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# 'I want to survive, I want to win, I want tomorrow'

An exploratory study of African men living with HIV in London

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This report examines the lives of a group of African men living with HIV in London. The men have responded to HIV infection in a variety of different ways and many still feel optimistic about the future. But the main theme in these accounts is one of loss. Many do not have the jobs or the money they had planned to acquire. Others are not able to enjoy the sexual experiences which they see as a mark of manhood. Some do not have the relationships with wives or children that would give their lives meaning and connect them with past and future generations. Serious anxieties are expressed by many about their future in the UK, and ongoing access to the anti-retroviral drugs vital for survival. Religion has proved to be a great solace for many while others have gained support from their involvement in voluntary organisations. Most face significant challenges to their sense of themselves as African men.

## Background

About 480,000 people of black African origin are living in England and Wales. Almost 80% of these live in London (National Census, 2001). African residents in London are a diverse group showing a rich mix of cultural, religious, economic and political differences (McMunn et al, 1999, Mckintosh,2005). They have come as students, workers and asylum seekers, both alone and in family groups and make a major contribution to the vitality of many aspects of London life. Most come in order to improve their lives but despite being better qualified than the UK population as a whole, African migrants experience double the rate of unemployment (National Census 2001). Immigration policies and practices and discriminatory treatment often affect their living standards and many end up impoverished and socially excluded (Elam & Chinouya, 2000).

Africa bears the heaviest burden of the world's HIV pandemic, with over 25 million people estimated to be infected (UNAIDS 2004) The impact of this has been felt across the world and is reflected in the increasing numbers of HIV positive people from African backgrounds in the United Kingdom. (Sinka et al 2003). In 2003 it was estimated that 16,200 people of African origin were living with HIV in the UK and that 48% of new HIV diagnoses were in people of African origin (Health Protection Agency, 2005). Although a majority of these infections are acquired by sex between men and women almost twice as many women are diagnosed and are attending for care as men (Health Protection Agency, 2005; SOPHID, 2003). This is in contrast to recent data on the prevalence of HIV infection within the African community in the UK which has demonstrated similar rates in both men and women (Mayisha ii Collaborative Group, 2005).

Although both African men and women present later than white British people with HIV (Saul et al, 2000; Burns et al, 2001; Barry et al, 2002; Boyd et al, 2005). African men present later than their female counterparts as demonstrated by their significantly lower Cd4 counts at diagnosis (SOPHID, 2003). As a result the substantial decline in mortality and progression to AIDS associated with potent HIV therapy in white patients has yet to be fully realised by Africans in the UK, with progress being even slower amongst men (Sullivan et al, 2004).

A high level of unmet need (Weatherburn et al, 2003; Department of Health, 2005), and of stigma (Dodds, et al 2004) has been described in Africans with HIV in the UK, serving to exacerbate what are already complex medical challenges. Recent work has examined the lived experiences of 62 HIV sero-positive African women living in London (Anderson and Doyal, 2004; Doyal and Anderson 2005). However there are no equivalent studies of men despite the widespread acceptance that gender is an extremely important factor shaping experiences of the epidemic. The project reported on here is an attempt to fill that gap. The objective of the study was to explore the circumstances of African men living with HIV in London with a particular focus on the relationships between gender, masculinity and HIV that would inform health and social care issues in the UK.

## Study design and implementation

Because this was the first study of its kind, the most appropriate research method was a series of qualitative semi-structured interviews. These were planned with the help of members of the peer support group Organisation of Positive African Men (OPAM). An advisory panel was also established to run for the duration of the project with representation from appropriate voluntary sector and patient support groups (OPAM, Terrence Higgins Trust, African HIV Policy Network, UK Coalition, Ethnic Minorities Unit of the Greater London Assembly and the RAIN Trust). The study was approved by the East London and the City Research Ethics Committee.

Men were recruited to the project through one of two routes: either as patients of specialist hospital based HIV clinical services or through their involvement with OPAM. The main sample was made up of 37 patients attending specialist HIV clinical services at Homerton, Newham, St Bartholomew's and the Royal London Hospitals. Twelve men involved with OPAM were later included as a supplementary sample.

The main sample was made up of men aged 18 and over who self identified as black African, who had been born in Africa, diagnosed HIV positive for at least six months and had lived in the UK for at least six months. Men fulfilling these criteria were identified from hospital records and were approached to take part in the study by their regular clinician at routine outpatient visits. Approximately 60% of men contacted in this way initially agreed to participate.

Those who expressed interest in the study were either introduced to the researcher for further information about the project, or permission was sought for the patient's contact details to be passed to the researcher for follow up. The study details were then discussed with potential participants and written information provided. Translators were available if required. Men who agreed to take part were asked to give their written consent and were allocated a study number to maintain confidentiality. A further 20% of attrition occurred in these later stages with men either declining to participate after the initial meeting with the researcher or failing to attend for interview as arranged. Hence around 40% of those approached eventually took part in the study.

The interviews with the 37 participants took place on hospital premises. Demographic data was collected from each man in the sample using a structured written questionnaire immediately prior to interview. The researcher administered the questionnaire verbally to those who had difficulties with the written version. This was followed by a semi-structured interview. The men were asked to talk about HIV infection in the broader context of their life history and current circumstances. Interviews were tape recorded where permission was granted and transcribed verbatim. Six men declined tape recording and extensive contemporaneous notes were taken during these interviews. Interviews were carried out between November 2003 and August 2004.

During this fieldwork period, a focus group was held with 12 men from the support group OPAM in order to clarify topics and develop emergent themes. At this point it was decided to carry out supplementary interviews with these men. This decision reflected in part the relatively small numbers of men from the population of hospital users who were willing to talk about their experiences. But it also offered a unique opportunity to document the very extensive knowledge of the OPAM group both from their own experiences and from those of the men with whom they had worked in a volunteer capacity. Nine of the original twelve men in the OPAM focus group agreed to give individual interviews and these were carried out using the same methods described above.

