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Awareness of and attitudes toward pre-exposure prophylaxis among African American women living in low-income neighborhoods in a Southeastern city

Lauren M Hill[1,2,*], **Alexandra F Lightfoot**[1], **Linda Riggins**[2], **Carol E Golin**[1,2,3]

[1]Department of Health Behavior, University of North Carolina at Chapel Hill, Chapel Hill, NC

[2]Cecil G. Sheps Center for Health Services Research, University of North Carolina at Chapel Hill, Chapel Hill, NC

[3]Department of Medicine, University of North Carolina at Chapel Hill, Chapel Hill, NC

Abstract

African American women in the South are disproportionately affected by HIV but have often been ignored in HIV prevention efforts, including in the rollout of pre-exposure prophylaxis (PrEP). To inform strategies to promote PrEP awareness and access in this population, we conducted a venue-based community survey with 53 African American women living in low-income neighborhoods of a Southeastern city to understand women's knowledge of and attitudes toward PrEP. Awareness of PrEP was very low (37%) with only 16% being aware that PrEP is used for HIV prevention. The vast majority of women (85%) reported that they would use or would consider using PrEP, most frequently citing a general interest in HIV prevention or a lack of awareness of their partners' HIV status as motivations for their interest. Some women expressed concerns about side effects or low perceived HIV risk as disincentives for PrEP use. Information regarding side effects and HIV risk assessments will be needed to ensure the acceptable delivery of PrEP in this population.

Keywords

PrEP; African American; women; awareness; Southeastern US

INTRODUCTION

African American women in the Southern United States (US) are disproportionately affected by the US HIV epidemic (Adimora, Schoenbach, & Doherty, 2006). More than half of all

[*]**Please direct all correspondence to:** Lauren M Hill, 324 Rosenau Hall, CB #7440, Chapel Hill, NC 27599, hilllm@email.unc.edu.

Ethical approval:
All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent:
Informed consent was obtained from all individual participants included in the study. This consent was obtained verbally to protect participant anonymity.

Conflict of interest:
The authors declare that they have no conflicts of interest.

new HIV cases in the US in 2016 were in the South despite its having only 37% of the US population (Prevention Centers for Disease Control and, 2016). The Deep South, including North Carolina (NC), has more people dying from HIV than any other region (Reif, Safley, & McAllaster, 2015). As of 2015, women represented 23% of all Americans living with HIV in 2015, and the incidence of HIV among African American women is about 16 times that of White women (CDC, 2016). Structural, rather than individual behavioral, factors put African American women who live in low-income communities at elevated risk for HIV. These factors include poverty, substandard housing, unemployment, and lack of access to services (Adimora et al., 2006). Through household surveys and a photovoice study we previously conducted in low-income public housing communities in Durham, NC, we identified numerous structural barriers to sexual health service utilization, including lack of childcare, transportation, health insurance and other financial resources (Jones et al., 2018).

Despite the disproportionate burden of HIV among African American women and the structural factors limiting their access to prevention services, HIV prevention efforts including the rollout of pre-exposure prophylaxis (PrEP), a highly effective and woman-controlled prevention method (Baeten et al., 2012), have often overlooked them. Though women represented 19% of incident HIV infections in 2017, they represent only 10% of PrEP users (Giler et al., 2017), indicating the urgent need for efforts to promote equitable awareness of and access to PrEP in this population. To inform these efforts, we sought to understand women's knowledge of and attitudes toward PrEP through a venue-based community survey in Durham, NC. We sought to provide evidence of African American women's current knowledge of PrEP, to understand the extent to which awareness-raising campaigns may be needed in this population. Furthermore, we sought to understand key incentives and disincentives for PrEP use among African American women in low-income communities that might inform the development and tailoring of PrEP awareness campaigns and service delivery in this population.

METHODS

Study context

This community assessment survey was conducted in the context of Project IFE (I'm Fully Empowered; R34MH104081), a community-engaged study to adapt a CDC evidence-based HIV prevention intervention, called the Real AIDS Prevention Program (RAPP), for residents of Durham public housing communities. The brief surveys presented here were conducted to inform the adaptation of this intervention. Survey data were collected to provide information about women's knowledge of and attitudes toward HIV prevention approaches, including PrEP, among a community-based sample of the intervention target population. This study was conducted in census tracts previously identified to have elevated population HIV risk (Hodder et al., 2013).

