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Men “missing” from population-based HIV testing: insights from qualitative research

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ABSTRACT

Men’s uptake of HIV testing is critical to the success of “test and treat” strategies in generalized epidemics. This study sought to identify cultural factors and community processes that influence men’s HIV testing uptake in the baseline year of an ongoing test-and-treat trial among 334,479 persons in eastern Africa (SEARCH, NCT#01864603). Data were collected using participant observation at mobile community health campaigns (CHCs) ($n = 28$); focus group discussions ($n = 8$ groups) with CHC participants; and in-depth interviews with care providers ($n = 50$), leaders ($n = 32$), and members ($n = 112$) of eight communities in Kenya and Uganda. An 8-person research team defined analytical codes and iteratively refined them during data collection using grounded theoretical approaches, and textual data were coded using Atlas.ti software. Structural and cultural barriers, including men’s mobility and gender norms valorizing risk-taking and discouraging health-seeking behavior, were observed, and contributed to men’s lower participation in HIV testing relative to women. Men’s labor opportunities often require extended absences from households: during planting season, men guarded fields from monkeys from dawn until nightfall; lake fishermen traveled long distances and circulated between beaches. Men often tested “by proxy”, believing their wives’ HIV test results to be their status. Debates about HIV risks were vigorous, with many men questioning “traditional” masculine gender norms that enhanced risks. The promise of antiretroviral therapy (ART) to prolong health was a motivating factor for many men to participate in testing. Flexibility in operating hours of HIV testing including late evening and weekend times along with multiple convenient locations that moved were cited as facilitating factors enhancing male participating in HIV testing. Mobile testing reduced but did not eliminate barriers to men’s participation in a large-scale “test & treat” effort. However, transformations in gender norms related to HIV testing and care-seeking are underway in eastern Africa and should be supported.

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HIV testing; antiretroviral therapy; ART; gender; men; sub-Saharan Africa

Background

An estimated 35 million individuals are living with HIV globally (Joint United Nations Programme on HIV/AIDS, 2013). Over the past decade, prevention and treatment efforts have been successful in decreasing HIV incidence and mortality. However, over 2 million new infections occurred in 2013 and HIV-related morbidity and mortality remain high (UNAIDS, 2014). “Universal HIV test-and-treat” strategies hold great potential for reducing HIV transmission and reducing morbidity

and mortality in the context of a generalized epidemic (Granich, Gilks, Dye, De Cock, & Williams, 2009). The effectiveness of such strategies depends upon broad HIV testing uptake, expedient linkage to care and consistent engagement in care including adherence to antiretroviral therapy (ART) among HIV-positive individuals. Challenging this potential is the historically low uptake of HIV testing and poor linkage to care among men compared to women, particularly in sub-Saharan Africa (Mitchell, Cockcroft, Lamothe, & Andersson, 2010; Staveteig, Wang, Head, Bradley, & Nybro, 2013). To explore gender,

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cultural factors, and community level processes that influence men's HIV testing uptake, we implemented a qualitative study embedded in a large-scale, ongoing test-and-treat trial in eastern Africa.

Methods

Study design

A longitudinal qualitative research study is embedded within an ongoing HIV test-and-treat trial of 334,479 persons in eastern Africa (the Sustainable East African Research in Community Health study – SEARCH, NCT# 01864603). SEARCH is a community cluster-randomized controlled trial in 32 communities of approximately 10,000 persons each in three regions in Kenya and Uganda, in which all communities received a community census and population-wide HIV testing at baseline. SEARCH uses a hybrid mobile HIV testing approach in which 2-week multi-disease community health campaigns (CHCs) are followed by home-based testing (HBT) of CHC non-participants (Chamie et al., 2016).

