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## Getting HIV self-test kits into the home for young African American MSM in Los Angeles: A qualitative report

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## Abstract

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### Disclosures

The authors report no real or perceived vested interests that relate to this article that could be construed as a conflict of interest.

Expanded access to HIV self-testing has the potential to increase the number of young adult African American men who have sex with men (MSM) who are regularly aware of their HIV status (Krause, Subklew-Sehume, Kenyon, & Colebunders, 2013; Marlin et al., 2014). Because African American MSM communities have the highest HIV risk rate of all risk groups, regular testing behaviors are essential for HIV prevention (McNairy & El-Sadr, 2014; Young et al., 2015). Yet, stigma toward HIV has been shown to be particularly high in these communities, which in turn decreases willingness to test for HIV (Earnshaw, Bogart, Dovidio, & Williams, 2013; Mahajan et al., 2008). Advances in HIV testing, including self-testing, may reduce HIV stigma by making the testing experience private and self-controlled (Sharma, Stephenson, White, & Sullivan, 2014; Stephenson, White, Darbes, Hoff, & Sullivan, 2014); however, the ability to make testing private may be difficult for young adults who live with family. Therefore, we explored the feasibility of HIV self-testing at home by conducting focus groups with young adult African American MSM who live in Los Angeles County.

### Keywords

families; HIV self-testing; young Adult African American men who have sex with men (MSM)

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## METHODS

### DESIGN

The study was approved by the University of California Los Angeles Institutional Review Board. We utilized interpretative phenomenological analysis to understand the feasibility of HIV self-testing in the home. Interpretative phenomenological analysis focuses first on understanding individual or group meaning-making of a phenomenon, such as a health issue, and second on the application of the researcher's expertise to interpret this meaning in context (Sutton & Austin, 2015). We collected data on participant perceptions of barriers and facilitators for self-testing in their homes. We then drew upon our knowledge of HIV self-testing and this community to interpret the data to inform future efforts to implement HIV self-testing with this population (Davtyan, Farmer, Brown, Sami, & Frederick, 2016). We focused our study on young adult, African American MSM living in Los Angeles neighborhoods because regular HIV testing is low in this high-risk community (Krause et al., 2013; Marlin et al., 2014).

### SETTING AND SAMPLE

The study was conducted in a community center for lesbian, gay, bisexual, and transgender (LGBT) youth of color between June 2014 and January 2015 in Los Angeles and used a purposive sampling method to recruit participants (Clark et al., 2013). Participants were required to live in Los Angeles, speak English, identify as an African American MSM, and be 18–35 years of age. A key informant, who was a member of the community organization and familiar with the community as a whole, recruited participants for the study. Each participant was randomly placed in one of two groups of 10 or 11 people. Participants provided written consent prior to completing focus group activities and were given a gift card (\$25 USD) for their study participation.

## FOCUS GROUP DISCUSSIONS

We used a semi-structured focus group protocol that addressed feasibility using three domains: (a) experiences with current HIV-testing modalities (mobile, clinic-based, or community-based); (b) perceptions of and experiences with HIV self-testing; and (c) barriers to and facilitators of using HIV self-test kits in the home (Charmaz, 2004; Taegtmeier et al., 2013). Across these domains, we were interested in understanding how participants defined and perceived social support and barriers for HIV prevention, testing, and care within their communities, and how those factors influenced uptake of HIV self-testing in their homes. Two researchers conducted the focus groups with one facilitating the discussion and the other taking field notes on participant social interactions, engagement, and emotions. Each focus group discussion lasted about 1.5 hours, was conducted in English, and was audio-recorded and transcribed.

## DATA ANALYSIS

We analyzed the transcripts using a constant comparison approach that allowed themes to develop iteratively (Horter et al., 2017; Mitchell et al., 2016). Two researchers coded the transcripts separately, and then all researchers met to discuss the coded transcripts and field notes to identify feasibility themes for using HIV self-testing in the home for African American MSM in Los Angeles (Njau et al., 2014).

## RESULTS

Twenty-one individuals participated in the study. Of these, 17 were 18–25 years of age and 4 were 25–35 years of age. Two major themes about what influenced the feasibility of HIV self-testing at home were identified.

### THEME 1: ENGAGING COMMUNITY THROUGH LEADERSHIP

Participants discussed that implementing HIV self-testing would require community tailored messaging to engage community leaders to work with MSM and their families. Participants wanted community leaders to support and talk about self-testing with MSM in their communities. This approach would build on shared values and understanding of HIV in their communities. As one participant explained:

I would like to see testing change, and this, I don't know how this could happen. But, I would like to see testers look more like me in terms of people havin' more people of color who are testers and getting people tested, and more younger people who can talk the same language that I talk...I think there's a divide [with current HIV testing practices] and I think that conversation can be different.

