‘I count myself as being in a different world’: African gay and bisexual men living with HIV in London.

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In this report we describe the ways in which HIV infection shapes the lives of a group of black African men who are gay or bisexual. The report contributes to the very sparse literature both on HIV amongst Africans in the diaspora and on African sexual minorities. It is the third in a series of interlinked projects exploring the lives of people from African backgrounds living with HIV in London. The first illustrated the experiences of heterosexual women (1, 2), while the second examined the lives of heterosexual men (3). The research reported here makes a contribution to increasing knowledge about an important and vulnerable group of men.
Background

Much of the research work that has been carried out among people living with HIV in the UK has considered gay men and black African heterosexual men and women separately. However this means that the experiences and needs of people who simultaneously belong to both populations - African men with HIV who have sex with men - have been overlooked. The invisibility of African men who have sex with men (MSM) within the HIV epidemic is compounded by the extensive stigma associated with both HIV and same-sex relationships in many African communities (4, 5). This makes it particularly difficult for men in this situation to disclose either their sexual orientation or their HIV infection to others.

About 480,000 people (0.8%) of the UK population are black African, of whom 78% live in London (6). Despite accounting for less than 1% of the UK population, African people carry a disproportionate burden of the HIV epidemic. In 2005, of the 45,344 people in England and Wales who were seen for HIV care 21,152 (46%) were people of African origin. In the same year 7,645 new diagnoses of HIV were reported of which 3,345 (44%) were in people of African origin. Of these new diagnoses amongst African people 2,202 were in women and 1,143 in men (7). 26 of the men had acquired HIV from same-sex relationships (8).

During 2005, 251 black African MSM accessed HIV-related care in England, Wales & Northern Ireland (9). In a hospital-based survey of 1,687 people attending specialist HIV clinical services in East London in 2004, 13 (1.7%) of the 758 MSM who took part described themselves as black African (10). However these figures are likely to be an underestimate because some men from Africa will be reluctant to identify as ‘homosexual’ at the point of registration in GUM and HIV clinics (11, 12). Accurate data on the numbers of African MSM living with HIV are therefore difficult to obtain and as we shall see, almost nothing is known about the wider circumstances of their lives.

The research that is described in this report is important because it begins to fill that knowledge gap through describing the experiences of African MSM. We believe that this information will be particularly relevant to the development of appropriate health and social care services and prevention initiatives for this population.
Study design and implementation

The research that we describe here happened in two stages. An initial review of the published literature revealed no studies that focussed specifically on gay/bisexual African men in the UK. In order to explore the particular issues faced by men with HIV we felt it important to first obtain a more general view of the life experiences of African gay and bisexual men. The fieldwork for this first phase of the project was completed in 2006 and consisted of a focus group with 15 participants of unknown HIV status and a series of eight individual semi-structured interviews.

The findings provided an important overview of the key issues faced by a group of African gay/bisexual man living in London - whatever their HIV status. Information collected from phase 1 was then used to inform the second phase, which explored the experiences of gay and bisexual men from African backgrounds who were also living with HIV. It is this phase two study, which is reported on here.

Ethics approval for both research stages was obtained from the relevant committees and recruitment was carried out between February 2006 and February 2007 through voluntary organisations for people living with HIV, e-networks of black gay/bisexual men, and HIV clinics across a number of London hospitals. This process 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 agreed to be interviewed and to be included in the study.

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 (around 250 in all) (9). Hence it is clear that participants could only be sought from what is currently a small pool. There were also inevitable difficulties in accessing networks that are often underground. Both HIV and homosexuality are highly stigmatised, making it hard to find men who are willing to discuss their life experiences. Hence this study can only be seen as exploratory.

Individual semi-structured interviews were carried out with black African men who reported having sex with men, were born in Sub-Saharan Africa, were living in London, and had been diagnosed HIV + for more than six months at the time of the interview.

All the interviews were conducted on hospital premise but in non-clinical spaces. All participants spoke English. Before agreeing to take part all the men were given detailed information about the study and their written informed consent was obtained if they agreed to take part. Travelling expenses were reimbursed but no other payments were made. 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. All the data from the interviews was then subjected to thematic analysis that elicited the key issues presented in this report.

The voices of the men are represented in the report using quotes from their narratives, but with no identifying data about which of the men is speaking.
Characteristics of the sample

The eight men in the sample came from seven different African countries. Age range was 27 - 43 years old with the majority being over 30 years old. 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). The majority of the men were living by themselves in council houses or private homes. Five men were regularly employed and their economic situation appeared to be stable. Though some men discussed the desire to change jobs and careers, most were reasonably satisfied with their current positions.

