Perinatal HIV testing among African American, Caucasian, Hmong and Latina women: exploring the role of health-care services, information sources and perceptions of HIV/AIDS

Perinatal HIV transmission disproportionately affects African American, Latina and potentially Hmong women in the United States. Understanding racially and ethnically diverse women’s perceptions of and experiences with perinatal health care, HIV testing and HIV/AIDS may inform effective health communications to reduce the risk of perinatal HIV transmission among disproportionate risk groups. We used a qualitative descriptive research design with content analysis of five focus groups of African American, Caucasian, Hmong and Latina women of reproductive age with low socioeconomic status distinguished by their race/ethnicity or HIV status. A purposive stratified sample of 37 women shared their health-care experiences, health information sources and perceptions of HIV testing and HIV/AIDS. Women’s responses highlighted the importance of developing and leveraging trusted provider and community-based relationships and assessing a woman’s beliefs and values in her sociocultural context, to ensure clear, consistent and relevant communications. Perinatal health communications that are culturally sensitive and based on an assessment of women’s knowledge and understanding of perinatal health and HIV/AIDS may be an effective tool for health educators addressing racial and ethnic disparities in perinatal HIV transmission.
predict reduced perinatal HIV transmission via perinatal antiretroviral treatment and other preventive measures [4, 5]. Perinatal HIV transmission rates were less than 2% when pregnant women with HIV received combined antiretroviral therapy during pregnancy [6, 7].

Medicaid increased access to perinatal care for low-income pregnant women [8]. This led many states to implement universal prenatal HIV testing via an opt-out approach, which tests women unless they request not to be tested, in order to increase perinatal HIV testing among women receiving prenatal care [5, 9, 10]. These policies have not eliminated racial and ethnic disparities in perinatal HIV transmission due to implementation challenges [8].

Racial and ethnic groups reported different barriers to initiating prenatal care beyond access to health insurance. African American women reported negative feelings about their pregnancy, lack of knowledge about pregnancy symptoms, delays in access to prenatal care appointments and disrespect from providers as barriers [11]. Latinas cited lack of knowledge about pregnancy symptoms, not knowing where to receive prenatal care, and lack of transportation as barriers [8]. Hmong women’s desire for privacy, value of self-care versus medical care, resistance to medical examination and difficulty with communication were said to inhibit their perinatal health care [12]. With the exception of lack of knowledge about pregnancy symptoms, these preliminary findings reveal potential racial and ethnic differences in barriers to prenatal care.

African American women identified fear, lack of confidentiality and stigma as barriers to routine perinatal HIV testing [13]. Latina women who declined perinatal HIV testing reported doing so because of how the provider asked them to take the test, belief that they did not or could not have HIV, and fear of the test results [8]. Women born outside the United States were more likely to decline perinatal HIV testing [14]. With the exception of fear, these preliminary findings suggest differences in barriers to perinatal HIV testing across racial and ethnic groups. In contrast, strong social support, knowledge of perinatal HIV transmission, positive feelings about prenatal HIV testing, provider endorsement of prenatal HIV testing [15] and positive patient–provider relationships and open communication [16] are associated with perinatal HIV testing among pregnant women across racial and ethnic groups with low incomes.

Experiences with health-care services, access to health-care information and perceptions of HIV/AIDS and related testing all affect women’s perinatal HIV testing decisions. We explored women’s perspectives on these factors together to inform comprehensive perinatal HIV testing communication. We included several racial and ethnic groups of women with low socioeconomic status and at risk of perinatal HIV transmission to allow for direct comparisons among groups affected by or at risk of disparities in perinatal HIV transmission.

Methods

Design and procedures

We used a qualitative descriptive research design [17] and focus groups to explore factors affecting the perinatal HIV testing decisions of racially and ethnically diverse women with low socioeconomic status at risk of sexually transmitted infections (STIs) and adverse perinatal outcomes. The university’s institutional review board approved the research protocol.