## Characteristics of the main sample

37 men from 13 African countries were recruited from hospital based clinics. 35 of these self identified as having exclusively female sexual partners while two others identified as having sex with men (MSM). Although there was considerable common ground between all 37 interviews the two MSM had substantial and important differences. This analysis is therefore based on the 35 heterosexual men. Additional targeted recruitment of African MSM with HIV was later undertaken to obtain a larger sample which will be the subject of a separate analysis and publication.

The thirty five men who defined themselves as heterosexual came from 12 countries, with almost half being of either Ugandan or Zimbabwean origin. This reflected the wider distribution of men receiving HIV treatment in the target hospitals. Their ages ranged from 25 – 59 years, with 69% being between 35 and 45 years. Twenty (57%) had been found to be HIV positive within the two years prior to the study (range six months – 15 years). Seventeen (49%) had required inpatient treatment for HIV related complications. Eighteen (51%) had been in London for less than five years. Forty percent had secure residency status in Britain.

Nineteen (54%) of the men were married or living as married and 29 (83%) had children but of these only 11(38%) had children living with them. Seven (20%) were working full time and ten ( 28%) part time with nine ( 25%) undertaking some form of study. Nine cited health problems as the reason they were unable to work while four blamed immigration restrictions. Twenty two (63%) had at least secondary school level education and 12 (34%) had either undergraduate or postgraduate university qualifications. Twenty nine (83%) described themselves as having a religious affiliation, mainly based on some type of Christianity.

The 12 voluntary sector focus group participants who included the supplementary sample of nine men were broadly similar in age, distribution of country of birth, time in the UK and length of HIV diagnosis to the hospital recruited group.

Interview Key:

M = Individual interview – hospital clinic attending men

VS = Individual interview - voluntary sector group men

FGP = focus group participant

## Key themes

### Finding out about HIV: diagnosis and response

Many of the men in the study showed considerable reluctance to be tested. None were diagnosed as a result of routine screening and several had refused a test when it was initially suggested to them. Many had volunteered for testing only after discovering that their partners were HIV positive. Three had previously tested HIV negative.

*'As I said before, my ex – partner who died with HIV ...that left me feeling that I had to do the test. When I had the test then I also came out positive.' (M 4)*

*'I was tested purely because my wife was HIV positive. She was also not sick at that time and suspected nothing, we were both well and fit as we thought.' (M 15)*

But the majority were diagnosed relatively late in the course of their infection when they were already experiencing symptoms. Several reported that it was friends and especially female partners who had encouraged them to make contact with the health care system.

*'After about four weeks I was very, very ill. I couldn't sleep, I was sweating, I lost appetite and I started losing weight. So she said, its better you go straight to your doctor.' (M 7)*

Many went first to a GP and were referred for testing when they reported symptoms such as fever, headaches, weight loss and weakness. Few suspected that they might be HIV positive.

*'I was feeling sick, I was weak, I am not as strong as I used to be so I went to my GP and said I want a flu jab because I saw it on the television. He said "no, let me see your tongue, can you go for an HIV test?" ' (M 21)*

*'When I came to study, I had some rashes on my hand, so I went to see a GP. That time you know, when you come from Africa they know that you have high risk of coming with the virus. Then he suggested that I should take HIV test so I said "ok, I'm willing to take." ' (VS 8)*

*'I felt really sick, I was really, really sick. I thought at first it was the flu and that it would just go away and then my urine was really cloudy and dark... like it was the colour of some grapefruit juice that I had just drank you know...Well I went to the doctor and he couldn't tell me what it was, and I had the tests and the results came back and it was positive.' ( M 34)*

Others were diagnosed in hospital where they had been admitted as a result of the severity of their condition.

*'...my stomach was terribly sick. So I went to Accident & Emergency at xxx Hospital. ...They checked everything so there is no problem. So because I'm from Africa they said "let us test the blood": (VS 3)*

*'I was not feeling too good... I thought it was change of weather ...because when I came here it was very cold. But they found that I was anemic so they transfused, they put blood into me and found out why the blood kept going low. So that's when they discovered that also the HIV was in me.' (VS 9)*

*'It was around midnight, I was waiting for a bus, going to ... I don't know where I was going. It just felt like I had no power to walk so I collapsed at the bus stop... Then the people that were there called an ambulance and that's how I was brought here.' (M 3)*

For most of the men, the diagnosis came as a great shock. Their prior knowledge of HIV infection was often very limited. The future appeared to have been taken away from them and many felt that they were facing imminent death. Many reported severe distress which initially was very difficult to cope with.

*'It was heartbreaking, it was terrible when they told me. I knew that it's done, I'm going to die and it changed all my plans.' (M 16)*

*'After all the counselling, still the day when I was told that I was HIV positive. I just went weak in my knees. I could barely walk, I was just sat in this room for a while unable to move.' (M 37)*

*'It was like someone punched me. At that point in time, I didn't know anything about medication so when you are told, what comes into your mind is I am going to die. I don't want to die. We don't know anyone who has died and come back and told us how it is. You worry about it. How are you going to cope?' (M 32)*

## Keeping secrets and being alone

One of the most important decisions facing many men after diagnosis was whether or not to disclose their status. Their current partner was often the first person to receive the news and this was sometimes the foundation for a continuing (if changed) relationship.

*'When I told her initially she sort of was shaken but obviously she came back and give me support. So in that case again I was quite lucky because I know many people who after they are diagnosed just like the relationship collapse.' (VS 2)*

But for others their new status marked what was often the dramatic end of an existing partnership and sometimes the loss of children.

*'...She started calling me names. She took the phone, she rang [names an African country], she rang my mom, she rang her parents and she said she cannot stay with somebody that is AIDS.' (M 8)*

*'My marriage just crashed after my diagnosis, I came home and told my wife and she stopped talking to me, my children too were made to stop talking to me so it was total isolation and I realised that I was in a different world.' (FGP)*

Most of the single men in the study expressed the desire to have a partner to share what was often a very lonely life. But most recognized that this was unlikely to happen.

