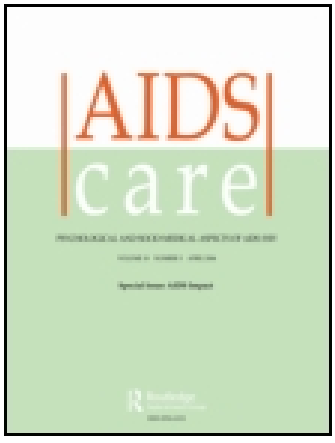

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"Getting tested is almost like going to the Salem witch trials": discordant discourses between Western public health messages and sociocultural expectations surrounding HIV testing among East African immigrant women

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"Getting tested is almost like going to the Salem witch trials": discordant discourses between Western public health messages and sociocultural expectations surrounding HIV testing among East African immigrant women

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Washington, DC, has the highest AIDS diagnosis rate in the USA, and Black women are disproportionately affected. Although HIV testing is the first entryway into vital treatment services, evidence reveals that foreign-born blacks have a lower rate of recent HIV testing than US-born blacks. To date, however, there are no studies that examine the culture-specific perceptions of HIV testing among East African immigrant women (who comprise a large share of Black Africans in DC) to better understand their potential barriers to testing. Adopting the PEN-3 cultural model as our theoretical framework, the main objective of this study was to examine East African women's HIV testing perceptions and partner communication norms. Between October 2012 and March 2013, trained interviewers conducted a total of 25 interviews with East African women in the Washington, DC, metropolitan area. For triangulation purposes, data collection consisted of both in-depth, semi-structured interviews and cognitive interviews, in which participants were administered a quantitative survey and assessed on how they interpreted items. Qualitative thematic analysis revealed a systematic pattern of discordant responses across participants. While they were aware of messages related to Western public health discourse surrounding HIV testing (e.g., Everyone should get tested for HIV; One should talk to one's spouse about HIV testing), divergent sociocultural expectations rooted in cultural and religious beliefs prevailed (e.g., Getting an HIV test brings shame to the person who got tested and to one's family; it implies one is engaging in immoral behavior; One should not talk with one's spouse about HIV testing; doing so breaks cultural norms). Implications of using a culture-centered model to examine the role of sociocultural expectations in HIV prevention research and to develop culturally responsive prevention strategies are discussed.

Keywords: HIV prevention; HIV testing; East African; immigrant women; qualitative; PEN-3 cultural model

Black women in Washington, DC, are disproportionately affected by HIV, representing 92.4% of all women living with HIV, and heterosexual transmission is the most common mode of acquiring HIV (District of Columbia Department of Health, 2011). Alongside this high HIV incidence among Black women, the Washington, DC, metropolitan area represents a part of the country with a Black African immigrant population (Wilson, 2012), which comprises 161,000 African-born immigrants or approximately 3% of the area's total population (Wilson, 2012). One of every five black African immigrants is from Ethiopia, which accounts for 19% of the total African immigrant population (Wilson, 2012).

Although HIV testing allows infected individuals to learn their status and is the first entry way into vital treatment, studies suggest that, in DC, between one-third and one-half of people who are HIV seropositive are unaware of their status (Institute of Medicine, 2010). Further, a recent study in DC found that foreign-born Blacks are more likely than native-born Blacks to be diagnosed with AIDS within one year of their HIV diagnoses, suggesting that they are testing late in the course of their infection (Willis et al., 2013).

To date, there are few studies that examine the HIV testing perceptions of East African immigrant women (who comprise the largest share of Black Africans in Washington, DC) to better understand their potential barriers to testing. Data that might shed light on unique barriers to HIV testing encountered by African immigrant communities are often aggregated with data of all "blacks" or "African-Americans" without reporting ethnicity or country of origin. This can often lead to inconsistent or incomplete data (Johnson, Hu, & Dean, 2010; Kerani et al., 2008). Efforts to engage East African immigrant women in HIV prevention initiatives will be hindered if there is limited understanding of their culture-specific perceptions of HIV testing. The aim of the current qualitative study, therefore, was to examine the HIV testing perceptions and partner communication norms among East African immigrant women using a culture-centered theoretical framework.