For the three men without work, the situation was clearly much harsher. They were living on welfare benefits with very small amounts of money 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.

‘It is hard living on benefit, because all you do is pay the water rate, your rent, your bill and you’re left with something like 40 pounds a week, you can’t even save to buy nice clothes or anything...’

‘They give me £28.00 and I have to go and look for my own money for clothes, people have to give me money, like, sometimes I have to have sex with people to get money...and then it’s no good, it’s no good for me to do that...’

Many expressed an aspiration to settle into some kind of job in which the employers will understand their needs as HIV positive people, and where they could be open as gay men.

‘I would love to find another job where I can actually come out and be myself. Rather than stick in that same job and living a double life...not telling them that I’m actually HIV positive, that’s one thing, not telling them I’m actually gay that’s another thing...’

Two of the men in the sample were experiencing difficulties in relation to their immigration status. For these men, the daunting possibility that they might have to return to their own country created constant anxiety and distress. They feared for their health if they had to live in a situation where treatment for HIV was not available. However they were also concerned for their safety if their sexual identity was revealed. Because homosexuality is illegal and highly stigmatised in their countries of origin, they would be vulnerable to blackmailing, harassment, violence and arrest.

‘That is my only fear because if I go back to my country, as a gay person I cannot live comfortably at all. The HIV is a worry...but that has a solution, which is having a good job, having money to get the medication. But being gay has no solution, because you are just surrounded by people that don’t like you...that is the main problem I have as a black African living in the UK’

‘If they say to go home, to tell somebody to go to a country where the person can’t get treatment you are looking for the person to be dead...my life is in danger because I have two things over there you understand. Either my HIV is gonna kill me, ‘cos I will get no medication, or just people will just take my life off...they would just break the house down...they would just put a fire in there because of me’

These men therefore 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/AIDS 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 their identity as black Africans and gay/bisexual men.
Key aspects of life with HIV/AIDS

Finding out about their status
The opportunities for counselling and testing in the UK are much greater than most of the men had been used to but still the choice to use them was often difficult. About half of the men decided to have the test either as a routine check, or because of doubts over their partner’s behaviour.

‘Just to know. I’ve always identified with the adverts that say ‘go for your test, know your HIV status’

‘Cos I was seeing someone and he just disappeared for a while, and we’d been having unprotected sex so...I thought ‘oh God maybe he’s ill or something’. I just freaked out and I went and had a test’

The rest decided to have an HIV test because they were feeling ill and their health did not seem to improve.

‘And usually I would feel very tired, very weak, and I would feel really completely different from how I was in Africa. I would say ‘what is happening with me?’ and I thought is it this type of job...or maybe the weather and the change in this country is affecting me...’

Some delayed investigations even after it had been suggested to them by clinical staff. The most common reasons given for this delay related to their anxieties and prejudices about HIV.

‘And one doctor said to me ‘it would be a good idea if you actually had an HIV test’. By that time I was really ignorant about it, you know. When people say ‘HIV test’...it’s just like ‘no, no, no, I’m not gonna have it, I’m not gonna have it, I’m not gonna have it!!’ I was scared, I was not really prepared...Because I was so negative...and because I was sick at the time, I was in hospital, and because of my condition, I didn’t want to know, I wasn’t actually prepared to go through that and being ill at the same time’

Only one man stated that he was not surprised by his diagnosis:

‘I’m not among those Africans who present late. I knew because of my sexual practice...but I kept it at heart until I said ‘I should go and test’...I knew already so it wasn’t a shock’

For the rest the result did come as a very great shock, and some thought they were going to die right away. For those men diagnosed in the early 1990’s, little information was available about the treatment for HIV. For those diagnosed more recently, the news still came as a massive blow. They were able to access information and counselling and quickly realised that their chances of surviving for a long time were quite high. However many were burdened by experiences of HIV/AIDS in their country of origin, and associated their own situation with that of people dying in terrible conditions in Africa. Reaction to their diagnosis was also influenced by worries for their current and previous partners.