A qualitative study is being implemented in 8 of the 32 communities across the three regions, consisting of four pairs of rural intervention and matched control communities in southwestern Uganda (Kazo and Nya-muyanja), eastern Uganda (Kameke and Kadama), and western Kenya island (Tom Mboya and Sena) and inland areas of the Nyanza region (Ongo and Othoro). For this paper, qualitative research methods were used to identify cultural factors and community-level processes that influenced HIV testing uptake, and in particular to elucidate the gendered patterns of participation in testing, in the baseline year of SEARCH trial implementation.

Data collection

Multiple qualitative data collection modalities were used to triangulate findings. Data were collected using in-depth semi-structured interviews (IDI) with cohorts of community leaders, community members, and service providers; focus group discussions (FGD) with CHC participants, and participant observation (PO) exercises at CHC campaigns. Baseline qualitative data were collected from February through November 2014 (Table 1), by three 2-person research teams in each of the regions. Team members were fluent in local languages and were trained in qualitative data collection and analysis methods by the Lead Investigator. Consistent with human subject research guidelines in Kenya and Uganda, participants were offered the equivalent of

Table 1. Methods, samples, and data sources by region (baseline year of SEARCH).

| Methods and samples/sources | Kenya | Uganda Southwest | Uganda East | Total <i>n</i> |
|---|-------|------------------|-------------|----------------|
| IDIs with community member cohort | 56 | 28 | 28 | 112 |
| IDIs with community leader cohort | 16 | 8 | 8 | 32 |
| IDIs with healthcare provider cohort | 28 | 12 | 10 | 50 |
| FGDs with CHC participants (<i>n</i> = 8–12 per FGD) | 4 | 2 | 2 | 8 |
| PO at CHCs | 8 | 12 | 8 | 28 |

IDI, in-depth interview; FGD, focus group discussion; CHC, community health campaign; PO, participant observation.

approximately U.S. \$4.00 to reimburse costs of participation. The team members prepared field notes from PO exercises and transcriptions, and translations of audio recordings of IDIs and FGDs into English for analysis.

Sample selection

Three longitudinal qualitative cohorts were established from December 2013 through January 2014 and recruited to participate in annual IDIs: a community leader cohort, community member cohort, and HIV care provider cohort. The sampling methods for each cohort differed, and are described here:

- *Community leader cohort* (*n* = 32). Four community leaders in each of the eight communities were purposively selected from a list of leaders of each community. Leaders included members of Local Councils (LCs), Village Health Teams (VHTs), and opinion leaders within the community who were actively engaged in mobilization efforts.
- *HIV care provider cohort* (*n* = 50). Providers were purposively selected from a list of providers of HIV services at the government health facilities serving SEARCH patients, including in-charges, clinical officers, nurses, and peer counselors.
- *Community member cohort* (*n* = 112). A sample of community members participating in a household socioeconomic sub-cohort within the SEARCH study were randomly selected for recruitment to a community member cohort from the following strata in each community: HIV negative (*n* = 5), and HIV positive with CD4 cell count >500 cells/microl (*n* = 3), participants who had initiated ART (*n* = 3), and ART-eligible participants who were not linked to HIV care services (*n* = 3) in each of the eight communities at the time the sample was recruited. The sample was designed to interface with a combination

of residents who had tested at CHCs (approximately 70% of the sample) and those who had tested via HBT (approximately 30% of the sample).

- *Focus groups* ($n = 8$ groups). The team conducted FGD in cross-sectional purposively selected samples of participants in CHCs. Ten to twelve FGD participants in each community were purposively sampled at CHC exit stations by research team members, who systematically selected members according to sampling categories of age group (youth and adults), gender, and time of arrival at the CHC. At these same CHCs, research team members conducted *PO exercises* ($n = 28$).

