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Engaging black sub-Saharan African communities and their gatekeepers in HIV prevention programs: Challenges and strategies from England

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Abstract

Objective: HIV infection is a sensitive issue in black communities [Serrant-Green L. Black Caribbean men, sexual health decisions and silences. Doctoral thesis. Nottingham School of Nursing, University of Nottingham; 2004]. Statistics show black sub-Saharan African (BSSA) communities disproportionately constitute two-thirds of people with HIV [Heath Protection Agency. Health protection report: latest infection reports-GOV.UK; 2013]. African communities constitute 30% of people accessing HIV treatment in the United Kingdom yet represent less than 1% of the population [Health Protection Agency. HIV in the United Kingdom: 2012 report; 2012], [Department of Health. DVD about FGM. 2012. Available from fgm@dh.gsi.gov.uk.]. This article explores the sociocultural challenges in engaging BSSA communities in HIV prevention programs in England and possible strategies to improve their involvement.

Methods: Twelve focus group discussions and 24 semistructured interviews were conducted in a 2-year period with participants from the BSSA communities and sexual health services in the West Midlands, England. The research was supported by the Ubuntu scheme, a sexual health initiative working with African communities in Birmingham, England.

Results: Ineffective engagement with African communities can hinder the effectiveness of HIV prevention programs. Skills and strategies sensitive to BSSA culture are important for successful implementation of prevention programs. HIV prevention programs face challenges including stigma, denial, and marginalized views within BSSA communities.

Conclusion: Networking, coordination, and cultural sensitivity training for health professionals are key strategies for engaging BSSA communities in HIV prevention programs.

Keywords: African communities; HIV prevention; gatekeepers

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Introduction

Black sub-Saharan African (BSSA) communities constitute two-thirds of people with HIV [1–3]. Thirty percent of people who are accessing HIV services in the United Kingdom today are from BSSA communities yet they constitute less than 1% of the total population [4, 5].

The social and cultural challenges affecting black and minority ethnic (BME) communities often hamper their engagement with sexual health promotion and HIV prevention programs in the United Kingdom. There is evidence that 'culturally unfriendly' sexual health services and programs result in some

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BME communities avoiding these services [6]. The term 'gate-keeper' is used within social sciences to refer to people who arbitrate access to a social role, setting, or structure. In this article, gatekeepers are influential people identified by BSSA communities themselves as community leaders, responsible for safeguarding the cultural, shared, and occasionally religious identity of the community. Gatekeepers are the primary contact for researchers seeking access to BME communities for the purposes of securing community engagement in their research.

Legislation and policies are important in improving and promoting healthier lifestyles and preventing diseases among BME communities [7]. Engaging BME groups in sexual health and HIV prevention may reduce the number of people presenting with sexual-health-related ailments at treatment centers [8].

Sexual health and HIV infection are culturally sensitive issues. Within BSSA communities, for example, they cannot be freely discussed [9, 10]. In addition, UK-based BSSA communities have been underresearched as they only became visible in the run up to the new millennium [11]. This poses a challenge for professionals working with BSSA communities in the United Kingdom. There is some consensus among sexual health professionals of the need to optimize health-seeking behavior in 'risk' groups, including understanding the impact of cultural issues and structural factors such as disadvantaged socioeconomic status [12]. There is therefore a need to increase sexual health professionals' knowledge of BSSA communities if health improvements are to be realized.

Many health systems attempt to address the cultural challenge of ethnic diversity by adapting existing generic interventions so 'one size fits all' without consideration of cultural factors [12]. However, culturally sensitive and socially acceptable interventions for BME communities need to be designed [13–15]. Currently in the United Kingdom, fundamental questions still remain pertaining to the appropriateness of sexual health and HIV prevention interventions for BME groups. What are the key factors to consider when these sexual health interventions are being developed? When the interventions are being developed, it is essential the BME communities in question are included, as advocated by the 1986 Ottawa Charter on health promotion initiatives.

More work is needed to identify the cultural norms likely to influence health-related behavior, and how specific target groups affiliate with these norms [16]. Simple modification of an intervention on the basis of culture may not necessarily increase its effectiveness [17]. There is a need to comprehensively map out the particular cultural aspects that should be factored into the intervention.

Sexual health professionals who lack the cultural competence to work with BME groups may find it difficult to optimize outcomes when trying to engage with the groups in question. Issues that have continued to undermine the delivery of health initiatives among BME communities, including BSSA communities, in the United Kingdom include (1) lack of information about existing services and fear of stigma and discrimination, (2) lack of culturally sensitive sexual health and HIV prevention interventions, (3) linguistic problems, (4) legal obstacles, (5) cultural and religious factors, and (6) migration policies. Few studies have investigated these issues to optimize BME sexual health outcomes within current health systems.

