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**Prenatal Care Providers' Perspectives and Practices: Informed Consent for HIV Screening among Latinas with Limited English Proficiency in South Carolina**

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**ABSTRACT**

The rapid increase in Latinos in South Carolina that has occurred within the past 15 years is associated with both in-migration and high birth rates. Limited ethnic-specific data and communication barriers between Latinas with limited English proficiency have contributed to difficulties in assessing the provision of recommended routine prenatal HIV screening among this vulnerable population. This qualitative descriptive study examined providers' perceptions and practices related to obtaining informed consent for routine HIV screening for pregnant Latinas with limited English proficiency. Findings indicate the need for focused educational interventions with providers and patients and implementation of culturally and linguistically tailored practice guidelines to improve patient understanding and acceptance of prenatal HIV screening options.

**Keywords:** Prenatal care providers, Latinas, HIV, cultural and linguistic resources

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### **INTRODUCTION**

Incidence, prevalence, and mortality data indicate that HIV/AIDS disproportionately affects African Americans and Hispanics. Although the perinatal HIV transmission rate in the United States (US) decreased 16% from 2008 to 2010 and is now less than 1%, a disproportionate number of affected newborns are children of Latina and African American mothers (Camacho-Gonzalez, et al, 2015; Centers for Disease Control and Prevention [CDC], 2014; CDC, 2015; Kropp, Montgomery, Hill, Ruiz, & Maldonado, 2005). The rate of perinatal HIV infection among African Americans dropped from 15.2 in 2007 to 9.9 in 2009 (CDC, 2014), while rates among Latinos (1.7) and whites (0.1) remained stable. Given the increasing Latino population in the US, this health disparity merits attention of public health policy-makers and maternal-child healthcare providers at local, state, and national levels.

In South Carolina, the Latino population grew by 169% between 2000 and 2014 (U.S. Census Bureau, 2015) and currently accounts for 5.3% of the state's population (U.S. Census Bureau, 2015). During the same period, births to Latina mothers rose 93% (South Carolina Department of Health and Environmental Control [SC DHEC], n.d.). Despite higher birthrates, Latinas are less likely than other women to receive adequate prenatal care services in South Carolina. Based on the Kotelchuck Index, more Latinas in South Carolina received inadequate prenatal care (i.e., 305.5 per 1,000 live births) than African Americans (235.1) or whites (157.1) (SC DHEC, n.d.). The adequacy of Latinas' understanding and uptake of prenatal HIV testing is an issue that practitioners and researchers have not fully addressed.

#### **Perinatal HIV Screening Policies and Practices**

Nationally, institution of policies related to routine perinatal HIV screening resulted from the findings of the 1994 AIDS Clinical Trial Group Protocol 076 (ACTG 076) that indicated zidovudine use during pregnancy could decrease vertical HIV transmission from infected mother to unborn child by nearly two-thirds (Peckham & Gibb, 1995). Subsequently, major medical organizations and professional associations, including the American College of Obstetricians and Gynecologists (ACOG), American Academy of Pediatrics, and Institute of Medicine, endorsed HIV screening for all pregnant women. In 1995, the U.S. Public Health Services recommended universal and voluntary perinatal HIV testing (CDC, 2004). Based on research indicating pregnant women are more likely to agree to HIV screening when it is administered to all women seeking prenatal care rather than offered on an individual basis, the CDC (2006) currently recommends that HIV screening be included in the routine panel of prenatal screening tests for all pregnant women and that the providers notify and obtain patient consent for HIV testing. Inclusion of the HIV test in the standard prenatal screening panel reflects an intentional effort to decrease stigmatization of minority women and those from lower social economic status and is also designed to encourage prenatal care providers to screen all women regardless of their race and socioeconomic status.

Providers may offer adults and pregnant women either opt-in or opt-out options for the HIV test. With the opt-in approach, providers offer pregnant women the opportunity to consent to have the HIV test, preferably during their first trimester (O'Connell, Martin, Cutler, & Birkhead, 2015; Royce, et al, 2001). The opt-out approach, which is preferable from a public health perspective, consists of including routine HIV testing with the battery of other tests, unless

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the pregnant woman explicitly refuses to be tested for HIV. It is the responsibility of the health care worker to verify that a pregnant woman understands that she is agreeing to have the various tests, including the HIV test, and that she is informed of the right to decline the HIV test if she so chooses (Lifson & Rybicki, 2007). The opt-out approach is founded on the premise that pregnant women will receive information that is culturally and linguistically appropriate; including written materials presented at an appropriate reading level, in order to make an informed choice. There are valid concerns of the potentially detrimental impact if women who are not aware that they are being tested for HIV subsequently receive notice of a positive test result (American Civil Liberties Union [ACLU], 2007). The opt-out approach is predicated on assurance that pregnant patients be adequately informed that they will receive an HIV test unless they actively decline to be tested.

