

Special Edition
"HIV-related Stigma across
the Lifespan"

Brief Research Report

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Barriers and Facilitators to HIV Testing Among Women

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ABSTRACT

Aim: The purpose of this secondary analysis was to analyze for barriers and facilitators to HIV testing in women attending community health clinics.

Introduction: The Centers for Disease Control and Prevention (CDC), reported that all women account for 20% or 1 in 5 of new HIV cases (CDC, 2012). Of those new cases in heterosexual women, 5,300 were Black, 1,300 were White, and 1,200 were Hispanic/Latina. The CDC estimated that in 2012 there were 9,268 individuals living with a diagnosis of HIV or AIDS, of which 19% were women.

Results: The existing de-identified data consisted of thirty individual interviews conducted using a semi-structured interview guide was collected as the initial phase of the parent study, "HIV Testing and Women's Attitudes on HIV Vaccine Trials". This secondary analysis addressed the identification of key obstacles to HIV testing and only those related portions of the transcripts were analyzed. The major themes identified were familiarity with testing, stigma, fear, perceived risks, and access to care.

Conclusion: The themes implicated the need to further assess women for barriers and facilitators to testing, tailor community based interventions that have the ability to decrease fear and stigma, increase trust in testing methods and offer counseling to positive results.

KEYWORDS: HIV testing; Women; Barriers; Facilitators.

ABBREVIATIONS: CDC: Centers for Disease Control and Prevention; HIV: Human Immunodeficiency Virus; NIMH: National Institute of Mental Health; AIDS: Acquired Immune Deficiency Syndromes; HAART: Highly active antiretroviral therapy; STDs: Sexually Transmitted Diseases; NIH: National Institutes of Health.

BACKGROUND ON BARRIERS TO TESTING

The largest prevention trial of low income at-risk men and women (N=3,706) at 7 US sites funded by the National Institute of Mental Health (NIMH) found that the behavioral intervention was not able to explain the outcomes of condom use, knowledge and skills and self-efficacy to initiate safe sex behaviors. The researchers concluded that unmeasured factors may have influenced the outcomes.¹ Other studies found that 140 Hispanic women between the ages of 18-44 with higher self-esteem were less likely to worry about acquiring sexually transmitted diseases (STDs) and HIV. Self-esteem and motivation for sexual health were significantly associated and this lead the women to use condoms.²⁻⁴ Stigma was also a concern for these women. The researchers also found medication side effects and weight gain influences medication adherence. During the early epidemic of HIV, women and young female adolescents went highly under diagnosed.

The knowledge of HIV status among women is related to the barriers to diagnosis and engagement in HIV care.⁵ Barriers included delay in not receiving care, delay in undergoing treatment, late initiation of highly active antiretroviral therapy (HAART), mistrust of care providers, substance use.⁶ Women were found to have more barriers to HIV testing than men. Studies have identified multiple barriers including lack of awareness and misconceptions related to HIV screening by physicians and patients, barriers at the facility and legislative levels, costs associated with testing, and conflicting recommendations concerning the value of routine screening.⁷ Another research team found that culturally specific interventions that are tailored for Hispanic women have the ability through multiple pathways to prevent HIV infections.⁸ Women with and at risk for HIV face several challenges to getting the services and information they need, including socio-economic and structural barriers, such as poverty, cultural inequities, and sexual violence, and women may place the needs of their families above their own.^{9,10}

Presently, there is a rise in HIV infections among women. The CDC, reported that women account for 20% of all new HIV cases.¹¹ In the US, women account for 1 in 5 new HIV diagnoses and deaths caused by AIDS with the number of new cases has tripled since 1985. Minority women have an HIV prevalence rate 3.5 times higher than white women. Eighty-six percent of the women contracted the virus through heterosexual sex. Even though African Americans and Hispanic women represent 28% of all women, they account for 80% of HIV among women; 63% of women diagnosed with HIV/AIDS were African American.¹² Research about barriers and facilitators to HIV testing and prevention implications are an urgent and observable need among women.¹³

This leads many women being unknowledgeable about HIV testing and their HIV status. Most of the knowledge of HIV testing results among women solely is from research done at antenatal clinics. There needs to be research that focused on women and what their barriers and facilitators are for HIV testing.

