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ATTITUDES ABOUT PRENATAL HIV TESTING IN TURKEY

Nermin Ersoy and Aslıhan Akpınar

Key words: attitudes about prenatal HIV testing; clinical ethics; disclosure; opt-in testing; opt-out testing; prenatal HIV testing

The aim of this study was to assess the attitudes of Turkish pregnant women and antenatal health care providers towards prenatal HIV testing. A self-administered questionnaire was used. The relationships between the different groups' knowledge and attitudes were analysed by using the chi-squared statistic. A total of 494 pregnant women and 181 care providers participated. Forty-four per cent of the pregnant women thought that prenatal HIV testing should be mandatory, and 84% of the health care providers thought it should be performed routinely or be mandatory. The majority of the pregnant women (74%) and half of the care providers agreed that the test results should be disclosed first to the pregnant woman. The study results also revealed that most of the prenatal care providers would not protect pregnant women's autonomy and privacy, contrary to the pregnant women's own preferences. It is essential to establish national prenatal HIV testing policies in order to prevent unethical practices and ensure satisfaction for pregnant women and health care providers.

Introduction

The main purpose of HIV testing during pregnancy is to prevent any possible infection being passed on to the unborn child. Mother to child transmission can occur during pregnancy, labour and birth, or through breastfeeding. However, with appropriate treatment and management, the chances of a child becoming HIV positive can be decreased. In areas where antiretroviral therapy is available, testing in pregnancy also allows a mother’s infection to be identified and treated.1,2

In Turkey, prenatal HIV tests are conducted in all hospitals and in primary health centres without women’s consent or even informing them, even though they must pay the test fee. However, in Turkey in 2006, there were 1662 men and 750 women living with HIV/AIDS and 41 infected babies. The mother to baby transmission rate was 1.7% between 1985 and 2004.3–8

The burden and cost of testing pregnant women is high for individuals and society.6,9 For example, in Turkey, apart from legally mandatory HIV testing, 1 857 209 tests were performed for unknown reasons in 2005. Most of these were probably...
prenatal tests or routine testing prior to surgery. Only 186 of these tests were positive. In the town of Kocaeli alone, 57 720 tests were performed, with no positive results.5

According to the Joint United Nations Programme on HIV/AIDS, countries like Turkey may not have an adequate level of pre- and post-test counselling services, and there is limited opportunity for free antiretroviral treatment for mothers and babies. Legal regulations to deal with the psychological, social and economic burdens on infected mothers and babies are also not well established.6

The objective of routine HIV testing has also been criticized because of discrimination against HIV positive pregnant women who cannot afford the treatment; this stigmatization can result in breaches of their autonomy and privacy.10

For this reason, it is recommended that each country should declare criteria for prenatal HIV testing according to the prevalence of AIDS in their country and then establish policies that should consider pregnant women’s individual right of decision making, their willingness and their privacy and safety, and should also protect them from discrimination and stigmatization.6,10,11

This study was designed to obtain verifiable data about attitudes and preferences of pregnant women and prenatal care providers towards prenatal HIV testing.

Materials and methods

Setting

The city of Kocaeli (total population 1 206 085 and annual birth rate 14.02‰ in 2005)12 is near Istanbul and one of the most industrialized areas in Turkey. This study was conducted in this location because people have settled there from other regions of the country13 and the city is among the 10 with the highest prevalence of HIV/AIDS in Turkey.5 Five primary health centres that have a high birth rate, and eight hospitals with antenatal care units were chosen for the study. Questionnaires were given to pregnant women between September and December 2003, and to antenatal health care professionals between January and February 2004.

Participants

The study participants were healthy pregnant women (n = 494) receiving routine prenatal care, and physicians, midwives and nurses (n = 181) who were regularly examining pregnant women at these centres and maternity, university and state hospitals. The participation rate for prenatal care providers and pregnant women were 95% and 98%, respectively.

Materials

The self-administered questionnaire consisted of questions on preferences and attitudes about prenatal HIV testing and on participants’ sociodemographic characteristics. After being informed about the survey, the volunteers were left alone to answer the questionnaire. The study was approved by the Ethics Committee of Kocaeli University. The differences between attitudes and preferences of the participants were analysed using the chi-squared test.

