Women’s Perceptions of the Opt-Out Approach to HIV Testing During Pregnancy

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Linda S. Podhurst, Ph.D

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Objectives

- To describe the differences between the opt-out and opt-in approaches to HIV testing during pregnancy

- To present data on the impact of these approaches on HIV testing during pregnancy
Objectives

- To present data on women’s perceptions of HIV testing and methods for obtaining consent
- To discuss recommendations and next steps based on women’s perceptions
Prenatal HIV Testing Policies

- **Opt-in**
  - Pre-test counseling and written consent specifically for an HIV test

- **Opt-out**
  - Notification that HIV test will be routinely performed unless it is refused
Background

- **1995**
  USPHS recommends HIV counseling for all pregnant women and encourages HIV testing

- **1998**
  IOM report recommends opt-out approach to HIV testing for pregnant women
Background

- 2001

USPHS strengthens recommendation for routine HIV testing for pregnant women
  - Simplify HIV testing process
  - Allow for various types of informed consent
  - Providers address reasons for refusal of testing
Background

- 2003
  USPHS initiative
  Advancing HIV Prevention: New Strategies for a Changing Epidemic
  - recommends opt-out approach for prenatal HIV testing
Rationale

- Increasingly effective interventions to prevent perinatal HIV transmission
  - Without medical intervention, risk of transmission is about 25%
  - With combination ARVs, risk of transmission is 2% or less
Rationale

- Comparison of increased HIV testing rates during pregnancy using opt-out vs. opt-in approach
Comparison Data
Opt-out vs. Opt-in

- **Canada**
  - Provinces with opt-out testing reported 94% and 98% testing rates compared to 54%, 80% and 83% in provinces with opt-in policy

- **U.S.**
  - States with opt-out testing reported 71% and 85% testing rates compared to 25% and 69% in states with opt-in policy

MMWR 11/15/02
Purpose of study

- To learn about women’s opinions on HIV testing and methods for obtaining consent
  - How do women feel about routine HIV testing during pregnancy?
  - Do women feel that special consent is necessary before HIV testing?
Methods

- One-page anonymous survey in English and Spanish to assess
  - Women’s opinions about elements of opt-out approach
  - Reported knowledge about pregnancy and HIV transmission
  - Amount of information available about HIV and pregnancy
- UMDNJ Institutional Review Board approved survey, cover letter and advertising flyer
Methods

- Target population
  - Women of childbearing age (18-45), pregnant and non-pregnant women of differing HIV status

- Site selection
  - Title IV/DTTA staff recommended sites with geographic and demographic diversity
Data Analysis

- Participant and site characteristics
- Associations among opinions, reported knowledge, site and participant characteristics
Survey Sites

- Albany, NY
- Casper, WY
- Chicago, IL
- Detroit, MI
- Hattiesburg, MS
- Mayaguez, Puerto Rico
- New York City, NY
- Newark, NJ
- Tampa, FL
Site Characteristics

- 6 community health centers
- 3 community health clinics with case management services
- OB/GYN clinic
- Support group
- Internal medicine/pediatric clinic
- Doctor’s office
Site Characteristics

- 6 urban sites
  - 73% of surveys
- 3 rural sites
  - 27% of surveys
On-Site Survey Distribution

- Women were given cover letter, notified of survey and asked to fill out questionnaire
- Secure survey box provided for completed surveys
- Site representative responsible for distributing and returning surveys to National Resource Center
- 857 completed surveys were analyzed
Results

- Participant characteristics
- Opinions on HIV testing during pregnancy and consent
- Reported knowledge on HIV transmission
- Associations between opinions, knowledge and participant characteristics
Participant Demographics

Race/Ethnicity

% of respondents

- Black
- Hispanic
- White
- Other/NR

N = 857
Participant Demographics

Age

% of respondents

N = 857
## Participant Characteristics

<table>
<thead>
<tr>
<th>Category</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Language</strong></td>
<td>- 73% English</td>
</tr>
<tr>
<td></td>
<td>- 27% Spanish</td>
</tr>
<tr>
<td><strong>HIV Status</strong></td>
<td>- 75% HIV-negative</td>
</tr>
<tr>
<td></td>
<td>- 7% HIV-positive</td>
</tr>
<tr>
<td></td>
<td>- 13% Never been tested</td>
</tr>
<tr>
<td></td>
<td>- 5% Did not report status</td>
</tr>
<tr>
<td><strong>Pregnancy Status</strong></td>
<td>- 36% Pregnant or gave birth recently</td>
</tr>
<tr>
<td></td>
<td>- 56% Not pregnant</td>
</tr>
<tr>
<td></td>
<td>- 9% Not reported</td>
</tr>
</tbody>
</table>
## HIV Testing During Pregnancy

