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Original Citation

Owuor, John O. A., Locke, Abigail, Heyman, Bob and Clifton, Andrew (2015) Concealment, communication and stigma: The perspectives of HIV-positive immigrant Black African men and their partners living in the United Kingdom. Journal of Health Psychology. ISSN 1359-1053 (In Press)

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Concealment, communication and stigma: The perspectives of HIV-positive immigrant Black African men and their partners living in the United Kingdom.

Journal of Health Psychology

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Acknowledgements

We would like to thank all the 23 participants who informed the present study and the six organisations that facilitated access and recruitment of the research participants.

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Abstract

This study explored the perspectives of Black men, originally from East Africa, living in the United Kingdom and their families on what it means to live with diagnosed HIV. This article reports on concealment of HIV-positive status as a strategy adopted by the affected participants to manage the flow of information about their HIV-positive status. Analysis of the data, collected using in-depth interviews involving 23 participants, found widespread selective concealment of HIV-positive status. However, a few respondents had 'come out' publicly about their condition. HIV prevention initiatives should recognise concealment as a vital strategy in managing communication about one's HIV-positive status.

Keywords

HIV, stigma, African immigrants, concealment, psychosocial support, family, disclosure risks

Introduction

Immigrant Black Africans, a culturally heterogeneous group (Daley, 1998), are the heterosexual group most affected by HIV in the UK, accounting for about 32% of the 98,400 people estimated to be living with HIV in the UK in 2012 (Aghaizu et al., 2013). About 34% of those accessing HIV treatment in London in 2011 were Black Africans (Forde and Cook, 2013), making London a suitable study site. Data from Public Health England (2013) suggests that about 5% of HIV-positive individuals in the UK by the end of 2011 were from East Africa; Burundi, Kenya, Rwanda, Somalia, Tanzania and Uganda. The present study focused on immigrant men originally from different East African countries, each with its own diverse socioeconomic and political cultures; and relocated to another socioeconomically and culturally very diverse nation. As such, the participants' understandings of family were likely to encompass all their experiences of the dominant models of family in both their countries of origin and the UK.

The men and their partners originated from countries where HIV infection was moralized and perceived by some people as a punishment for an individual's sins (Braid, 2001) or acts of evil (Idemudia and Matamela, 2012). In the UK, HIV is largely viewed as disease for gay men and immigrant heterosexual Africans. Such societal attitudes towards HIV influenced the way the present study population perceived and managed their life with HIV, as well as their access to and use of HIV services in the UK. The participants therefore managed communication about their HIV status within a complex cultural background that was in constant interaction with yet another complex multicultural host society. Symbolic interactionism thus provided a means of understanding how the participants perceived their lives with HIV.

The importance of HIV-positive status disclosure HIV is well documented (Obermeyer et al., 2011a; Wilson et al., 2014). Disclosure can open up access to psychosocial support (Kaaya et al., 2013), but it can also introduce risks of social rejection, violence (Maman et al., 2014) disrupted interpersonal relationships, irreversible family role changes and discrimination (McDermott, Disclosure creates uncertainty about potential responses, since the person who discloses sensitive personal information cannot predict the meanings that the recipients will give to it (Alegría, 2010). To minimise such potential risks of disclosure, some HIV-positive individuals conceal their serostatus. Saiki and Lobo (2011) argue that linguistic choice of the term 'disclosure' involves more than merely revealing information, but carries the implicit connotation that the content is potentially stigmatizing. Likewise, 'concealment' rather than 'non-disclosure', a term commonly adopted in other published literature (Lehman et al., 2014; Mumburi et al., 2014), is used in this paper to convey an active decision to hide information about HIV-positive status from certain individuals.

Obermeyer et al. (2011b) reviewed all peer reviewed published literature on HIV status disclosure between 1997 and 2008 and concluded that a majority of HIV-positive individuals selectively reveal or conceal their disease. However, concealment of HIV status can also create new risks for those concealing their

status. Lee et al. (2013) noted that the risk of being depressed is threefold among HIV-positive individuals who conceal their infection from significant others. Concealment can also facilitate behaviours which result in increased risk of HIV transmission such as having unprotected sex (Tsai et al., 2013). Furthermore, concealment does not guarantee confidentiality as other people may still find out through other cues, such as the presence of anti-HIV medications in the house.