There were five focus groups; four with women who were HIV negative and one with women who were HIV positive. A purposive stratified sampling method [18] resulted in diversity in preselected variables of race/ethnicity, perinatal development and HIV status. Women were recruited for voluntary participation by social service providers serving low-income women with high-risk pregnancies in the two largest cities of a Midwestern state. Providers explained the purpose of the focus groups to their clientele and screened them for eligibility on a first-come, first-served basis using the following criteria: age 18 to 45 years; perinatal (pregnant or postpartum -up to 1 year following the delivery of an infant); self-identified as African American,
Caucasian, Hmong or Latina; and ability to speak English, Spanish or Hmong. Hmong women were included because of their lower rate of screening amid a growing risk of HIV infection in the state. All four providers recruited pregnant women who were HIV negative; one provider also recruited African American women living with HIV/AIDS.

Eight participants were outside the perinatal period. None of the five African American participants living with HIV were in the perinatal period because no such women were identified through the community partner. Three African American participants who were HIV negative were outside the perinatal period. We learned of this issue upon completion of their focus group, and these women were retained in the sample after confirming their reports were consistent with those of the other participants.

We collected data via semi-structured, open-ended focus group interviews [17] conducted at the community-based organizations between May and September 2010. Groups were organized by racial and ethnic identity and HIV status to facilitate open discussion [19] and data comparison. Participants provided written informed consent. Focus groups were audio recorded and lasted approximately 75–120 min. Participants selected pseudonyms to protect their identity. The first and second author led each focus group—the first author facilitated the research discussion and probed participants, and the second author took notes to capture nonverbal information and ensure comments were accurately attributed. Interpreters participated in the Hmong and Latina focus groups to provide Hmong-to-English and Spanish-to-English interpretation, respectively.

We asked open-ended questions that explored participants’ prenatal health information sources, their feelings during a typical prenatal health visit, their perceptions of perinatal HIV testing and their understanding of HIV/AIDS (see Appendix for focus group questions). We modified the interview for the focus group of women living with HIV who were outside the perinatal period. These participants were encouraged to share their thoughts or experiences with health care and services during pregnancy and after they gave birth. If they could not recall those experiences or did not have them, we asked for their current reflections or thoughts on these experiences if they or someone they knew and cared for was pregnant.

We used follow-up questions such as ‘Tell me more about what made you feel good about that visit to your doctor’ to increase the likelihood of gaining a complete and accurate understanding of experiences. This probing occurred until no new information resulted from it. Participants’ understanding of their perinatal experiences guided the discussion. The facilitators and the interpreters (when present) debriefed after each focus group. Notes and reflections were recorded in a journal throughout the research process to address any biases and their potential effect on the facilitation or interpretation of the discussion. Upon completion of the focus groups, individuals received $35 for their participation.

Analysis

Audio recordings of focus groups were transcribed verbatim and data was managed in QSR International’s N8 software [20]. Codes were identified inductively from the focus group data by topic or question. Significant statements were considered in the context of the focus group conversation to better interpret their meaning. The meaning of significant statements and phrases in each topical category was interpreted with attention to present or missing information and discrepancies [21]. These data-derived codes were applied systematically across focus group data [14]. Codes were grouped by emergent themes through a reflexive and interactive process that considered the manifest and latent content of the data [17]. Transcripts were reread multiple times to evaluate accuracy and fit of the identified themes to the coded statements. Decisions were documented in memos. Final themes were developed from coded statements that reached saturation in depth and breadth for each focus group. Themes were also compared across focus groups for additional insight. Participant
quotes were retained to allow for examination of language and to demonstrate the range and variation of data [21].

**Credibility of findings**

We employed several techniques to establish confidence in the truth of our findings [22]. Organizing focus groups by race/ethnicity and HIV status allowed us to evaluate the triangulation, or consistency, of our findings across different sources. The two researchers independently reviewed a cross-section of the transcripts, presented their themes to each other and came to a consensus on the final themes to counteract interviewer bias in analysis. Two study participants who participated in the focus groups reviewed preliminary themes for accurate representation of their personal and focus group experiences. Two interpreters reviewed the original interpretation of the Hmong and Spanish focus group content for accuracy and completeness. Both interpreters found most of the original interpretations to be accurate and provided full reinterpretation in the few cases of incomplete interpretation.