Although South Carolina was among the two states to states to recommend the opt-out HIV testing for pregnant women and one of ten states to implement newborn testing if the mother's HIV status is unknown (Kaiser Family Foundation, 2008), to date there are no statewide opt-out testing regulations or statutes. Because of multiple access barriers (e.g., language, health insurance, transportation), pregnant Latinas in South Carolina may seek prenatal care relatively late. Although HIV testing is a standard component of prenatal care, pregnant Latinas may or may not be offered the HIV test, and when it is offered may not understand what test is being offered, or that they do have an option to either accept or the test (Torres, Smithwick, Luchok, Rodman-Rice, 2012). If not tested prior to delivery, the potential risk for perinatal HIV transmission increases and access to appropriate treatment for mother and child decreases.

Barriers related to language, culture, literacy, and health literacy may deter routine prenatal HIV screening among Latinas. Patient-provider communication is of the utmost importance and can often impact the quality of the healthcare provided. Individuals who do not speak English as their primary language and who possess a limited ability to read, write, speak or understand English are considered limited English proficient (LEP; Meaningful Access, 2002). In health care settings, language and communication barriers may contribute to potentially adverse health consequences. In areas where the rapid growth in the Latino population is a relatively new phenomenon, health care facilities are not readily equipped to provide adequate services to LEP patients. Limited Latino health data have made it difficult to assess how well prenatal care providers are communicating the opt-out approach to prenatal HIV testing to pregnant patients in South Carolina. To our knowledge, no other research has examined prenatal care provider's perspectives on their experiences sharing information about HIV screening and testing among LEP populations in the state.

### **RESEARCH PURPOSE AND SETTING**

The purpose of this qualitative descriptive study was to explore South Carolina prenatal care providers' perceptions and experiences in communicating information about the HIV test to pregnant Latina patients. The research setting consisted of 7 prenatal care clinics in 5 South Carolina counties, 4 of which are classified as rural (U.S. Census Bureau, 2015). According to the U.S. Department of Agriculture (n.d.), rural locations are those outside Census Urban Areas with a population greater than or equal to 2,500. The patient populations of these obstetric and gynecological clinics consisted predominantly of minority women. Three clinics were Federally-

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Qualified Health Centers (FQHC), 3 were hospital-based clinics, and 1 was a private physician office. At the time, the 3 FQHC clinics provided obstetrics services to over 200 pregnant Latinas annually and employed bilingual receptionists who provided ad hoc, informal language assistance to English-only clinic staff who needed to communicate with LEP patients. The majority of these employees worked in the patient in-take areas, had no medical training and served informally as medical interpreters upon provider request.

One of the hospital-based prenatal clinics used trained medical interpreters, was associated with a medical residency program and had a monthly patient population of 1,800, of which 20%-25% of the patients were Latinas. Trained healthcare interpreters include individuals who have received some type of training, either through a formal educational program or an on-site training program provided by health services. Until very recently there were no national standards or guidelines for the training of healthcare interpreters. Currently there is a national organization that certifies medical interpreters (National Board of Certification for Medical Interpreters, 2012). The remaining 3 clinics reported an average of 10-15 pregnant Latinas per week, usually scheduled to coincide with the presence of a bilingual Latina prenatal program worker and designated as the *Latina Obstetrics Day*. Although this outreach workers' formal role was perinatal education and support, in response to provider or staff requests she also served as an ad hoc interpreter (McDowell, Messias, & Estrada, 2011; Messias, McDowell, & Estrada, 2009).

