

Exploring the enablers and impact of Internalized HIV Stigma Among Black Sub-Saharan African (BSSA) Men in the East Midlands Region, UK

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BACKGROUND: Black Sub-Saharan African (BSSA) population are disproportionately affected by HIV compared with the total UK population. The latest data shows an increase in HIV public health authorities to engage with these communities to combat the spread of HIV infection in their community and the wider population infections among BSSA communities. It is therefore important for public health authorities to engage with these communities to combat the spread of HIV infection in their community and the wider population. This research aim is to explore the impact of internalised HIV stigma (IHS) among BSSA men in Nottingham. A more evidence-based approach in dealing with sexual health issues of the BSSA community is therefore needed.

METHODS: The silences framework and hegemonic masculinity theories were adopted as guiding theoretical frameworks for this study. The Silences Framework neither helps to understand that reality is never objective nor fixed, but rather

subjective, and human beings define their social world from their lived experiences. Hegemonic Masculinity, it is used in this research to explain health issues relating to men. It seeks to establish the fact that men, in general, are in denial about their health-seeking behaviours.

RESULTS: The study found that perceived HIV stigma, blame through ignorance, religion, gender and culture competency were enablers of internalised HIV stigma among BSSA men. These HIV stigma enablers also impacted the BSSA men's sexual health seeking behaviour.

CONCLUSION: There is a need to engage with BSSA men and support them to mitigate the enablers and impact of internalised HIV stigma. Such an initiative can increase the uptake of sexual health and HIV services among BSSA men whose reception to sexual health and HIV messages has been reported as low.

Key Words: BSSA; IHS; Hegemonic masculinity; Silences framework

Abbreviations: BSSA: Black Sub-Saharan African; HIV: Human Immunodeficiency Virus; IHS: Internalised HIV stigma; ART: Antiretroviral therapy; NAT: National AIDS Trust; EQA: Exploratory Qualitative Approach

INTRODUCTION

Although the black Sub-Saharan African (BSSA) population makes up only about 1% of the overall UK population, it accounted for almost 30% of all new HIV diagnoses in 2012 in the UK [1]. This means that they are disproportionately affected by HIV compared with the total population. Furthermore, their potential to benefit from available treatment and care is limited by many factors, such as late diagnosis, stigma and discrimination, unemployment, poor living conditions and uncertain immigration status for some [2]. The Framework for Sexual Health Improvement in England (2013) highlighted the need to put the sexual health of the BSSA communities as a matter of priority [3]. A more evidence-based approach to dealing with sexual health issues of the BSSA community is therefore needed. Evidence shows that HIV remains a significant infectious disease with profound implications for co-morbidity and the cost of treatment and care [4-10]. Since the introduction of antiretroviral therapy (ART) in the early 90s, there has been a significant reduction in HIV mortality in the UK. However, there is less cause for optimism as the above applies only to those who are diagnosed and take up treatment in good time to benefit from treatment [5]. BSSA communities continue to bear the brunt of this estimates that there are 101,600 people living with HIV in the UK, and around 1 in 12 of them do not know that they have the virus. Although the UK is on course to achieve the UNAIDS GLOBAL 90-90-90 targets, more work needs to be done to scourge [6]. The National AIDS Trust (NAT) encourage uptake in testing and diagnosis among the BSSA community whose members have been identified as presenting late for treatment [7]. Moreover, figures from Public Health England [8] show that black African men and women comprise 38% of heterosexual adults with a new HIV diagnosis, even though these groups account for a relatively small proportion of the overall UK population. Some civic groups, including the NAT, (2014) have called for the abolition of a generic approach to sexual health services in England and Wales and advocated establishing a more targeted approach for most affected communities and social groups [9]. Despite the introduction of NICE (2011) guidelines aimed at encouraging these specific sexual health services, the absence of any statutory obligations for health

authorities provide bespoke sexual health services to specific communities means that the implementation of NICE guidelines remains optional [10]. There are high stigma and discrimination within many BSSA communities; this has resulted in the reduced uptake of HIV testing treatment [11]. Both Avert, [7] and UNAIDS, [12] noted that a consequence of HIV stigma is the discrimination of being perceived as HIV positive. Therefore, it is important that both the impact and concept of HIV stigma are fully understood in order to deal with these effects. Although HIV-related stigma is widely recognised as a barrier to both HIV prevention and engagement with HIV care, little is known about the mechanisms through which stigma leads to worse health behaviours or outcomes [13].