*'They know you are unemployed, so you cannot afford even a pint of beer. So how come this woman will go with you? There is no way she will go with you.' (VS 5)*

*'Mmm a partner is on and off because of my situation. I'm not a breadwinner, I'm not earning a living because I am depending on income support and a small amount of money because I am sick so that cannot sustain me and a partner so just occasional friendship I maintain.' (VS 3)*

*'You know they are giving me £97. If you are in a relationship, that £97 is not enough for you... I can't be dating a woman now. So because of the money problems that is why I ...you know?...I just remain in my shell.' (M 7)*

Among the most difficult decisions to make was whether or not to tell family members in Africa about their condition. Mothers in particular were usually kept in ignorance due to fear of their likely distress.

*'I tell my mum that this is the condition I am in, that may cause so much problem to her...she cannot imagine ...someone that she looks up to bury her when she dies.' (VS 4)*

*'By the time I was diagnosed my father was now reaching something like 77, 78, he was so old now, he used to rely on me, I'm the one feeding him...I knew if I told him that I'm positive he would have died that time because of sorrow.' (VS8)*

Most of the men disclosed their status to very few people outside their immediate family because they feared being stigmatised in the wider community.

*'Medications are not so available in our country so the moment you are associated with HIV then you're a dead man. People don't like to be associated with dead people, with people that are going to die.' (VS 7)*

*'If I have the sort of scenario where all my fraternity get to know that I'm HIV positive, I will die psychologically because I will be rather the scum of society ...you know us black people don't treat each other very well when it comes to such diseases.' (M 2)*

*'Some African families have thrown a member of the family out because he's HIV positive! It has happened, even here. Some people have committed suicide because they found out they're HIV positive ... it has gone to that extent.' (VS 5)*

For many this need for secrecy made life very lonely. They talked about their social isolation and the loss of relationships that had been highly valued.

*'If you are living alone without the help of friends, someone you love, you just wake up in the morning, you take your bath, you read, ... You cannot go out, you cannot go to club, you...you are not yourself.' (M 7)*

*'I do my things alone. ... I just do my thing, I get up, nobody knows where I'm going ... HIV is something that has taught me a lesson, taught me a real lesson that ah... from a family man to being a loner, you know its not easy.' (M 7)*

*'It is difficult because all the time you are thinking about having a relationship which you cannot have because of your status, you are thinking of maybe people discovering when maybe you have not told them and you feel that perhaps you should have told them, or something like that. So there is that stigma that keeps on haunting you.' (M 34)*

## Men and sex in the context of HIV

Most of the respondents identified sex with women as a basic need and saw their own sexuality as a central feature of their identity.

*'It's part of what I'm designed to be, I'm a man and you know, we are identified as such, and how do we use the tools that God has blessed us with? Sex is the way.' (M 1)*

*'You know when you are a man, or a woman, sex is part of life really, you see. And...you know...positive relationships...having sex in a proper way... that's part of the normal life of any human being.' (VS 5)*

*'How could one say they are a man if they are not in any way participating in sex...it's a prerequisite...you must enjoy sex with the opposite sex.' (M 25)*

But most reported that their sex lives had been greatly affected by their infection. Those without partners had few sexual encounters and those who were in long-term relationships often reported a reduction in the frequency of sexual intercourse. For some, sexual desire itself had become a much less powerful emotion.

*'When I was diagnosed it was like it affected my brain. I didn't actually have sex a lot. I wasn't sexually active. You know, it took some time.' (M 8)*

*'Sex just crosses my mind once in a while, it is not like I think about it..I don't think about it positively anyway. The interest is not...it is very minimum.' (M 1)*

Others described how physical and psychological pressures prevented them from fulfilling their own desires or those of the women they were with. Many talked about their 'weakness' which they attributed both to the illness and also to the medication.

*'Look at the way I look. Do you think I can go out now, to see a woman when they know the truth...(laughs) I only have the body but the engine is no more there now.' (M 7)*

*'At times I feel you know, like I'm not capable of doing some things...Like sometimes if I'm at home with my girlfriend, there are some things she expects me to do and I say...wait a minute wait, I don't tell her direct. Cause I know I won't be able to ...She'll ask me to be more energetic with her at times, and I won't be in the mood.' (M 11)*

*'Yes certainly the medication does affect how you perform and it does affect things. What can I say?... I am not as strong as I felt I should be when I was okay. I feel that I am weaker.' (M 15)*

A number also attributed the decline in their sexual lives to their fear of infecting potential partners. They felt contaminated and did not want to be responsible for putting others in the same situation.

*'I don't have sex a lot. A long time ago before I was HIV positive I would just go anywhere and if I fancy a woman I will go to bed with her. But not now with this on my conscience, I can tell you that I am still as black as I am, and its very, very difficult to stick to one partner, but not anymore, not anymore.' (M 37)*

*'If I have a relationship now I don't want to contaminate people's lives. You understand what I mean? Cause when you have a relationship, it will develop from friendship to...ah then you will be physical... I don't want that, I don't want to tell a lie and I don't want to say ok I love someone and I take her to bed without telling her my situation.' (M 7)*

Even men who had partners often found it difficult to enjoy or even to desire sex when so many other aspects of their lives were distressing. They talked about sex as an expression of love and joy that was not easily achievable in the context of insecurity, isolation and fears about the future.

*'I don't have sex... Yes, maybe once in a blue moon...When you are happy you have sex, but when you are not happy... both of us are not really happy because we're not allowed to work in this country. If we were allowed to stay... we could go out, come back happy, but now there's nothing like that. Now we come to hospital or we go to a solicitor. That's what makes me unhappy and then I can't have the sex; because I'm not happy.' (M 12)*



## Dreams of fatherhood

Those men who lived with their children referred to them often as a source of support and a reason for continuing to struggle with their illness.

*'When I was first admitted, I know death was on my mind. But I think one of the most worrying things was that my kids won't have a dad and that was a big thing ... I know that if my youngest child is 18 to 20, I don't mind dying...'* (VS 2)

*'I've got a wife who is very understanding and that makes a huge difference and I've got also my little kids who can even bring me water... When it's time to take medication they run and bring it to me and I take it. So that in itself is very helpful in a way. So that has made the burden quite light.'* (FGP)

The majority of the men who were not fathers expressed a desire to have children if their circumstances were different. Several of those who already had children wished to have more but saw their illness as a major obstacle.