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Findings

Of the total of 675 participants, 27% \( (n = 181) \) were prenatal care providers (i.e. midwives, nurses and physicians) and 73% \( (n = 494) \) were pregnant women.

Demographic characteristics of the groups

Pregnant women

The mean age of the pregnant women was 26.5 ± 5.3 years. Just over half of them had undergone primary education. The majority were multiparous and almost all of them were married (Table 1).

Prenatal care providers

Since prenatal and antenatal care is mostly provided by these professions, many of the participants were midwives (47.5%) and nurses (33%). Their mean age was 32.6 ± 8.2 (Table 1); 23% worked in primary health centres and 77% worked in hospitals.

Disease and HIV test knowledge and HIV test experience

Forty per cent of the pregnant women and 85% of the prenatal care providers declared that they had adequate information about HIV/AIDS and HIV testing. As expected, statistically significant relationships were observed between the pregnant women’s and the health care providers’ answers (Table 2). Only 7% of the care providers and 2% of the women who did not have adequate information about disease and testing had

<table>
<thead>
<tr>
<th>Table 1</th>
<th>Participants’ characteristics ( (n = 675) )</th>
</tr>
</thead>
<tbody>
<tr>
<td>Characteristic</td>
<td>Pregnant women: no. (%)</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>494 (100.0)</td>
</tr>
<tr>
<td>Age (years)</td>
<td></td>
</tr>
<tr>
<td>≤ 30</td>
<td>381 (77.1)</td>
</tr>
<tr>
<td>&gt; 30</td>
<td>113 (22.9)</td>
</tr>
<tr>
<td>Married</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>492 (99.6)</td>
</tr>
<tr>
<td>Child(ren)</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>314 (63.6)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>≤ 5 years</td>
<td>271 (54.8)</td>
</tr>
<tr>
<td>11 years</td>
<td>175 (35.4)</td>
</tr>
<tr>
<td>Higher education</td>
<td>48 (9.7)</td>
</tr>
<tr>
<td>Profession</td>
<td></td>
</tr>
<tr>
<td>Midwives</td>
<td>86 (47.5)</td>
</tr>
<tr>
<td>Nurses</td>
<td>60 (33.1)</td>
</tr>
<tr>
<td>Physicians</td>
<td>35 (19.3)</td>
</tr>
</tbody>
</table>

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experienced an HIV test. In addition, most of the pregnant women agreed that ‘all pregnant women should be informed about HIV/AIDS testing’.

**Practices of prenatal care providers**

More than half of the midwives, nurses and physicians recommended HIV testing, invariably during routine prenatal visits, and a quarter of them recommended such testing if there was a high risk of infection. Nearly 10% of them recommended testing of pregnant women on demand, and 11% never recommended an HIV test.

**Attitudes to prenatal HIV testing**

Different preferences were shown between the two groups concerning the approach taken to HIV testing. The largest group of pregnant women agreed that HIV testing should be mandatory for pregnant women (44%); however, the prenatal care providers thought mostly that it should be either a routine part of prenatal care (45%) or mandatory (39%) (Table 3).

**Voluntary HIV testing (opt-in)**

Very few prenatal care providers (7%) agreed with voluntary prenatal HIV testing for pregnant women after counselling. However, nearly a quarter (24%) of the pregnant women did agree with this suggestion, resulting in a significant difference between the two groups ($P < 0.001$) (Table 3).

The prenatal care providers who preferred voluntary prenatal HIV testing emphasized that ‘the test should be conducted voluntarily for pregnant women after pretest counselling in order to prevent significant worry’. However, those who were against voluntary HIV testing were concerned that ‘pregnant women would not like to be tested when it was left to their preference’.