Data analysis

Data collection team members were trained and engaged to participate in coding and interpretation of data, in collaboration with the Lead Investigator. Team members prepared and loaded translated transcript and field note documents into Atlas.ti software for coding and interpretation. An initial analytical code list was defined by the 8-person research team under the guidance of the Project Leader, on the basis of the initial empirical data, and theories that guided the development of the instruments. As new data were added and reviewed, this analytical code list was reviewed and iteratively refined by the team members, in accordance with principles of Grounded Theory (Charmaz, 2006). Code query reports related to the research questions were generated and reviewed, and emergent themes in the data for this paper were summarized.

The study received human subject's research and ethical approval from the University of California at San Francisco Committee on Human Research, the Ethical Review Committee of the Kenya Medical Research Institute, the Makerere University School of Medicine Research and Ethics Committee, and Uganda National Council for Science and Technology. In this article, pseudonyms are used.

Results

Prior analysis of data on HIV testing coverage in the first year of SEARCH showed that overall, men engaged in

HIV testing at high rates under the SEARCH hybrid testing strategy (HIV testing coverage of 86% among men) but were less likely than women to participate in testing (92% HIV testing coverage among women). Additionally, men were more likely than women to engage in HBT than testing at a visible CHC (Table 2) (Chamie et al., 2016). Analyses of IDI, FGD, and PO data for this study revealed a range of structural and cultural barriers to men's participation in the study's hybrid HIV testing approach that included mobile CHCs and home-based HIV testing (HBT) for campaign non-attendees (Table 3.) These barriers were especially salient for men's participation in testing at CHCs and present in the HBT, which proved to be an important alternative testing opportunity for many men. Emergent themes related to men's participation in the test-and-treat trial's HIV testing strategy are noted in the findings presented below.

Structural barriers to men's participation in HIV testing

Among the multiple dimensions of barriers to participation in HIV testing at CHCs for men, structural barriers related to the livelihood strategies available to men in rural Uganda and Kenya, and the mobility associated with those strategies. In some settings and during certain seasons, informal sector labor opportunities for men often required extended absences from rural households. This qualitative study's findings confirmed that as in many regions in sub-Saharan Africa, households in rural eastern Africa rely on a mix of livelihood strategies that usually involve at least periodic mobility of some of its members. Agricultural labor performed by men did not necessarily lead to their being nearby to their rural homesteads; in some areas, fields were cultivated on nearby mountaintops. Whether nearby or distant, men who engaged in this labor often could not leave fields to attend CHCs, especially during planting season. In both interviews and discussions and FGDs, participants noted that newly planted seedlings needed to be guarded by men from dawn to nightfall, otherwise they would be destroyed by monkeys (monkeys, one male participant

Table 2. Sex differences in HIV testing by mode of outreach.

| | Enumerated stable population | CHC-based testing coverage | HBT coverage | Hybrid testing (CHC + HBT) coverage |
|-------------------------------|------------------------------|----------------------------|--------------|-------------------------------------|
| Stable adult residents: total | 149,906 | 104,635 (71%) | 26,672 (18%) | 131,307 (89%) |
| Men | 66,726 | 42,622 (64%) | 14,771 (22%) | 57,393 (86%) |
| Women | 80,180 | 62,013 (77%) | 11,901 (15%) | 73,914 (92%) |

CHC, community health campaign; HBT, home-based testing.

Source: Chamie et al. (2016)

Table 3. Barriers to men's participation in testing, among SEARCH study participants (illustrative quotes).*Structural barriers: Men's livelihoods*

- Fishermen who returned to shore at daybreak slept all day, and those who fished during the day were away from dawn to nightfall. As one participant noted, "many men leave at 6 a.m. for fishing ... they would be back to the house at 7 p.m" (Male FGD participant, Tom Mboya).
- "He told me, "Most men are in the gardens harvesting millet, ground nuts and maize. Some of them just fear testing" (Participant Observation field notes, Kadama).