In BME communities living in the United Kingdom, including the BSSA communities, gatekeepers have always played an important role, controlling what goes in and out of the communities [18]. Sexual health professionals therefore need to acquaint themselves with the gatekeepers within BME communities to ensure that their sexual health messages and interventions can filter through to the communities in question, including access to their social systems [19].

This article explores the challenges, skills, and strategies in engaging BSSA communities and their gatekeepers in sexual health promotion and HIV prevention programs, using a community approach and focusing on the West Midlands in the United Kingdom.

Methods

This research was underpinned by the Silences Framework [10], which asserts that reality is not objective or fixed, but rather human beings are the authors of the social world in any society at a particular time [10, 20]. The framework emphasizes the importance of 'screaming silences' in individual and group interpretations of events and human experiences that can be viewed as 'truth.'

Screaming silences can be regarded as marginalized discourses that occupy identified research gaps [21]. In this article, discourses are explored in relation to gatekeepers' power to promote sexual health and HIV prevention among the BSSA communities of the West Midlands. The screaming silences relating to cultural practices and structures within BSSA communities are explored to ascertain the skills needed to help improve their sexual-health-seeking behavior.

A qualitative approach was adopted for the study, with use of focus group discussions and follow-up one-to-one semistructured interviews. Data were collected from BSSA communities resident in the cities of Birmingham, Coventry, and Wolverhampton in the West Midlands, areas with a high percentage of BSSAs communities. Purposeful sampling was used to select the study participants on the basis of location, sex, age, and origin to include BSSA men and women aged 16–60 years resident in the West Midlands [22].

Twelve focus group discussions were conducted, four in each of the three cities, with each focus group comprising 10 people, with an equal sex balance. Each focus group discussion was followed up with two one-to-one semistructured interviews. A further 12 one-to-one interviews were held with key informants, i.e., community/religious leaders (gatekeepers) split evenly by sex and location. A few potential participants declined to participate because of work commitments and discomfort with the subject; however, they were replaced by others from the same communities. The research was performed under the ethical supervision of the Sexual Health Promotion Service (National Health Service), Heart of England Foundation Trust, United Kingdom, and the University of Wolverhampton Research Ethics Committee.

All the research participants were identified and contacted through the BSSA community groups and local sexual health organizations in Birmingham, Coventry, and Wolverhampton. Participation was on a voluntary basis, and all participants gave written consent.

The participants discussed cultural issues concerning barriers to engaging with sexual health services and HIV programs in BSSA communities. They appraised and commented on current sexual health promotion strategies and HIV prevention

programs, suggesting opportunities for further development. The roles of the communities' gatekeepers were scrutinized, and strategies to engage them were discussed.

Focus group discussions and community leaders' interviews lasted 1 h, with the follow-up interviews lasting 30 min. All interviews and focus group discussions were audio-taped and transcribed verbatim, and the transcribed data were subjected to the following Silences Framework analytical phases [10]:

- *Phase 1.* Following transcription, outputs from interviews and focus group discussions were analyzed by the researcher, and recurrent themes were identified as initial findings.
- *Phase 2.* Phase 1 findings were then reviewed by research participants. Feedback on the early findings from the participants was used to enhance further critique, confirming or refuting the findings in phase 1. A robust discussion of the 'silences' (findings) was formulated.
- *Phase 3.* Further analysis of phase 2 findings was done in this stage by social networks of research participants. The participants in this phase were drawn from the BSSA communities that had not taken part in the interviews and professionals working in the sexual health promotion service. The aim was to buttress the findings from phase 2 with a critical indirectly associative eye.
- *Phase 4.* The researcher reflected on the findings of phase 3, revisiting, reviewing, and developing emerging research findings, which were then taken as the final output of this study.

Results

Analysis of the data identified challenges in engaging gatekeepers and BSSA communities and suggested strategies for optimizing engagement with sexual health and HIV services.

Challenges in engaging gatekeepers

The gatekeepers identified fear of losing status within, ownership of, or influence over the communities as a key concern. In addition, they asserted that they mistrusted many organizations that work in sexual health as they felt that they bring disharmony among the communities through misinformation. Religious leaders particularly felt that uncontrolled sexual health information could lead to communities being

contaminated with non-Christian/non-Islamic values, leading to a loss of respect for leaders. In the light of the assertion previously mentioned, one gatekeeper commented:

"Uncontrolled sexual health information in the community will lead to promiscuity and loss of respect for community leaders."

(Peter, male faith leader, aged ≥25 years).

The gatekeepers also agreed HIV infection was a very sensitive subject and was viewed as a taboo subject within the BSSA communities. Comments highlighted that African communities find HIV hard to discuss with members of the opposite sex, children, and young people as discussing it associated discussants with flawed characters deemed dangerous to young people:

"This is an uncomfortable subject to discuss; discussions such as this subject may be associated with a flawed character poisonous to the young generation."