Theoretical framework

The organizing framework that guided this study was the PEN-3 cultural model, which was developed to examine

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the role culture plays in addressing health behaviors and decisions (Airhihenbuwa & Webster, 2004). Culture in this context refers to shared values, norms, expectations, and codes that collectively shape a group's beliefs, attitudes, and behavior through their interaction in and with their environments (Airhihenbuwa & Webster, 2004; Figure 1).

Situating public health discourse surrounding HIV testing

Discourse refers to socially referenced ways, or discursive frames, of talking, interpreting, and representing and is framed by ideology (Mulwo, Tomaselli, & Francis, 2012). In the context of public health discourse, the Western ideology of individual responsibility for health and health behaviors leaves out of the discourse the *sociocultural* expectations within immigrant communities, which may impact members' health behaviors and decisions. Sociocultural expectations are defined as group identity-based beliefs that are not explicitly codified but rather implicitly understood and disseminated through social interaction with other community members (Sofolahan & Airhihenbuwa, 2013).

Furthermore, health behavior models based on the rational-choice concept assume that people are free to make individual rational choices (Amaro & Raj, 2000) and neglect to capture implicit sociocultural and gender expectations. For example, a study with Cape Verdean immigrant women revealed that a woman negotiating condoms with her partner implies that the woman's partner is not sexually exclusive and signals distrust, disrespect, or infidelity (Anonymous, 2007). Current public health programs surrounding HIV testing leave out the cultural discourse related to HIV testing of different immigrant communities. This study, therefore, foregrounds the voices of East African immigrant women to understand their cultural discourse surrounding HIV testing perceptions and partner communication norms.

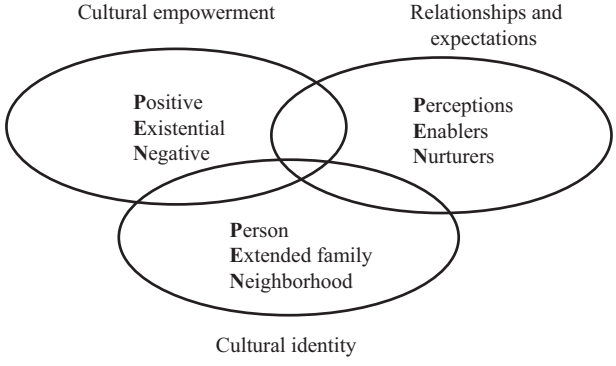

Figure 1. The PEN-3 cultural model.

Methods

Between October 2012 and March 2013, trained interviewers conducted a total of 25 interviews with East African women in the Washington, DC, metropolitan area. For the purposes of triangulation, we conducted both in-depth, semi-structured interviews (n = 20) and cognitive interviews (n = 5), in which we asked participants to respond to a quantitative survey and assessed how they interpreted each item. Cognitive interviewing is a valuable technique to ensure questions capture intended concepts (Beatty & Willis, 2007). The study sample comprised 25 East African women (from Ethiopia, Eritrea, Kenya, Tanzania, and Uganda) between the ages of 18 and 49 who resided in the Washington, DC, metropolitan area.

This study was part of a larger community-based participatory research project in collaboration with *The Women's Collective* (a DC-based nonprofit community health service agency that serves mainly low-income Black women living with or at risk for HIV). For the purposes of this article, the findings related to HIV testing perceptions and partner communication norms of East African immigrant women are reported. Approval for this study was obtained from the American University Institutional Review Board.

Adopting a nonprobability maximum variation sampling technique, trained female recruiters invited women who met eligibility criteria to participate in this study. Trained interviewers conducted hour-long in-depth, semi-structured qualitative interviews in English, except for one, which was conducted in Amharic. Sample interview questions related to the three domains of the PEN-3 model cultural identity, relationships and expectations, and cultural empowerment (Airhihenbuwa & Webster, 2004) can be found in the Appendix.

