither been tested for HIV or had a child before. Women were more likely to decline an HIV test with each additional child they had. Age was not an independent risk factor and parity probably accounted for the observed relationship between age and HIV test acceptance (96 per cent of 15–19-year-olds accepted an HIV test compared with 78 per cent of women 40 years or over). The effect of parity was much stronger in women who have been tested for HIV before this pregnancy compared with women who have never received an HIV test. Women who have had more children and have been tested for HIV in the past may be more confident of their HIV status. Women who have had more children may be in a more stable relationship, may be more confident of the processes of antenatal care and are more prepared to decline testing.

Another strong risk factor for declining an HIV test was Jewish religious affiliation. Jewish women made up 7 per cent of our sample and 16 per cent of women who declined an HIV test. There are strong orthodox and non-orthodox Jewish communities in North London. Jewish women have not to our knowledge been identified to be at higher risk of HIV infection and may be at much lower risk.

Women from sub-Saharan Africa made up just over 10 per cent of the women in our sample but were of much greater concern because the high number of HIV-infected children born to women of Black African origin in London.² It is reassuring that women of sub-Saharan African origin declined an HIV test with almost exactly the same frequency (14 per cent) as women born in the United Kingdom (15 per cent) (data not shown). Although some have argued that this is a sign of failure; given that in London this is the group that is at particularly high risk.¹⁰

We found limited evidence that institutional factors explained part of the variation in HIV uptake. There were small differences (range 7 per cent) in uptake between the three hospitals. The odds of declining a test were 1.6 times higher at the hospital with the lowest uptake after adjustment. Differences in uptake between units¹⁰,¹¹ and between midwives¹²,¹³ have been highlighted before.

In conclusion, a significant minority of women in three inner London hospitals declined antenatal HIV screening. These women were generally of higher parity. They may have been at lower rather than higher risk of being HIV positive. As the proportion of women who have had an HIV test in a previous pregnancy becomes higher as antenatal testing improves, then it is possible that a higher proportion of women will decline an HIV test. It may be precisely because women are more educated about HIV infection than other transmissible agents (hepatitis B, rubella, syphilis) that they feel more confident that they are at low risk and are more likely to decline testing. If pregnant women are well educated about HIV and have well-founded confidence of their HIV status then 10–20 per cent of women declining an HIV test may be entirely reasonable and may not lead to women missing out on the benefits of diagnosis. Further research will be needed to identify the precise reasons why women are declining antenatal HIV tests and what may increase uptake. This research is less urgent if women who decline are at low risk and their confidence in their negative status is well-placed, however, if anonymous unlinked surveillance and confidential linked reporting indicate that substantial numbers of women in London continue to term with undiagnosed HIV infection, then other approaches to antenatal HIV testing may need to be considered.

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**Author contributions**

S.J.C. wrote the paper and oversaw analysis, writing and production of the report (which formed the basis of the paper), U.H. assisted with design of the audit, distributed, collected, entered and analysed audit data, wrote the original report and commented on the paper, P.W. supervised U.H. during the audit and contributed to designing the audit, writing the report and the paper, L.S. contributed to writing, drafting, completion and interpretation of the report and the paper, worked on the steering group, gained support for the initiation of research and initial
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9 NHS Executive. Reducing mother to baby transmission of HIV. Health Service Circular 1999/183.