Data collection methods

Three separate interviewers conducted surveys with 53 women recruited from community venues on a convenience basis in the neighborhoods surrounding 5 public housing communities in Durham, NC from February and March of 2018. Venues were selected using

a community mapping exercise carried out by our community academic partnership (CAP) during a monthly CAP meeting in which community members gave input into research methods. During this exercise, using enlarged maps of the target communities, community members worked in small groups to identify venues where women commonly visit, by placing markers on the maps. The final venues selected included shopping centers, beauty salons, a grocery store, a community college, and community and county health clinics.

Prior to data collection, flyers were posted in and around the selected venues to announce the dates that surveys would be conducted. To recruit participants on data collection days, trained research assistants approached each woman who appeared to be African American as she was approaching or leaving selected venue to invite them to answer a brief anonymous questionnaire about health programs. No names were collected.

All survey questionnaires were completed anonymously but women were asked to report their age in years and their racial/ethnic identity. Questionnaire topics included: best things about living in this community, community health concerns, community attitudes toward condom use, access to HIV testing, PrEP knowledge, and PrEP attitudes. All questions were posed in an open-ended short-answer manner and participant responses were recorded in writing by the interviewer verbatim. Regarding PrEP, participants were first asked “have you ever heard of PrEP?” For those participants who stated that they had heard of PrEP, they were asked to describe in their own words what PrEP is. Following this question, all participants were then provided with the following explanation of PrEP: “PrEP is a medication that helps HIV-negative people from becoming infected. It is a single pill that a person takes daily. It is FDA approved, safe, and shown to work. It gives women choice, privacy, and control over HIV prevention.” Following this explanation, participants were asked “would you take PrEP and why or why not?” Open-ended participant responses were recorded verbatim on a paper questionnaire form by the research assistant. Completing each questionnaire took approximately 5–10 minutes per participant.

Ethical Review

All study procedures were approved by the institutional review board of the University of North Carolina. To protect their anonymity, all participants provided verbal but not written consent before completing the questionnaire.

Analysis

Verbatim participant responses were entered into an Excel spreadsheet with a row for each participant and a column for each interview topic. For the PrEP knowledge questions, each participant was coded as responding either “yes” or “no” to the question “Have you ever heard of PrEP?” For those participants responding “yes” to this awareness question, the content of their explanation of PrEP was coded as falling into one of two categories: a) correctly identifying that PrEP is used for HIV prevention; or b) no specific knowledge (name recognition only) or incorrect/incomplete knowledge.

For the question “would you take PrEP and why?” women who replied “yes” or “maybe” to the question were coded as one group because even those women who responded affirmatively “yes” typically expressed a condition to their likelihood of using PrEP (e.g., I

would if I were having sex) thus responses of “yes” and “maybe” were judged to be qualitatively equivalent. Those responding definitively “no” were coded as a separate “no” category. Principle themes in participants’ responses to the question of why they would or would not use PrEP were identified across both “yes/maybe” and “no” coded participants as women in both categories sometimes provided incentivizing and disincentivizing motives for PrEP use regardless of the valance of their overall assessment of their likelihood of using PrEP. *In vivo* coding was used to characterize the reasons for or against PrEP use provided by each participant. These in vivo codes were then reviewed and clustered into the overarching topics presented below. Topics identified were excluded from presentation if they were represented in only one participant’s response.

RESULTS

53 women with an average age of 32 years old completed the questionnaire. All participants identified as female and as non-Hispanic African American. Table 1.

PrEP knowledge

Only 16 (37%) of respondents had ever heard of PrEP, with many of those having heard of it only having name recognition and no knowledge of the function of PrEP: Only 7 of the 16 of women who had ever heard of PrEP knew that it is used to prevent HIV infection. Of the remaining 9 women, 7 had no functional knowledge of PrEP or name-recognition only (e.g., “Can’t remember, it’s a medicine for something.”) and 2 shared incorrect or incomplete knowledge of PrEP’s use (e.g., “Yes, something [gay] men take to not give their partners AIDS.”).

Willingness/likelihood of using PrEP

Very few women (8) said that they would be categorically unwilling to use PrEP (“no”), with most women (45) expressing that they would use or would consider using PrEP under certain conditions or with specific additional information (e.g., safety information) about PrEP (“yes/maybe”). Of the 8 women who said they wouldn’t use PrEP (“no”), 3 gave no specific reason, 3 were worried about side effects or never take medications of any kind, and 2 shared that they were not at risk for HIV (“No, because I have a husband and I’m not sleeping around with everyone”).