For the cognitive interviews, we asked participants to rate survey items using a 5-point Likert scale to assess the level of agreement or disagreement with items related to HIV knowledge, attitudes, and perceptions; the barriers and facilitators to testing; and HIV communication norms. We then asked the participants pre-scripted questions related to comprehension of survey items as well as open-ended probing questions based on the information that they provided. A sample survey item included the following: My family would support me if I decided to be tested for HIV.

Given the potentially sensitive nature of signing formal documents, interviewers obtained verbal informed consent from those who were willing to participate in the interview. A brief demographic questionnaire was also collected following the interviews to assess age, education level, income level, geographical residence, and other relevant variables. Participants received a gift card worth $40 as an incentive.

Data analysis

The interviewers transcribed the interviews, and the second author checked them for accuracy. One of the interviewers first transcribed and then translated the Amharic transcript to English. The transcript was then back-translated for accuracy. Using ATLAS.ti 7, the investigators used qualitative thematic analysis to analyze the interview data. Results were validated through the use of multiple independent coders, triangulation of emerging codes across interviews, and the search for negative cases (Corbin & Strauss, 2008). Following code revision, an interrater reliability of 94% was achieved. To see if this agreement was due to chance, the intercoder reliability was tested using Cohen's kappa (Bernard, 2000). The overall kappa coefficient was 0.96.

To ensure validity, the lead author conducted four member-checks with the project Community Advisory Board (CAB) and two member-checks with smaller subgroups of women who did not participate in this study but possessed similar sociodemographic characteristics as the sample. We identified the data's core meanings, searched for relationships among themes, discussed points of disagreement, and identified areas of further research. Consensus was reached on key themes related to HIV testing perceptions.

For the cognitive interviews, two levels of analysis were performed (Mehrotra, 2007): (1) within-interview analysis, to examine potential problems with survey items based on cognitive responses of respondents (e.g., Does the respondent understand the survey item as intended?); and (2) across-interview analysis, to examine patterned differences and similarities across respondents as well as provide insight into the sociocultural factors that impact the response process (e.g., Do East African respondents make meaning of survey items in similar ways?).

Results

Table 1 summarizes the sociodemographic characteristics of the study sample.

Three salient themes emerged as described below. The data from the in-depth, semi-structured interviews and the cognitive interview data converged, revealing a systematic pattern of discordant responses between public health messages and *sociocultural* expectations across participants. The findings are organized in accordance with the three primary domains of the PEN-3 model (Table 2).

Domain 1: Relationships and expectations

This domain focuses on the influence of sociocultural expectations on perceptions and behaviors related to HIV testing. In this way, individual HIV testing is examined as a function of broader social cultural contexts (Airhihenbuwa & Webster, 2004).

"*Everyone should get tested for HIV*"

All participants agreed that getting tested for HIV was an important mechanism to stop the spread of the virus. As an Ethiopian stated: "Being responsible and taking care of one's health is important. Everyone should get tested for HIV." Similarly, during the cognitive interviews, all participants strongly agreed or agreed with the survey items that supported HIV testing (e.g., Anyone who is tested for HIV is smart).

"*One does not need to get tested for HIV if one is following sociocultural expectations*"

However, when further probed during the in-depth interviews about when they themselves last got tested, conflicting responses emerged. An Ethiopian described: "When you're in a monogamous relationship, you do not need to get tested. I do not feel like I need to get tested." Despite many of them having had female family members die of AIDS, from their perspective, there is no need to get tested for HIV if one is following the expectations of their culture.

A similar response pattern emerged with the cognitive interview data. While they agreed with survey items related to HIV testing, when probed further, they stated that they would rate the items differently depending on whether they were talking in general/hypothetical terms versus more personal/concrete terms. For example, participants shared that, in general, they believed getting an HIV test is a smart thing to do because everyone should know their status to protect themselves. However, they also stated that HIV testing was not relevant to them personally because they were either unmarried or were in a monogamous relationship.