**Results**

Participants \( n = 37 \) ranged in age from 20 to 45 years \( M = 29 \). Most were 0–12 months postpartum \( n = 23 \), single \( n = 22 \), held a high school or equivalent degree \( n = 26 \), were unemployed \( n = 29 \) and had an annual family income of less than $9,000 \( n = 19 \). The majority \( n = 29 \) reported having been tested for HIV. Beyond race/ethnicity and HIV status, the focus groups differed in average age, perinatal development and average number of children at home. African American and Latina participants reported lower levels of employment and family income than Hmong and Caucasian women. Latina and Hmong participants reported lower levels of education than African American and Caucasian participants. Participants living with HIV were older, outside the defined perinatal period and provided unique insight; their results are presented separately. Table I summarizes participant demographics by focus group.

**Perspectives of women who are HIV negative**

**Experiences with health care during the perinatal period**

**Positive experiences.** Participants across focus groups expressed positive experiences with perinatal health care. Information on fetal development and physical well-being (nutrition, weight gain) and to a greater extent procedures (ultrasound, physical exams) reassured women that the pregnancy was progressing as expected. One Hmong participant stated, ‘I’m happy when they’re gonna do the ultrasound so I get to see my baby.’ A Caucasian participant described the reassurance gained from these procedures:

Telling you everything’s going to be OK when they do the blood work . . . and everything looks good, and that kinda helps you ‘cause you know at least . . . so far, everything’s good with the baby and so far there’s not any risks you have to worry about.

Participants across groups also shared examples of their positive provider relationships. They valued informative responses to their questions, prompt use of procedures and reliability. One Latina participant stated, ‘They do a good check-up. They examine you well. They ask questions and answer your questions and address your concerns.’ Participants also attributed less tangible characteristics to their providers—character, energy, personality and gestures of caring. Providers’ ability to make the women feel welcome and cared for as individuals contributed to positive experiences. An African American participant noted, ‘She [my obstetrician] was just wonderful—her personality and her character. She was just loving, and I, I mean she was just understanding, and wasn’t judgmental, or nothing like that. She, she made the office visit warm.’

**Negative experiences.** Negative experiences with perinatal health care were more diverse among participants in the African American, Hmong and Latina groups, whereas Caucasian participants identified the acknowledgement of their weight gain as the only negative. Latina and
Hmong participants noted invasive medical procedures as a primary negative of perinatal health care. Hmong participants revealed ongoing reconciliation between self-care and medical care. They reported difficulties adjusting from the independence and privacy of traditional Hmong perinatal care to the medical interventions and high level of provider involvement in the United States. A Hmong participant described why she was embarrassed when receiving perinatal health care in the United States: ‘Back in where we came from, you know, we kneeled down and have our baby and nobody sees, you know, us. And here in America, you know, we lay down in a bed and doctor [does] all these things.’

Issues of privacy related to language barriers represented a negative aspect of perinatal care for some Hmong participants. One participant stated her preference to interact directly with her provider, despite language barriers, and to avoid the obtrusive presence of an interpreter who stayed in the exam room when procedures such as pap smears were performed. She described her desire for privacy: ‘We don’t like...the interpreter seeing us [during the physical exam]...Yeah, so um, like Hmong people, they’re not like American people....They tell other people that, you know, this person is like this.’ She feared the interpreter would convey private information to members of her tight-knit community. Providing services in the patient’s primary language through an interpreter may conflict with the patient’s desire for privacy when discussing potentially sensitive, private and stigmatized topics such as HIV testing. Language issues were not raised in the Latina group, whose participants received services at a bilingual clinic and reported very few negative experiences.

African American women reported difficulty accessing services during pregnancy and the postpartum. One African American woman stated, ‘Waiting around. They backed up all day.’ A few African American participants reported obstacles to negotiating and scheduling tubal ligation (sterilization) and cesarean section procedures with their providers. One participant changed providers after being refused a tubal ligation, feeling that it was her choice. ‘My doctor told me she does do it but then she told me she would not do it for me because she didn’t want me to come back in 5 years and say I want more kids.’ These experiences impaired the development of positive interpersonal relationships with providers and trust in the respective clinics.