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>Not Sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you feel comfortable being tested for HIV during pregnancy?</td>
<td>90%</td>
<td>5%</td>
<td>4%</td>
</tr>
<tr>
<td>Should HIV testing be part of a routine pregnancy check-up?</td>
<td>88%</td>
<td>3%</td>
<td>7%</td>
</tr>
</tbody>
</table>
Sample write in comments

Yes, HIV testing should be part of a routine pregnancy check-up

- “If you can stop transmission to the unborn baby, why not?”
- “Most of the time the moms have no idea that they can affect their baby or if they are infected”
- “For your baby!”
No, HIV testing should NOT be part of a routine pregnancy check-up

- “Monogamous relationship shouldn’t have to have testing”
- “Could be very upsetting”
- “May be an invasion of privacy”
Consent for HIV Testing

Do you think it is OK to test for HIV during pregnancy without getting special consent for the HIV test?

- Yes 44%
- No 47%
- Not sure 7%
HIV Testing During Pregnancy

Comfortable with HIV testing

OK to test without special consent

Testing should be routine

- Yes
- No
- Not Sure
HIV Status and Consent for HIV Testing

<table>
<thead>
<tr>
<th>HIV Status</th>
<th>% of Respondents</th>
<th>OK to Test w/Out Special Consent</th>
<th>Not OK to Test w/Out Special Consent</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV-Positive</td>
<td>28</td>
<td>31</td>
<td></td>
</tr>
<tr>
<td>HIV-Negative</td>
<td>301</td>
<td>290</td>
<td></td>
</tr>
<tr>
<td>Never Been Tested</td>
<td>38</td>
<td>59</td>
<td></td>
</tr>
</tbody>
</table>
Characteristics NOT Associated with Opinions on Special Consent

- Age
- Pregnancy
- Race/ethnicity
- Having children

- Reported knowledge
- Receipt of information
- Language of survey
## Information Available

### Have you received information on the types of blood tests done during pregnancy?
- Yes: 59%
- No: 28%
- Don’t know: 11%
- Did not report: 2%

### Was information on HIV included?
- Yes: 55%
- No: 20%
- Don’t know: 15%
- Did not report: 9%
<table>
<thead>
<tr>
<th>Is enough information about HIV and pregnancy available to women?</th>
<th>Yes</th>
<th>45%</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No</td>
<td>34%</td>
</tr>
<tr>
<td></td>
<td>Don’t know</td>
<td>19%</td>
</tr>
<tr>
<td></td>
<td>Did not report</td>
<td>2%</td>
</tr>
</tbody>
</table>
Language and Information *

Is enough information available?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Not Sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>English</td>
<td>263</td>
<td>225</td>
<td>132</td>
</tr>
<tr>
<td>Spanish</td>
<td>124</td>
<td>68</td>
<td>30</td>
</tr>
</tbody>
</table>

*p < 0.001
# Knowledge about HIV and Pregnancy

<table>
<thead>
<tr>
<th></th>
<th>% correct</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Women can get HIV by using public toilets</td>
<td>92</td>
</tr>
<tr>
<td>2. Women can give HIV to their babies during pregnancy</td>
<td>81</td>
</tr>
<tr>
<td>Knowledge about Perinatal HIV Transmission</td>
<td>% correct</td>
</tr>
<tr>
<td>------------------------------------------</td>
<td>-----------</td>
</tr>
<tr>
<td>3. Women can give HIV to their babies during delivery</td>
<td>64</td>
</tr>
<tr>
<td>4. Women can give HIV to their babies through breastfeeding</td>
<td>62</td>
</tr>
<tr>
<td>5. There are medicines that can help keep newborn babies from getting HIV when the mother is HIV-positive</td>
<td>61</td>
</tr>
</tbody>
</table>
Knowledge about HIV

% of respondents

Number of questions answered correctly

1 2 3 4 5
<table>
<thead>
<tr>
<th>Percentage of women who answered four or five questions correctly</th>
<th>Number of clinics</th>
</tr>
</thead>
<tbody>
<tr>
<td>80% or more</td>
<td>7</td>
</tr>
<tr>
<td>60%-79%</td>
<td>1</td>
</tr>
<tr>
<td>50%-60%</td>
<td>5</td>
</tr>
<tr>
<td>Less than 50%</td>
<td>1</td>
</tr>
</tbody>
</table>
### HIV Knowledge and Demographics