Domain 2: Cultural empowerment

Culture as an instrument of empowerment is born of the belief that culture represents the continuum of values and relationships ranging from positive which promote HIV testing, existential which pose no threat to health, to negative which impede HIV testing (Airhihenbuwa & Webster, 2004).

"*One's friends/family/community would be supportive if one decided to get tested for HIV*"

Participants described how they thought their family, friends, and community would be supportive if they learned that the participant got an HIV test. An Eritrean described: "I don't think any sort of friction would arise if they know I

Table 1. Sociodemographic information of East African immigrant women in Washington, DC, metropolitan area (n = 25) collected during October 2012 to March 2013.

Participant (pseudonym)	Age	Education level	Employment status	Annual household income	Marital status	Health insurance	Religion
Abeba	40	High school or less	Unemployed	$5K–$24,999K	Single	Government program*	Orthodox Christian
Berhane	29	Associate's/bachelor's degree	Employed	$25K–$49,999K	Married/in relationship	Private**	Other Christian
Desta	24	Graduate degree	Employed	$50K plus	Single	Private**	Orthodox Christian
Fannah	28	Some college, no degree	Unemployed	$5K–$24,999K	Married/in relationship	Government program*	Orthodox Christian
Jazarah	36	High school or less	Unemployed	$5K–$24,999K	Single	Government program*	Orthodox Christian
Kelyle	49	Associate's/bachelor's degree	Employed	$25K–$49,999K	Married/in relationship	Private**	Orthodox Christian
Lishan	25	Graduate degree	Employed	$50K plus	Single	Private**	Other Christian
Magdala	26	Some college, no degree	Employed	$25K–$49,999K	Single	Private**	Orthodox Christian
Mandera	38	High school or less	Unemployed	$5K–$24,999K	Single	Government program*	Orthodox Christian
Negasi	20	Some college, no degree	Employed	$25K–$49,999K	Married/in relationship	Private**	Other Christian
Nuru	20	Some college, no degree	Unemployed	$5K–$24,999K	Other	Government program*	Non-Christian
Adongo	22	Graduate degree	Employed	$25K–$49,999K	Married/in relationship	Private**	Other Christian
Dembe	46	Some college, no degree	Employed	$5K–$24,999K	Married/in relationship	Government program*	Orthodox Christian
Gonza	22	Some college, no degree	Employed	$50K plus	Single	Private**	Other Christian
Kabiite	21	Associate's/bachelor's degree	Employed	$25K–$49,999K	Other	Private**	Orthodox Christian
Kisembo	34	Some college, no degree	Employed	$25K–$49,999K	Single	Private**	Orthodox Christian
Nangoma	30	Some college, no degree	Employed	$25K–$49,999K	Single	Private**	Orthodox Christian
Setimba	34	Associate's/bachelor's degree	Employed	$25K–$49,999K	Single	Private**	Orthodox Christian
Himaya	47	Associate's/bachelor's degree	Employed	$50K plus	Other	Private**	Orthodox Christian
Tuliza	29	Some college, no degree	Unemployed	$5K–$24,999K	Single	Government program*	Other Christian
Umija	34	Associate's/bachelor's degree	Employed	$50K plus	Single	Private**	Orthodox Christian
Usia	22	Associate's/bachelor's degree	Employed	$50K plus	Married/in relationship	Private**	Orthodox Christian
Zuri	29	Some college, no degree	Employed	$25K–$49,999K	Married/in relationship	Private**	Other Christian
Winda	49	Associate's/bachelor's degree	Employed	$50K plus	Married/in relationship	Private**	Orthodox Christian
Zawati	33	Some college, no degree	Unemployed	$5K–$24,999K	Married/in relationship	Government program*	Other Christian

*Government program: Medicaid/Medicare.
**Private health insurance: employer-based or self-bought.

Table 2. Overview of themes based on the three primary domains of the PEN-3 Cultural Model.