(Choto, male community leader, aged ≥55 years)

Most of the community leaders felt that they were custodians of the communities, responsible for what goes in and out of the community. They saw this as protecting the community against stereotyping and falsehood. The leaders indicated that they were sensitive to issues around stereotyping. They believed that anyone performing sexual health work in the communities should be scrutinized by the leaders, to avoid misleading the community and spreading falsehood about sexual practice or stereotyping BSSA people:

"I am the custodian of the community and my obligation is to defend it against falsehood including unnecessary generalizations and stereotyping of negative issues.... No one wants to see their community being negatively portrayed with unfounded claims."

(Normara, male community leader, aged ≥45 years)

Stereotyping was a core issue for community leaders, who felt the image of the community must be defended and respected. They suggested that some sexual health issues should be avoided as they could damage the image of the community if they are

not well handled. They sometimes advocated censorship of sexual health information used to teach or work in BSSA communities in case the image of their community was tarnished:

"We need to guard against certain information being used in the community lest it promotes a negative picture about our communities. Once depicted in a negative light the community may never recover and will always be portrayed in a bad light."

(Chanda, male community leader, aged ≥55 years)

Community leaders and gatekeepers were suspicious about the teaching of sexual health to their communities. Religious leaders in particular felt that not all the teaching was good and some of it aimed to undermine the community's culture:

"Some of these sexual health teachings can be used to undermine our culture by bringing in those things as taboos in our culture. We need to filter all the sexual health matters taught in communities to make sure that the community is not contaminated."

(Jamu, male community leader, aged ≥35 years)

Some of this fear was underpinned by existing stigma around sexual health, especially HIV. The religious leaders tended to blame the people with from sexually transmitted infections (STIs) and HIV, and tried to give a religious explanation for the sexual health conditions:

"If people believe and live in the light of the Lord, then they do not worry about all these problems, God can deliver anyone from any ailments."

(Rita, female community leader, aged ≥55 years)

Challenges in engaging BSSA communities

Most of the research participants felt the current UK sexual health delivery system was culturally unfriendly and there were a number of things that put them off engaging with the services:

"There are so many things that go against my culture in the service, for example being examined by men in a

treatment room. I feel so embarrassed. Or having two people to examine me, it is so embarrassing, you feel there is no confidentiality."

(Rhoda, African woman, aged ≥50 years)

Participants openly expressed fear of being discriminated against, especially when their HIV-positive status was discovered. Some questioned why organizations wanted to talk to them about HIV, and even felt they were being targeted because they were 'Africans' living abroad. Some research participants believed that they were being targeted in the way that they had been during the colonial days back home in Africa:

"I don't believe that this is a genuine call to test Africans for HIV and STIs. This is mere targeting of our communities, we know it. We experienced it back home during the colonial days."

(Sando, African man, aged ≥35 years)

Furthermore many of the participants agreed that the sensitivity of sexual health and HIV within African communities was never highlighted as it was not prioritized in the community agenda. They felt this marginalization arose because of sensitivity and taboos about it in the communities:

"No one wants to talk about sexual health and HIV; people are discouraged from talking about it as it is seen as taboo and sensitive."

(Rudo, African woman, in her late 30s)

This was further underpinned by most of the research participants, who indicated they were not comfortable discussing issues around STIs and HIV because of the stigma attached to them within their communities. However, there were others who felt that, despite the stigma, there was a need to discuss sexual health and HIV, as they affected African communities much more than other communities. This sense of stigma was evident in both the communities and the sexual health delivery system:

"I would like very much to address the issues of HIV and sexual health but the huge stigma attached to it makes me uncomfortable to discuss it. It is the African communities that

are mostly affected and there is need for action. This stigma is not only limited to our communities but also extends into services where we are supposed receive treatment."

(Mandla, African man, aged ≥45 years)

Participants acknowledged that there was a lot of denial among African communities with regard to HIV and sexual health, leading to many people taking a long time to go to get tested, let alone take the prescribed medication. They also felt that denial caused many people to disengage with the services and any initiatives pertaining to sexual health and HIV. They asserted that many people affected by HIV often tried to find an alternative explanation for their sexual health and HIV condition.

Skills and strategies for engaging BSSA communities

Some participants expressed how African communities have other needs apart from those to do with sexual health, some of which can overshadow their ability to engage with sexual health and HIV services. They also indicated a preference for one-stop services and advocated the networking of different services to provide such a facility:

"We also have other needs that need to be addressed apart from the sexual health needs; these needs can affect our ability to cope with other needs if they are not addressed. We would prefer a one-stop service where we can get different services, meaning that there is a need for organizations and professionals providing services to network in order to make referrals easy."