*'Well as a man, you know, you want to have a family if you can... If you don't have them, the elders in that clan or in that extended family begin to say something like "you're useless, you're worthless,... up to this age you haven't got children", that kind of thing.'* (VS 5)

*'If you are married and if you don't have kids there is no happiness. If I don't have kids my future is hopeless. If I'm working very hard I'm working for my kids not the cat and the dog.'* (M 16)

*'It is children who will look after you and if you don't have children who are better placed, if they're not working and so on then you'll suffer because the government is not going to look after you when you're old. Children are our social security in the future... but if you don't have children, you've buried the whole generation.'* (VS 8).

The main reason the men gave for not having children was the fear that they would die before raising them into adulthood. And they could not be confident that their extended family would be willing or able to look after a child who was orphaned.

*'I don't see any point into bringing a child into life when I'm not going to be there for him or her.... I look at a fifteen year old child left alone without a parent... either that kid is going to be a burden to the world or he is going to be a burden to himself.'* (M 1)

*'I have seen lots of children orphaned by AIDS, suffering a lot. My Dad died when I was 15. I suffered a lot. Imagine if I die when they are seven or eight, what will happen to them? My future would have been with kids but at the moment it's hopeless.'* (M 16)

*'Here, in the UK, they will take your kids into social care. The way you wanted your kids to be, they can never be and your shadow would follow them and cry. The way you wanted to treat your kids, the way you wanted them to behave, the way you wanted them to talk to people, the way you wanted them to go to church...'* (M 21)

A number of men also talked about the fears they had for the health of either their partner or a potential child. Though knowledge about safe conception was reasonably widespread, this rarely alleviated their concerns.

*'Though I have learnt through reading and so on that there is more research that is leading to people who are HIV positive having children, but I still feel that it is a big risk both to the parents and the child...'* (M 37)

*'I would like to have more children but I am fearful for my wife's health... I think my wife wants a child but we have said, no, we are not having a child. That child will be brought up suffering... I mean I wouldn't like to see my child go through what I've gone through.'* (M 10)

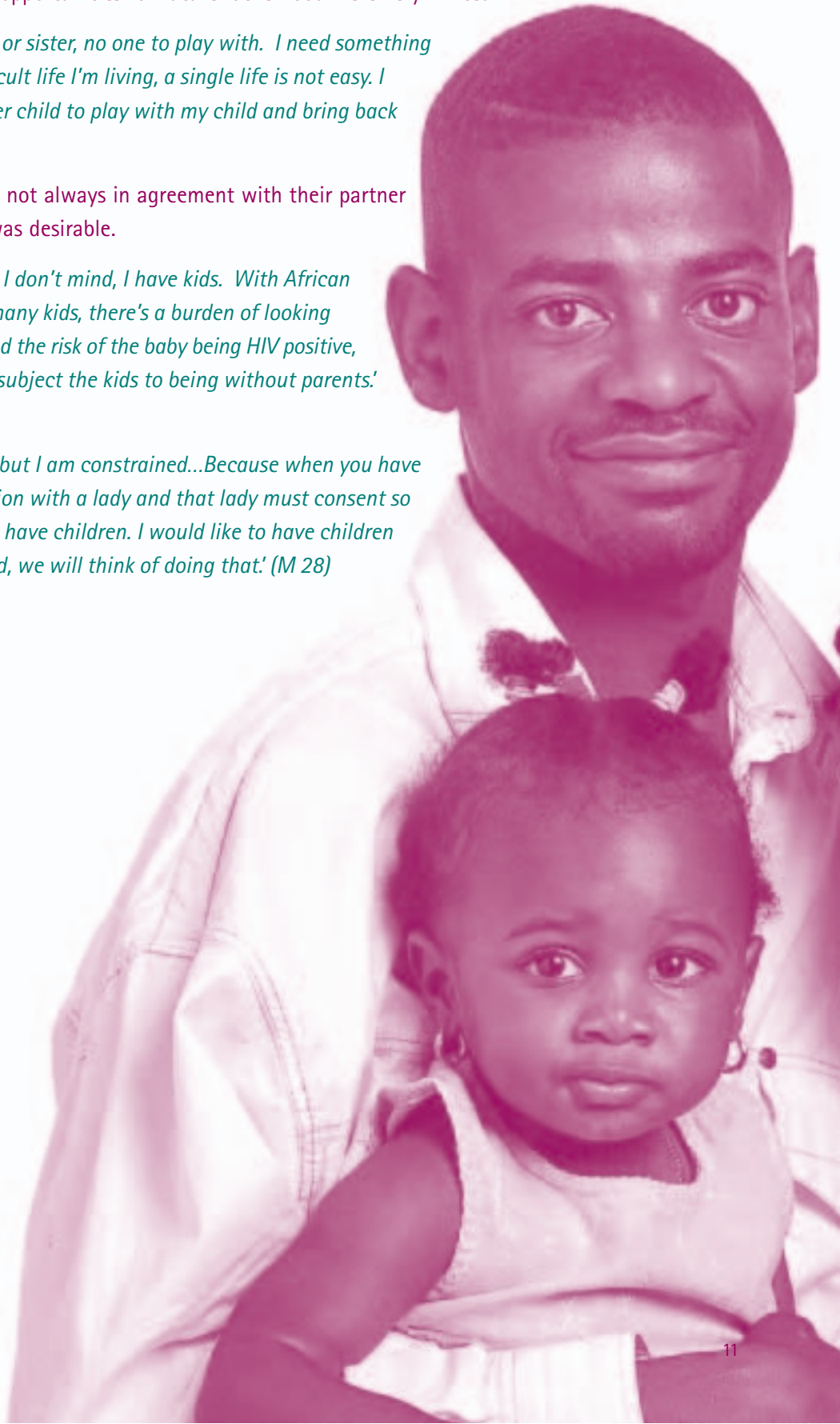
For those men who were single, the opportunities for future fatherhood were very limited.

*'My child is lonely; he has no brother or sister, no one to play with. I need something to bring smile on my face. It's a difficult life I'm living, a single life is not easy. I need to have a partner, I need another child to play with my child and bring back joy to me.'* (M 9)

But even those in relationships were not always in agreement with their partner about whether or not a pregnancy was desirable.