Narratives of entrenched gender norms

- "Men are generally lazy ... 'I am already infected and still want to show my male ego without considering my family' ... many men as well are not ready to take up HIV test and would push their partners to go first and rely on their results" (Male youth Focus Group Discussion (FGD) participant, Sena).
- "As men we have a lot of fear ... Men also like giving excuses, that they are ever busy in the name of searching for the family, even if they have gotten this food that they are ever looking for [laughter]" (Male adult FGD participant, Sena).
- "Many men believe that medical issues are women's affairs" (Male adult FGD participant, Ongo).
- "Men are people with hardened hearts. They will hardly rush for any program. They can release their wives and children first to go, and for him, he assesses before going" (Female adult FGD participant, Kameke).

Debates and questioning surrounding gender norms

- "Interviewer: You have mentioned that most people do not test as couples; please tell me more about this?"
- A good percentage of men are not faithful. It is men who would even end up enrolling for HIV care at a very far facility. Men should change and be free to test as couples so as to build trust. They should stop frustrating their women as well. [Female adult participant]
- Gender based violence is real and rampant in this community. This is so because there is no family dialogue to discuss family issues. I do dialogue in my house but when I introduced the HIV topics, many started avoiding the dialogue" [Male adult participant], FGD Tom Mboya.

said, "do not respect women"; thus, women could not fulfill this function):

Men are too busy even for their own lives. The CHC timing for this community was not right, as well; this time is the planting season and people are really busy [...] After planting, they have to watch for monkeys not to remove already planted seeds. (FGD Sena)

Yet, even at other times, agricultural work was said to keep men away from CHCs: "they were busy in the gardens since it is harvest season". For men living in lake-shore communities and nearby, livelihoods generally include working in the fishing industry, as a boat owner, crew member, or broker. For these men, the requirements of maintaining livelihoods often led to their simply not being present in the community during CHCs. Yet, other activities, it was readily noted, also kept men away, whether or not these activities were seasonal or extraordinarily demanding: "Most men graze animals, some are occupied in the bars drinking alcohol, and others are businessmen. For those reasons men were reluctant to go for the health campaigns" (FGD Kameke).

The structural barriers to men's participation in testing were not, however, easily extricable from cultural barriers, notably the gender norms upheld in communities related to male gender role expectations to provide food for their families. This was reflected in many comments such as, "Men are involved a lot into family care and they are out searching for food. In most cases they are looking into how the family can survive, hence have less time for such events" (FGD participant, Tom Mboya). Indeed, participants joked about how these role expectations were often invoked by men as an excuse to avoid testing:

As men we have a lot of fear ... Men also like giving excuses, that they are ever busy in the name of searching for the family, even if they have gotten this food that they are ever looking for [laughter]. (FGD participant, Sena)

Cultural barriers related to gender

Data collected in interviews and discussions supported the finding that entrenched male gender norms acted against men's participation in testing. Care-seeking in general was often viewed as counter-normative for men (an activity of women and children); and clinics were said to be seen by men as "female spaces". Numerous narratives reflected perceptions that men viewed health care-seeking as an activity of women, illustrated by comments such as, "Most men are very poor in seeking medical attention; they are just pushed to go to the hospital when sick", "Men will only visit the hospitals when critically sick", and "Most men are out to take care of their families and they have to engage in hard work despite being sick, which normally cuts short their lives." Perhaps as a result of unfamiliarity with health care-seeking, even routine care-seeking could be intimidating, as illustrated by the following comments from FGDs:

I think we were just trying to look into why men are poor in seeking health services. One thing that we need to know about men is that they fear and don't like anything that troubles their mind, unlike women who can withstand a lot of conditions and can easily cope with different situations. I went to one health facility for an anti-tetanus injection having been pricked by a thorn; the nurse told me, "we have to test you for HIV first". This was a very wrong approach to give a man and I intentionally refused the HIV test. (FGD Othoro, author emphasis)

Male involvement in health issues is a national problem. Men are ready to provide finances but fail to personally avail themselves for the services. (FGD Sena)

Many men believe that medical issues are women's affairs. (FGD Ongo)