The present study arose through a need to explore the perspectives of Black African men with HIV to highlight the impact of intra and intercultural interactions, as well as their marginal socioeconomic status in the UK, on their family life, in a society that had become less immigrants' tolerant. The study focused on Black East-African immigrant men and their families because of limited research focusing specifically on this study population which experiences high prevalence of HIV and persistent late diagnosis, particularly among the men (Fakoya et al., 2008). The men and their families were additionally prone to mental health problems stemming from their lower socioeconomic status and racism. The study offers insights into ways in which members of an important sub-population respond to HIV, and has significant implications for public health policy and practice.

The aims of the study were to explore what it means for immigrant Black East-African men and their families resident in London to live with diagnosed HIV; and how services could be improved to meet the needs of such populations. To compare the perspectives of both negative and positive individuals, a sero-discordant couple in which the man was HIV-negative was also included. The inclusion of female partners enabled comparison of gender on family life with diagnosed HIV. The study also involved a sample of workers from the collaborating agencies to explore their perspectives on what living with HIV meant for their service users from the theoretical population and how services could be improved.

Method

Participants' recruitment

The overall sample was made of 23 participants, including: 11 HIV-positive men; 6 HIV-positive women (partners of the men who participated in the study); 1 HIV-negative man in a sero-discordant relationship with an HIV-positive woman; and 5 workers from London-based (United Kingdom) community organisations accessed by HIV-positive Black Africans. All the men and their partners identified as heterosexuals. All the men, and their partners, were immigrant Black Africans originally from East Africa.

The initial sample, HIV-positive men, were self-selecting individuals recruited through community organisations that were willing to facilitate participants' access. The men were initially contacted for the study using fliers and information sheets. The study fliers were strategically made accessible to

the prospective participants within the collaborating agencies. The study information sheets were distributed at the HIV-support groups by the key persons in charge of such groups. After the interviews with the HIV-positive men, the first author asked for their consent for their partner's involvement in the study. Those who consented were asked to take an information pack to such partners. Seven of the 11 HIV-positive men expressed willingness to involve their partners. Four partners were eventually interviewed. Two other women, HIV-positive, and their partners were also recruited directly as part of theoretical sampling when the researcher was seeking sero-discordant couples, those in a relationship in which one partner is HIV-negative and the other one HIV-positive. One of the two women was in a sero-discordant relationship and her HIV-negative partner was interviewed as well.

Recruitment of employees of the collaborating agencies involved seeking their line managers' consent first before approaching such individuals to invite them to consider taking part in the study. The study was approved by the University of Huddersfield's School Research Ethics Panel.

Data collection

A loosely structured interview guide was used to enable the participants to freely discuss their views and experiences. The men and their partners were asked to discuss their views on what it meant for them and their families to live

with diagnosed HIV, and their views about and access to HIV-related health and social care services in London and how such services could be improved to best meet their needs. The sample of workers were asked about their views on how HIV-positive diagnosis affects members of the study population accessing their services, and their views about access and use of HIV-related services by the theoretical population.

With the respondents' consent, the interviews were audio recorded and subsequently transcribed. However, one participant declined to be audio recorded, for confidentiality concerns, prompting note taking instead. At the end of data analyses, a summary of the key findings was sent to the participants, to verify the findings and to check if their perspectives on family life with diagnosed HIV changed since the initial interviews. All participants were offered a £20 token of appreciation for their time.

Analytical approach

Data analysis focused on communicating HIV-positive status, which emerged as the core category around which three important subcategories – HIV status disclosure, exposure and concealment were organized. Data were analysed using the cyclical three-stage data analysis approach of Grounded Theory (Strauss and Corbin, 1990), moving from open and axial coding to selective coding, the most abstract stage of coding, which joined all of the categories identified together. Data coding was done by the first author. The other three

authors reviewed the codes against the data transcripts to ensure analytical quality.