*'My partner wants more children but I don't mind, I have kids. With African women they say they want to have many kids, there's a burden of looking after them – me being HIV positive and the risk of the baby being HIV positive, if either of us dies, we don't want to subject the kids to being without parents.'* (M 27)

*'I am wanting to have more children but I am constrained...Because when you have children, you have to come into a union with a lady and that lady must consent so currently my partner doesn't want to have children. I would like to have children so maybe when she changes her mind, we will think of doing that.'* (M 28)



## Work and money: struggling for social status and economic survival

For most of the men, having a job and the money that goes with it was central to their self-image. Around half were currently employed but many were in jobs well below their original qualifications. Some were prevented from working full time (or even part-time) by their state of health and this was a source of great distress.

*'I cannot see as I used to see before so I have been refused a driving license and that's how I cannot get those jobs that I know I can do very well. So that's the way that HIV has just really destroyed my life.'* (VS 4)

*'I think with me HIV has had so much negative impact on my life in this country. Actually I was in a good employment, but somewhere along the line, I became very ill and my employer had opportunity or no alternative than to, you know, get rid of me.'* (FGP)

Those who were fit but not working were often unable to understand the reasons for their exclusion from the labour market.

*'I don't know. I'm just an abled person. I can walk properly, I can do up and down, I can do a part time job but I don't know why I cannot get a steady job.'* (VS 3)

*'So that is my life at the moment, looking for a job and getting the right job to do ...it would be nice to be somebody that is valued...yes because if you are not working nobody will respect you...'* (M 15)

Some felt that employers excluded them unnecessarily when they discovered their health status from hospital letters and other official communications.

*'I got my papers from the Home Office... they put something on the back saying this man is HIV positive.... When you go for employment they ask you to fill out a form. So everything is just flat...flat...I don't have any future now.'* (FGP)

*'The stigma, the prejudice, the discrimination, the social exclusion, you know. You can't get employment easily as an HIV positive. I know there's a DDA, the Disability Discrimination Act, but a number of employers don't practice that, they don't implement that.'* (VS 5)

The refusal to let asylum seekers take on work was bitterly resented and many talked about how they disliked being dependent on the state.

*'Given that I did not grow up here it is kind of hard for me to look at benefits as a way out... I don't know why, it is just one of those things that I find hard to explain.'* (M 36)

*'I don't want to be fed by the state, I want to feed myself and the money the state gives is not enough. But I don't blame the state because it looks after so many people.'* (M 16)

Life on benefits was materially hard as well as psychologically distressing for men who expected to be able to fend for themselves.

*'I'm not used to this money you get from social benefits, yeah, it's...you can't do much with it...it's just for eating, most of the time you get tired at home just doing nothing...'*(VS 8)

*'Yes, it's very difficult ....I get £70 vouchers, at Tesco's, after a fortnight. At times they used to give us change, so let's say if you take not for £10, but for five, they give you change for £5. But now they stopped it, the only change which they give you it is 90p...So no change is given so everything is tight.'* (VS 6)

Some of the men who were unemployed chose to work in the voluntary sector supporting others in the situation as themselves. This gave them a sense of purpose and helped to fill a gap in their own lives.

*'I think the knowledge I've acquired through working with people living with HIV has somehow empowered me and I think I've used that opportunity for the better...'* (VS 2)

*'As much as possible I want to remain active. As you see me, I'm an abled person... I have contracted this sickness and I have been away from work. So I cannot secure a job so I do some voluntary job in service providers.'* (VS 3)

*'When you go there you see men like yourself, they are, you know, I mean... they are making it in life so...why can't you?...they are an inspiration to you, they are doing things that you should be able to do as well.'* (VS 4)

*'You feel you're very lonely, you know, feel you're doing nothing and that can exacerbate the situation. So that's why this kind of thing I do has really helped me a lot in these areas, actually, being involved...'* (VS 5)

## **Masculinity, strength and weakness: being an HIV positive African man**

The men in the study faced serious challenges. It was not easy for them to live up to their own and other people's perceptions of manliness. They often felt too weak to do things which they had taken for granted in the past. Most of their plans for the future had been ruined. Yet the expectation was that they would remain strong and in control.

*'I want to survive, I want to win, I want tomorrow, that's what I'm thinking about.. See, I want to be strong all the time ... But that is not available now so if it is not available, what can you do?'* (VS 6)

*'No I don't feel like as much of a man, no I don't. If I said that I do feel as much of a man as I used to then I would be lying to you. I don't feel that I am a man as I used to be when I was not HIV positive . Now I am very restricted in what I do...'*(M 15)

*'You have to show that you are okay all the time. If you are sick they think you are going to die....you have to say "No, look I am okay I'm not going to die" because people, your loved ones are very concerned about you. It seems that you have to keep saying, I'm okay, I'm okay all the time.'*(M 15)

*'So sometimes you're down, sometimes you're up, and sometimes you haven't got the morale. You go along with it. That's how you survive, you should be strong, you are a man.'* (VS 3)

Often, because of HIV infection, they were unable to achieve what their family and the community back home had expected of them. With little hope of achieving these aspirations it was sometimes hard to sustain a positive self-image.

*'To be successful you must get a wife, a proper wife and have your permanent house in a village where you grew up. You have another house in the city... you must have a good job. We must at least help some people. Then you will be respected in the community... But if you don't do this then you are just like a woman in that village. So that is what I am now.'* (M 20)

*'You have your family there and you're here and you're not working. And there is that expectation of these people, they don't know whether you are sick or you have those problems. For them when you are from those poor countries and you come here they expect you to start...making money.' (VS 7)*

*'There's a lot I really wanted to do. There's a lot that I wanted to prove. I just don't have motivation within me anymore. I just don't have it now. I wonder what has happened to the person that I was when I first came to this country. My life has been shattered.' (M 31)*

In the context of these losses in the wider world the dynamics of the men's personal relationships with women often took on an added significance. Some expressed the belief that they should have the final say in all domestic decision making and any loss of authority was felt very deeply.