While men were seen to prefer to avoid seeking health-care services in general, testing for HIV was particularly fraught due to the associations of HIV with sexual promiscuity, and the concerns men had surrounding their potential risks due in part to marital infidelities. As a result, men often “test by proxy”, inferring their own HIV status from wives’ HIV test results. The following comments from both male and female participants are illustrative of this broad phenomenon:

In most cases it is men who do not want to test as couples and will urge their wives to test so that they learn their status from the wife’s test result. (IDI CC Kenya)

I have heard many men saying that once the wife has been tested and found negative, then they are “clean” as well. (FGD Ongo)

Men are generally lazy ... “I am already infected and still want to show my male ego without considering my family” ... many men as well are not ready to take up HIV test and would push their partners to go first and rely on their results. (FGD Sena)

Indeed, there were instances in which men whose female partners tested HIV positive assumed that they themselves were HIV positive – and, thus did not seek testing to confirm their status, until tracking efforts by study team members led to many finally obtaining HBT. These efforts were necessary in many instances to counter men’s fatalism surrounding their status, as illustrated by the following comment, “Many infected men argue that ‘a cow dies with grass in the mouth’” (FGD Sena).

Male gender norms in study communities operated to counter men’s health-seeking behaviors, and also valorized men’s sexual risk-taking. The moral insecurities both male and female participants expressed surrounding men’s extramarital affairs, were at times inextricable from stigmatizing narratives of blame for the epidemic, as illustrated in comments such as, “The men are so promiscuous – they are the ones that bring the disease” (FGD Kazo). Gendered power differences related to consequences for men and women of disclosure of HIV-positive status is summarized well by the following IDI comment: “Women are more disadvantaged, as they stand being separated from their spouses with all the blames attached on them. Men, on the other hand, fear their wives blaming them for the unfaithfulness.”

Yet, debates among men about HIV risks were vigorous, and there were indications that many men in the communities were questioning traditional masculine gender norms related to sexuality and sexual behavior. Many men also wanted to open up discussions with

women about HIV, but found it difficult. As one male participant noted,

Gender based violence is real and rampant in this community. This is so because there is no family dialogue to discuss family issues. I do dialogue in my house but when I introduced the HIV topics, many started avoiding the dialogue. (FGD Tom Mboya)

SEARCH intervention activities to promote men’s participation in HIV testing

SEARCH study investigators and implementers anticipated that engaging men in the study would prove more difficult than engaging women, and many of the design elements of SEARCH were directly aimed at promoting male involvement in testing. This was especially true of lottery incentives that were designed especially to attract men to attend CHCs, in which campaign participants have the opportunity to win relatively small prizes upon completing CHC activities. Initially, it was expected that men would be motivated to attend by a few “high value” lottery prizes such as bicycles, rather than by more widely distributed smaller lottery prizes. Over time, as data were collected and fed back to CHC implementers for each community, it emerged that, in some communities, the value of incentives was less important than a higher likelihood of winning prizes that were smaller but geared to men, such as gum boots, *pangas* (machetes), and radios. These changes were implemented in the subsequent CHCs according to the study’s pre-specified within-community implementation optimization procedures. Qualitative data provided evidence that the incentives did function as designed to increase men’s participation in HIV testing at the CHCs. The lottery incentives at CHCs appeared to act as a counter-influence on men’s preference for HBT over what they perceived to be more “public” testing at CHCs, and especially motivated young men who were seen to have been otherwise uninterested in the campaigns. This is illustrated in the following field notes excerpt:

... One of [the young men] who looks and acts as their leader concludes “the prizes are true!”, speaking loud as though making an announcement. He decides he is going to win the only bicycle and four other youth follow him plus the one who won the radio and they head towards the CHC. I follow them [...] and they say they also have to test so that they win something. Everyone we meet on the way comes to the group to see the radio that has been won. This motivates those who have not yet tested to quickly hurry to test and win prizes ... (PO field notes, Kazo)