‘Well, it was shattering, you know. It’s not the best of news. I’ve always just wanted to have the test and this society made it more easier for me, because back home you cannot just go for that test...So I just had a test and it was really not a good news’
‘I took a deep breath and I said ‘oh, my God’...all the plans I had, of wanting to go to college, wanting to make something out of my life, I wanted to have a family, I wanted to have children...now I’m told this...because then we still had this stigma of ‘if you’re HIV positive, you’re dying, tomorrow’. And there was...a counsellor...so they started talking it through ‘this is nothing new, you don’t have to worry, there’s help, there’s this organisation, you can come here for counselling or blah blah blah’. And I was just there, I just couldn’t understand them, because my mind then switched off completely in a different world...It was a nightmare’

‘When I was young there was one lady who lived close to us...she was HIV and (her) appearance was very bad...she was very skinny, and nobody would touch her, and nobody would even sit on a chair if she had been on the chair, or even touch the chair, nobody wanted to eat with her, and everybody just ignored her, that’s what I knew about HIV ever since I was young...I was sort of shocked ‘cos I knew I was going to die...I assumed that my life is going to end very soon...And the doctor he sit down with me for about 3 or 4 hours and explained it to me ‘you have HIV and we can treat HIV...not to damage you badly, and ruin your life’. And he showed me how they can treat the HIV’

After their 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.

‘I didn’t want to blame anybody...I just didn’t want to point a finger at anybody...so it’s just like imagining where you could have had anything’

‘I just refuse to think of that. I see it as a responsibility...if it was a mistake I made, I made it by myself and I don’t think I have to blame anyone for it...I tell a lot of people, they say ‘how did you have it, why did you get it?’ I say ‘that’s nothing I want to go into’. I mean, it’s the past, it’s already happened...I’m an adult...I think if both people are adults, they should take responsibility for whatever risk they’re going into’

‘I’m not going to lie down in bed and think ‘oh God, where did I actually get infected? From who? From this, from that’, blaming people...that’s me, that’s what I am. And I just move on and get on with my life. I put all the negative side away, I grab the positive side and just hold it. I know I’m not going to feel well, I’m not going to get better. But who knows in ten years time, in fifteen years time there might be a cure for it! Who knows?’
Dilemmas of disclosure

Disclosure of their HIV diagnosis was very difficult because of what they saw as the social stigma against the disease especially among fellow Africans. For some of the men 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.

‘My flatmate, he’s the only one I trust...He’s my best friend, yeah. And he was giving me all the support. I trust him well. And if anything happened to me at home, he would know what to do’

‘It’s only my girlfriend, my previous girlfriends, and the group friends, we go to the organisations or the groups...the positive circle’

Very few of the men had disclosed to members of their family. A few told a brother or sister but parents were rarely informed. Like other Africans living in the UK, some men in this study explained their secrecy in terms of stigma against HIV and not wanting to worry their relatives ‘back home.’

‘I have not told my mother...it would be just like scaring her to death... I have not told my closest family back home. Say...my distant cousins, people that come from my tribe, that we know each other from my country, I have not told them. And I would not tell them because there’s a stigma deep down...But yeah nobody knows to be honest, apart from the circle of HIV people’

But they also expressed the additional fear that they might be blamed for their own infection because they are gay. 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 their illness.

‘It would just kill her. Because of all the things that are going on in XXX, and the plight of someone with HIV in that part of the world...is like a death sentence, you know. You either have to have a lot of money or you have to know somebody who can take bloods for you and get you medication...She just wouldn’t understand it...but I still think she’d probably turn around and say ‘oh, God, you’re HIV positive’, she’d worry for a while and pray, knowing my mum, and then turn around and say ‘oh God, you know it’s a punishment from God’

‘It’s probably the same thing...not telling my parents that I’m gay straight forward...it’s probably relating to that...I mean my sexual life, my life belongs to me. I don’t feel the point of wanting to tell them. It won’t change anything. I totally don’t want to have people saying...feeling sad for me’

‘No, I haven’t told anyone, I’ve never told them...because it will destroy the family and I don’t think they will be able to cope with it...And I think they would distance themselves completely away from me...it’s bad enough me being gay, and if they found out that I’m HIV I don’t think they will give in...they will find it very difficult for me to be around them, I think, anyway’
Social relationships: separation and secrecy

The social lives of these men 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.

‘I would say I have two lives because I am always free and confident, and free to talk about things when I am in support groups, HIV groups, I feel this is where I belong. But when I go somewhere to visit...I would feel uncomfortable...’

‘When I’m stressed...that’s when I think about HIV and I say ‘I’m gonna die’, the thought comes sometimes. But when I’m talking to people who know HIV, I’m actually better off around people who have HIV than with people who are not HIV’

Some men said they were open about being both gay and HIV positive in every social network. More accurately perhaps, they only frequented those settings where this was possible. However this very often seemed to exclude other African people. Only one man appeared to be socialising regularly with other gay/bisexual men from Africa. For most of the others it was a question of socialising either with white gay men or with heterosexual African men.