## METHODS

The Institutional Review Boards at the University of South Carolina, Centers for Disease Control and Prevention, and all collaborating clinics reviewed and approved the research protocol. Permission to contact clinic staff was obtained from the medical directors and business managers of each site. Two Latino Advisory Groups, representing the communities participating in the research had been established to provide input and assistance in recruiting clinic participation in the research. Each advisory group consisted of bilingual Latino community members, stakeholders and leaders; Latino prenatal care outreach workers, and study site personnel. Based on input from the advisory group members, we contacted potential provider participants either by phone or in person to recruit clinic staff members that have direct contact with pregnant Latinas for individual interviews. We extended an invitation to 21 clinic staff at the 7 clinics, 20 (95. 2%) of whom agreed to participate in an individual interview; 17 interviews were conducted face-to-face at the clinic site and 3 were conducted via telephone. Participants provided verbal or written consent prior participating in an interview; all interviews were conducted in English and the average length was 23 minutes. We report the characteristics and self-assessed Spanish proficiency of study participants in Tables 1 and 2.

Table 1. Characteristics of providers interviewed

Characteristic	n
Age	
18-29	3
30-39	7
40-49	4
50-59	5
60-69	1

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Sex		
Male		3
Female		17
Race/Ethnicity		
African American/Black		7
Caucasian/White		8
Hispanic/Latino		5
Professions		
<b>Professional Healthcare provider</b>		
Physician		3
Nurse Practitioner		1
Nurse		4
<b>Paraprofessionals</b>		
Licensed Practical Nurse		1
Medical assistant		6
<b>Bilingual Support Staff</b>		
Outreach Worker/Volunteer		1
Health Educator/Multicultural Healthcare Professional (worked in two sites)		1
Interpreter		2
Patient Service Representative		1
Research Associate/Interpreter		1
Employment History (years)		
Length of Employment in Health Field		Mean (SD)=10.8 (10.2)
Length of Employment/Volunteer in Specific Clinic		Mean (SD)=4.5 (6.2)

Table 2. Spanish Language Proficiency among Health Care Providers

Proficiency in Spanish	Number
Able to read	1
Able to read and speak	2
Able to read, write and speak	1
Able to read, write, and speak (Native Spanish speakers)	5
Unable to speak, write and read	10

The analysis reported in this manuscript pertains to data related to prenatal HIV screening and testing services and practices related to prenatal patients' option to decline the HIV test. We conducted a systematic review of clinic documents for specific content related to HIV testing, using a directed content analysis approach (Hsieh and Shannon, 2005). To analyze the staff interview data we used qualitative coding techniques (Strauss and Corbin, 1998) and employed QSR International NVivo.8 software (NVivo.8, 2008) as an organizational and data management tool. The coding of the qualitative interview data was conducted by two of the researchers, one an experienced qualitative investigator. After independently open coding several transcripts we reviewed and compared our initial coding schemes and subsequently developed a consensual descriptive coding scheme for the analysis of the subsequent interview data. Through an iterative process of collection and analysis of the data from the subsequent interviews, we identified, developed, and refined salient themes related to HIV screening principles, providers' perspectives and reported clinic practices of informed consent for HIV screening among Latina patients at participating clinics. Throughout the process we employed Lincoln and Guba's (1985). In the following section we present our analysis and interpretations of five salient findings from the descriptive qualitative analysis: *Adherence to the Principles of Informed*

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*Consent for HIV Screening: Conflicting Perceptions and Practices; Lip Service to the Opt-Out Option; Latina Patients' Passive Receptivity to HIV Screening; Dealing with Health Education and Health Literacy Gaps, and Lack of Clarity and Consensus on HIV Screening Policies and Procedures.*

### **RESULTS**

#### **Adherence to the Principles of Informed Consent for HIV Screening: Conflicting Perceptions and Practices**

Although providers noted their intent to adhere to the principles of informed consent, they reported conflicting perceptions and practices. Across the interviews, participants made repeated references to prenatal HIV testing as the “*standard of care*,” which they also associated with “*quality of care*” and “*best practice*” in adherence to policies and guidelines based on clinical trials. Yet when asked, “What is your current clinic policy or guideline on offering HIV testing for pregnant women?” providers reported widely divergent practices. For example one medical assistant reported her personal experience and understanding of prenatal HIV screening as mandatory:

*I think they're [HIV tests] mandatory, as far as I understand... We have to tell them [pregnant Latinas]...it's the standard of care. We draw – in our prenatal panel there's automatically an HIV test run - and I just have to have you sign here, saying that you know that we're running the HIV test... I haven't seen any patient refuse. Since it goes with the (routine) blood work, so that there is not a chance for them to refuse... I don't think the first time they're given the option. That's not my experience...Every pregnant woman that walks through the door, when we draw their prenatal panel, the HIV test is in it, whether they want to have it done or not. It's a standard of care.*