The 45 women who said they would or might use PrEP most commonly cited a general interest in HIV prevention as the reason they would consider PrEP (17 women). Some of these women implied that they held this interest despite the fact that they perceived themselves to be at low personal risk of HIV infection (e.g., “you never know,” “to be on the safe side”). Another 9 women attributed their interest to the fact they often do not know the HIV status of their sex partner(s), with some women relating this to their perception that male partners may not be honest about their HIV status or about having other concurrent relationships, as this woman shares: “I think people would take the pill because there wouldn’t be too much worry about when you’re dating a guy that’s not truly honest in the beginning of the relationship.” Only 2 women attributed their interest in PrEP to a current perceived HIV risk (e.g., “Yes, ‘cause I have unprotected sex with my boyfriend.”). Nine of

the women in the “yes/maybe” category also described conditions in which they would *not* be interested in using PrEP. Five of these women said that they would not use PrEP if they didn’t believe themselves to be at risk of HIV infection. Another 2 women expressed concerns about possible side effects.

DISCUSSION

Awareness of PrEP was very low in this population of African American women living in low-income communities. Many of those who had ever heard of PrEP were unable to correctly identify what it is or that it is used for HIV prevention. However, when provided with an explanation of PrEP, the vast majority of women said that they would use or would consider using PrEP for HIV prevention, with the few who stated definitively that they would not use PrEP citing concerns about side effects and their low perceived HIV risk.

Our findings corroborate other studies of African American women in the Southern and Mid-Atlantic United States which have found similar low levels of awareness but high initial interest in PrEP use among African American women (Koren, Nichols, & Simoncini, 2018; Patel et al., 2019). To ensure equitable access to PrEP, efforts to promote African American women’s awareness of PrEP are a badly needed first step. Potentially promising awareness-raising strategies include peer education (Kwakwa et al., 2018), mass media campaigns (Bond & Ramos, 2019), and social media communication. As self, peer, or partner referrals may promote greater PrEP uptake than clinician referrals (Kwakwa et al., 2018), PrEP awareness raising among high-prevalence social and sexual networks may be the most effective strategy promoting PrEP uptake among those women who may be the most likely to benefit from it.

In addition to raising women’s awareness of PrEP, it is critical that we put in place accessible PrEP services for uninsured or underinsured women living in the South with poor access to health care. Some strategies that may be appropriate include pharmacy-based provision of PrEP (Farmer, Koren, Cha, Grossman, & Cates, 2019), or a mobile clinic model of distribution (Hill et al., 2014). None of these models have been tested to provide PrEP to this population to our knowledge, and such efforts should be undertaken. No matter the delivery strategy, the results of this study highlight the importance of helping women to evaluate their level of HIV risk to assess appropriateness of PrEP use.

Limitations

The results of this study should be interpreted with key limitations in mind. Women were recruited for interview on a convenience basis, thus the sample cannot be said to be representative of the target population of African American women living in Durham, NC. As we did not assess participants’ HIV risk, the study sample is not necessarily representative of women at greatest HIV risk in the study neighborhoods. Furthermore, because women received only a brief explanation of PrEP before responding to questions about their interest in PrEP, their responses and reasoning provided were based on more limited information and consideration than would have available in a clinical setting. Finally, interviews were conducted face to face in public settings, thus participant responses may have been susceptible to social desirability bias.

Conclusions

The results of this study indicate that PrEP interest is likely to be high in this population of African American women living in low-income communities, but that awareness campaigns are greatly needed to promote women's awareness of this new tool for HIV prevention. Awareness campaigns about PrEP should include basic information about the side effects of PrEP, and accessible PrEP delivery models should include tools and provider trainings to conduct HIV risk assessments for women expressing an interest in PrEP.

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Table 1.

Descriptive Statistics (n=53)

	n (%) or mean [range]
Age	31.6 [18–63]
Black/African American	53 (100%)
PrEP knowledge	
Ever heard of it	16 (37.2%)
Knows used to prevent HIV infection	7 (16.3%)
Would use PrEP	
Yes/Maybe	45 (84.9%)
No	8 (15.1%)
Reasons would use PrEP *	
Interested in HIV prevention	17
Partner(s) HIV status unknown	9
Believe are at risk for HIV	2
Reasons would not use PrEP *ɬ	
Side effects	5
Not at risk for HIV	7

* reasons included cited by at least 2 participants

ɬ includes reasons from both participants who said they would or would not use PrEP