*'From an African man's understanding, once he marries I think a women gives up a number of rights because actually she comes under a man's responsibility.' (FGP)*

*'What makes me a man is my brain, is my capacity to take care of a family or somebody else, and my capacity to be consulted. Like if something is to be done then people should come to me and say "ok, what should we do here?"...' (VS 9)*

*'I personally think a man should be really....more stronger than a woman. Looking after her if he's got a partner. Looking after the women and bringing up the things in the house....like if a question comes up...I have the right to say yes or no, more than her.' (M 11)*

Male control was harder to sustain in the more egalitarian context of the UK than in Africa. Many of the men believed that women were given unfair advantages in employment, benefits and other services including housing. This feeling was especially strong among those who were involved in a male support group.

*'There in Africa the man is in the top but here it's like this (he starts drawing a triangle with a man on the top). In Africa, man on the top and then a lady follows, children down. But here in Europe ... they consider children first, then the lady next, then man last... And even if you use a loud speaker, they can't hear you...it is the system here, women first.' (VS 6)*

*'Here the system favours woman, not man. If you are looking for jobs and you are a woman, African woman, they will give you the job, they will tell me "sorry you didn't go through the interview".' (VS 9)*

*'Very few men get good jobs here, but women they just work in shops...Like my wife is working for the trains, Underground, which can't employ me. How did she get that employment? You can't know!' (VS 9)*

Some of the men were economically dependent and were unable to control their partners or to run their own households in ways that they felt were appropriate to their status. This in turn contributed to their own sense of loss and vulnerability.

*'If there is any conflict or so between two of you... the government will come and hand-pick the man "you leave this house, don't get anywhere near", they give you a certain distance "don't get to that distance"...' (FGP)*

*'Here in this country sometimes you get home you find no food. Your wife is just lying in the chair. So you're a different person, there's nothing. I just go to the restaurant and grab a cup of tea there.' (FGP)*

*'Cause first of all you don't have money in the family, you have nothing to eat in the house or a glass of wine for your wife. So you go in the bed and you're fearing to touch her. She's in charge of the house, she's got the money, she's not receiving benefit, you are just like a beggar. You can't say can you turn this way? No definitely you can't.' (FGP)*

*'Here, it is believed that what a man can do a woman can even do better, and that's why they are highly placed, compared with men. So in this case we have lost that character or that right as African men. So as we are here we tend to dance to the tune of the culture in this country. So we don't really claim that identity of African men.'* (FGP)

## Health services: finding assistance

All the men in the study were receiving care at hospitals in London and their overall response to these specialist HIV/AIDS services was very positive. The relationships they had with doctors were especially valued.

*'Well the health services are powerful, very helpful, very supportive, very sign-posting.'* (VS 9)

*'It's just my relationship with the doctor. Whatever we talk we agree, if we disagree we always come to a compromise, like that, it's not one person dictating another.'* (VS 8)

*'You have a say in what you want to have, what you feel is right for you... like if you say "I can't do with that" at least you have got different alternatives.'* (M 2)

*The fact that I am treated like a human being that's all that is important to me, I have never seen any difference because I'm black.'* (M 2)

*'They treat me good and normal. Some doctors don't use gloves. Some nurses don't use gloves. They know I'm HIV positive but they don't care.'* (M 21)

Though the service was still viewed very positively, some men complained that levels of care had deteriorated in the recent past as resources were strained by growing numbers of patients. They felt especially frustrated by increases in waiting times and problems with telephone contact.

*'At first I used to think that only, let's say African people, they are being treated in such a way. For example when I had a delay in removing my tooth.... But so many people are complaining about the services...it is not only for Africans. To see a GP it is like winning a lottery.'* (VS 6)

*'Let's say, you have £2 credit on your phone, it can get finished ...your phone is through. You call, there is a wait, wait, wait, "we know you are on line, thank you for being patient". It is cut off. When it's through, let's say the receptionist can say, 'now try tomorrow, now there is full up'. You have to wait another day.'* (VS 6)

*'The minutes you spend with the doctor who is examining you is less...There are times you want to tell your doctor something...as you are listening the doctor will be hastening you, hurry up! hurry up! ....You will forget, when you get to the bus you will start to think, what is the point of going to this place?'* (M 7)

The majority of men in the study were taking antiretroviral drugs which were highly valued as a survival strategy.

*'At the end of the day I've lost four brothers out of HIV so I know how it is. Out of the boys I'm the only one alive, so I basically know that its very vital that I hang onto this last straw that I have which is the combination therapy and that is why I have to follow it religiously.'* (M 2)

Many talked about the side effects they experienced including diarrhoea, rash, changes in body shape, nightmares, nausea, dizziness, pain and weakness. However most appeared to take their regimen extremely seriously despite the difficulties they often faced in doing so.

*'...say on a simple regime of four tablets a day, you wake up in the morning and you take like I just did but if I now move out of here I may find myself in public by the time I am supposed to be taking my dose and there is a problem. If you don't have money to buy yourself a drink so you are going to miss your dose.... If you are in a lecture and that's the time you're supposed to be taking your drugs it may be very difficult for you to just take the tablets right there and then...'* (M 1)

When they were asked how they thought the health services could be improved for African men with HIV some talked about the need for more cultural sensitivity especially in the provision of information. But the most frequent request was for more attention to be paid to their particular needs as men.

*'I think what they should do is bring back a number of services for African men. There are only two or three that I know of. There are more groups for women than there are for men, and the ones that are there for men, you find that only a few come up and then after that they fade away. I think some of the men, don't want to be brave enough to come out and join others who are also HIV positive.'* (M 11)

*'When we think about the GU care, it is not 'man friendly'. The clinic when you go there, all of you are mixed up, so when you walk in there they all just look at you and know that it is for a sexual infected disease, there is no other disease that you would be expected to go there in the GU clinic. Whereas ladies they go there for various things... But as a man you go there and everybody looks at you and they know that you are HIV or something wrong sexually, so you are treated with suspicion as a man.'* (M 15)

*'I think that men do actually feel a fear of going to these places and explaining about their health as it is off putting. I think that men in general, not just African men find it difficult in accessing or talking to a women about their sexual problems or their health problems...because men always want to show that they are macho, they want to show that they are strong at all times, so off they go and meet a woman they may just say oh yeah, I just wanted to take this leaflet and leave.'* (M 15)

Overall, the men were satisfied with the care they received especially their access to drugs. But at the same time they recognised that this life- saving treatment would not be available if they were unable to remain in Britain or wished to return to their country of origin.