‘...the only African people that I would hang around with are my friends. If they went to an African do...I'm quite hesitant to go there, even though they’re people of my own background. Reason being that I still get insults, I still get people saying all kinds of comments, even though we’ve all grown up with the same upbringing...because it’s not a black thing or it’s not an African thing, on top of that as well. And because the African society is family orientated, sometimes you feel like you’re that sore-thumb that’s throbbing all the time...’

‘A lot of African men they are gay, they know that they’re gay, but they’re living a double life...because of what the family are going to think about it, or what their parents are going to say about them. So, I don’t think that’s right for me. I wouldn’t live that kind of life’

‘My friends are mostly white... since I was born most people think I’m white. I think I just like whites. For friendships, intimate friendships, everything. I just say that because I like people to live as themselves, which is something I don’t find in the black community. People live according to what they expect another person to believe in. Back in my country...you are gay, they cannot accept you are gay because people will not accept you, so I just don’t like that sort of life’

Many of the men had close women friends but with them too they often felt compelled to conceal key aspects of their identity.

‘To me when I’m with someone, and I feel comfortable with that person...it’s like a secret...we go in there, we do this thing, and when I come out I’m a different person, you know, the feeling. But I wouldn’t be out in the open with it...and whenever I’m with girls or my girlfriends, deep down I feel guilty...them knowing that ‘this is my man, he’s straight with me’, but they don’t know what my inside is...’

‘Because I’m African and I must have a woman, so I’ve got a woman...but I do gay advocacy for Africans...we are men who have sex with men in that group. Then when I go into the heterosexual...and you pretend to be...because...in a very heterosexual community gay is taboo...’
Naturally 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 be challenging because of racist attitudes and cultural differences leading to fears of being misunderstood.

‘I find it very difficult going out with an African man. Everybody is different, all African men are different, I personally live my life in a way that I want to be happy with what I’m doing. I’m not going to do something just to make you happy when I’m not happy. So that’s why I actually came out to my family. That’s why I actually come out to the few people who ask me’

‘We grew up, and then go into this culture. Here is more free, but African people are still African. This community, as I was telling you, they bring out the gay…there’s a lot of discrimination, so that’s why I keep secret…But when you’re in the white community then it’s different. Most African people they would even resent what I do, actually, if they know I have sex with men…that’s why me I have white boyfriends, I do much with white boyfriends because they really like me’

‘The gay scene does tend to be quite racist…But there is a lot of division within the gay scene that I’ve noticed, and I don’t feel as welcome as I thought I would have. And because of upbringing I didn’t feel I fitted very well in there…It’s very hard, and if you do go out, if someone is African, they wouldn’t identify themselves as being African, because outside of that clubby scene, when they’re doing their normal 9 to 5, they don’t really want to be acknowledged, the people I’ve met’

For some men their immigration status may pose additional problems in developing long term relationships with white gay men.

‘My relationship has always been with white people and then the fear is that the people think of the future: ‘if I have a relationship with him, he can’t stay in this country, he’s going back’. So even though I’m always looking at long-term stuff, it’s not always possible…some people have this notion that ‘oh, you’re trying to come on me because you want to use me to get your immigration status sorted out’…And if someone is thinking that, he’s not trusting that it will go for a long time, he’s thinking ‘when he gets what he wants he will always go’. And it’s the worst part of it’
Sexuality, sexual practices and HIV

Five out of eight of the men in this study had a sexual partner at the time of the interview, though most described their relationships as not stable or not serious. Two of the men have both female and male sexual partners. The majority of the men reported being sexually active with one or more partners and mostly talked of sex in the context of emotional involvement.

‘I see sex as bonding, something that you do and you go beyond the ordinary face-to-face connection. It’s something that bonds your spirit, your inner person... That is why I cannot really have anybody just because I want to have sex. I have sex with people that I admire so much, people that I think there’s something between me and them that connects us’

‘Sex... I think I am more into the affection, rather than sex, at this moment in my life... I need more body language rather than the physical reality... maybe because I want to fall in love or maybe I want somebody to love me for who I am... I do enjoy sex, I love sex, but it has to be with the right person’

‘I’m not into too much sex now, I’m more into love... but if I get a stable boyfriend then we’d have sex, but then there’s no boyfriend who’ll be faithful’

Most of the men denied a relationship between how much sex they have and how much of a ‘man’ they are. Indeed a number were critical of the ‘macho’ ideas regarding sex which they saw as common among both heterosexual and gay men.