In addition to the exercising of power, stigma can be a response to the fear or threat of a disease that is incurable and potentially fatal [14]. According to this analysis, the more rapid the spread of the disease and the greater the uncertainty of how the disease is transmitted, the more likely that stigma will result. This can be potentially be equated to how Covid-19 is currently being perceived in communities. Moreover, epidemics that present an overt threat to the values of a community are especially likely to evoke stigma because stigma is used to enhance or secure social structuring, safety and solidarity, as well as reinforcing societal or community values by excluding so-called divergent or deviant individuals [15]. Mbwambo et al. [16] also concurred that stigma related to medical conditions such as HIV/AIDS is highest when the condition is associated with deviant behaviour or viewed as the individual's responsibility. This illness-related stigma becomes particularly strong when the illness is associated with religious beliefs and morally sanctionable behaviour [17]. Stigma is evident when the condition is unalterable, incurable, severe, degenerative, and leads to readily apparent physical disfigurement or an undesirable death [17,18]. The latest data shows an increase in HIV infections among BSSA communities [19]. It is therefore important for public health authorities to engage with these communities to combat the spread of HIV infection in their community and the wider population [11]. Thus, there is a need to identify the social and structural factors that perpetuate not only the construction but also the continued existence of HIV stigma within the BSSA communities.

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Sexual health services need to obtain reliable and up-to-date information about factors affecting sexual health decisions among the BSSA community, to enable them to address the challenges of HIV [11]. Historically, sexual health disparities among ethnic minorities have been researched using a quantitative methodology [20]. While this method has managed to provide vital information required to identify groups of particular sexual health illness, it falls short of explaining both the causes and factors relating to the sexual health of these groups [20,21]. In light of this gap, there is a need to undertake more research using a qualitative approach that seeks to understand sexual health issues from the lived experiences of those affected with HIV. This research, whose aim is to explore the impact of internalised HIV stigma (IHS) among BSSA men in Nottingham, contributes to the research on wider sexual health issues concerning BSSA men by involving them in the discussion relating to internal stigma and sexual health matters.

RESEARCH METHODOLOGY

Theoretical frameworks underpinning the study

The Silences Framework [22] and 'Hegemonic Masculinity' theories were adopted as guiding theoretical frameworks for this study. As Serrant-Green [22] rightly pointed out, 'screaming silences' is applied to a sexual health and ethnicity context and provides a useful basis for a theoretical framework for researching sensitive issues of the healthcare needs of marginalised populations. Screaming silences define areas of research and experience which are little understood, researched or even silenced. Silences denote the unshared or unsaid aspects of how beliefs, values and experiences of some groups affect their health and life chances [22]. These aspects, are crucial parts of the jigsaw, helping to understand issues of internalised HIV stigma among the BSSA men in Nottingham. More importantly, the Silences Framework helps to understand that reality is never objective nor fixed, but rather subjective, and human beings define their social world from their lived experiences [23]. Hegemonic Masculinity, it is used in this research to explain health issues relating to men. It seeks to establish the fact that men, in general, are in denial about their health-seeking behaviours [24]. Beliefs and behaviours associated with contemporary issues of hegemonic masculinity include the denial of vulnerability or weakness, physical and emotional control, the appearance of being robust and strong, dismissal of any need for help, as well as the display of aggressive behaviour and physical dominance [25]. Such characteristics of men could potentially account for some of the behaviours underpinning the health problems confronting them. For instance, the belief in invulnerability could lead to a lack of concern for risk, and the need to appear in control could militate against seeking assistance.

Research paradigm

This research study employed an exploratory qualitative approach (EQA). As with all exploratory research methods, the intention here was merely to explore the research questions to offer a better understanding of issues rather than offering final and conclusive solutions to existing problems [26]. Moreover, this approach was appropriate as it was felt that the problem relating to internalised HIV stigma among BSSA men in Nottingham has not been researched and clearly understood. The EQA is grounded within the interpretivist/constructivist paradigm that dismisses the notion of a single reality but holds that people understand the world through the meaning they give to their experiences [27]. It is therefore appropriate that a qualitative method is used for this study.

Research Setting

The research took place at the Umoja African Centre (UAC) in Nottingham. This is a community centre run by the African community in Nottingham and was a natural choice to collect data from participants for two reasons. First, this was the BSSA men's natural setting where participants would be free to take part, given the sensitive nature of the subject within the community. Secondly, the environment was not manipulative or controlling for the participants [27]. The research participants were made up of men from the BSSA communities in Nottingham. Nottingham has become home to people from different parts of the world, including the BSSA communities.