**Table 2** Groups’ information about HIV/AIDS and HIV test experience

<table>
<thead>
<tr>
<th></th>
<th>Prenatal care providers: no. (%)</th>
<th>Pregnant women: Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Having adequate information about HIV/AIDS</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>154 (85.1)</td>
<td>197 (39.9)</td>
</tr>
<tr>
<td>No</td>
<td>27 (14.9)</td>
<td>297 (60.1)</td>
</tr>
<tr>
<td>Total</td>
<td>181 (100.0)</td>
<td>494 (100.0)</td>
</tr>
<tr>
<td><strong>HIV test experience</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>111 (61.3)</td>
<td>81 (16.4)</td>
</tr>
<tr>
<td>No</td>
<td>70 (38.7)</td>
<td>413 (83.6)</td>
</tr>
<tr>
<td>Total</td>
<td>181 (100.0)</td>
<td>494 (100.0)</td>
</tr>
</tbody>
</table>
Nearly all the care providers (91%) and a large majority of the pregnant women (79%) did not think that prenatal HIV tests should be given only to pregnant women who are in high risk groups (Table 3).

**Mandatory HIV testing**

Although a quarter of the pregnant women expressed that they had no opinion on this issue, mandatory prenatal HIV testing was their most frequent preference (44%), but it was the second preference for the prenatal care providers (39%) (Table 3). The reasons given for the pregnant women’s choice were, for example: if the test is not mandatory many women will forgo testing; or the woman has no other chance to learn her HIV status; or it is possible to save the life of the mother and the baby. The prenatal care providers proposed that their main reason is to protect themselves, the other patients and the baby.

**Preferences about disclosure of HIV status**

The majority of the pregnant women (74%) and half of the prenatal care providers (50%) thought that positive test results should be disclosed to pregnant women first ($P < 0.001$) (Table 4). The pregnant women’s desire to be the first to learn the results increased with their level of education ($P = 0.009$) and knowledge about HIV/AIDS testing ($P = 0.006$).

A significant difference was observed among the various groups of prenatal care providers. Although a majority of nurses and midwives (49% and 60%, respectively) thought that positive results should be disclosed first to pregnant women, 37% of the physicians would prefer to disclose the results only to a public authority ($P = 0.004$).

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**Table 3** Attitudes towards prenatal HIV test

<table>
<thead>
<tr>
<th>Prenatal HIV test</th>
<th>Prenatal care providers: no. (%)</th>
<th>Pregnannt women*: no. (%)</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Should be part of other routine prenatal tests</td>
<td>82 (45.3)</td>
<td>Not asked</td>
<td>–</td>
</tr>
<tr>
<td>Should be mandatory for all pregnant women</td>
<td>70 (38.7)</td>
<td>217 (43.9)</td>
<td>Not significant</td>
</tr>
<tr>
<td>Should be mandatory only for pregnant women in high risk groups</td>
<td>17 (9.4)</td>
<td>104 (21.1)</td>
<td>$\chi^2 = 58.959; df = 2; P &lt; 0.001$</td>
</tr>
<tr>
<td>Should be applied voluntarily to pregnant women after test counselling</td>
<td>12 (6.6)</td>
<td>118 (23.9)</td>
<td>$\chi^2 = 94.441; df = 2; P &lt; 0.001$</td>
</tr>
<tr>
<td>Total</td>
<td>181 (100.0)</td>
<td>494 (100.0)</td>
<td></td>
</tr>
</tbody>
</table>

*a55 (11.1%) pregnant women did not answer these questions or stated that they did not know anything about this issue.
Attitudes about prenatal HIV testing in Turkey

The pregnant women who preferred non-disclosure of a positive result proposed that it could harm the health of the baby and the mother and thus it should be disclosed only after delivery. Similarly, the care providers thought that there is no need to worry the pregnant woman. The pregnant women who said there was no need to inform the partner were concerned about being ‘left with the baby’. On the other hand, some said that it should be disclosed to the partner because the woman might have the virus from her partner and he must explain the situation to her.

The majority of prenatal care providers (66%) and well over a third of the pregnant women (41%) preferred that the partner should be informed by the physician and the woman together. However, nearly a quarter of the pregnant women said that the partner should be informed only by the physician or he should be informed only by the pregnant woman ($P < 0.001$) (Table 5).

Table 4 If the HIV test result is positive, should it be disclosed to pregnant women first?