‘No, I don’t wake up in the morning thinking ‘I’ve got to have sex’, no. I would just say that sex is not that important... it’s not about having sex, I’m a man anyway, so I’m not going to be more of a man when I’m having sex. I’m a man full stop’

‘I just woke up one day and thought ‘well, I’ve just been really wasting my time’, because sex is important on the gay scene... if the sex isn’t good then it’s not going to work. For me, it’s not an important factor because I’ve done that and yeah... I think you don’t have to prove your animalistic side, to be honest!’

‘Without love it means nothing, if it’s with love, it means everything... having sex all the time doesn’t make you more of a man... sex to an African man is power, but they are not romantic enough... What is it to be a man? Being macho and aggressive and taking control, but yet being aloof when it comes to loving. When you show love and affection, you are weak, which I am because I show love and affection. So to the eyes of our people, I don’t think I’m a man, because when you’re also classified gay, black, you’re worse... but in my feelings I know I’m a man’

HIV/AIDS appeared to have influenced the sexuality of these men in a number of different ways, both directly and indirectly. Some talked about how their illness had made them less sociable and how this in turn has reduced the likelihood of sexual encounters. There were also a number of references to problems relating to disclosure, and the fear of rejection by potential partners.

‘I’m scared of having sex sometimes. I’m scared of meeting someone who goes like ‘ah! Let’s just go crazy’ and I know that ‘look, to myself I have a limit, I cannot just go like that’. Even if it’s someone I don’t want to tell, which is the most difficult aspect of it, and you find that I don’t want to do this or that. And the person is like ‘why wouldn’t you do this?... are you HIV?’ and I don’t want him to go into that question ‘cos I don’t want to lie about it, but I don’t want to tell him about it... And sometimes I don’t really like it... I’m worrying, you know. And it makes me speechless sometimes...’
‘I count myself as being in a different world...because, then, that would mean telling someone ‘ok, look, this is what is happening’, or ‘I’m HIV positive’...I wouldn’t want to disclose to people like that...I’d rather be happy with someone who is positive as me, who will understand what exactly is happening inside me, yeah...I wouldn’t dare lie to someone...pretend I’m negative and have a relationship as some people would do, to be honest. I wouldn’t, that to me would be killing someone, you know. That to me, to God even, it’s bad’

‘Subconsciously it is because you’re thinking ‘everyone else is so healthy’, you’re thinking that ‘everyone looks so happy and I’m not, I’m just coming out, just going with emotions, I don’t really fit in’...then you get the immediate rejection, if you meet somebody and say ‘do you want to come back to mine’, or ‘I’d really like to sleep with you’, ‘well, actually, I feel I should let you know...’

All the men displayed clear awareness of safe-sex practices. They all reported using condoms all or most of the time since they had been aware of their HIV status. This was to avoid infecting their partners but also in order to protect themselves. However most also stated that they find them intrusive and disruptive. Only in the context of sexual intercourse with another HIV positive person did some men say that they prefer not to use condoms.

‘..You must have heard this about how some African men don’t actually like using condoms...They find it very difficult to use condoms. Mmm. I, personally, don’t really like using condoms. And being in a long relationship...I never had to use condoms’

‘I can never meet an HIV negative person because then that would be a completely different way of living...you’ll have to be on condom throughout. And being on medication, and the way that the medication has affected me...if I have condom, I have no feelings at all...’

‘...I know that condom is a must, now...Because I’m not going to tell them, I don’t want them to get infected anyway at all from me, so it affects my life in that order’

Some men volunteered quite detailed information as to what they do and do not practice sexually. Most were very concerned with ensuring safe sex and had given the appropriate methods for achieving this considerable thought.

‘Now that I’m HIV positive it (safe sex) means a lot...not only do you protect the people you are with but you protect yourself, because when you are HIV positive you cannot afford to have any foreign bodies in your body...Safe sex is also not to get so drunk and just kiss or be with anyone you meet or by thinking that because you’re not having sex and your giving them oral...just because you didn’t have sex with them and your going down on them and you think that is safe. NO, it is not safe, not any more’

‘I don’t let anyone...because if you are having oral sex, for instance, I’ve never let anyone use their fingers to play around with my anus or anything like that, because I start thinking all kinds of weird things. I don’t get fisted, ‘cos that’s one practice that a lot of gay men do. And I prefer not to penetrate because there’s a fear of passing it on to somebody...Yeah, because (condoms) they’re not 100% safe...And I’m just worried that if I pass it on, because of what I’ve gone through, I don’t want anyone else to go through that’
Health services

The overall view of the participants of their health care was a positive one. Many of the men stated that they considered themselves privileged to receive such care in comparison to their compatriots in Africa. Most also valued their relationships with their doctors and they often spoke enthusiastically about hospital staff.