Staff reported that all pregnant women at their clinics, regardless of race/ethnicity were screened for HIV. All three physician participants reported there was a policy in place to ensure a patient could opt-out of the routine HIV screening, as indicated by this physician's response: *We are opt-out and offer to everybody unless someone says specifically, 'I don't want it.' It's included in the routine prenatal labs and you tell them, but we still get a consent.*

Although there were no reports of any Latina patients having refused HIV screening at any sites, there were clear indications of a widespread lack of updated information and general misunderstanding of how to obtain informed consent for HIV screening for Latina patients with limited English proficiency. Staff and providers working at the same clinics described varying, sometimes contradictory, approaches to obtaining consent. This is one physician's description of what he construed as an active consent approach:

*They have a consent that they sign, but we're more like an opt-out rather than an opt-in in terms of how we practically work... I mean, [for] HIV you do specific consent form, but for gonorrhea and chlamydia it's just part of the consent for the bloods to be drawn... I tell them, I'm gonna be screening you for the STIs and included will be HIV,*

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*syphilis, hepatitis, gonorrhea and chlamydia. Do you have any problems with being screened?" Most of them say, "No, screen me."*

Another physician reported the incorporation of patient education into the HIV screening consent process:

*Before the opt-out came in, when we first started screening all prenatal patients, we had to get a consent form to screen them. So we don't utilize it [the consent form] as we did before, but we utilize it as an educational tool to tell people what HIV is ...to tell people that we will be screening you and what happens if the test is positive and that we won't deny care to you if you're positive or negative.*

However, another physician candidly admitted not knowing the content of an HIV-specific consent form that supposedly was provided to pregnant Latinas at the clinic:

*Yeah, the nurses give them a consent form. I don't even know what it says, really. I know it exists but I don't know what it says. I have no idea. I'm gonna be honest. I don't know what it says.*

### **Lip Service to the Opt-Out Option**

Professional, paraprofessional and support staff repeatedly reported that pregnant Latinas were asked to provide written consent form requesting permission to administer the HIV test. One nurse explained a process in which all Latinas received a detailed explanation of what the prenatal panel entails and were asked to sign a "waiver" indicating their consent, noting "We always explain what the prenatal profile is up front, and basically they sign that waiver, and they give us consent at that time to screen for those tests." Similarly, participating LPNs and medical assistants consistently described a routine process that suggested the consent was essentially passive and essentially amounted to *lip service* in terms of active consent: *When she first comes in with her original OB interview, we draw a prenatal panel. At that time an HIV is drawn also, and she's to sign the paper saying its okay for us to send one of the tubes of blood off for an HIV testing.* These data indicated a lack of provider familiarity with the HIV screening procedures and a tendency to attribute to others the responsibility to adequately inform patients. This physician noted that pregnant women should have already decided prior to their first prenatal visit whether to take or not take the HIV test:

*From my perspective, this is the stuff that we feel you need as part of the pre-natal panel. So once they're done with their exam, they go off and get their blood work... that's why I was saying for the STI stuff, it's pretty much more of an opt-out in the sense that if you know in advance you have a strong opposition to something, you'll say it. Otherwise you're getting the same stuff.*

In contrast, a bilingual health care professional, who also provided ad hoc interpretation for other clinic staff, provided a different perspective, reporting that pregnant Latinas did not receive HIV-specific information at any time during routine prenatal visits. This staff person clearly acknowledged the lack of an HIV-specific screening consent form as well as absence of provider guidelines and patient education regarding the screening tests included in the standard prenatal panel:

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[They receive] a demographic information sheet and then [sign] a general consent...I'm not 100% sure, but I know it's a signature that they are willing to be a patient... and just general information...We don't see any guideline here, because, I mean, the HIV test, there is not a consent form where the patient is informed they are having HIV tests done that day. So they are unaware. They [pregnant Latinas] go to the lab to have some blood work done. But what I see is that the patient don't know what kind of blood work is gonna be done and sometimes the patient don't know what chlamydia or gonorrhea is.

These data suggest a generalized lack of awareness and understanding of HIV screening policies and procedures among clinic staff and a tendency to attribute the responsibility for obtaining active consent for HIV screening to others.