	Domain 1: Relationships and expectations	Domain 2: Cultural empowerment	Domain 3: Cultural identity
Western public health message	*"Everyone should get tested for HIV"*	*"One's friends/family/ community would be supportive if one decided to get tested for HIV"*	*"One should talk to one's spouse about HIV testing"*
	Versus	Versus	Versus
Sociocultural expectations	*"One does not need to get tested for HIV if one is following sociocultural expectations"*	*"Getting an HIV test brings shame to the person who got tested and to one's family; it implies one is engaging in immoral behavior"*	*"One should not talk with one's spouse about HIV testing; doing so breaks cultural norms"*

Source: Airhihenbuwa and Webster (2004).

got tested. I think they would be open." Similarly, during the cognitive interviews, all participants strongly agreed or agreed with the survey items that related to social support surrounding HIV testing (e.g., My family would support me if I decided to be tested for HIV).

"***Getting an HIV test brings shame to the person who got tested and to one's family; it implies one is engaging in immoral behavior***"

However, when asked probing open-ended questions (e.g., May you share with me an example of how someone you know who got an HIV test was viewed in your community?), the responses conflicted with their earlier responses. As a Kenyan stated:

> Getting tested is almost like going to the Salem witch trials. The witches are doers of all evil, it is a metaphor of everything they have done wrong. Especially if you are not supposed to be having sex because you are not married, they assume that is the only way you can get it.

Similarly, a Ugandan shared: "I think people don't want to be judged by the community. Getting an HIV test brings shame to the family."

A similar pattern emerged with the cognitive interview responses. When probed further, participants disclosed that if individuals in their ethnic community found out about a woman getting tested for HIV, they would look down on the woman and her family, assuming that her getting an HIV test meant that she had engaged in immoral behavior (i.e., sex before or outside of marriage).

Domain 3: Cultural identity

In this domain, we examine how HIV testing communication is produced through multiple identities that are manifested in women in the contexts of their spousal relationships, families, and communities (Airhihenbuwa & Webster, 2004).

"***One should talk to one's spouse about HIV testing***"

Participants stated that they thought talking with one's partner about HIV testing is important. As a Kenyan stated: "My spouse and I need to be big on talking about testing and it's not only for HIV, but for everything just to make sure that we are in perfect health at all times." During the cognitive interviews, all participants strongly agreed or agreed with the survey items that related to communication with spouse about HIV testing (e.g., I would discuss HIV testing with my partner/spouse).

"***One should not talk with one's spouse about HIV testing; doing so breaks cultural norms***"

However, when asked probing open-ended questions (e.g., Have you ever discussed HIV testing with your spouse? How did the discussion go?), conflicting responses emerged. As an Ethiopian stated: "Asking a partner is something that never happens. Like that topic of saying: 'Let's get tested together' has never happened. I think it's just that you do not do this in my culture." The cognitive interview responses revealed a similar pattern. Participants shared that talking with their spouse about HIV testing was not necessary or appropriate given that they were in a monogamous relationship.

Discussion

Qualitative thematic analysis facilitated the identification of important themes across the interviews. Triangulation of data from the qualitative interviews and the cognitive interviews revealed a systematic pattern of discordant responses across participants. While East African participants were aware and able to express messages related to Western public health discourse surrounding HIV testing, they also expressed divergent sociocultural expectations that were rooted in cultural and religious beliefs. Participants believed that if one is following their

community's sociocultural expectations (e.g., being in a monogamous relationship), then HIV testing is unnecessary or inappropriate as is talking with one's spouse about HIV testing. Furthermore, choosing to get an HIV test or communicating with one's spouse about HIV testing is not only going against sociocultural expectations, but it also implies that one is engaging in "forbidden" behavior, which is shameful to oneself and one's family. Consistent with the PEN-3 model, these sociocultural expectations were implicitly understood and influential in shaping East African women's HIV testing perceptions and communication norms.

While most health behavior models assume that people are free to make individual rational choices (Amaro & Raj, 2000), East African women's narratives are steeped in cultural and social meanings; therefore, it is pertinent to address the cultural context that informs their HIV testing behavior. Furthermore, within a community context of silencing and secretiveness surrounding HIV testing behavior, some of the participants shared how getting tested or even talking about getting tested is culturally taboo. The women face a divergence between public health discourse related to HIV testing which dictates what they should do and the prevailing cultural ideology that is innate to them from their own home culture.

