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Sara Paparini, L. Doyal, Jane Anderson

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Sara Paparini, L. Doyal, Jane Anderson. ‘I count myself as being in a different world’: African gay and bisexual men living with HIV in London. An Exploratory study. AIDS IMPACT. AIDS Care, 2008, 20 (05), pp.601-605. 10.1080/09540120701867040 . hal-00513447

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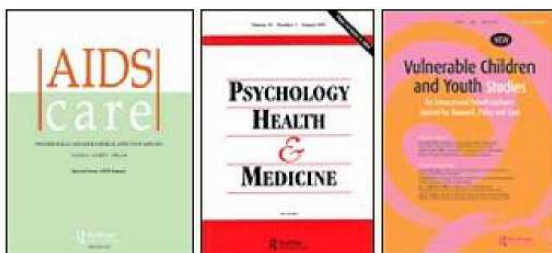
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'I count myself as being in a different world': African gay and bisexual men living with HIV in London. An Exploratory study.

Abstract

The experiences of men from African backgrounds living with HIV who are gay/bisexual have so far been overlooked in the research on HIV in the UK. Little is known about the ways that HIV impacts on this population.. We report on an exploratory qualitative study with 8 gay/bisexual men from 7 different African countries living with HIV in London, using in depth semi structured interviews and modified grounded theory thematic analysis. HIV testing and diagnosis, disclosure to others, social and sexual networks, sexual relationships and practices, use of health services and coping mechanisms emerged as key themes. Men with insecure residency status in the UK and those without work had additional challenges to meet. Men described the constant juggling required to balance the complex and sometimes contradictory realities of life as a gay/bisexual man, an African and an HIV positive person. Actual and perceived stigma was a key barrier to accessing appropriate practical and emotional support from families, social network or religious organisations.

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Introduction

People from African backgrounds (mostly heterosexual) and men who have sex with men (mostly white) are the populations most affected by HIV in the UK (Health Protection Agency, 2007). Much of the research carried out among people living with HIV in the UK has considered the experiences of gay men and black African heterosexual men and women separately (Dodds et al., 2004; Elford et al., 2007; Ridge et al., 2007 Weatherburn et al , 2003). However the needs and experiences of people living with HIV who are part of both populations, (African men who have sex with men (MSM) have so far gone largely unnoticed (Prost, 2006).

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This invisibility has been compounded by the stigma associated with both HIV and same-sex relationships in many African communities both at home and in the diaspora, (IGLHRC, 2007, Doyal, Anderson and Paparini, 2008 in press). This paper describes an exploratory study of the experiences of a group of black African men who define themselves as gay and are living with HIV in the UK. It is part of a wider project investigating the experiences of people of Sub-Saharan African origin who are receiving treatment for HIV/AIDS in London. Studies of black African women and men with HIV who defined themselves as heterosexual have already been completed (Anderson & Doyal, 2004; Doyal & Anderson, 2005; Doyal, Anderson and Apenteng, 2005).

Comment [JA1]: Referee 1 comments

"it would have been interesting to have had a wider black African sample, including heterosexual men and women - the latter in particular represents a substantial proportion of HIV positive people and it would have been valuable to know more about them"

Here are some references to contextualize the study within the African data in the UK and our previous work on this topic.

Accurate numbers of African MSM living with HIV in the UK are difficult to obtain. In 2005, 251 black African men defined themselves as gay or bisexual when accessing HIV-related care in England, Wales & Northern Ireland, the majority being in London (The UK Collaborative Group for HIV and STI Surveillance, 2006). In a hospital-based survey of 1,687 people attending specialist HIV clinical

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services in East London in 2004, 13 (1.7%) of the 758 MSM who took part described themselves as black African (Elford et al.2006). A review of ethnicity data from two National HIV/AIDS Surveillance Systems found that of the 1040 Black and Minority Ethnic MSM newly diagnosed with HIV from 1997 to 2002, 12% were black African. However this is likely to be an underestimate since some men may not feel able to reveal their sexual orientation to clinicians in GUM and HIV clinics (Dougan et al. 2005a; Dougan et al., 2005b).