### Perceived Passive Receptivity to HIV Screening

Staff and providers consistently described obtaining consent for HIV screening among Latina patients as a passive process. Monolingual providers described pregnant Latinas as “pleasant and compliant patients that never complain.” In response to the interview question, “Among Latinas who have refused the HIV test, what are their primary concerns?” respondents consistently noted not having encountered a Latina patient who had refused to consent to the HIV test. A one nurse noted, “Everybody that we have offered it to takes it. We've not had anybody that I know of that has rejected.” Providers therefore concluded Latina patients were receptive to HIV testing.

Overall, we noted monolingual, English-speaking participants tended to focus less on cultural and communication barriers than did bilingual, Spanish-speaking participants. Several English-only speakers reported they interpreted Latinas' silence as a sign of lack of interest in personal health or the result of limited education and health literacy that prevented the women from making informed choices. Similarly, providers tended to construct Latinas' compliance as a function of forced submission and lack of effective communication rather than an active and engaged response to providers' recommendations or orders. A medical assistant observed, “I would say they [Latinas] don't take it too much seriously. They have full trust in the system because they have low education. They very, very seldom object.” In contrast, the comments of one bilingual interpreter reflected concerns that Latina patients might not be aware of the fact that an HIV test was automatically included in the prenatal panel and that they might be unaware of their right to accept or decline HIV screening:

*I have heard patients saying they fill out all these forms and “I don't even understand what I was signing, but I just signed it.” We don't see any guideline here. There is not a consent form where the patient is informed they are having HIV tests done that day. So they are unaware.*

In comparing patients' decisions regarding other tests, one medical assistant noted, “They have refused the second gonorrhea and chlamydia [test], but it's because the doctors give them the option to refuse it or to accept it.”

### Dealing with Health Education and Health Literacy Gaps



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A consistent finding across all clinic sites was that providers were confident that the provision of Spanish language pamphlets on prenatal health care services was adequate and sufficient to communicate with limited English proficient patients. In examining providers' responses regarding their confidence that pregnant Latinas understood they were consenting to have an HIV test, we noted staff at clinics that employed bilingual staff or provided Spanish language consent forms tended to report that their Latina patients were aware of the tests included in the prenatal panel. In response to the question, "How do you present information about HIV screening to Latinas?" this medical assistant's response was typical: "*We have pamphlets [in Spanish] about the risk and what it can do to you and your baby, how they can get it and why's it important to have it and what the test includes.*" However, some staff members were not convinced that Latina patients were actually informed of the option to refuse HIV testing. Furthermore, monolingual providers at these sites acknowledged that because they served patients with low levels of education, Latina patients may not be able to read materials in Spanish; they also noted their inability to determine whether the bilingual workers were advising the women what was on the consent forms prior to asking them to sign the forms. Several providers did note that low literacy might be an issue, as evidenced by this nurse's identification of gaps in clinic policies and procedures:

*Sometimes we have to ask them, because we've handed them stuff. And you cannot pinpoint them, but the...translators will say, "Do you understand what this says, and can you read it?" I mean, you almost have to just ask them, 'cause some have third-grade reading levels. We've mailed stuff out to patients about appointments, and then they've missed it, and then they said they didn't get it... but we confirm the address and it's the same. So we feel like there's some reading comprehension to some degree there. So having the material available [in Spanish] is not always the right answer. You've gotta make sure that they can read it.*

A common health education strategy was to provide HIV educational materials to patients. In describing the process of sharing HIV information with pregnant Latina patients, one nurse noted: "*Part of that interview we give them some literature about all the tests that will be run on them throughout pregnancy, so they understand why each test is done.*" Similarly, a medical assistant reflected on the fact that health care workers should not assume Spanish-speaking patients will understand the information provided in pamphlets or other medical documents, even when provided in Spanish: "*Yes they understand what they are signing because we do – we provide those instructions. We provide that in Spanish, too, so I mean, they understand. And if they have questions, they'll ask.*" These responses suggested that pregnant Latina patients tended to ask very few questions, which in turn made it difficult for providers to assess their understanding and comprehension of instructions and explanations.