Women are highly understudied and most of the current research is not focused on women. A systematic review found that women represented a median of 19.2% participants in antiretroviral drugs (ARV) studies (387), 38.1% in prophylactic vaccines (VAX) studies (53), and 11.1% in curative strategies (CURE) studies (104). Funding source was correlated for ARV studies with the proportion of female participants but not in VAX and CURE studies. Publicly funded ARV trials had the lowest female participation (16.7%) however those funded by private non-commercial sources had the highest proportion of women. The median proportion of women in ARV trials that were fully or partially funded by the National Institutes of Health (NIH) was significantly lower (19.6% vs. 22.3%) than the median in trials funded by other sources.¹⁴ The high rise in infected women with HIV, has given purpose and an implication to investigate the facilitators and barriers to HIV testing among women solely. Recent evidence from 135 studies revealed that mortality was significantly higher among people with mental disorders than

among the comparison population. The researchers determined that worldwide 8 million deaths occur each year that attributable to mental disorders.¹⁵

PURPOSE

The purpose of this study was to analyze existing de-identified data for barriers and facilitators to HIV testing in women attending community health clinics. Thirty individual interviews conducted using a semi-structured interview guide was originally collected as the initial phase of the parent study “*HIV Testing and Women’s Attitudes on HIV Vaccine Trials*”. This secondary analysis addressed only the identification of key obstacles to HIV testing and only those related portions of the transcripts will be analyzed.

METHODS

Ten women identified themselves as Latinas, 10 as non-Latina White, and 10 as non-Latina Black. They were 22-67 years of age (median=30). Participants in this study were adult women seeking clinical services at one of three urban community health clinics located in Indianapolis. The project had Institutional Review Board (IRB) approval through the Indiana University School of Nursing. A purposeful sampling method was used to ensure diverse ethnicity. Participants were recruited from clinic waiting rooms to complete in-depth, in-person, semi-structured individual interviews. Bi-lingual research assistants conducted individual interviews with women attending the three clinic sites. The participants were compensated \$25 each for the time and effort involved. Individual interviews were audiotaped for subsequent transcription and coding. The Oraquick[®] rapid HIV was described, after which a series of open-ended questions were asked regarding reactions to the test, emphasizing issues of perceived barriers to testing and perceived benefits of testing. After the open-ended questions, interviewees were asked to respond to a list of reasons for and against testing derived from the research literature on this topic.

Data Analysis

Content analysis was accomplished by conducting a line-by-line analysis of the interview transcripts. Pattern recognition was utilized by reviewing the sentences and phrases for patterns or core meanings. The patterns were then refined and synthesized into descriptive statements of the data provided by the participants. The interview guide served as a structure to organize the data. The data was analyzed thoroughly by three different people to check for validity among concluded themes.

RESULTS

Participants responded to the interview and major themes were suggested from their answers. The major themes congruent with the interviews were familiarity with testing, stigma, fear, perceived risks, and access to care. Each theme was not seen exclusively as a barrier or facilitator, but was interpreted to be

one or the other depending on the aspect of HIV testing being discussed.

Familiarity with Testing

Participants responded to having major concerns with being tested for HIV. Many expressed the concern of how the test is performed and how long results would take to get back. The responses from the interviews expressed that many did not understand the test and thought that there were side effects and reactions to having the HIV test. A major concern about testing was how accurate it was and what would happen if the test came back positive. Confidentiality was another major concern about testing.

"Would my results come back you know, right then and there?"

"I would ask if the things she is going to use with me no one has used them, if the test is precise, no mistakes, like sometimes happens that is positive and is not yours and you are negative, that the doctor is sure about what she is doing".

"How they're gonna to do the test. To have to be stuck with the needle and all that. Confidentiality, how long will it be before I get results. And if I'm afraid to know the results".

"...how long, how accurate it is, if you do come back with a positive, how more in depth will the testing go".

"If it would be like a confidential test. Um, what the doctor would do to help, you know, if the test came back positive, what the doc would do to help me fight the disease or whatever".

Stigma

Participants expressed that they do not want to be rejected from society or family if they tested positive for HIV. There was a congruent theme amongst participants that people with HIV are "shunned" from society. The responses suggested that participants were scared to how people will react to being tested positive to HIV or if people would talk about them.

"Because she is afraid to be discriminated or not accepted, you know that there are families that don't accept and they don't want her to be part of the family anymore".

"It's very embarrassing. And you know, people talk about you, not most highly".

"They're embarrassed, scared, and don't know how others will react".

"...to be discriminated or not accepted, you know there are families that don't accept and they don't want her to be a part of the family anymore".

Fear

Participants expressed fear of being tested. Many admitted to being involved in high-risk actions and feared testing positive.

The interview responses suggested that the women feared getting results. Participants responded they would much rather not know than have the results.

"I think because they are scared, no one likes to know that you are sick, especially with an incurable disease, they can keep them but never cure them".

"I know what I've been doing, but I don't really wanna say cause I'm scared to get tested".