Previous literature were also reviewed to compare the emerging theory and previous research. In cases where the findings were unclear, follow-up phone calls were made to solicit clarification from the relevant participants.

Findings

Concealing HIV-positive status

We found widespread selective disclosure and concealment of HIV-positive status. The relevant participants reported concerns about losing control over who else gets to know about the diagnosis, rejection and stigmatization; leading most research participants to attempt to selectively conceal their condition from selected family members and their wider social networks. However, in some cases, participants learnt that some of the people from who they had been concealing their status were, in fact, already aware of it, suggesting that these participants had unwittingly lost control over their HIV status information, through exposure (reported in a separate paper). However, four participants provided an alternative response to selective disclosure or concealment by being 'open' about their HIV-positive status.

By attempting to conceal their status from certain individuals, the relevant participants not only forsook potential sources of support, but also faced a constant risk of exposure, the risk of unintended individuals learning about their condition. A majority of the participants concealed their HIV status, or the partner's HIV status, from their parents and non-family members. The findings also show widespread concealment from children, siblings and friends. Concealment from friends was seen as a means of maintaining friendships. However, the social categories most commonly mentioned by the participants as people they were least likely to tell were elderly parents and younger children. Thus, the participants framed concealment as a risk reduction strategy to protect perceived vulnerable parents and young children.

Managing concealment

The participants used different tactics to conceal their status from unintended individuals. The most commonly reported strategy was keeping all HIV-related resources such as medicines away from living rooms and other shared spaces that might be accessed by those they were concealing their status from as ill in the following excerpt.

Excerpt 1: 'Dan'

Interviewer: And for you in your family how do you deal with visitors or friends

who visit and may be its medication time?

Dan: We make sure all the materials, [HIV/AIDS materials] ... I will just keep them in

files in the bedroom. Medication time, you go to your bedroom and take your

medication. These days, there are small, even portable, fridges. If you need to keep

your medication in the fridge, you just have a small portable fridge in your bedroom.

Dan was involved in HIV prevention work with a London-based

community organisation. He was part of an outreach workforce who worked in

the community to educate and sensitize people about HIV and other STIs.

However, he was cautious to ensure that no HIV-related resources were left

lying around his house. By managing any unwanted discovery of HIV related

material, he minimised the clues that might expose his disease. Dan's example

highlights the care taken by some participants to conceal their HIV-positive

status.

According to one of the participant support workers (Anne), there were

some cases involving sexual partners who concealed their infection from each

other. This was not the case with the couples included in the present study, who had

all disclosed their infection to their partners. This worker gave an example of one

couple she supported, both HIV-positive, who managed concealment from one another by each hiding their medication.

Excerpt 2: 'Anne' (HIV Support Worker)

Interviewer: How do they manage things like medication?

Anne: They hide the medication in a secret place. [Laughs heartily]. In fact the woman was telling me the medication is kept at a friend's house. The friend is also HIV-positive and they met at a support group ... the friend lives nearby to her. So she is able to go and have her medication in the morning and in the evening. So that's what they told me.

Interviewer: How about the man?

Anne: The man said medication is in a secret place in the house.

The above example was an exceptional but interesting illustration of concealment maintenance. In addition to hiding their medication, they accessed different HIV clinics and support services, thereby reducing their risk of exposure to the other. The concealment behaviour of this couple potentially put each of them at risk of re-infecting the other with different strains of HIV. Many studies (e.g Aebi-Popp et al., 2012; Cohen et al., 2012;) have demonstrated that individuals on successful treatment and with undetectable viral load pose low risk of transmitting HIV to their sexual partners. However, successful therapy doesn't completely eliminate the risk of HIV transmission between sexual partners, hence the risk of transmission or acquiring drug resistant viral

strains (Castro et al., 2014). There was also the potential for criminalization of such couples in case sexual transmission of HIV is confirmed. This example also highlights the efficacy of HAART (Highly Active Antiviral Therapy) in aiding concealment. As long as the said couple remained well, with no major health concerns, they could easily conceal their HIV status from one another.