Participants at clinics that did not provide Spanish language documents reported that bilingual staff members were responsible for explaining the content of the general and HIV consent forms to the pregnant Latinas. Even though the prenatal clinics participating in this research had been serving Latinas for a number of years, many had not had clinic documents translated into Spanish. This nurse's description indicated that providers had limited knowledge and understanding of language translation and interpretation processes and procedures:

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*The waiver is given to the other patients...they can decline, but that's only given to the English patients....The Hispanics, we don't have a form for them yet, so he (bilingual worker) explains to them what they're being screened for, and they just kinda, I guess, just accept it upon verbal consent...He is reading it in English, but telling them in Spanish.*

We specifically asked participants to describe how they knew if Latina patients understood the HIV testing process. Although generally recognizing that the HIV test is a key component of the standard prenatal panel, the majority reported they believed the pregnant Latinas were not aware that an HIV test was automatically performed as part of the prenatal panel, unless the patient declines to be tested for HIV. One nurse candidly noted, "*Honestly, a lot of them probably don't [know they are having the HIV test]. Even though we tell them as best we can, they don't really know.*" This comment suggested that although providers intended to provide adequate, informed care, they acknowledged that Latina patients were probably not aware they were undergoing HIV screening. Other comments indicated some providers considered pregnant Latinas to be unconcerned about the issue – or appeared to believe that these patients did not merit equitable attention. For example, a medical assistant who did not speak or understand Spanish attributed an attitude of "*not caring*" to the Latina patients: "*I don't think that they really care what kind of test that they're gonna do, but I don't think they understand.*" Yet a bilingual staff member's comments reflected a similar attitude of ignorance begetting ignorance: "*With the Hispanics they don't [know that they are having the HIV test] – we don't have to go through this kind of information.*"

These data also suggested Latinas were ultimately responsible for overcoming the language barriers with their providers. As another medical assistant aptly noted, "*Unless we tell them and they have somebody there that's with them that speaks [Spanish], they may not know [they are having an HIV test].*" Providers' descriptions of the issues surrounding the HIV test reflected the broader obstacles pregnant Latinas face in accessing quality prenatal health care in South Carolina. Several providers admitted their struggles with the delivery of culturally appropriate services and the lack of clear, efficient communication between monolingual English-speaking staff and Latina patients with limited-English-proficiency. However, the lack of both information and clear policies also contributed to sub-optimal practices related to HIV screening.

### Lack of Clarity and Consensus of HIV Screening Policies and Procedures

National prenatal HIV testing guidelines recommend that women who refuse to be tested should be offered the test again at a later time and the American College of Obstetricians and Gynecologists recommends noting HIV testing refusal in the patient's medical record and repeating the HIV test in the third trimester for high risk women and for women who declined testing earlier in their pregnancy (American College of Obstetricians and Gynecologists, 2010). Yet 90% of providers interviewed were not sure how to answer the question, "What guidelines are there for those who refuse HIV testing?" One physician actually described a woman's right to refuse the HIV test as unethical:

*If somebody refuses HIV testing, then sometimes that kind of issue may be something you bring to the ethics committee. You keep offering them, but I think if that situation – like I*

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*said, I have not had that. If that situation arises then you have to bring it up to the ethics committee... you have to get the ethics committee involved because of course the baby has to come into the picture.*

Other participants used phrases such as “*I guess*” and “*let him [the physician] make that decision,*” indicating either a lack of familiarity with clinic HIV screening policies and procedures or a lack of ownership related to the issue. Although none of the participants reported having experienced the situation of a pregnant patient refuse HIV screening, several anticipated how they might respond. One physician noted, “*I haven't had any who refuse, but I guess if they did refuse we would try and make – like find out why they're refusing.*” Similarly, a medical assistant's response reflected the position that this issue pertained to the physician's domain:

*If I did, I would have to talk to my doctor and let him make that decision...if he has somebody that does not want to go along with standard of care, then he would have the right to either see them or not to see them.*

## **DISCUSSION**

Despite inherent design limitations in his exploratory, descriptive study conducted within the context of a specific geographic area, these findings may be applicable to clinicians in other settings and contexts and may also serve as a basis for more expanded research initiatives with other at-risk populations. However, our findings clearly suggest the need for ongoing education and training for both providers and patients, including specific HIV screening standards and guidelines and instruction in cross-cultural and interpreter-mediated communication with Latinas with limited English proficiency. We identified differences and variations in prenatal HIV screening policies and procedures and in staff perceptions and interpretations of how these policies and practices applied to pregnant Latinas among the 7 clinics. Previous research indicates pregnant women who are aware that they are being screened for HIV are more likely to accept the test and treatment if diagnosed with HIV (Kropp, et al., 2005). Furthermore, when the benefits of HIV testing are explained to patients, they are far more likely to choose to protect their health (ACLU, 2007). Presenting patients with written or verbal consent, as well as pretest counseling that explains the nature of HIV testing and gives patients information about HIV disease, will provide many patients with important HIV information they may not already know.