"I think that when a person is afraid, he doesn't want to be tested. I don't know. He hides something, like he's afraid of knowing the results".

"I think a lot of it is they just don't want to know".

Perceived Risks

Some participants expressed that they felt that because they believed that they had risks that they should be tested. Others felt that because they had participated in high-risk behaviors that they did not want to be tested because they did not want people to think they participate in high-risk behaviors. Some participants did not even perceive some of their behaviors as high-risk behaviors to come in contact with HIV.

"...had quite a few sex partners in their past. And they abused the needle and drugs, and that's why they should, I feel".

"...because they out here doing too much and they don't want nobody to know they did some stuff".

"You should get tested every 6 months if you think you've been exposed".

"She wouldn't want to acknowledge that she has been around somebody or been with somebody that could possibly have the disease".

"I think there's some people that think there's no way that they could have gotten it".

"They feel they possibly couldn't of contracted it".

Access to Care

Some of the participants thought that having access to care to treat the HIV would motivate them to get tested. They saw it as a positive reason to get tested. Some women were concerned with what the treatment would be and if they would even have access to care to treat the disease. The major concern among them was whether or not treatment would be readily available to them.

"...you know, there's not a cure right now, but it can hopefully take some of the current different things that they have to hopefully maybe slow the process of the progression of the AIDS. So then maybe they could live longer. And it might not have a cure, but eventually just live longer, so hopefully it could help".

"Need to know, get it treated early, you know, get it taken care of

before it really gets out of hand”.

“...if she sees in my files that something is wrong with me, what she recommends me to do”.

DISCUSSION

This secondary analysis identified obstacles to HIV testing. The most unique aspect of the qualitative study was the mixed ethnic sample that included 10 Latina women, or one-third of the sample. The women were recruited in various community agencies in the State of Indiana.¹⁶ The CDC reported that in 2012 all women account for 20% of new HIV cases.¹⁷ Of those new cases in heterosexual women, 15% or 1,200 were Hispanic/Latina.

The findings suggested that the mixed sample of ethnic women were open to new learning about the disease and were eager to learn to take care of themselves. This qualitative analysis contributed a unique set of findings expressed by women in the prime of their lives and add to our knowledge of the barriers to HIV testing. For example, in this sample of women access to care, perceived risks, fear, familiarity with testing, and stigma accounted for the primary concerns of these young adult women. A major finding from this qualitative study was that the women identified the importance of both mental and physical health care in their plans. Since mortality is greater among people with mental disorders, an integrated system of care would possibly deaths occur each year. Primary care settings are not often equipped to handle mental disorders that require time and unique treatments.¹⁸ The integration of electronic medical records may facilitate this holistic approach to care.

The findings lend support the need to further assess woman for barriers and facilitators to testing, in order to increase testing rates from women’s perspectives. The themes also suggest the need for tailored community based interventions that decrease fear and stigma associated with HIV testing, such as public health announcements and educational outreach. The findings also suggest that we need to increase trust in testing methods and providers, by forming better relationships between providers and patients. Finally, the results suggested that we should offer counseling with positive testing results.

Our findings have implications for informing delivery of care for people with HIV and AIDS, there are some limitations. Patients with these diseases from other parts of the country may have different or unique experiences in managing these diseases and very different interactions with health care providers in the system. This small convenience sample and the study we conducted in a single urban area limits the generalizability of the findings. These limitations are offset by our qualitative methodology described in the methods section. In addition, the data that we gathered is unique and not reproducible.

In conclusion, approximately 9,500 women accounted for the new cases of HIV infections in 2010. Black women are disproportionately affected by HIV and account for the majority

(64%) of the new HIV infections in 2010. The estimated incidence of new HIV infections has remained stable with approximately 50,000 new infections per year. An estimated 13,712 people with an AIDS diagnosis died in 2012, and approximately 658,507 people in the United States with an AIDS diagnosis have died overall.¹² Women comprised 5,232 deaths, or one-quarter 26% of deaths with an HIV infection in 2010 and 84% were infected through engagement with heterosexual sex.

The CDC estimates that 1,218,400 persons aged 13 years and older are living with HIV infection, including 156,300 (12.8%) who are unaware of their infection. The target population for encouragement of HIV testing is among young gay Black or White men. This fact is related to the numbers of new infections of men who have sex with men (MSM). In 2010, White men represented 11,200 new infections and Black men 10,600 new cases.

CONFLICTS OF INTEREST/ACKNOWLEDGEMENTS

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CONSENT

The authors obtained written informed consent from the participants for submission of this manuscript for publication.

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