Some participants said that they used their native language to conceal their condition from their own children. All the parents interviewed in the present study could speak at least one native language, in addition to English, whereas some of their children, having been raised in the UK, could only speak English. This was particularly true of the younger children, from whom the parents were more inclined to conceal their infection.

Excerpt 3: 'Robin'

Robin: Sometimes we discuss about other families, about their medication and things like that. But ... we switch over to Swahili. Yea ... it just comes naturally ... We switch off! ... They [the children] don't understand Swahili. So we switch off when they are around ... even the word HIV we don't use in the house.

Robin was one of the parents who believed that young children were ignorant about HIV, and that concealment would shield them from distress. But

the extract also illustrates that he was also aware that children could pick up hints about HIV from daily family conversations. By switching to their common native language, Robin and Harmony could discuss HIV whilst maintaining concealment.

Another approach for maintaining concealment was to sustain silence about HIV in the family. Some of the participants said that HIV was never discussed in their families, as illustrated below.

Excerpt 4: 'Lucy' and 'Robert'

Interviewer: Are there any of your family members also living with diagnosed HIV?

Lucy: Not that I know of, but again you can't tell. Just like if I didn't tell them, they wouldn't know.

Robert: That one is very difficult to know ... Unless someone tells you, you can't tell. Or unless they get really sick then you can start thinking whether they have HIV or not.

Like many other participants in the present study, Robert and Lucy concurred that HIV was rarely discussed within families unless someone became visibly ill. This suggests a rule of 'don't see, don't ask' among some of the families. As discussed above, the participants were more likely to discuss

HIV with other people, including family members, whom they knew were HIV-positive. Silence about one's HIV-positive status was in consequence more likely to be met with reciprocal silence from others who were also infected and concealing their HIV-positive status. However, four of the participants had become HIV awareness activists and were happy to reveal their HIV status to individuals they interacted with as part of their involvement in HIV awareness activism, as role models, in their attempt to de-stigmatize the disease. Consistent with previous research (Maman et al., 2014) which found that concealment creates tension and anxiety for those concealing their HIV status, we found that concealment of HIV-positive status created multiple challenges which could be detrimental to the participant's health, including stress about concealment, fear of exposure and breakdown of their relationships when concealment failed.

Distance as an aid to concealment

When it came to concealing HIV from relatives and significant others, the distance between the UK and their countries of origin was advantageous in concealing the disease from Africa-based family and friends. Such strategies included; hiding medication and other HIV-related resources; limiting social contacts; accessing carefully selected services to prevent exposure by individuals from their country of origin; using their native language to exclude

non-speakers in HIV-related conversations; and silence about HIV within their

families.

Many of the participants' family members and friends resided in their

countries of origin. Some of the participants, perhaps relying on distance to

facilitate concealment, felt that disclosing to family and friends in their home

country would have little benefit to them, but considerable risk of causing

psychological stress to all concerned parties.

Excerpt 5: 'Phil'

Interviewer: Have you told any other family members?

Phil: No. No one knows ... They are out there. They won't be of any help. They will

instead just worry and add to my stress while they are stressed there. I prefer to tell

someone here who can offer support when I need it.

Interviewer: And how comfortable are you that your family [partner and son] are

keeping the status secret?

Phil: Yes, I told them, "Keep it as a secret. It is between me and you".

In Phil's view, his family members could not be of help since they were in

Africa, negating the need to tell them. But Phil, and other participants with

similar concerns, had to rely on individuals they had confided in to maintain their

confidentiality. Phil told his partner and son to keep his secret from the rest of

the family, thereby trying to prevent chains of exposure initiated by those he had confided in.

Limited physical contact between the present participants and their social contacts in their countries of origin implied that any HIV-related changes in the participants' appearance or behaviour were unnoticeable, enhancing their concealment efforts. This was very important for the participants, given the impossibility of hiding the visible effects of HIV, particularly in Africa where HIV was visually recognisable and somewhat anticipated as illustrated below.