*'Yes, it's a double jeopardy. Because if I go back then there is a chance I might not be able to get the medical treatment I've been getting, then there's a chance I might die. So it's either going back and facing this or staying here and being separated from my family.'* (VS 7)

*'I told them I am going in three weeks, so check me out, I want to go back home, I want to leave here as I do not have my relatives here, I just want to go but they said "No, if you go there, then you will die. Unless you have money to buy the medication, but at the moment try just to live here, then you can go home later.'* (M 3)

*'I think about going back home but there are no drugs there. It's like you're in prison. I am going to be here for a long time, things like that. Maybe in the future there may be a lot of drugs back home and I can go back.'* (M 10)

For those whose immigration status remained uncertain, the most frightening prospect of all was that they might be forced to go home where their one chance for survival would be beyond reach.

*'No, no, no, no I can't risk thinking about my future cause I don't know where I'm going to end up either here or in Africa.'* (M 4)

## Handing over to God?

The men in the group had very different approaches to religion and spirituality. Some described how the discovery of their HIV status had turned them against God. Several returned to their beliefs as they came to terms with their illness but a number expressed continuing ambivalence.

*'God and Faith is sometimes yes and sometimes no. When things go wrong you could cuss him and when things go great, sometimes you are thankful you know, ummh.'* (M36)

*'Religion has not helped me to cope with my diagnosis. Actually the diagnosis changed my vision...I was a very religious person but I've changed as I thought "mmmm, I am religious so why did I get this?"...so that bad feeling about religion came when I was diagnosed but I'm coming out and now I feel that I have to go back to my religion because I cannot blame my religion.'* (M 15)

For the majority, their belief in the power of God was an essential element in sustaining their hopes for the future.

*'With my strong religious belief, I know that I will be ok. In fact sometimes I don't even feel as if I have HIV no more... So that's what I believe and what keeps me going as well. Because I've seen for myself where God has made it possible that HIV is taken out of people who were HIV positive for a very long time.'* (VS 4)

*'I really think that its God's work for me to live up to now, so many people didn't make it, and I keep on praying to God to keep me alive like he did, because I don't think I am so special not to have died like the rest did.'* (M 24)

*'I think it helps because I've prayed, family has prayed, everybody who knows is praying so I just put everything in the Lord's hands that His wish shall be done. I feel the Lord is on my side, He's done me a favor. My health has improved and I am happy with the help.'* (M 30)

While some drew on their individual spirituality, others were active participants in a church congregation. - Many faith communities were very supportive to those who were known to be HIV positive, but others were reported to be hostile.

*'I am a Christian, I was born into a Christian family, you know the fact that I've got HIV does not mean that I cease to be a Christian, I love a sense of belonging to the Christian community and that's it, that's why I go to church...'* (M 2)

*'When I go to the church you get a lot of testimonies from people who talk about all sorts of problems. Some people talk about their health, some people talk about financial problems, people talk about problems in their relationships.... so it is very, very good to know that you are not alone.'* (M 34)

*'I am religious but it is not accepted by my religion, you see. The church has not changed because they say...this is from God. So they don't accept this kind of sickness. Even they don't want to talk about it, you see.'* (VS 3)

*'The time I'm believing in religion I'm nearly dying. They will tell you no, don't take medication, don't take that. ....Then since I stop going to church and I was using my medication I am healthy and happy.' (M 7)*

The majority perceived religion and medicine to be working together to improve their survival chances. But for most it was God who would make the final decision on when their life would end.

*'Fortunately I believe in God, so my God gives me the strength to do things... Well I take medicines for my condition, and I take food for the body and then I do the rest.' (VS 7)*

*'While I stick to my medication I also focus on the fact that I have an undetectable viral load and if I keep with the medication it will remain like that and I will keep living forever until one day God's says ok it's enough. That is it.' (FGP)*



## Looking to the future

For many of the men in the study, the future was very uncertain. Not only did they have to face the probable progression of their HIV infection but their immigration status was also precarious.

*'You can't settle down when you don't know how your family is, where you are heading to, whether you are going back to prison, with the HIV still that's a problem.'* (M 13)

*'My future now is clearly unpredictable...How do I talk about my future when the case is not determined, how do I talk about my future? The Home Office, I've applied and they have not told me whether I'm staying or if they are deporting me. There is no way I can talk about my future now. It gives me sleepless nights.'* (M 24)

Acquiring a job was often seen as the key to a better future and this was clearly tied up with the right to stay in the UK.

*'If I can get a job, I see my future will still be bright, the way I expected it to be. But if I don't get now work, then I'll say that my future is really spoiled.'* (VS 8)

*'My future...it's good, I can see my future being bright. If I'm allowed to stay here, if I can work, I will have a good life. I would have money, I can buy a car, if they can allow me to stay in this country I can have a good life. So my life will be better.'* (M12)

There were also a number of men who saw their future in activist terms, campaigning for more resources for HIV/AIDS and for the removal of the stigma especially in Africa.

*'Right, my future... I'm trying to really play a key role in how to really help people living with HIV... to sort of challenge the taboos that we sort of cherish as African men...'* (VS 2)

*'There is more to come, there is a better day, that's what I am thinking... I hope the future will be better...I will change the world... to accept the HIV people to get them back into jobs.'* (VS 3)

They hoped for a cure. But they also stressed the need to be strong, to be positive and to make the best of the resources they had in whatever might remain of their lives.

*'Yeah, I pray that the scientists out there will find a cure for it. In my life time or... or when I'm gone. I don't know how long I will still be around.'* (M 5)

*'Obviously immigration and health are issues, but those shouldn't keep our dreams dead, you know. The main thing is to have a dream, because unless the dream is there...when you feel well then you know you'll be ready for it.'* (VS 2)

*'Well my future is bright, I believe. And I can only make it bright by walking towards it, not sitting by and letting the brightness of it come out...It means forgetting about HIV and you do those things that as a man you should, those things that those men without HIV are doing, you should be able to do them as well.'* (VS 4)

*'It all depends on me. I think what will make life easier is to think positively and think ahead. We have to prepare ourselves for the Almighty.'* (M 21)

## Policy Recommendations

speaking out and to seek help. Immigration and asylum policies may add to men's insecurities and exacerbate the problems caused by HIV itself. Finally, little attention has been paid to the mental health of African men with HIV who often suffer great loss of self esteem. The policy recommendations below give some indication of how these needs might begin to be met.