**Sources of information on perinatal health**

African American, Caucasian and Hmong participants identified family as a source of new health information. An African American participant said she sometimes resisted ‘old-school’ sources such as

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**Table I. Participant demographics by focus group**

<table>
<thead>
<tr>
<th>Variable</th>
<th>AA HIV-</th>
<th>Hmong HIV-</th>
<th>Latina HIV-</th>
<th>Caucasian HIV-</th>
<th>AA HIV+</th>
</tr>
</thead>
<tbody>
<tr>
<td>n</td>
<td>12</td>
<td>8</td>
<td>8</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Primary language, n</td>
<td>English</td>
<td>Hmong</td>
<td>Spanish</td>
<td>English</td>
<td>English</td>
</tr>
<tr>
<td>Pregnant, n</td>
<td>2</td>
<td>1</td>
<td>4</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Postpartum, n</td>
<td>7</td>
<td>8</td>
<td>4</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Neither pregnant nor postpartum, n</td>
<td>3</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>Ever tested for HIV, n</td>
<td>10</td>
<td>4</td>
<td>6</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Age, M (range)</td>
<td>27.8 (20–45)</td>
<td>24.6 (21–29)</td>
<td>31.6 (23–38)</td>
<td>21.8 (20–24)</td>
<td>38.4 (33–43)</td>
</tr>
<tr>
<td>Children at home, M (range)</td>
<td>2.25 (0–6)</td>
<td>3.25 (1–5)</td>
<td>2.75 (2–6)</td>
<td>1.75 (1–4)</td>
<td>2.60 (0–5)</td>
</tr>
<tr>
<td>Married, n</td>
<td>0</td>
<td>8</td>
<td>4</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>High school education, n</td>
<td>9</td>
<td>5</td>
<td>4</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Employed (at least part-time), n</td>
<td>1</td>
<td>3</td>
<td>1</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>AFI &lt; $9,000, n</td>
<td>11</td>
<td>1</td>
<td>4</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

*Note.* AA = African American; AFI = annual family income.
‘grandparents, great-grandparents, or moms and dads’, but added that ultimately ‘they help you and they got a lot of knowledge.’ Caucasian participants contrasted the experiential wisdom of mothers to peer support provided by sisters, but valued both perspectives. However, one Caucasian participant stated, ‘I would ask my mother-in-law before I would ask somebody my age. ... They’ve already learned, you know, what to do, what was best.’

Providers were a source of new information across groups. Caucasian women highlighted their providers as their primary and most trusted source of information. One woman described, ‘[my doctor] has been with me for all four pregnancies... so she knows my history, she knows... my specific needs.’ A Hmong participant noted information from doctors was preferred to information from family because of the lack of prenatal care in her country of origin, ‘when we get here in America, you know, the older generation, they don’t know what to do, so, whatever the doctor said, you know, that’s what mainly we do’. Hmong, Caucasian and African American women valued written materials from providers to raise their awareness and processing of health information.

Participants in the African American, Caucasian and Latina focus groups obtained information from community resources. African American participants accessed the broadest range of community resources, including the Women, Infants, and Children (WIC) program, social service programs and prenatal care coordination programs. They valued the instrumental and sustained support of these programs. One African American participant stated, ‘Prenatal care coordination program. Yeah... they help you get a car seat, they, you know, continue to stick with you till the child is a certain age.’ Latina and Caucasian participants spoke more generally about the services provided by the community, which were not referenced by Hmong participants. The greater relative socioeconomic disadvantages experienced by African American women (lower income and lower rates of employment) may account for their greater use of community resources.

Perceptions of perinatal HIV testing

Opportunities. Participants across focus groups supported HIV testing. Hmong participants perceived the perinatal period as an opportune time for testing. A Hmong participant explained, ‘If you’re not pregnant, then you wouldn’t go for a medical exam or things like that. But when you’re pregnant, and you go in and they check you and everything is fine, then it’s good.’