Another participant elaborated by stating, "The content would be amazing because they would finally feel a need, and then it would also take a lot of the stigma that has to go around with people getting a test." Participants stated that current HIV testing practices were not culturally specific and did not consider the intersections of age, race, and language. This lack of inclusivity sustained stigma that participants thought limited the perceived need for testing in the MSM community. HIV self-testing would benefit from promotions that

appealed to the sense of trust and familiarity within these communities. Community leaders could assist by evoking trust from their communities to reduce HIV testing stigma.

## THEME 2: ADDRESSING FAMILY COMMUNICATION

While there was support for targeted promotion to the African American MSM community, there was a common concern that a family member would find out they were using a self-test kit. This concern negatively impacted participant acceptance of using an HIV self-test kit. As one participant stated, “You got to worry about comin’ to your family, then you got to worry about goin’ to get this big ol’ test, your momma findin’ this thing under the bed. What’s to say, it’s so, I mean...” Participants discussed the challenges of hiding the self-test kit in their homes and its potential discovery by family members. They expressed concerns about their abilities to explain the test kit to family members given the directions provided. Also, there was discussion on gossip reaching a family member if a kit were purchased, that the postman “could tell their family members.” Participants wanted their family members to support HIV testing, but they didn’t feel their family members understood why it was so important. However, community leaders were seen as potential brokers here, as well:

I was to even come and want to be tested or anything like that, like I did, I would come, ‘cause [X as community leader] is older since I was younger, so if I was to get that result like, “You’re positive,” I would rather hear it comin’ from [X] because [X] knows me, knows my mom, knows my family. So, it would be easier for me to kind of take that result, you know what I mean?

It was important to participants that community leaders were familiar with HIV self-testing because they could talk with their family members if a test kit was discovered in their homes or if a participant tested positive using an HIV self-test kit.

## DISCUSSION

We found that community leaders and families influenced the feasibility of HIV home self-testing among young African American MSM. Our findings suggest a potential causal pathway characterized by a two-step process that involved community leaders and families.

The first step in this causal pathway is introducing self-testing to the broader African American community with the assistance of community MSM leaders. These leaders were seen as essential due to their work in building bridges around health and social issues both within and outside the African American community. Similarly, a recent study also found that the broader community, including churches, was essential to HIV prevention efforts that targeted young African American MSM (Powell, Herbert, Ritchwood, & Latkin, 2016).

While participants recognized HIV self-testing as valuable to their own health, they wanted community leaders to promote self-testing through education activities that directly spoke to both the general African American community and the MSM community within it. They believed that the first step toward feasibility of home self-testing was the education of the general African American community to scaffold subsequent conversations about home self-testing with family members.

The second step in the causal pathway is the use of community leaders to broker self-testing with families. Because self-testing was a new technology for this group, community leaders were perceived to be more effective at explaining and justifying this testing process to families; however, there had to be a community conversation about self-testing first so that community leaders could introduce the idea to individual MSM families. Family connectedness was an important issue for participants, similar to a previous study that found that family connectedness was a factor in reducing HIV infection for young MSM (Garofalo, Mustanski, & Donenberg, 2008). Participants believed that family discovering self-testing kits could further isolate them from their families and communities, exacerbating the stigma experience.

It was perceived that a two-step process, that started with community education and led to family education about self-testing, would reduce the effects of stigma so that individuals would actually use an HIV self-testing kit in their homes and use it openly rather than in secret. Interventions that target these two steps may reduce HIV infection rates among young African American MSM.

## IMPLICATIONS

We found that collaboration between families and community leaders might improve uptake of HIV self-testing technologies; however, more research is needed to confirm and explicate our posited causal pathway. Participants in our study wanted to communicate with their families about HIV testing; integrating family communication tools into the test kits may, therefore, be beneficial to users. Further studies are needed to identify best practices for kit users when communicating with their families.

## LIMITATIONS

The results of our study were from a small sample of African American MSM who participated in a local community-based organization. Results are, therefore, not generalizable to all African American MSM in Los Angeles County; however, our findings complement results from studies that have shown the importance of family members in MSM decision-making about HIV testing, including home self-testing (Garofalo et al., 2008).

## CONCLUSION

HIV self-testing kits have the potential to increase the numbers of African American MSM who know their HIV status and subsequently receive treatment and reduce transmission in the community. Home self-testing may be facilitated by community leaders who can educate both the general community and individual MSM families.

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