‘Because I’ve been to Africa where HIV is rife and people are struggling to get bloods taken, let alone be given medication, I’m just glad to get tablets or whatever it is’

‘I think my health adviser has been, I don’t even think of it as an NHS service because she’s more than ever the biggest support I have now’

‘I think I find them to be very…nice, friendly, and the amount of money who goes to the health service…I think they’re actually using it, putting it to some good use’

‘People are, here in London, are really committed…they are really caring, you feel that they want to make a difference, they want to have progress, they want change…’

‘They certainly look after me, my nurse…everybody looks after me, from the way they talk, the way they make me feel like I am a part of life…and that I am still alive…’

Nevertheless, some highlighted difficulties they have experienced themselves and views as to how the health services could be made better for men like them. Confidentiality was sometimes an issue, both in terms of hospital staff and in terms of the risk of meeting other people to whom the participants could be known.

‘…Because of the stigma…I don’t want to bump into a lot of other African people who are going to know me and then they’ll start talking about it. Then your life is in the cycle’

Others criticised the care they received from staff that were not doctors and hence were perceived to offer a lower quality of service.

‘…The services are not good in terms of junior staff, like the nurses…no…They give people who are staff nurses to deal with people living with HIV. These people are just there to treat…they even overtalk people…the junior professionals talk over the patients…not on professional grounds. I believe only people who are qualified should work in HIV, and I believe in my hospital only my doctor is qualified’

With regard to the information they receive about their health, most men appeared to be quite satisfied though there were areas they would like to see explored more.

‘I do have all the information I need, and if I need something more I just have to ask. Or there’s also the Internet. If you do some research you can find a lot there as well’

‘I think not a lot of people actually can do things like that, or can actually get access to the Internet. I think a one-to-one communication with people talking to them and explaining to them would be much better, yeah, rather than giving them a leaflet and saying go and read, that kind of way’
‘But I think there should be more of a focus on people who are non-compliant, or who are compliant, just looking at the progression of the illness, how cultural background may play into it’

Some men described the difficulties encountered in finding support that is specific to their needs as African men with HIV.

‘There are a lot of African men who actually can’t speak English…I think as an African man, the African people have to be more, people in the NHS should provide more foreigners…because some African men, some African people feel more relaxed to talk to their own body, rather than other people, they would be open to them...as they would say ‘their own brother’, that kind of way other than other people’

‘Like my family situation, and coming to terms with understanding it as a black African...’cos it’s like you’re a leper. If it’s out, in Africa, it’s like ‘oh my God, he’s got it’ and you’re treated like a leper. So you’ve still got that at the back of your head...but the person who was counselling me, because they didn’t come from that background maybe skimmed through that bit...’

However the care was not always seen to be lacking in cultural sensitivity.

‘I can ask my worker so many questions because she is from XXX ...so when I met her...I was very shocked...she is from Africa...she was so lovely, it made me feel that she was so easy to talk to, so I know that I could talk to her...’

Some of the men lamented the lack of organised groups and networks for African gay/bisexual men with HIV. They ascribed this to the reluctance of men like themselves to attend the support groups that some organisations have set up, but also to a lack of commissioning by the NHS. 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.

‘It’s a difficult one, because the people don’t want the service. So you know, if I was looking at, say, myself, for instance, it’d be good to have focus groups with people who are in the same situation. But no one wants to do it...No, no one wants to go. Because they are just closed’

‘The main message is that the whole statutory and voluntary sector, everybody should know there are African gay men and they would love to be organised. And I would also need to see services available for us as HIV+ bisexual or gay African men. Separate ones and then a general uniform one at one time. That would be good’
Religion: conflict and support

All of the men reported believing in God though only three were regular attenders at church, mosque or other religious gatherings. Some of those who did attend reported that they often felt guilty because they were aware that homosexuality was regarded as sinful, and felt they were hiding an unpleasant secret. Not all of the men talked directly about the conflict between religious and sexual feelings but the most common reason given for not attending church or mosque was stigma against homophobia. Only one man spoke about stigma against HIV as one of the reasons for not actively participating in religious activities.