Excerpt 6: 'Robin'

Robin: But when I went back [to country of origin] the second time, they [family members and friends] saw a completely different, opposite, ya! And at that time also ... around 1996 ... the combination therapy had just started. It had not reached Africa by then. So, in Africa, when you reach the stage of ... skinniness as I was [Switching off from English - ka ngato ne odhero kamano - when someone was skinny like that], you knew that he was going to die [of AIDS]. And they could not see how I changed [meaning family members and friends could not understand how he regained weight and became 'healthy']

Robin was one of the few participants who said he had travelled back to his country of origin several times during his 13 years stay in the UK. Most of the other participants had not travelled to their countries of origin due to their uncertain immigration status. Robin had been to his country of origin just before he was clinically diagnosed as HIV-positive. At that time he was so skinny that people naturally concluded he was ill and he claimed that his family members in his country of origin could 'tell' he had HIV because they noted stereotypical HIV related symptoms such as severe weight loss. However, after years of medication in England, he went to visit relatives in his country of origin as a 'changed man'. The following excerpt picks this up.

Excerpt 7: 'Robin'

Robin: They saw the changes, everybody was shocked. What is this? This man again! Uncles are coming, [Interviewee switched from English - eeeh dendi ber! dendi ber! Denda ber? Kara denda berni Kara denda ne rach?] - Your body is good your body is good, my body is good? Was my body bad?]. In other words they thought that I was, HIV-positive and I was soon dying.

The reference to 'good body' in the excerpt above is a vivid example of how a person's physicality affects how others treat them. In the case of Robin, his relatives now believed that he could not be HIV-positive because he was apparently healthy and 'normal' once again. As Robin explained, medication was not widely available in his country of origin at the time and his relatives were possibly not yet aware of the potential efficacy of HAART. Therefore, due

to his now rejuvenated physical appearance, he was able to conceal his (previously suspected) HIV diagnosis from extended family. Thus the lack of regular contact with family members and friends in their countries of origin acted as a concealment strategy by enabling some of the respondents to avoid scrutiny and suspicion about their health. Whenever they visited their countries of origin, mainly looking healthy, their health was judged based on their appearance at the time.

As the analysis has demonstrated, the participants claimed to use a variety of strategies to conceal their HIV positive status. The discussion will pick this up further.

Discussion and conclusions

Our findings add a new dimension to the existing body of knowledge on communication about HIV-positive status by illustrating that concealment, commonly referred to as non-disclosure in the literature (Jasseron et al., 2013; Manning, 2013) is not merely about not telling others about one's HIV-positive sero-status. The issue of concealment, only arises for those who opt to conceal a stigmatised status; and gives rise to the risk of exposure. Concealment involves very deliberate and targeted efforts to prevent certain individuals from learning about the concerned person's HIV-positive status or other stigmatized

conditions, such as mental illness (Pandya et al., 2011; Ueno and Kamibeppu, 2012). The affected participants were thus in a constant state of alert with their social contacts, making ongoing decisions about whether or not to conceal their condition. In contrast, non-disclosure of HIV status implies lack of communication about the underlying infection.

Our findings supplement previous knowledge that a perceived lack of need to discuss one's HIV-positive status justifies concealment (Gaskins et al., 2011). The HIV positive participants were on successful HIV treatment and did not exhibit any obviously discernible HIV symptoms that could raise suspicions about their health. Those concealing their condition were thus able to present a normal, healthy self, while concealing their underlying disease, thus presenting 'the self' (Goffman, 1959) that they believed was socially acceptable. The participant's narratives suggested that HIV had stereotypical symbolic markers that identified those perceived to be infected in the participants' native countries, such as severe physical wasting (Van Wyk and Larkan, 2011). The lack of such markers therefore enhanced concealment efforts. However, our findings also suggest that concealment might be a means of avoiding the psychological and emotional stress involved in narrating one's sexual past to family members and others in their social networks. Those who resorted to concealment therefore avoided immediate psychosocial challenges, such as the

risk of rejection or stigmatization by family members, but faced a long-term risk of exposure because they created a false social position which they were forced to maintain until they were ready to reveal their status. These findings are similar to those reported in research into other stigmatized conditions such as mental illness (Ueno and Kamibeppu, 2012), where concealment may be used to musk painful past experiences.