Women’s lack of confidence in their partners’ report of sexual behaviors outside their relationship motivated HIV testing across all groups. A Caucasian woman explained that partners may not disclose their HIV or testing status: ‘Because you don’t know if your partner is being honest about what they contracted... they could be lying about having ever gotten tested.’ Women cited possible infidelity as a motivator for HIV testing. A Latina participant said, ‘You don’t know what our husbands are doing and so I want to know.’ A Hmong participant echoed this sentiment: ‘It’s a good thing that they [test] because you don’t know if your husband is faithful to you.’

Caucasian participants also discussed social responsibility. One Caucasian participant stressed the necessity of perinatal HIV testing to identify cases of HIV that otherwise would be missed for women engaged in high-risk sexual behaviors. She stated, ‘If she gets pregnant, then thank God she has to get tested for HIV and she had to be notified about it. I do think it’s necessary for the health of her and her baby and other people.’

Participants across focus groups also valued perinatal HIV testing as a preventive measure for fetal and infant health. One Caucasian participant stated, ‘It’s just nice to know they [test] ‘cause it... helps not only you but it helps the baby, so that if there is something wrong they can catch it and try and help it early on.’ An African American participant reported experiencing premature labor as the result of not testing for other STIs. Another African American participant avoided an adverse birth outcome by testing for STIs:

It’s good to know because it’s something that don’t just affect you, it affect the baby
I actually didn't know I had chlamydia and I found out when I was 7 months pregnant and if I would have been able to give vaginal birth and I didn’t find out, my baby could have been blind from that.

Barriers. African American, Latina and Caucasian participants believed fear of positive HIV test results and associated social isolation may lead women to avoid perinatal care and HIV testing. One African American participant said, ‘Scary. Yeah, ‘cause it’s like nowadays [in this city], like everybody got something… and they won’t tell you, until you go to the doctor and find out yourself.’ Comments during the African American and Hmong focus groups suggested a complex interplay of emotions surrounding the unknown results of perinatal HIV testing. A Hmong participant suggested that learning of positive HIV status during pregnancy would cause the mother to experience stress and that stress may have independent adverse implications for the baby’s health. She stated, ‘If you find out… you have HIV during your pregnancy you would be real stressed out, and your baby might be at risk if you’re stressed.’

African American and Hmong participants also identified lack of social support and expected social isolation resulting from a positive perinatal HIV test as a barrier to testing. An African American participant added that these feelings of isolation were a factor in the transmission of HIV because ‘the person who has it is ashamed to say this is what I have and then they don’t protect themselves’. A Hmong participant stated, ‘If you have [HIV], and other people know about it, then wherever you go, they see you, they’ll be afraid of you too.’ This led to hypervigilance regarding limiting knowledge of one’s actions in a close-knit community.

Perceptions of HIV/AIDS in general
Women across focus groups associated HIV/AIDS with death. Reactions of anger to HIV/AIDS overlapped with fears of death for those in the African American group, in which one participant stated she would ‘kill the person that gave it to me’.

Judgments regarding the transmission of HIV/AIDS surfaced during the discussion in the Caucasian group. A Caucasian participant associated HIV/AIDS with same-sex and multiple sexual partners. She stated, ‘I wonder if they’re gay or… they’re just going around having unprotected sex with everybody… I know you can contract it from like a one-time thing, but it’s just a little irresponsible to me that they get it.’

Among the Hmong participants, there was a lack of basic knowledge about HIV/AIDS transmission, prevention and symptoms. Some Hmong participants felt that their lack of knowledge of HIV/AIDS was the result of not knowing anyone in their social network who had the disease. One woman said, ‘Back in our country… we do hear people talking about the disease, but haven’t have any relative that had the disease, so we don’t know how it is.’ One participant acknowledged the increased discussion of and information about HIV/AIDS upon her arrival in the United States.