Influence of the new era of HIV care and treatment on men's participation in HIV testing

Finally, qualitative data from IDIs and FGDs in the first follow-up year of SEARCH revealed a new emergent theme regarding men's motivations for participating in HIV testing. The positive benefits of ART to improve health became rapidly more apparent to community members, as many very ill community members recovered from acute illnesses, and many more HIV-positive individuals began to disclose their status and speak of the benefits of ART. Participants spoke about how the "good news" of ART gave men (*and* women) the courage to test, as illustrated in these comments:

The ARVs give peace, and the people may want to test more, because they are seeing how these ARVs are helping others. (Female, IDI, Kazo)

These people were also empowered by others who had started disclosing their status freely. It is something that is slowly catching up, and these days the infected approach the newly infected who are still in hiding, and they give them support by giving advices: "*just be free with your status, because the drugs work very well with those who have accepted their status and feel free to talk about themselves to others*" ... (IDI male Community Leader, Sena, author emphasis)

Discussion

In this qualitative study embedded within a large HIV test-and-treat trial, we found that mobile, population-wide HIV testing – via CHCs and HBT – reduces but does not completely eliminate barriers to male engagement in mobile community HIV testing. Key structural barriers to men's participation related to the livelihood strategies available to men in rural Africa, and the mobility associated with those strategies. Likewise, entrenched male gender norms acted against men's participation in testing, with care-seeking viewed as counter to masculine gender norms and social role expectations for men. Gendered power differences related to consequences of disclosure of an HIV-positive test status were also identified, but operated differently for men and women: HIV testing was inextricably linked for many men to insecurities related to their sexual freedom and worries about how to maintain marital relationships in the face of potential disclosure of an HIV-positive test result. Stigmatizing attitudes toward people living with HIV/AIDS persist and in many respects, these attitudes are linked to moral judgment and blaming of men for the spread of HIV. Yet, moral uncertainties and debates about HIV risks were vigorous among men. Despite the negative influences on male participation in HIV testing, countervailing influences of optimism toward the

effectiveness of HIV treatment in prolonging life, and discussions of a desire for changing of gender norms for men were observed among community participants.

The programmatic implications of these findings recognize that complex gender norms can operate as significant barriers to HIV diagnosis and care (Barker, Ricardo, Nascimento, Olukoya, & Santos, 2010; Dworkin, Fleming, & Colvin, 2015; Dworkin, Treves-Kagan, & Lippman, 2013; Small, Nikolova, & Narendorf, 2013). This study's findings are consistent with prior research demonstrating that while men's enactment of masculinity often results in personal advantage, these same constructs and associated behaviors concurrently serve to configure vulnerabilities for men in terms of HIV acquisition, engagement and retention in HIV care, and HIV-related mortality (Baker et al., 2014; Braitstein et al., 2008; Cornell, McIntyre, & Myer, 2011; DiCarlo et al., 2014; Hawkins et al., 2011; May et al., 2010; Mburu et al., 2014; Ochieng-Ooko et al., 2010; Skovdal et al., 2011). We caution that findings of this study are not necessarily generalizable to all populations throughout sub-Saharan Africa and that participants' accounts are potentially subject to recall and social desirability biases. Nevertheless, these findings contribute to a deeper understanding of contextual factors that can influence men's uptake of HIV testing and care services in eastern Africa.

Attention to the complexity and fluidity of masculinities and the tensions that men face in negotiating masculinity within today's context of changing gender dynamics and economic uncertainty is necessary for supporting men's health-seeking behavior. Opportunities exist for future interventions to build upon many men's desire to engage in more open discussions with their female partners about gender, sexuality, and health concerns. It will be crucial to identify ways to fully involve men in HIV testing and care in order to achieve the promise of universal HIV test-and-treat strategies.

Disclosure statement

No potential conflict of interest was reported by the authors.

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