These findings illustrated concealment of HIV-positive status from some family members and friends. Concealment from friends was framed in terms of preserving friendships. As immigrants, the relevant participants had very limited friendship networks in the UK that they did not want to sabotage by revealing their disease. Similar findings were reported by Calin et al (2007), who observed that Black Africans living with HIV in the UK were likely to conceal their sero-status from friends. The present participants were predominantly men (67%) whereas Calin and colleagues' participants were mainly women (69%) from Sub-Saharan Africa in general. Unlike Calin et al.'s (2007) study who noted no gender differences in concealment, we found that men were more likely than women to conceal their HIV status from their family members and friends. We would also suggest tentatively that the results are potentially reflective of the study population as a whole, given that our sample arose through community organizations, whilst Calin et al's were recruited through an

NHS HIV clinic, yet both sets of findings reported widespread concealment of HIV status from friends. However, our findings also highlight an alternative to concealment as an option to communication about one's HIV-positive status. Four participants had transitioned from selective concealment to openness about their HIV status.

We found widespread concealment of HIV status from children. Consistent with previous research into stigmatized conditions (Puhl and King, 2013; Schaeffer et al., 2011), concealment from children is common and complicated because it involves concealment of both parental HIV and, in some cases, concealment of the HIV status of infected children, including those receiving treatment but who are unaware of their illness. However, the present findings are different from most previous studies because they reflect a cultural divide between the adult respondents and their UK raised children. Whereas the participants hailed from settings where parents were culturally perceived as the bearers of knowledge and controllers of communication about sensitive issues in the family; some of the children in this study grew up in the UK, were culturally aware of their right to information and able to access multimedia sources of information through which they could learn about HIV. Some of the parents might have incorrectly assumed their children's ignorance of HIV, thinking they were concealing their HIV status from children who were, in fact,

fully aware of the concerned parents' disease and who were also managing their own concealment of their discovery. This suggests a mutual pretence awareness in which each party conceals their own knowledge and assumes the other party's lack of such knowledge, again highlighting the relevance of the theory of awareness contexts identified by Glaser and Strauss (1965) to HIV-positive status as a stigmatized condition. They framed concealment from children in terms of protecting them from harmful information (Heeren, 2011) and related risks such as stress, shock, stigma and information overload.

Lastly, we found that despite the effort involved in concealing an invisible stigmatized condition such as asymptomatic HIV-positive status, exposure is an ever-present threat which, if it becomes a reality, negates the sacrifices made by the sero-positive person, such as forsaking potential sources of social support in order to sustain concealment. Concealment, whilst intended to retain control over the sharing of confidential information, can lead to loss of control. We found that those concealing their sero-positive status were constantly on edge with those they were concealing their status from, such as their children, parents, siblings, other family members and friends; and were constantly making decisions and judgements about whether or not they should conceal their status. Although concealment of one's HIV status is blamed by health promoters for hampering HIV prevention efforts and for perpetuating stigma

(Obermeyer et al., 2011b), we suggest that the decisions surrounding concealment and the subsequent efforts to conceal one's status are complex emotional experiences. Unlike non-disclosure, which merely refers to retaining information, concealment is not likely to hamper HIV prevention because it involves careful risk-benefit analyses requiring consideration of the risk of onward transmission. This may explain why all the participants had revealed their disease to their sexual partners. However, four participants who had 'gone public' about their HIV-positive status demonstrated an alternative to selective concealment, that majority of the participants could not adopt due to 'inductive prevention paradox' (Heyman et al., 2013). They could not tell the potential responses of their social contacts to their HIV-positive status without risking their confidentiality, yet once they revealed their illness they could not retract the information.

The exclusion of children, for the reasons outlined above, was, in hindsight, a limitation of the study. The children's perspectives would have further contributed to the understanding of how families from the study population manage communication about HIV in the family. However, given the sensitivity of the research topic, we felt that exclusion of children was the appropriate decision at the time of the study's inception.