Perspectives of women who are HIV positive

Experiences with health care during the perinatal period

Positive experiences. Participants living with HIV reported the same positive aspects of perinatal care and sources of perinatal health information as the other groups. They valued reassurance of fetal development and physical well-being, positive patient–provider relationships and information from health-care providers regarding perinatal health care. One participant described a positive relationship with her perinatal provider:

And you know when you have a, you know, a relationship that, you know, a talking, we talk, we just, it’s more, more than just like, what I’m there for, you know. It’s like she, you know, care.

Negative experiences. Participants living with HIV reported both similar and unique negative aspects of perinatal care compared to the other groups.
They reported long wait times for perinatal care as reported in the other focus groups. Unlike other groups, participants living with HIV reported issues of inferior care from providers who were not medical doctors, such as nurses and medical assistants, and apprehension related to tests, diagnoses and guidance from these providers. One woman living with HIV said, ‘I had to switch clinics ‘cause I was with a nurse practitioner. It was not a real doctor.’ Women living with HIV also indicated the adverse effect of antiretroviral drugs on the fetus as a drawback of perinatal care. One woman explained, ‘You gotta think, if you on some [antiretroviral] medicine, what that medicine gonna do [to] that little baby.’

**Perceptions of perinatal HIV testing**

**Opportunities.** Participants living with HIV expressed strong support for perinatal HIV testing, much like the other groups. Although partner fidelity was cited as a reason for their support, these participants highlighted the responsibility of a pregnant woman to know her HIV status for the health of herself, her partner and their baby. One participant living with HIV stated, ‘So people can know. The parents can know . . . what is going on with them and their baby.’ This participant also recognized engaging women in perinatal care as a critical barrier to testing: ‘I strongly feel that they should [be tested for HIV] but the thing is getting them to go see a doctor.’

**Barriers.** Women living with HIV also suggested anticipatory guilt generated conflicting feelings surrounding perinatal HIV testing. If a woman learned of her positive HIV status during pregnancy, she would feel bad for putting the infant at risk of contracting HIV. One participant explained, ‘Every stage of pregnancy your baby [can] catch it and you have to be under doctor’s special care . . . . And then, if your baby get it, you got a sick baby. Who’s to say it’s even gonna make it?’ Like other focus groups, participants living with HIV identified fear of positive results and isolation from social networks as a barrier to pregnant women being tested for HIV.

**Perceptions of HIV/AIDS in general**

Several participants living with HIV noted that experiencing HIV as a ‘death sentence’ was followed with a realization they were as likely, if not more likely, to die by another cause. One woman found life with HIV bearable through provider support and her pregnancy:

> As I thought about it as a death sentence, this doctor told me, when I was pregnant with my son . . . ‘You don’t have it, your body has it.’ That give you a better outlook . . . . It’s giving me a reason to be alive . . . . I’m gonna take care of my kids and make sure I keep myself healthy and happy.

These participants also identified and attributed public misconceptions regarding HIV transmission to ignorance, lack of education and fear. Even among participants living with HIV, confusion persisted regarding transmission of HIV to a fetus or infant during pregnancy, labor and delivery and the postpartum period. See Table II for a summary of the findings by racial/ethnic group and HIV status.

**Discussion**

Participants’ perinatal health-care experiences, information sources and perceptions of HIV testing and HIV/AIDS revealed opportunities and challenges for perinatal HIV communications. Participants across groups were reassured by perinatal care, but African American and Latina women also valued interpersonal relationships with their providers during this transition. This is in line with the literature on the importance of patient–provider relationships in perinatal care among African American, Mexican American, Puerto Rican and Caucasian women [11, 16]. Negative experiences were rooted in divergent values, beliefs or expectations regarding perinatal health care. In particular, divergent views on perinatal procedures between African American women and their providers found in this study generated negative feelings about perinatal care. A dislike of invasive perinatal procedures has also been linked to Hmong
Table II. Summary responses of focus group participants regarding factors associated with perinatal HIV testing decisions by racial/ethnic group and HIV status