‘I felt very guilty for a long time, being gay I was very confused...Now since I’m bigger, since I got older, religion is important to me. I pray to God, but I find it very guilty when I go to church being gay, positive, and I was thinking, it’s wrong...because I have sex with men before I even got to church and I can’t take the Holy Communion because I have sex with a man. It’s taboo to allow another man, so I go to church and pray, I don’t take Holy Communion, that’s it’

‘...My mum used to drum into me that you can’t be a Christian and be gay...the people who I looked up to believed that this God does not accept it...I thought ‘well if he created me like this, why are you creating all this hatred amongst people?’...God supposedly created a man in his own image...but if that’s the case then why are we being rejected?’

Though some of the men could probably benefit from religious support in dealing with their illness, they may be inhibited by their expectations of being stigmatised. Most of the participants did mention prayer as one of their coping strategies despite their feelings of separation from church or mosque.

‘For example if I go to a church now, you know like a black church, and they find that I’m HIV positive, they’re not going to behave in the same way they would behave to that man who is HIV negative. They would push me far. Which I don’t believe that’s the kind of way religion is supposed to be like’

‘I don’t go to church, I believe in God but I can’t lie to you and say, I go to this church or I go to this...Because I don’t. I know God, I pray on my own’

‘It is in the Bible to pray anywhere and everywhere you are, you can pray and you can worship your God, you don’t need to go where everybody goes, you can just stay in and God will listen to you’
Meeting the challenges of living with HIV

The challenges faced by African people living with HIV in the UK have been documented in a number of studies in recent years (1-5, 13, 14). Naturally the men in this group reported very similar problems of everyday life. But they also faced additional difficulties because they are African and gay/bisexual.

Only one man in the sample stated that living with HIV had not changed his life in any way and he was not worried by the virus. This could perhaps be explained in large part by the fact that he has been able to maintain both his relationship with his partner and his career. For the rest of the men, HIV represented a break in the narrative of their life. Even though the nature and the intensity of the effects varied between individuals, a positive diagnosis usually meant that plans were abruptly overthrown and relationships with family, friends and partners began to change.

‘It’s hard, it’s hard, it’s hard. My whole life has changed... I have to always be conscious of looking after myself, try to look healthy. The fear about my health, the things I cannot do...before when I wasn’t HIV positive...I can go out and drink, I can go out and enjoy, I can walk around the road with just a T-shirt...but now I can’t’

‘It can be debilitating, sometimes I take tablets...it’s just a constant reminder. But I’ve tried to put it at the back of my head and say ‘well, it’s like anything, cancer or whatever, if and when I need to be debilitating by it, I’ll take it’. But right now I’m just trying to seize the day and enjoy it. Because like when I first started there was the whole denial thing, and panicking, reclusion, all sorts of things all put together. But now I’m just living each day as it comes’

‘It ruled out my plans, everything that I have planned in my life...all my future plans were shattered because I don’t know how long I’m going to live for, and I can never plan anything ahead. It has stopped my future plans...I have the future to think about, staying healthy to survive, but I can not go long term beyond that, it has cut my life short, my HIV’

Many of the men suffer or have suffered from depression, and most of them described feeling low at times mostly because of the fear of death.

‘One time I was really badly depressed and I thought actually I was going...I went a little bit off-rail...I had to see a psychiatrist one time and I was put on medication, which I’m still on, but slowly by slowly...I’m getting to be myself now’

‘It’s very hard...sometimes I think about it and sometimes it makes me depressed, like talking and hearing voices in my ears...The way I live, I think my life is in a halfway...It makes me feel so sad in my life...sometimes I will stay at home and get emotional and I will cry, just cry, and then I will come back to my normal’

‘Mentally I try to stay strong...sometimes when I’m not feeling very well, I have to mentally switch on a block and think positive, because the more you think negative the more it affects your immune system. It’s very difficult when you see programmes on telly and see all these people dying and you know you’re carrying the same virus, and you can feel so sad sometimes. You want to end it all’
Yet with time some of the men have re-adjusted and have grown progressively stronger and self-confident.