Research, policy and practice implications

Black Africans are a highly heterogeneous group that tend to be treated in the UK, at least, as a homogenous population with similar experiences and needs. As Bourne et al. (2012, p. 1) pointed out, much of the previous HIV social research involving Black Africans in England has been survey-based studies focusing on sexual risk behaviours and HIV prevention knowledge. There is a need for further qualitative research to explore the complex array of experiences and perspectives of family life with HIV and the resultant responses by both the infected and affected family members of immigrant Black Africans from other geographic and cultural regions of Africa, such as Southern Africa. There is also a need for similar studies involving other high-risk populations, such as MSM and injecting drug users, to explore family responses to HIV in relation to various HIV transmission modes. Additionally, there is need for further research on communication about HIV status, even among heterosexual white British families affected by HIV, to compare how different cultural nuances affect family life with HIV.

The present findings showed that Black Africans, particularly the men, seem to be more likely to conceal their HIV-positive status than do others with the same condition, such as HIV-positive MSM. Practitioners and support workers should use this knowledge to help HIV-positive Black Africans think

about managing communication about their, or a family member's, HIV status. Policymakers need to understand the difficulties faced by Black Africans regarding communication about their HIV status, and should continue to invest in support services for HIV-positive or affected Black Africans. One practice implication could be to continue funding psychosocial support and counselling services.

With regards to health promotion, the role models who 'come out' could be used to sensitise members of the study population about being 'open' about HIV-positive status as an alternative to selective disclosure/concealment. Health promoters and policy makers should respect the rights of those who selectively conceal their HIV status since they don't necessarily pose a public health threat as the present study has illuminated.

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Supplementary data

Table 1. Demographic details of the study participants

| Pseudonym | Age | Country of Origin | UK residence status | Years in the UK | Year tested +ve | Where tested |
|--|------------------------|-------------------|----------------------------|-----------------|-----------------------|--------------|
| Paul | 51 | Uganda | Permanent British resident | 23 | 2000 | UK |
| Robin | 45 | Kenya | Permanent British resident | 23 | 1998 | UK |
| Harmony | 48 | Uganda | Permanent British resident | 21 | 1997 | UK |
| Troy | 57 | Uganda | Permanent British resident | 20 | 1999 | Home country |
| Luke | 41 | Uganda | Indefinite leave of stay | 12 | 2000 | UK |
| Dan | 49 | Uganda | Asylum seeker | 8 | 1999 | Home country |
| Damien | 52 | Uganda | Asylum seeker | 7 | 2004 | UK |
| Lorna | 52 | Uganda | Permanent British resident | 12 | 2000 | UK |
| Bill | 31 | Uganda | Indefinite leave of stay | 11 | 2004 | UK |
| Rachel | 37 | Kenya | Asylum seeking | 12 | 2003 | UK |
| Biden | 43 | Burundi | Indefinite leave of stay | 13 | 2002 | UK |
| Melisa | 43 | Uganda | Permanent British resident | 20 | 1998 | UK |
| Trevor | 47 | Kenya | Permanent British resident | 15 | 2008 | UK |
| Phil | 51 | Uganda | Asylum seeker | 9 | 2002 | UK |
| Millie | 54 | Uganda | Asylum seeker | 5 | 2008 | UK |
| Tyron | 45 | Somali | Indefinite leave of stay | 9 | 2004 | Home country |
| Robert | 40 | Rwanda | Asylum seeker | 8 | HIV -ve | UK |
| Lucy | 35 | Rwanda | Asylum seeker | 5 | 2003 | Home country |
| Mean | 45,6 | NA | NA | 13 | NA | NA |
| Participants from service provider agencies (All pseudonyms) | | | | | | |
| Anne | Female (Black African) | | | | | |
| Oliver | Male (White British) | | | | | |
| Graham | Male (Black African) | | | | | |
| Rose | Female (Black African) | | | | | |
| Peter | Male (Black African) | | | | | |