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Study design and implementation

Comment [JA2]: Referee 2 says "Analysis not referenced and very few details given. This makes it appear anecdotal"

Here is extra background and reference to the analysis



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The qualitative methodology used in previous studies with people of African origin living with HIV in London (Anderson and Doyal 2004, Doyal, Anderson Apenteng 2005) was used as the basis for this work. The study was carried out between February 2006 and February 2007. Men were alerted to the project through voluntary organisations for people living with HIV, e-networks of black gay/bisexual men, and specialist HIV clinics across a number of London hospitals. Recruitment proved to be extremely difficult and, although at least 25 men discussed the study with either their regular clinicians, voluntary sector agencies or directly with the research team, in the end, only eight men eventually agreed to take part.

The limited size of the sample reflects in part the small number of African men known to be gay/bisexual and receiving HIV related health care in the UK. Thus participants could only be sought from what is currently a small pool. There were also inevitable difficulties in accessing networks that are often underground. Within African communities in the UK both HIV and homosexuality carry substantial stigma, (Mayisha- II Collaborative Group 2005; Dodds et al 2004), making it hard to find men willing to discuss their life experiences. For these reasons our sample is likely to reflect the views of those men who were most confident about their situation, and should not be considered to be representative.

Individual semi-structured interviews were carried out with eight black African men living in London but born in sub-Saharan Africa, who reported having sex with men. Interviews were conducted on hospital premises but in non-clinical spaces. Travelling and subsistence expenses were reimbursed but no other payment was

Comment [JA3]: Referee 1 say "the authors are aware of the limitations of their study, in particular the very selected and possibly unrepresentative sample included"

We have emphasized this more robustly



made. All participants spoke English. Men were provided with information about the study and gave written informed consent. All participants agreed to be tape-recorded, though a choice was offered if they preferred the interviewer to take notes. Interviews lasted between one and two hours. Verbatim transcripts were then subjected to thematic analysis, using a modified grounded theory approach (Glasser and Strauass 1967). The study was approved by the relevant research ethics committees.

Characteristics of the sample

All the men who took part defined themselves as 'gay' or 'bisexual', hence these are the terms we use in describing the cohort. The eight men came from seven different African countries. The age range was 27 - 43 years old with the majority being over 30. The participants had lived in the UK for 10 years on average (range 2 -17 years) and the majority had been diagnosed HIV positive for more than five years (range 1 - 17 years). Most lived by themselves in council houses or private homes. None had children. Five men were regularly employed and their economic situation appeared to be stable..

For the three men without work, the situation was much harsher. They were living on welfare benefits and some had been doing so for lengthy periods. One man stated that he sometimes resorted to sex work to make ends meet. Amongst the reasons why they were not employed, physical and psychological health problems, HIV-related stigma and immigration status were all mentioned.

Two men were experiencing difficulties in relation to their legal status in the UK. and they faced the daunting possibility that they might have to return to their own

country, which was a source of constant anxiety. They feared for their health if they had to live in circumstances where treatment for HIV was not available. However they were also concerned for their safety if their sexual orientation was revealed. Because sex between men is illegal and highly stigmatised in their countries of origin, they would be vulnerable to blackmailing, harassment, violence and arrest.

The participants in the study shared the experience of being African and living in London. They also had their homosexuality/bisexuality in common. All had to find their own ways of managing HIV and the choices were often very difficult. Life in London offered considerable benefits in the way of access to health care and more liberal sexual attitudes. But at the same time the men had to negotiate complex realities reflecting not just their illness but also their identity as black Africans and gay/bisexual men.

KEY ASPECTS OF LIFE WITH HIV/AIDS

Finding out about their HIV status

The opportunities for counselling and HIV testing in the UK were much greater than most of the men had been used to but still the choice to use them was often difficult. About half the men decided to have the test either as a routine check or because of doubts over their partner's behaviour. The rest did so because they were feeling ill and their health did not seem to improve. Some delayed testing even when suggested to them by clinical staff. The most common reasons given for this related to their anxieties and prejudices about HIV.

Only one man stated that he was not surprised by his diagnosis. For the rest the result came as a very great shock, and some thought they were going to die right away especially those diagnosed in the early 1990's before the advent of potent antiretroviral therapy. Many were burdened by experiences of HIV/AIDS in their country of origin, and associated their own situation with that of people dying in Africa. Reaction to the diagnosis was also influenced by worries for their current and previous partners.

After the diagnosis most men did not describe feelings of anger towards any particular person that they believed might have been responsible for their infection. Instead most stressed the importance of thinking positively about their future and learning to accept what had happened.

Dilemmas of disclosure

Disclosure of the diagnosis of HIV was very difficult because of what men saw as the associated social stigma especially among fellow Africans. For some this was compounded by what they assumed would be a negative attitude towards their sexual identity. However most reported having disclosed their HIV status to a few people close to them. This usually included their current partner if they considered themselves to be in a serious relationship.