‘You think you’re going to die. Actually I didn’t expect I would be alive by 2000. I would be dead by 2000, that’s what I was thinking, counting years… and I’m there to challenge that as well, you know, I’m there to tell them that despite I’m HIV I can still make a difference and I can still do something’

‘...Now things have gotten better and I’ve lived for the last ten years, and I’m still here, and things now are getting better and better, and my depression is going down a little bit. Because I thought I would never have children and I always wanted to have a family but now even HIV people are having HIV negative families and people are living normal... so this is strengthening me...

‘I’ve matured a bit... I know it’s there and fair enough I get reminded every day, but it doesn’t weigh me down as much as it used to. I look at life as being so precious. And because I’ve seen other people who are not in the same situation as me, like, say, South Africa... because your life style is extended and you’ve got a better quality of life, because you’re living and not actually having all these AIDS-defining illnesses. So I’m more appreciative of life than I was maybe six years ago’

‘And so I sat down and worked it out and said “fine, this can be cured”, you understand. So I just have to live my life and just be like a normal man and fight hard to have a future’

Overall, the majority of men stressed the importance of positive thinking and keeping up with their treatment and knowledge of HIV as the fundamental aspects of maintaining their wellbeing.

‘I think if you actually become HIV+ you have to be strong, you have to be positive about the whole situation, about your life, and stop thinking about the negative things. And as far as I am concerned a lot of people actually end up with AIDS or whatever the things, or whatever the problem, because mentally it’s the way they take it’

‘Being positive, I’m used to it really... and as I say it doesn’t change that much... in a way I’m still doing everything I want to do, travel and that, and trying to have a normal life, and not thinking 24/7 about being positive... I never say to myself ‘oh, if I knew I would do it like this’

‘I think about my mum... she’s lost my father, she’s lost my brother, she’s lost cousins around her and I cope by making sure I take the right stuff. I protect myself, I make sure I take the right tablets all the time... nutrition-wise I’ve changed my ways, what I used to eat, just my body to stay healthy and I read a lot to find out what I can take to boost the immune system to stay healthy. That’s what I do’
When thinking about their future, some men also talked about their desire to be fathers, and some of them were actually planning to do so. Half of the men stated that they would like to have children either via adoption, or with a woman. Amongst the reasons why they would want to be fathers men talked about passing on their knowledge and experience, having company when older, giving someone love and also feeling more part of their own family. Most of the men would like to have a child within the context of a stable relationship with another men.

‘Maybe I would fit into my family a little bit better...if I had had a kid maybe the pressure would be off me. But not only for that, I would have given that kid the love that my father never gave me’

‘I’d love to give someone that special thing that I never had...I didn’t have a father, and I’d love to give that to somebody. But it doesn’t necessarily have to be my own flesh and blood...Ideally I’d love to get married to a gay guy and adopt’

‘It’s just my way, all my brothers, or cousins, have children and in African way, you have to have children, what’s wrong with you, if you don’t have children? It’s not that I want to have children because someone wants me to have children...no, it’s just because I want to be a father and I want to have a child, and love him, or her, and give him, or her, my love and know that I have a child...’
Conclusions: managing the contradictions

The main theme to emerge from these accounts is 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. Yet one theme was common to all and that 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.

Living in London, and not being 'at home', has meant both benefits and challenges that are peculiar to this group of men because they are both gay/bisexual and HIV positive. Most have been able to live more openly in London as gay/bisexual. But for most this openness has 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 were especially acute and sometimes provoked negative feelings of a life lived in secrecy. At the same time their HIV status has created a new set of practical and emotional needs, which often cannot be met because of stigma and discrimination. These problems are especially challenging for those with little money or insecure immigration status.

This 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. However it can only be seen as a first step increasing the visibility of 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

The study only happened because of the men who were prepared to give their time to take part. Thank you all for taking the time to explain so much to us and for the insights that you have provided. We hope that we have properly represented the lives we have been privileged to study.

The success of this project depended on many people’s help and goodwill. In particular all the staff at The Department of Sexual Health, Homerton University Hospital NHS Foundation Trust who found the time and space to accommodate the project. The researchers depended on the help of clinicians in specialist clinics across London and workers in voluntary sector settings who spent time bringing the study to the attention of their clients and facilitating introductions to the team. Advice received from the African HIV Policy Network, the RAIN Trust, The Organization of Positive African Men, Terrence Higgins Trust, UK Coalition, and the Ethnic Minorities Unit of the Greater London Assembly was invaluable in setting up the study. Funding, without which this work would have been impossible, was provided by the trustees of The Derek Butler Charitable Trust.
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African women with HIV surviving in London Terrence Higgins Trust

I want tomorrow’: an exploratory study of African men living with HIV in
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