This research study was the first of its kind to investigate East African women's HIV testing perceptions and partner communication norms using a culture-centered theoretical framework. Despite the limited generalizability, this study was innovative and contributed to extant literature in that it generated new and in-depth knowledge related to HIV testing and East African women in the Washington, DC, Metropolitan area. Other strengths of this study include the use of a community-based, participatory research approach, method triangulation, the use of multiple coders to check reliability, and member-checking with the CAB and subgroups to ensure data validity.

Study findings have implications for the development of effective HIV prevention strategies. For instance, the findings suggest the importance of adopting a culture-centered approach in developing effective and culturally-imbued HIV prevention messages. Indeed, studies using the PEN-3 model demonstrate how cultural context matters when developing interventions focused on addressing health behaviors (Airhihenbuwa & Webster, 2004). Whereas many of the conventional health behavior theories often focus on the individual to promote change, the PEN-3 cultural model offers a culture-centered approach to health that extends analysis to other contexts that either facilitate or constrain health decisions (Airhihenbuwa & Webster, 2004). For example, based on our study findings, it is clear that the way East African women perceive their HIV testing is rooted in relationships and interactions characteristic of their culture. The PEN-3 cultural model helps to focus research and intervention development on the role of the relationships and collective (e.g., couple, family, and community) in influencing health behaviors.

Existing studies with other immigrant groups also challenge the assumption that promoting preventive health behavior is solely the function of individual responsibility. For example, studies conducted with Mexican women demonstrate that male spouses play an important role in influencing their wives' adherence to breast and cervical cancer screenings (e.g., Thiel de Bocanegra, Trinh-Sheyrin, Herrera, & Gany, 2009). Another study conducted among South Asian women revealed that families influenced women's health and health-seeking behavior (Grewal, Bottorff, & Hilton, 2005). Taken together, our study findings illustrate that these East African women's HIV testing behavior cannot be decontextualized as their decision-making power resides within their broader couple-family-community context.

Furthermore, study findings have implications for routine testing in clinical and nonclinical settings. Our findings underscore that the potential stigmatization within family/community contexts related to HIV testing among these women is of greater concern than possible individual-level advantages of HIV testing. Thus, a focus on individual behavior alone without addressing the interpersonal and community contexts may limit the success of routine HIV testing interventions with these groups.

In conclusion, study findings provide important insights related to HIV prevention with East African women. First, a focus on individual behavior alone at the exclusion of the cultural context may limit the effectiveness of HIV prevention interventions with immigrant women. An essential ingredient for promoting HIV testing is an understanding of not only individual-level factors but also need to address the couple, family, and community networks. Efforts to effectively promote and expand HIV testing and early treatment will be critical for achieving the goals of the US National HIV Strategy.

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Disclosure statement

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Appendix. Sample interview questions related to the three domains of the PEN-3 model

Domain and associated categories	Sample questions
Relationships and expectations	
• Perceptions	– Can you share with me an example of how someone you know who got an HIV test was viewed in your community?
• Enablers	– How would you feel if family members knew that you were tested for HIV?
• Nurturers	– Do you think religious beliefs affect how you think about HIV testing? If so, how?
Cultural empowerment	
• Positive	– Do you think members in your community feel that getting an HIV test is important? Why or why not?
• Existential	– What first comes to mind when you hear the word HIV testing?
• Negative	– Do you think of different types of abuse (e.g., sexual, emotional, verbal, or physical) when you think of being at risk for HIV? If so, how?
Cultural identity	
• Personal	– Do you talk to your partner about HIV testing? If yes, how did the discussion go? If not, why not?
• Extended Family	– Does your family talk about HIV at all?
• Neighborhood	– Do you "see" HIV prevention messages in or around DC that promote HIV testing for African immigrant women? (for example, in the metro, ads on the streets, in the newspapers, etc.)