Exclusive provision of written information, in any language, is not appropriate for illiterate or low-literate patients. There are ethical and practical implications of asking patients to sign a form without making sure that he/she completely understands what he/she is agreeing to and/or signing (ACLU, 2007). Provision of inaccurate information to Latinas who may know little about HIV and STIs can further complicate their ability to understand the need for prenatal screening such as the HIV test.

Similarly, there are recognized limitations to the mere distribution of pamphlets, booklets, or instructions to explain medical procedures among low-literate populations. Medical materials can be difficult to comprehend regardless of the language. Health literacy is defined as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (Williams, Davis, Parker, & Weiss, 2002, p. 383). Research indicates a strong correlation between low health literacy and poorer health status outcomes (Rosal, Goins, Carbone, & Cores, 2004). The less education a person has, the more likely he/she is to be low literate. About two thirds (62.8%) of

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pregnant Latinas in South Carolina have less than high school education (Torres, Smithwick, Luchok, Godman-Rice, 2012). The inability to read, write, or speak any language well (or at all) can be detrimental to the health of persons needing specialized medical attention like those with chronic diseases or those who are pregnant (Okraimec, Booth, Hollands, & Bell, 2015).

Although the providers who participated in this research reported they have never had a pregnant woman refuse the HIV test, our findings suggest that pregnant Latinas were not receiving adequate information about the inclusion of the HIV test as part of routine prenatal blood work, nor were they informed of their option to actively accept or refuse such testing. The opt-out prenatal HIV screening preserves the pregnant patient's right to know exactly what types of tests she is being offered, ensuring a more equitable patient-provider relationship and ultimately contributing to optimal clinical and preventive care. These findings suggest these providers caring for Latinas in South Carolina had not adopted the opt-out approach for prenatal HIV screening consent, despite recommendations by the CDC, NIH, ACOG and the US Preventive Services Task Force (CDC, 2006).

### **CONCLUSION**

Clinical implications of this research include the need for clear, culturally-tailored information on the provision of HIV screening that specifically communicates both the implications of the HIV test and its results for both the pregnant woman and her child, and women's options to participate or not in the screening, particularly for Latinas with limited English proficiency. Further research in other settings and contexts and with other racial and ethnic populations is clearly warranted in order to more fully examine both clinical and policy implications of informed consent and consequences of providers' communications with pregnant patients related to HIV screening. Beyond collective efforts to enhance provider education on HIV testing policy guidelines, additional research is needed to assess provider training and understanding of the opt-out approach to prenatal HIV testing. It is important to inform Hispanic patients and community advocates about prenatal care process and procedures in the US. Further intervention research is needed to guide the implementation of evidence-based practices of obtaining informed consent for HIV screening among diverse prenatal care populations, furthering the goal of reducing perinatal HIV transmission and HIV-related health disparities.

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### **REFERENCES**

American Civil Liberties Union. (2007). Increasing Access to Voluntary HIV Testing: The Importance of Informed Consent and Counseling in HIV Testing. Retrieved from <http://www.aclu.org/hiv-aids/hiv-testing-and-privacy>

American College of Obstetricians and Gynecologists (2010). Clinical Recommendations. Retrieved from: [http://www.kdheks.gov/hiv/download/KS\\_side-by-side\\_ss\\_edits\\_09-07-10.pdf](http://www.kdheks.gov/hiv/download/KS_side-by-side_ss_edits_09-07-10.pdf)

**13 Prenatal Care Providers' Perspectives and Practices: Informed Consent for HIV Screening among Latinas with Limited English Proficiency in South Carolina, Meetze, E., et al.**

Camacho-Gonzalez, A., Kingbo, M-H., Boylan, A., Eckard, Al, Chahroudi, A., Chakraborty, R. (2015). Missed opportunities for prevention of mother-to-child transmission in the United States: a review of cases from the state of Georgia, 2005-2012. *AIDS (29)*, 000-000.

Centers for Disease Control and Prevention. (2004). Prenatal HIV testing and antiretroviral prophylaxis at an urban hospital-Atlanta Georgia 1997-2000. *Morbidity and Mortality Weekly Report, MMWR*, 52, 1245-1248.

Centers for Disease Control and Prevention. (2006). Revised recommendations for HIV testing of adults, adolescents, and pregnant women in health-care settings, *Morbidity and Mortality Weekly Report, MMWR*, September 22, 2006 / 55 (RR14),1-17).