<table>
<thead>
<tr>
<th>Factor</th>
<th>AA HIV-</th>
<th>Hmong HIV-</th>
<th>Latina HIV-</th>
<th>Caucasian HIV-</th>
<th>AA HIV+</th>
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<tr>
<td>Perinatal care</td>
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</tr>
<tr>
<td>Positive experiences</td>
<td>Provider relationships</td>
<td>Reassurance</td>
<td>Provider relationships</td>
<td>Reassurance</td>
<td>Provider relationships</td>
</tr>
<tr>
<td>Negative experiences</td>
<td>Long waits</td>
<td>Procedure choice</td>
<td>Invasive procedures</td>
<td>Privacy</td>
<td>Invasive procedures</td>
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<tr>
<td>Sources of perinatal health information</td>
<td>Community</td>
<td>Family</td>
<td>Providers</td>
<td>Community</td>
<td>Family</td>
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<tr>
<td>HIV/AIDS</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reasons for perinatal testing</td>
<td>Infant health</td>
<td>Partner fidelity</td>
<td>Infant health</td>
<td>Partner fidelity</td>
<td>Infant health</td>
</tr>
<tr>
<td>Barriers to perinatal testing</td>
<td>Fear</td>
<td>Isolation</td>
<td>Fear</td>
<td>Fear</td>
<td>Fear</td>
</tr>
<tr>
<td>Perceptions of HIV/AIDS</td>
<td>Anger</td>
<td>Death</td>
<td>Death</td>
<td>Death</td>
<td>Death</td>
</tr>
</tbody>
</table>

Note. AA = African American; ARV = antiretroviral medicine.
immigrant populations in the literature [12]. Our findings further elucidated the interaction between different barriers to testing among Hmong women [12], whose preference for privacy when receiving perinatal care outweighed desire for communication assistance from an interpreter during procedures. Although family was reported by several groups as a source of perinatal health information, providers were the most widely trusted source of information across groups. This was true even for Hmong women, despite cultural values of self-care and resistance to invasive perinatal exams identified in both this study and the literature [12]. Community-based organizations were also a valued source of information during the perinatal period.

Perinatal HIV testing was strongly supported by participants. Participants across groups expressed that they could not be sure of their partners’ sexual activity outside their relationship and viewed testing as an act of personal, family and social responsibility. This extends knowledge beyond predictors of perinatal HIV testing in the literature, such as knowledge of perinatal HIV transmission and social support [15], to specific intrinsic motivators to testing for HIV during the perinatal period across diverse groups. In contrast, women who feel they are in a monogamous relationship are more likely to decline testing [14]. Participants illustrated the complex emotions surrounding the potential implications of perinatal HIV testing, including fear of test results and social isolation if results are positive. Fear of perinatal HIV test results is exacerbated by both knowledge and misconceptions of the implications of HIV for the mother and her fetus or infant. This echoed the literature, which focused on women’s fear of results, breaches of confidentiality and stigma, as well as lack of knowledge about perinatal HIV transmission, as barriers to perinatal HIV testing [8, 13, 15].

Implications for perinatal HIV testing

Barriers

Our findings suggest two primary barriers to perinatal HIV testing among racially and ethnically diverse women with low socioeconomic status. First, divergent patient–provider values in perinatal care inhibit the development of strong patient–provider relationships. Second, misconceptions regarding HIV and perinatal transmission of HIV to the fetus or infant interfere with informed perinatal decision making. Race, ethnicity and culture further complicate these potential barriers to perinatal HIV testing among communities, especially tight-knit communities whose members are less informed about HIV, such as the Hmong. Women who perceive less risk in their community are less likely to be tested for HIV during the perinatal period [23].

The interaction of these barriers affects perinatal care seeking and perinatal HIV testing. Divergent patient–provider values without open communication inhibit trust, and the opportunity for necessary patient–provider communication related to HIV, pregnancy and perinatal HIV testing is lost. When patient–provider values are in line or when divergence is openly discussed, there is space for trust and communication about HIV, pregnancy and perinatal HIV testing in a private and confidential manner. Women who do not receive general information about HIV or specific information about HIV and pregnancy are more likely to decline perinatal HIV testing [14]. In contrast, private communication regarding perinatal HIV information in the context of a strong patient–provider relationship may address women’s fears regarding HIV and breaches in confidentiality and increase acceptance of perinatal HIV testing [13].