Inclusion Criteria and study sample

It was necessary to draw up inclusion and exclusion criteria, as it was impractical to survey every man from the BSSA community because of the sheer large number of people. A purposive sampling approach was adopted to select the study participants based on origin, sex, age, number of years in Nottingham as well as excluding those from health profession. The age restriction to above 18 was done to meet the widely accepted age of majority

in the UK and many other African countries [11]. The term 'black' was used with specific reference to race to make a distinction from other races of sub-Saharan origin which, upon inclusion, would have altered the outcome of the study. A total of 6 focus groups comprising of 10 men each were held, N=60. Each focus group was followed by 2 one-to-one semi-structured interview, N=12.

Recruitment and ethical consideration

After an approval letter was signed by the chairperson of the UAC to facilitate the research on their site, a meeting was organised with the help of Umoja to explain to prospective participants the purpose of the study. The Umoja chairperson acted as a contact for the participants and details of the researchers were also provided for those that wished to have direct contact. Participants were also offered the chance to ask any questions they might have, after which participant information sheets were distributed to those who had indicated to take part in the study. They were also asked to sign the consent form.

The Nottingham Trent University Social Sciences Ethics Committee granted ethical approval for the study.

Data analysis

A thematic approach underpinned by the four phases of the TSF [22], was utilised to analyse the data. In phase 1, the researchers analysed the data by putting it into emerging themes and supporting it with captions from the focus groups and one to one interview. In phase 2, the researchers took the draft from phase 1 to the research participants for them to confirm or refute the analysis by the researchers. In phase 3, the draft from phase two was subjected to a user's voice. This was a group of people who mirrored the participants but did not take part in the research study. This was to subject the findings to an associative eye for validation. Finally, in phase 4, the researchers refined the themes in light of feedback from the previous stages, and the findings were taken as the final output of the study.

RESULTS

The study found that perceived HIV stigma, blame through ignorance, religion, gender and culture competency were enablers of internalised HIV stigma among BSSA men. These HIV stigma enablers also impacted the BSSA men's sexual health seeking behaviour.

Perceived HIV Stigma

Most participants agreed on their understanding of the perceived personal nature of internalised HIV stigma, including the shame associated with being HIV positive and the fear of being discriminated against.

"It is best to keep your HIV status to yourself without telling anyone because as soon as people know about your status, then that's it. Many of your family will reject you and even your close friends do not want to see you anymore." (Natty 31-year-old, married).

"Everything becomes negative once that disclosure is known in the community. It's like you are given a new name called 'HIV' because that is what everybody would associate you with. Everything else about you is forgotten apart from the fact that you are HIV positive." (Foster 25-year-old, single).

Perceived blame through ignorance

The lack of knowledge and understanding of HIV/AIDS as a 'building block' of internalised HIV stigma was highlighted during the research by most participants. Participants acknowledged that HIV/AIDS has all the characteristics associated with heavily stigmatised medical conditions.

"In our community, if you are HIV positive, people think of you as someone indulging in prostitution. As you know, prostitution is viewed badly, and the community tend to blame you when you end up being HIV positive. People do not look at the underlying causes of prostitution, they are quick to make judgements." (Smart 33-year-old, living with a partner).

"In our community, many people think you can transmit HIV by touch or just being near someone who is positive. There is a need to educate our people about the disease. Once they know you are HIV positive, even the food you cook may not be acceptable. I mean, this is real, you hear others say, 'accept his offers at your own risk'. With HIV, you may think you know it all, but anything is possible. You are completely disempowered once your status comes out." (Lovhu 47-year-old, married).

Religion

Participants also pointed to religion and religious beliefs as one of the building blocks in the construction of HIV stigma.

"Every day in church you get told that sex outside marriage is a sin and is forbidden. If by chance your status is known, you are cast out as deviant and sinful. They think HIV infection is the outcome of 'sinful' behaviour that is condemned in the bible. I know of a preacher who used to say that HIV infection was a result of one's disrespect for the body resulting from disobedience of God's commandments." (A 28-year-old, man).

"My brother, these people use religion to control people. When you are in church, you do what they say or else the next sermon will be about you and how bad you are. Our religious elders are people who claim to know everything about your life. Religious leaders are very powerful people, and no one can challenge their authority in the church." (A 54-year-old man).

Culturally competent professionals

The research participants also felt that the way they were treated in sexual health services by the professionals caused HIV stigma

"The approach to delivering service in the NHS appears to be a one size fits all. For a start, you go and see a white doctor who does not know your culture and delivers services in a manner that is not respectful of your culture or individual identity."