(Chanda, African man, aged ≥25 years)

Most of the research participants felt that, unlike other BME communities in the United Kingdom, BSSA communities only became visible in the run up to the new millennium, meaning that they were not well established. Some advocated coordinating events within the communities, also indicating that they would want to be involved in the initiatives, as opposed to just getting instructions:

"Our communities are not well established in this country, we are still new, we therefore want a lot of assistance

in organizing ourselves, and we also want to be involved in carrying out the tasks ourselves so that we can learn rather than being told what to do."

(Sasha, African woman, in her late 30s)

Culturally sensitive services were important to participants. The view of the participants was that they would prefer a sexual health intervention sensitive to their culture in case they found it difficult to participate in the initiative. Some of the areas singled out for consideration included appropriate questioning and issues of confidentiality, bearing in mind the cultural implications:

"I would prefer sexual health interventions which take into cognizance my culture lest I find it difficult to participate. I would also prefer appropriate questions which do not encroach into my private life alongside confidentiality as reflected in my culture."

(Kamba, African man, aged ≥40 years)

Discussion

The overall findings identified improper engagement of gatekeepers and BSSA communities themselves hinder delivery of sexual health and HIV prevention programs. Furthermore, skills and strategies sensitive to the culture of the BSSA communities are vital for professionals attempting to build a robust comprehensive sexual health and HIV prevention program.

The findings suggest that engagement of community leaders/gatekeepers and BSSA communities could facilitate delivery of sexual health and HIV prevention programs. Community leaders lacked trust in the organizations that work in sexual health, fearing they would bring disharmony among their communities through misinformation. In light of this, there is a clear need for sexual health practitioners to gain the trust of community leaders/gatekeepers and work to remove or restructure any aspects that may infringe on the practices of the community [12].

Among the community leaders and members there was a shared consensus about protecting their communities against stereotyping and 'peddling of falsehood.' It is therefore important that practitioners and community representatives agree on the content and resources to be used so as to avoid misunderstanding and blocking of information. It would also

help community leaders/gatekeepers and BSSA community members to feel that they are part of the initiatives and own them [23].

Although some of the community leaders believed certain issues associated with sexual health and HIV needed to be avoided, in case they damaged the image of the communities, the implications for sexual health practitioners are to clearly articulate the importance of discussing sexual health and HIV matters, showing how they have adversely affected the African communities [24].

Both community leaders and community members were suspicious of sexual health teaching in the communities and viewed it as undermining their culture. It is thus imperative that sexual health practitioners declare their objectives and intentions to the communities at the outset of the program to help dispel any suspicions around the subject.

There were issues raised about the stigma surrounding sexual health and HIV such that some of the participants advocated avoiding the subject. It is important, however, for the sexual health practitioners to emphasize the positive gains and benefits to the community of confronting the stigma [25]. Practitioners need to engage all communities in this and help facilitate a supportive environment for effective sexual health delivery.

Culturally unfriendly services and fear of discrimination were also noted by community members as signifying the importance of soliciting feedback from communities about their culture. Appropriate questioning needs to be used by sexual health practitioners to avoid their embarrassing people as well as to keep them engaged with the services. Denial was one of the common problems acknowledged; it is important for sexual health practitioners to continue to explain to the communities the facts about HIV and sexual infections, including how they can be prevented.

The consensus among research participants for a one-stop service for all their needs highlights the importance of sexual health practitioners being able to network with other organizations providing the different services, so that sexual health clients can be easily referred to them, thereby building confidence and easy access to the system. This strategy has already proved effective with a project called Ubuntu in the Sexual Health Promotion Service (National Health Service) in Birmingham, where an African forum has been established [26].

Coordination is another important skill identified for the delivery of sexual health and HIV prevention programs among BSSA communities. Unlike other well-established communities, the BSSA communities became visible in the United Kingdom only in recent years and need a lot of help with organization. Sexual health practitioners with good coordinating skills can therefore help to enhance the delivery of sexual health programs among BSSA communities.

Finally, most of the research participants agreed that cultural sensitivity was vital for the delivery of a sound sexual health initiative. This is another key attribute that sexual health practitioners need to master if they are to succeed in providing a robust and comprehensive sexual health and HIV prevention program among ethnic minority groups of BSSA origin.

The research suggests that there are considerable challenges in trying to engage the BSSA communities and their gatekeepers when sexual health and HIV prevention programs are being delivered. A skills audit is therefore important for all professionals working with the social group in question, and there is a need to regularly review key strategies used to deliver the service. Most importantly, constant engagement with the ethnic minority groups is necessary to understand the social changes and contemporary issues affecting them in terms of accessing sexual health services.

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