<table>
<thead>
<tr>
<th></th>
<th>Percentage with 4-5 correct responses</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age:</strong></td>
<td></td>
</tr>
<tr>
<td>18-24</td>
<td>55%</td>
</tr>
<tr>
<td>25-34</td>
<td>62%</td>
</tr>
<tr>
<td>35-45</td>
<td>68%</td>
</tr>
<tr>
<td><strong>HIV Status:</strong></td>
<td></td>
</tr>
<tr>
<td>Positive</td>
<td>79%</td>
</tr>
<tr>
<td>Negative</td>
<td>62%</td>
</tr>
<tr>
<td>Never tested</td>
<td>50%</td>
</tr>
<tr>
<td><strong>Language of Survey:</strong></td>
<td></td>
</tr>
<tr>
<td>English</td>
<td>68%</td>
</tr>
<tr>
<td>Spanish</td>
<td>41%</td>
</tr>
</tbody>
</table>

- **Age:** p < 0.05
- **HIV Status:** p < 0.01
- **Language of Survey:** p < 0.01
Summary of Study Findings

- Vast majority of women are comfortable with HIV testing during pregnancy, and believe that it should be a routine part of prenatal care.
- 47% of women felt it was not acceptable to test for HIV during pregnancy without getting special consent compared with 44% who felt it was acceptable.
Summary of Study Findings

- 41% of Spanish-speaking women answered 4 or 5 knowledge questions correctly, compared to 68% of English-speaking women.

- Spanish-speaking women were more likely to report that enough information was available about HIV and pregnancy.
Study Limitations

- “Opt-out” is an unfamiliar term so survey could not elicit opinions directly on the opt-out approach
- Survey was not designed to or determine the acceptable form of “special” consent
- No direct causative associations can be drawn between opinions and reported knowledge, demographic or site characteristics
Conclusions

- Specific populations may benefit from more information
  - Young women
  - Spanish-speaking women
  - Women who have never been tested
Conclusions

- Since most women felt that HIV testing during pregnancy should be routine, but fewer than $\frac{1}{2}$ of surveyed women felt comfortable getting tested without consent, support and educational materials should be developed to improve acceptability of opt-out approach.
Further Research

- Follow-up study to better understand what women mean by special consent for HIV testing during pregnancy
  - Survey
  - Focus group
Acknowledgments

- Funding for this survey was provided by the Health Resources and Services Administration, HIV/AIDS Bureau, Division of Training and Technical Assistance, Title IV Program to the HIV/AIDS National Resource Center at the Francois-Xavier Bagnoud Center
Acknowledgments

- Very special thanks to the---
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    - Sarah Dolgonos
    - Linda Podhurst, Ph.D.
    - Rianna Stefanakis
    - Deborah Storm, Ph.D.
    - Emily Zackin, MA
- Questions
- Comments
Opt-Out Case Studies
Theresa

- Theresa is 28 years old
- 15 weeks pregnant with her third child
- English is her second language
- Theresa’s family recently moved to the area, Theresa is new to the clinic
When Theresa comes to the clinic, the receptionist hands her a prenatal information packet.

It includes a list of routine blood tests performed during the first visit; HIV is on that list.

The packet mentions that most of the tests are voluntary.
Theresa is seen by a nurse, who says:

- “I see this is your third pregnancy, you’ve been through this before. Did you get a chance to look at the information packet? Do you have any questions?”

Theresa does not have any questions, the information packet and HIV are not mentioned any more.
Next, Theresa is seen by the doctor who goes over the information in the prenatal packet and says:

- “Let’s review the things that you can expect during your pregnancy, and what we can offer in the prenatal clinic. Unless you decline, we will do the routine prenatal blood tests.”
Jane

- Jane is 18 years old
- 20 weeks into her first pregnancy
- This is her first prenatal visit
In the waiting room, Jane watches a video on prenatal care.

The video covers information on HIV testing and mother-to-child transmission of HIV.

The video clearly explains why the HIV test is important.
The intake nurse mentions that blood will be drawn for routine blood tests.

The nurse asks Jane if she has any questions; Jane does not ask any questions or voice any concerns.
While drawing the blood, the nurse explains that the standard tests include hepatitis B, rubella, syphilis, HIV, blood type and others.

The nurse tells Jane that she can decline some of these tests but they are all recommended in pregnancy.
Mary

- Mary is 32 and 12 weeks pregnant
- Working professional
- Regular patient at the health center, which has an opt-in policy
- In the waiting room, Mary receives prenatal information packet which lists all routine blood tests; HIV is on that list
During the exam, the doctor skims Mary’s file, and says: “We have HIV testing available. If you think you need it, please sign the consent form.”
During the exam, the doctor tells Mary about HIV and the importance of HIV testing during pregnancy, and says that HIV testing is recommended for all pregnant women.

The doctor tells Mary that she should sign the HIV consent form if she would like to be tested.