Opportunities

Our findings also provide insight into opportunities to improve perinatal HIV testing rates among racially and ethnically diverse women with low socioeconomic status. First, perinatal providers can work to develop productive patient–provider relationships based on a foundation of mutual respect and trust. Patient–provider relationships play an important role in facilitating perinatal HIV testing [13]. Participants highlighted the influential role of verbal communication with trusted health professionals.
when making decisions related to their health and well-being. The interpersonal component of the patient–provider relationship is a critical factor in a woman’s engagement in health-care services and receptiveness to HIV testing.

Second, perinatal providers can assess individual knowledge and values regarding perinatal care, HIV and perinatal HIV transmission. A brief initial assessment of a woman’s general knowledge and understanding of HIV is a critical first step to reduce miscommunication and improve patient–provider relationships in perinatal care settings. To engage in culturally sensitive communication, providers must understand each client in her sociocultural context. Assumptions based on women’s culture of origin are problematic. Having experienced pregnancy and childbirth in both their country of origin and the United States, Hmong participants welcomed many of the Western medical diagnostic tools but, based on cultural beliefs, feared the long-term health consequences of cesarean sections. Given participants’ recognition of ‘old-school’ or culturally traditional information from family that may conflict with information from health-care providers, the role of family in disseminating health-related information should be considered in the individual context. The ability of providers to facilitate actions that are respectful of and congruent with women’s values is critical. Sensitivity to different and nuanced philosophies and practices in perinatal health contributes to early trust and strong interpersonal patient–provider relationship and facilitates a forum for perinatal HIV testing discussions.

Third, perinatal providers can work with an extended network of community-based organizations (e.g. Women, Infants and Children) to promote clear, consistent and accurate information about HIV, perinatal transmission and perinatal HIV testing. Community-based organizations have a unique capacity to develop and deliver effective frontline, community-relevant HIV/AIDS health education and promotion programs in partnership with providers [24, 25]. Respected community liaisons with direct experience with HIV may also serve as trusted information sources.

**Limitations**

The recruitment approach resulted in a sample of women who were engaged in health services. Future studies should include women who do not seek health services and may be at higher risk of perinatal HIV transmission. Recruitment through specific community-based partners limited our ability to secure a sample of racially and ethnically diverse women living with HIV in general, and more specifically, of pregnant or postpartum women living with HIV. Conducting the focus groups in the community-based partner clinics providing health services may have limited negative comments related to health-care services and providers. This is especially relevant in the Hmong and Latina groups, where a staff person was present to translate. Latina and Hmong participants were recent immigrants; however, the specific length of time in the United States for each individual was not collected. This information, or more detailed information on acculturation, would help to further interpret the data. We described the sample and presented the depth and breadth of perspectives within and across focus groups to help the reader assess the transferability of the findings.

**Conclusions**

Strong patient–provider relationships and individually tailored health education and communications in both perinatal health care and community-based settings are critical for increasing the reach of HIV testing and knowledge about HIV and optimal perinatal health. A brief initial assessment by the provider of an individual’s reproductive health values, current understanding of HIV/AIDS, and implications related to perinatal care will serve as a foundation for a meaningful patient–provider dialog that translates across cultures. These findings provide tools for providers working with racially and ethnically diverse women in this context to eliminate perinatal HIV transmission among women who are disproportionately affected.
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Conflict of interest statement

None declared.

References


Appendix

(1) What does a ‘healthy baby’ mean to you?
(2) Where do you get new information on your health and health care in pregnancy?
(3) Think of an example of a typical visit to the doctor or nurse during pregnancy.

(a) What made you feel good about the visit? OR What did you like best about this visit?
(b) Are there any benefits to visiting the doctor?
(c) What made you feel bad about the visit? OR What did you like least about this visit?
(d) Are there any drawbacks to visiting the doctor?
(4) How do you feel about HIV screening in pregnancy?
(5) What does HIV/AIDS mean to you?