"It is embarrassing to have a female nurse or doctor sit in front of you asking you questions about your sexual behaviours in my culture. Worse still to have them examine your private parts." (52-year-old, man)

Gender blame

The participants also indicated that men are usually blamed for being risk-takers and thought to be the ones who cause HIV.

"We are always viewed as risk-takers not only by our women but also by other communities. I just feel that there is a culture of blame against us as men". (A 35-year-old man).

I am aware that there is a silent blame of us men for anything concerning sexual health and HIV. I just feel like sinking when the subject is under discussion". (A 29-year-old man).

DISCUSSION

An interesting perspective that emerged about the nature of HIV stigma from the BSSA men was that it is de-humanising, shared, involves control and is discriminatory. Although these aspects of HIV stigma are not new in the literature, they are interesting here as they impact on both the affected and the infected. Arguably, this view provides another dimension in the definition of HIV stigma divorced from the usually assumed one involving attributes or characteristics whose effects, solely on the HIV patient, are profoundly discrediting [11,28]. As the participants pointed out, it is not only the HIV patients, or those perceived as such, who are victims of the stigma. They talked candidly about the infected as well as the affected, noting that when a family has a member whose HIV status is positive, it is a common practice among the BSSA community for the whole family to be stigmatised [29]. Participants talked about keeping a family member's status secret for fear of isolation and discrimination.

According to the BSSA men, there is more to gain by not disclosing one's status than doing so. This stems from fear of gossips and inaccurate stereotypes that could result from disclosure. As HIV/AIDS, in their view, is associated with people of loose morals and promiscuity, any disclosure would lead the community to believe that one is promiscuous. This view is also expressed by Fenton [30] who argues that HIV/AIDS has all the characteristics associated with heavily stigmatised medical conditions linked to socially improper forms of sex and socially censured behaviours that are viewed as the responsibility of the individual. There is the need to educate BSSA men on the benefits of disclosing their HIV status and seeking treatment. This can be embedded in a community-based initiative bespoke to the BSSA communities.

The common fear among participants of modes of casual transmission that carry extremely low, if any, risk, was striking. Many reported fearing even the most peripheral contact with blood, including any left on nail clippers, hair-cutting scissors or even mosquitoes and other non-sexual body fluid such as saliva and sweat. What was also striking was that this fear and preoccupation with contracting HIV through highly unlikely routes seemed entrenched despite high levels of knowledge about how HIV is transmitted. Perhaps the best explanation for this is given by Bond et al. [27] and Mbwapo et al. [16] who argue that when correct knowledge sometimes coexists with incorrect beliefs about transmission, there is often a lack of confidence about how HIV is transmitted.

Data from the literature seems to suggest that the persistence of doubts about

how HIV is transmitted, despite knowing otherwise, and the fixation on least likely modes of transmission could be the result of several interacting factors [31]. The first is the lack of depth of HIV/AIDS information. As most standard HIV information tends to focus solely on how HIV is transmitted, that it has no cure, and that it kills, such messages may have the effect of conveying the incorrect impression that HIV is highly infectious [32]. Interestingly, HIV/AIDS information rarely focuses on explaining how HIV is not transmitted, the relative infectiousness of HIV, and the fact that HIV is not easily viable outside the human body [32]. These messages, therefore, have the potential to allow fears of casual transmission to go unchallenged and to persist. By not specifically addressing the risk of HIV transmission through routes that are of common concern in people's daily lives such as non-invasive contact with blood, saliva, sweat and mosquito bites, the possibility is left open that these are indeed risk situations to avoid [14]. There is a need to increase community-based education among BSSA communities to mitigate against misinformation and reduce the impact of internalised stigma.

Religion was identified as one of the building blocks in the construction of HIV stigma in the BSSA community. The participants, in the focus group discussions and one-to-one semi-structured interviews, expressed concerns about the role of religion in promoting HIV stigma within their community. However, although the majority were of the view that religion needed to do more to combat HIV stigma, some participant felt that religion was vital in the fight against HIV.

Historically, many African countries have been characterised by a profusion of religious orders and sects, most relating either to Christianity or Islam, nearly all of which are layered over pre-existing African traditional belief systems. In traditional African religion, the community is arguably the most important part of someone's life [34]. Religion in most African societies also supports a moral order in which a sense of security and order is created in the community. Apart from a belief in the guidance of their ancestors' spirits, followers also abide by the teachings of religious scripts. Larkan (Ibid) observed that "religion permeates into all departments of [African] life so fully that it is not easy or possible always to isolate it".