<table>
<thead>
<tr>
<th>Prenatal care providers: no. (%)</th>
<th>Pregnant women: no. (%)</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes 90 (49.7)</td>
<td>366 (74.1)</td>
<td>$\chi^2 = 82.955$; $df = 2; P &lt; 0.001$</td>
</tr>
<tr>
<td>No 91 (50.3)</td>
<td>128 (25.9)</td>
<td></td>
</tr>
<tr>
<td>Total 181 (100.0)</td>
<td>494 (100.0)</td>
<td></td>
</tr>
</tbody>
</table>

Table 5 Preferences about informing the pregnant woman’s partner about a positive HIV test result

<table>
<thead>
<tr>
<th>Prenatal care providers: no. (%)</th>
<th>Pregnant women: no. (%)</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Should be informed by pregnant woman alone 10 (5.5)</td>
<td>108 (21.9)</td>
<td>$\chi^2 = 58.512$; $df = 3; P &lt; 0.001$</td>
</tr>
<tr>
<td>Should be informed by pregnant woman and physician together 119 (65.7)</td>
<td>202 (40.9)</td>
<td></td>
</tr>
<tr>
<td>Should be informed by physician alone 13 (7.2)</td>
<td>112 (22.7)</td>
<td></td>
</tr>
<tr>
<td>Other (e.g. should be informed by legal authority; no need to inform the partner; I have no idea; or no answer) 39 (21.6)</td>
<td>72 (14.6)</td>
<td></td>
</tr>
<tr>
<td>Total 181 (100.0)</td>
<td>494 (100.0)</td>
<td></td>
</tr>
</tbody>
</table>
Discussion

Although half the women in Turkey are aged 15–44 years, their knowledge and experience of HIV testing of pregnant women is inadequate. However, Turkish care providers’ knowledge and HIV test experience is significantly higher (Table 2). In order to educate pregnant women effectively, health care providers require even more knowledge about HIV/AIDS testing and their ethical responsibilities. Training programmes should be developed because midwives, nurses and physicians have responsibilities to promote public knowledge and wellness, which is a stipulation in the International Council of Nurses’ Code of ethics for nurses.

In addition, pregnant women should be educated about disclosure to their partner and the obligatory reporting of test results to the relevant authority, as well as about the disease itself (as noted by 85% of the participants in the current study). For prenatal care providers, updating their level of knowledge on HIV/AIDS and HIV testing would facilitate protection of the health of families, other patients and themselves. This training should include ethical aspects.

In this study, nearly half the care providers recommended HIV testing during routine prenatal visits. However, some considered tests such as for hepatitis (in 2001, of 5578 hepatitis B cases, 53 were in newborns) to be more important than HIV.

There is no world-wide prenatal testing practice. Every country has different policies on this issue. However, whether or not there is a high infection rate, it is important to provide information about the disease and testing, including prevention and early diagnosis. For this reason, besides training programmes, pre- and post-test counselling should be available.

That HIV testing should be a routine part of the prenatal tests was the first preference for the care providers (Table 3). Although similar results have been shown in other studies, the routine prenatal HIV testing (the ‘opt-out’ approach) preferred by the care providers in the current study is of concern. Routine HIV testing could infringe pregnant women’s autonomy and privacy and violate justice; we thus believe that this approach could be justified only in countries with a high prevalence of HIV, but not in Turkey.

In this study, few care providers (7%) and only a moderate number of the pregnant women (24%) agreed with voluntary (opt-in) testing (Table 3). Several other studies have indicated that informing and counselling pregnant women about HIV testing increased the testing rates and that women indicated they would have opted for HIV screening if they had had more information. For this reason, the prenatal care providers’ negative attitude to voluntary testing is of concern. In addition, in European countries, agreement has been reached on obtaining explicit consent by using an opt-in approach and the requirement of providing detailed information.

It can be concluded that an opt-in approach would be suitable for implementation in Turkey because of the moderate prevalence of HIV/AIDS in our country and because the pregnant women wanted both information about the disease and HIV testing. In addition, voluntary prenatal HIV testing could promote the autonomy of pregnant women.