### Alleviating poverty and supporting return to work

- Programmes are needed to enable African men who are HIV positive to develop their skills and get into work.
- Employment and volunteering should be part of all psycho-social support initiatives targeted at African men living with HIV.
- Programmes such as Positive Futures – an employment and training programme funded by the London Development Agency – need to recruit more African men and to be replicated across London.

### Masculinity and health care

- Both health care providers and advocacy and policy organisations need to have a clearer understanding of the importance of male and female gender in shaping the needs of their clients.
- Health care providers need to be more aware of the particular sexual health needs of African men and the barriers they face in access to services.
- Educational resources should be developed to give men from African countries more information about the organisation of the National Health Service, access to HIV counselling and testing and the diagnosis and treatment of HIV/AIDS.
- Culturally sensitive services are needed to help couples to come to terms with the implications of an HIV diagnosis for the future of their relationship.

### Immigration and Asylum Policy

- The Home Office and the Department of Health should carry out race equality and health impact assessments of immigration and asylum policy and legislation (including recent directives on access to healthcare).
- These assessments should look in particular at restrictions on employment and their implications on vulnerable groups such as migrants from developing countries.

### Restoring dignity and promoting mental health

- Religion is a powerful coping mechanism for many people from African backgrounds. More efforts and resources should be dedicated to involving black and African faith organisations in prevention strategies and into activities to reduce HIV related stigma.
- Positive role models and positive stories of African men living with HIV should be publicised in the various media accessed by African communities.
- Local and national HIV health promotion programmes need to strengthen work streams that address the stigma and taboos surrounding HIV/AIDS.
- Further research is needed in this population in particular to understand the needs of African men living with HIV who have sex with men.

## References

- Anderson J, Doyal L. **Women from Africa living with HIV in London: a descriptive study.** *AIDS Care* 16(1), 95-105. 2004.
- Barry SM, Lloyd-Owen SJ Madge SJ Cozzi-Lepri A Evans AJ Phillips AN Johnson MA. **The changing demographics of new HIV diagnoses at a London centre from 1994 to 2000.** *HIV Med.*2002 Apr;3(2):129-34. 3(2), 129-134. 2002.
- Boyd AE, Murad S O'Shea S de Ruiter A Watson C Easterbrook PJ. **Ethnic differences in stage of presentation of adults newly diagnosed with HIV-1 infection in South London.** *HIV Med.* 6(2), 59-65. 2005.
- Burns FM, Fakoya AO Copas AJ French PD. **Africans in London continue to present with advanced HIV disease in the era of highly active antiretroviral therapy.** *AIDS.* 15(18), 2453-2455. 2001.
- Census 2001:** National Statistics website: Crown copyright material is reproduced with the permission of the Controller of HMSO. www.statistics.gov.uk. 2005.
- Department of Health, AHPN, National AIDS Trust. **HIV and AIDS in African Communities – A Framework for Better Prevention and Care.** 2005. London, Department of Health.
- Dodds C, Keogh K, Chime O, Haruperi T, Nabulya B, Ssanyu Sseruma W, Weatherburn P. **Outsider Status: Stigma and Discrimination experienced by Gay Men and African People with HIV.** 2004. London, Sigma Research.
- Doyal L, Anderson J. **'My fear is to fall in love again' How HIV-positive African women survive in London.** *Social Science & Medicine* 60 (2005) 1729-1738
- Elam G, Chinouya M. **Feasibility Study for Health Surveys among Black African Populations living in the UK: Stage 2: Diversity Among Black African Communities.** 2000. London, Qualitative Research Unit. National Centre for Social Research.
- Health Protection Agency, Centre for Infection. **Survey of Prevalent HIV Infections Diagnosed (SOPHID).** Regional Data for 2003.
- Health Protection Agency (HIV/STI Department, Communicable Disease Surveillance Centre. **AIDS/HIV Quarterly Surveillance Tables Cumulative UK Data To End March 2005.** No. 66: 05/1 2005.
- Joint United Nations Programme on HIV/AIDS (UNAIDS) World Health Organization (WHO). **AIDS epidemic update.** 2004.
- Mayisha ii Collaborative Group. **Assessing the feasibility and acceptability of community based prevalence surveys of HIV among black Africans in England.** 2005. London, Health Protection Agency, Centre for Infections.
- Mckintosh M. **London – the world in one city, An analysis of 2001 Census results.** Greater London Authority, February 2005
- McMunn, A. Brookes M. and Nazroo J. **Feasibility Study of the Health Surveys in Black African Populations Living in Britain. Stage 1. The Demography of Black Africans In Britain.** 1999. London: Joint Surveys Unit. National Centre For Social Research and the Department of Epidemiology and Public Health, University College.
- Sabin CA, Smith CJ, Gumley H, Murphy G, Lampe FC, Phillips AN, Prinz B, Youle M, Johnson MA. **Late presenters in the era of highly active antiretroviral therapy: uptake of and responses to antiretroviral therapy.** *AIDS* 18(16), 2145-2151. 2004.
- Saul J, Erwin J, Bruce J, Peters B. **Ethnic and demographic variations in HIV/AIDS presentation at two London referral centres 1995-9.** *Sexually Transmitted Infections.* 76(3), 215. 2000.
- Sullivan AK, Curtis H Sabin CA Johnson MA. **Newly diagnosed HIV infections: review in UK and Ireland.** *British Medical Journal* 330, 1301-1302. 4-6-2005.
- Weatherburn P, Ssanyu-Sseruma W, Hickson F, McLean S, Reid D. **Project Nasah; An investigation into the HIV treatment information and other needs of African people with HIV resident in England.** 2003. London, Sigma Research.