Centers for Disease Control and Prevention. (2014). National HIV Prevention Progress Report, 2013. Retrieved from [http://www.cdc.gov/hiv/pdf/policies\\_NationalProgressReport.pdf](http://www.cdc.gov/hiv/pdf/policies_NationalProgressReport.pdf)

Hsieh, H. & Shannon, S. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, 15(9), 1277-1288.

Kaiser Family Foundation (2008). State Health Facts.Org. *South Carolina :HIV Testing* Retrieved from: <http://www.statehealthfacts.org/profileind>

Kropp, R., Montgomery, M., Hill, D., Ruiz, J., & Maldonado, Y. (2005). Unique Challenges to Preventing Perinatal HIV Transmission Among Hispanic Women in California Results of a Needs Assessment. *AIDS Education and Prevention*, 17(1), 22- 35.

Lifson, A., Rybicki, S. (2007). Routine opt-out HIV testing. *The Lancet*, 369(9561): 539-540.

Lincoln, Y. S & Guba, E. G. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage.

McDowell, L., Messias, D., & Estrada, R. (2011). The work of language interpretation in health care: Complex, challenging, exhausting, and often invisible. *Journal of Transcultural Nursing*, 22(2), 137-147.

Meaningful access for people who are limited English proficient. (2002). Retrieved from: <http://www.lep.gov/faq.html>

Messias, D., McDowell, L., & Estrada, R. D. (2009). Language interpreting as social justice work: Perspectives of formal and informal healthcare interpreters. *Advances in Nursing Science*, 32(2), 128-143.

National Board of Certification for Medical Interpreters. (2012). Retrieved from: <http://www.certifiedmedicalinterpreters.org/>

NVivo qualitative data analysis software; QSR International Pty Ltd. Version 8, 2008.

**14 Prenatal Care Providers' Perspectives and Practices: Informed Consent for HIV Screening among Latinas with Limited English Proficiency in South Carolina, Meetze, E., et al.**

O'Connell, D., Martin, E., Cutler, B., & Birkhead, G. (2015). The Evolution of HIV Testing Requirements in New York State, 1989-2013. *Journal Of Acquired Immune Deficiency Syndromes*, 68, S5-S9.

Okrainec, K., Booth, G., Hollands, S., & Bell, C. (2015). Impact of language barriers on complications and mortality among immigrants with diabetes: A population-based cohort study. *Diabetes Care*, 38, 189-196.

Peckham, C. & Gibb, D.(1995). Mother-to-child transmission of the human immunodeficiency virus. *New England Journal of Medicine*, 333, 298-303.

Rosal, M., Goins, K., Carbone, El, & Cores, D. (2004). Views and preferences of low-literate Hispanics regarding diabetes education: Results of formative research. *Health Education and Behavior*, 31(3). 388-405.

Royce R.A., Walter E.B., Fernandez M.I., Wilson T.E., Ickovicks J.R., Simonds R.J. (2001). Perinatal Guidelines Evaluation Project. *American Journal of Public Health*, 91.727-733.

South Carolina Department of Health and Environmental Control. (n.d.). SCAN. Birth Certificate Data 2000-2013. Retrieved from <http://scangis.dhec.sc.gov/scan/bdp/tables/birthtable.aspx>

Strauss A., & Corbin, J. (1998). *Basics of qualitative research: Grounded theory procedures and techniques* (2<sup>nd</sup> ed.). Newbury Park, CA: Sage.

Torres, ME, Smithwick, J, Luchok KJ, Rodman-Rice, G. (2012). Reducing Maternal and Child Health Disparities Among Latino Immigrants in South Carolina through a Tailored, Culturally Appropriate and Participant-Driven Initiative. *Californian Journal of Health Promotion*, 10:1-14.

U.S. Census Bureau. (2015). State and County QuickFacts. Retrieved from: <http://quickfacts.census.gov/qfd/states/45000.html>

U.S. Department of Agriculture. (n.d.). South Carolina: Three rural definitions based on Census Places. Retrieved from [http://www.ers.usda.gov/datafiles/Rural\\_Definitions/StateLevel\\_Maps/SC.pdf](http://www.ers.usda.gov/datafiles/Rural_Definitions/StateLevel_Maps/SC.pdf)

Williams, M., Davis, T., Parker, R., & Weiss, B. (2002). The role of health literacy in patient-physician communication. *Family Medicine*, 34(5), 383-389.