Very few had disclosed to members of their family. Some told a brother or sister but parents were rarely informed. Like other Africans living in the UK, most men in this study explained their secrecy in terms of hostility towards those infected with HIV and also the desire not to worry their relatives 'back home.' But they also expressed the additional fear that they might be blamed for their own infection because they were gay/bisexual. Some men reported how they had become detached from their parents because of wider issues pertaining to their sexuality. This meant that their private lives were hardly discussed, making it difficult to talk about a matter as intimate as HIV infection.

Social relationships: separation and secrecy

The men's social lives were often very complex. They described a variety of networks with ongoing negotiations between different groups of friends, some of whom were aware that they were gay/bisexual and/or positive, while others remained in ignorance.

Some men said that they were open about being both gay/bisexual and HIV positive in all their social networks. More accurately perhaps, they only frequented

those settings where this was possible and this very often excluded them from contact with other African people. Only one man appeared to be socialising regularly with other gay/bisexual men from Africa. For most it was a question of socialising *either* with white gay men *or* with heterosexual African men. Many of the men had close women friends but with them too they often felt compelled to conceal key aspects of their identity.

These patterns of socialisation affected the men's choice of sexual partners. Though some reported having had sexual encounters with other African men, these rarely appear to have developed into friendships or long-term relationships. Some clearly expressed their preference for relationships with white men. However these too could at times be challenging because of racist attitudes in gay networks as well as cultural differences leading to fears of being misunderstood.

Sexuality, sexual practices and HIV

Five out of eight of the men in the study had a sexual partner at the time of the interview, though most described their relationships either as not stable or not serious. Two of the men had both female and male sexual partners. None felt that their 'manhood' could be measured by how much sex they had. Indeed a number were critical of such 'macho' beliefs, which they saw as common among both heterosexual and gay men.

HIV appeared to have influenced the sexual identity and practices of the men in a number of different ways, both directly and indirectly. Some talked about how HIV had made them less sociable which in turn reduced the likelihood of sexual

encounters taking place. A number also referred to problems relating to disclosure, and the fear of rejection by potential partners.

All the men were very concerned with ensuring safe sex and had given the appropriate methods for achieving this considerable thought. All reported having used condoms all or most of the time since they had been aware of their HIV status. This was both to avoid infecting their partners and also to protect themselves. However most also stated that they found condoms intrusive and disruptive. Only in the context of sexual intercourse with another HIV positive person did some men say that they chose not to use condoms.

Health services and social support

The overall view of health care was a positive one. Several stated that they considered themselves privileged in comparison to their compatriots in Africa. Most valued their relationships with their doctors and they often spoke enthusiastically about hospital staff. Overall, the men also appeared to be satisfied with the health-related information they received. Nevertheless, some highlighted problems which needed to be tackled. For instance, confidentiality was sometimes threatened if they met people they knew in the clinic.

Some men also described the difficulties they encountered in finding support that was specific to their needs as African men with HIV. They lamented the lack of organised groups and networks for African gay/bisexual men with HIV. Some were happy to join voluntary organisations for African men that do not specify

sexual orientation, though none of the participants were open about being gay/bisexual in these circles. Conversely some attended support groups for gay men that do not specify ethnic background.

Most of the men talked about their spiritual faith as a source of support and all reported believing in God. However only three were regular attenders at religious gatherings. The most common reason given for not attending church or mosque was the homophobia they perceived in such settings. Only one man spoke about the stigma associated with HIV as one of the reasons for not actively participating in religious activities. Most of the participants mentioned prayer as a coping strategy despite feelings of separation from church or mosque.

Conclusions: managing the contradictions

Unsurprisingly , the men in this study describe aspects of life and experience with HIV that are shared by many people from African backgrounds living in the UK (Doyal, Anderson Apenteng 2005, Doyal and Anderson 2005). However the striking theme to emerge from these accounts is the extent of the constant juggling required to balance different aspects of the men's lives. Their narratives showed marked differences in their personal history, in their present circumstances and in their hopes and fears for the future. The theme that was common to all was the challenge of managing the complex and sometimes contradictory reality of life as a gay/bisexual man, an African and an HIV positive person.