Although it is necessary to perform HIV tests in some high risk groups, the majority of both care providers and pregnant women did not agree greatly with the proposal that prenatal HIV testing should be only for high risk groups (Table 3).
In Canada, screening programmes have failed in high risk groups of pregnant women, and the American College of Obstetricians and Gynecologists’ (ACOG) opinions on risk factors are not always clear. In addition, the inclination of physicians not to use regular criteria of risk assessment supports suggestions that women should be encouraged to undergo an HIV test after they had been given information about its benefits and risks. The suggestion by the ACOG that prenatal care should include HIV screening is also important in Turkey because 74% of transmission occurs mainly by heterosexual intercourse and 1.2% by intravenous drug abuse, with 9.6% being of unknown cause in women. Thus, the responses of the pregnant women and the care providers in our study appear to be as might have been expected.

A mandatory prenatal HIV testing approach was the first choice for the pregnant women and second choice for the care providers. These results are in agreement with the preferences of members of the ACOG, the majority of whom opted for mandatory HIV testing ‘to decrease the transmission rate from mother to baby’. However, the ACOG, like the Turkish government, declared that applying mandatory testing was not ethical and suggested distributing HIV information to pregnant women. A mandatory prenatal HIV testing approach would infringe pregnant women’s autonomy and, also, it is not possible to justify such testing in pregnant women for whom antiretroviral therapy will not be available. In addition, because of the lack of counselling and the risk of discrimination and stigmatization, it would be harder to defend this approach in our country. In Turkey, mandatory HIV testing is implemented by law only for high risk groups (blood donors, sex workers, people entering compulsory military service, etc.), 8‰ of whom have been shown to be HIV positive. For this reason, the attitudes of the care providers participating in our study are of concern. The pregnant women’s positive attitudes to mandatory testing, which could violate their autonomy, were interesting. These could arise because of their willingness to have the opportunity of learning their HIV status.

In agreement with the midwives and nurses, the pregnant women said they would prefer to have a positive test result disclosed to themselves first, probably because this could be of benefit to themselves and their babies; however, the physicians indicated they would prefer to disclose the results first to the public authority.

Based on the duty to respect persons’ privacy, confidentiality and autonomy, HIV test results should be disclosed to pregnant women first, and then the women and their health care providers should decide how third parties will be informed of positive results. Our study revealed that the midwives’ and nurses’ preferences were in accord with these ethical duties. In Turkey it is mandatory to declare positive HIV test results to the public authority to assist in planning infection and test policies; however, the results should be disclosed to pregnant women first.

Concerning the final question on how the women’s partners should be informed of a positive result, there was a moderate tendency towards general agreement between the care providers and the pregnant women (Table 5). One fifth of the women said they would prefer to inform their partner by themselves alone. Their perceived courage to do this was probably based on their self-confidence because of a monogamous relationship, or perhaps they did not want to inform their partner at all.

The prenatal care providers’ response that the partner should be informed by the legal authorities cannot be justified as an ethical and legal duty because to protect third parties’ interests is the physician’s primary responsibility and cannot be assigned to another.
Conclusions

In Turkey, routine prenatal HIV testing practices create ethical and legal problems. In the current study most of the care providers supported a system of opting out of prenatal testing. Most of the pregnant women were not well informed about HIV/AIDS during pregnancy and were not offered an HIV test. However, they claimed to be informed about the disease and testing, and said they would wish a positive HIV test result to be disclosed first to themselves personally.

In general, although all those involved are agreed on the goal of reducing prenatal HIV transmission, there is no agreement about how to protect pregnant women's autonomy and their right to give informed consent, or how to prevent discrimination and their possible stigmatization and ensure the confidentiality of test results.\textsuperscript{44} In Turkey, the lack of HIV test counselling services, free treatment opportunities for women, funds for third parties' test fees, and adequate measures to prevent social discrimination against mothers and babies are additional problems.

Recommendations

Primarily it should be ensured that pregnant women are informed about AIDS and HIV testing and that preventive methods should be put in place (especially for averting transmission from mother to baby, for example, by avoiding breast feeding). Counselling services should be established and written information prepared for both pregnant women and health care personnel.

The differences in the responses of the participant pregnant women and their prenatal care providers, especially concerning the opt-in approach and disclosure of positive HIV test results, lead us to suggest that Turkish national policies on this issue should be developed as soon as possible with the support of the Health Ministry and the national medical associations. Such national policies should protect the autonomy and privacy of pregnant women and prevent discrimination against and stigmatization of their babies. In addition, ethics training programmes for care providers should be planned.

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