One of the fastest-growing Christian denominations is the Pentecostal church [34]. Along with other denominations, but to a greater extent, Pentecostals focus on preaching morals, abstinence, and fidelity, and emphasise individual choice and a personal relationship with God [35]. It is interesting to note from the participants that churches in general and Pentecostal denominations, in particular, are attractive in the context of HIV/AIDS because they offer an escape route from HIV/AIDS. Arguably, religion may help people understand and come to terms with HIV/AIDS, given that HIV is a powerful metaphor for disruption to the social and moral order. There is the need for sexual health professionals to work with religious organisations to reduce misinformation and creation of stigma within community institutions. More importantly, faith organisations should be used as vehicles to fight against internalised stigma.

Matters of a sexual nature emerged as culturally sensitive subjects within the BSSA community. Even during group discussions, there was subtle but important evidence showing that such matters are difficult and complex to discuss among BSSA men of different age groups. All participants reported that they never discussed sexual matters with their fathers as they were growing up. Discussing HIV stigma meant talking about sexual health, a topic often avoided within the family and community at large. There is a feeling, among Africans, that the subject brings embarrassment to the family when discussed [11]. One plausible explanation for this 'culture of silence' surrounding sex generally is because the subject is associated with individuals who are regarded in the community as having loose morals. The association of sexual issues with loose morals has the effect of increasing HIV stigma, as members would try to live within expected community standards. Moreover, the 'culture of silence' creates difficulties for the community to access HIV services for fear of stigmatisation [11]. Professionals working in sexual health need to normalise the subject within these communities to enable frank discussions about the impact of HIV and its associated stigma.

It was a shared view among participants that sexual health professionals had a part to play in the construction of HIV stigma. These sexual health workers include, but are not limited to, nurses and doctors. Although participants did not see these professionals as directly linked to the spread of HIV, their view was that professionals could mitigate the social script of HIV stigma. The BSSA men in this study felt uncomfortable dealing with a female sexual health worker in matters concerning their sexual health. As already mentioned, sexual health issues are a sensitive subject within the BSSA community to the extent that its discussion is forbidden between people of

different sex [36]. Many felt embarrassed and stigmatised and would think twice about routine appointments. While it may be true that in the NHS, as a matter of policy, patients can have the option of seeing a sexual health worker of their preference, in line with the department's quality customer care, in most cases, that choice is not usually possible for logistical reasons. Most sexual health nurses in the NHS are female [37] and getting a male one could be problematic. Furthermore, BSSA men may not be aware of that option, so their request may not be registered. As part of a positive way forward, professionals need to have an appreciation of the culture of new communities. At the same time new communities need to be appraised of the benefit in embracing change in culture for the greater good.

Finally, participants cited their gender as a building block in the construction of HIV stigma. They explained that, based on their cultural values, as men growing up, they were expected to provide for their families, and were supposed to show no weakness, even in matters concerning their health. For them, admitting that one has a problem was a clear sign of weakness. From a young age, messages such as 'boys don't cry' were commonly used by elders in the community. These messages would decrease the likelihood of boys and men showing health symptoms to others as they quickly learn that others will not respond positively. As a result, behaviours associated with weakness and vulnerability, such as seeking help, are often viewed in a negative light and avoided [38-66]. These behaviours are likely to be reinforced among BSSA men by other building blocks that contribute to the construction of HIV stigma such as culture, religion and lack of knowledge. Considering the above, there is a need to develop a public awareness campaign designed to educate BSSA men about the importance of seeking sexual help early. Such a campaign should also carry the message that, contrary to beliefs, sexual health-seeking behaviour does not contradict their understanding of manliness, but rather enhances it. There is a need to support BSSA men with programmes that encourage them to be receptive to health promotion messages. This can be part of a targeted health promotion initiative to encourage uptake of sexual health and HIV services.

Implication for practices

There is a need to reshape the sexual health landscape of the UK to accommodate new emerging communities. Sexual health professionals need to have training in cultural appreciation and proficiency to support diverse communities effectively.

CONCLUSION

There is need to engage with BSSA men and support them to mitigate the enablers and impact of internalised HIV stigma. Such an initiative can increase the uptake of sexual health and HIV services among BSSA men whose reception to sexual health and HIV messages has been reported as low.

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CONFLICT OF INTEREST

All authors declare no conflict of interest.

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