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Living in London, and not being 'at home', has meant both benefits and challenges that are particular to this group of men because they are both

gay/bisexual and HIV positive. Most had been able to live more openly in London. But for most this openness resulted in a loss of contact with their own communities and the feeling of not belonging to their families. The tensions between being African and being gay/bisexual were especially acute and, sometimes, provoked negative feelings of a life lived in secrecy. At the same time HIV infection created a new set of practical and emotional needs, which often went unmet because of actual or perceived stigma and discrimination. These problems were especially challenging for those with little money or insecure immigration status.

This exploratory study has shed light on the lives of a group of men whose

experiences of HIV/AIDS have so far received little or no attention. Despite the

small numbers of participants we believe that the data, offer a first step in

increasing the visibility of African gay/bisexual men living with HIV and providing a knowledge base for the development of future services to meet their particular needs.

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Acknowledgements: Thank you to all the men who were prepared to give their time to take part and discuss complex and sensitive subjects with us.. Thanks to all the staff at The Department of Sexual Health, Homerton University Hospital; to the clinicians in specialist clinics across London and workers in voluntary sector settings for help with recruitment; to the African HIV Policy Network, the RAIN Trust, The Organization of Positive African Men, Terrence Higgins Trust, UK Coalition, The Metropolitan Community Church and the Ethnic Minorities Unit of the Greater London Assembly for their advice and support. Funding, without which this work would have been impossible, was provided by the trustees of The Derek Butler Charitable Trust.

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REFERENCES

Anderson, J, Doyal, L (2004) 'Women from Africa living with HIV in London: a descriptive study', *AIDS Care*, 16(1): 95-105

Dodds, C. et al. (2004) *Outsider status: stigma and discrimination experienced by gay men and African people with HIV*, Sigma Research, London.

Dougan, S. et al. (2005a) 'Epidemiology of HIV among black and minority ethnic men who have sex with men in England and Wales', *Sexually Transmitted Infections*, 81: 345-350.

Dougan, S. et al. (2005b) 'Men who have sex with men who are born abroad and diagnosed with HIV in England and Wales: an epidemiological perspective', *International Journal of STD & AIDS*, 16: 618 – 621.

Doyal, L, Anderson, J (2005) "'My fear is to fall in love again...": how HIV positive African women survive in London', *Social Science and Medicine*, 60(8): 1729-38.

Doyal, L, Anderson, J, Apenteng, P. (2005) "I want to survive, I want to win, I want tomorrow": an exploratory study of African men living with HIV in London. London: Terrence Higgins Trust.

Doyal, L, Paparini, S, Anderson, J (2008). 'Elvis died and I was born': black African men negotiating same-sex desire in London. *Sexualities*. In press

Elford J, Anderson J, Bukutu C, Ibrahim F. (2006). HIV in East London: ethnicity, gender and risk. Design and methods. *BMC Public Health* 2006; <http://www.biomedcentral.com/1471-2458/6/150>.

Elford J, Ibrahim F, Bukutu C, Anderson J. (2007). Sexual behaviour of people living with HIV in London: implications for HIV transmission. *AIDS* 2007; **21**(Suppl. 1):S63-S70.

Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. New York: Aldine

Health Protection Agency Centre for Infections and Health Protection Scotland (2007). *Unpublished. Quarterly Surveillance Tables No. 74, 07/1.UK data received to the end of March 2007.*

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International Gay and Lesbian Human Rights Commission (2007) *Off the map: how HIV/AIDS programming is failing same sex practicing people in Africa*, IGLHRC, New York.

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Mayisha II Collaborative Group.(2005). *Assessing the feasibility and acceptability of community based prevalence surveys of HIV among*

For Peer Review Only

black Africans in England.. London, Health Protection Agency Centre for Infections

Prost, A. (2006) *A review of research among black African communities affected by HIV in the UK and Europe*, MRC Social and Public Health Sciences Unit, Occasional paper n. 15, Glasgow.

Ridge, D. Ziebland, S. Anderson, J. Williams, I. Elford, J. (2007) 'Positive prevention: contemporary issues facing HIV positive people negotiating sex in the UK', *Social Science and Medicine* 2007;65:755-70.

Deleted: Social Science & Medicine

Deleted: Epub ahead of print, May 7.

The UK Collaborative Group for HIV and STI Surveillance (2006) *A complex Picture: HIV and other Sexually Transmitted Infections in the United Kingdom*. Health Protection Agency, Centre for Infections, London.

Weatherburn P, Ssanyu-Sseruma W Hickson F McLean S Reid D.(2003) *Project Nasah An investigation into the HIV treatment information and other needs of African people with HIV resident in England*. London, Sigma Research.