

My Heart is Loaded

African women with HIV surviving in London

Report of a qualitative study

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Background to the study

The literature on HIV/AIDS is now very large, with books, articles and reports filling many shelves. A great deal has been written about the biology of the disease itself and possible treatments and about the nature of the epidemic and possible strategies for prevention. But there have been very few accounts of the experiences of people living with HIV. This lack of knowledge is especially obvious in the case of women who now make up about half of all those living with HIV around the world. In sub-Saharan Africa, around 58% of those infected are female but we know very little about their strategies for survival.

In this era of globalisation, many women from African countries are living in other parts of the world and here too they often carry a heavy burden of HIV infection. In the UK for instance, 69% of all women diagnosed as HIV positive in 2001 came from Africa. Among attendees at London GUM clinics in 2001, 7.7% of African born women had HIV compared with only 0.2% of UK born women (Unlinked Anonymous Surveys Steering Group 2002). Yet we have very little information about the circumstances of these women. This study was designed to fill that gap. Its aim was to explore the daily lives of African women with HIV in the UK. The focus was not on how they came to be infected but rather on how they were living with the illness.

A small number of studies have investigated the health and social care needs of African women (and men) with HIV in the UK. However the aim of this project was much broader. We were concerned not so much with immediate policy issues but rather with identifying the main factors that shaped these women's lives. We wanted to know about their access to material, social and cultural resources, about the choices they faced and about the constraints that limited their options. In particular we wanted to know more about their strategies for their own and their families' survival and how these were implemented in difficult circumstances so far from home.

Designing the study

In order to achieve these aims we needed to identify a group of African women with HIV willing to talk about their lives. After considering various possibilities it was decided to base the study on a sample of women from different African countries receiving care in four London hospitals. Access to women through this route was made easier by the fact that one of the research team worked in HIV medicine in one of these hospitals. The selection of a sample from hospital records meant that the results could not be generalised in any simplistic way beyond those women living in London and receiving care in specialist units. However this was felt to be justified on the grounds that three quarters of all Africans in the UK live in Greater London and 60% are resident in the 10 boroughs which include all four hospitals.

The fact that the women would be approached to take part in the study in the same setting where they received their health care did raise certain ethical concerns. In particular it was possible that they might have been afraid to refuse in case it had a negative effect on the services they received. Great care was therefore taken to ensure that they were neither asked to participate nor interviewed by their regular clinician. Rigorous procedures were put in place to ensure that the women actively consented to the research and these arrangements were reviewed and agreed by the relevant ethics committees.

Sampling and data collection

A group of 62 black women with HIV from 11 different African countries was recruited from outpatient clinics at St Bartholomew's, the Royal London, Homerton, Newham and the Royal Free Hospitals. All the women were aged 18 and over, had been diagnosed as HIV positive for at least six months, had attended the clinic in the period January 2000 - June 2001 and had lived in the UK for at least six months. They were selected in such a way that the distribution of the women's country of origin reflected the distribution of nationalities in the clinic population as a whole.

The study was first mentioned to women who fitted these criteria by their regular clinician during routine clinic visits. Those expressing interest in the study were introduced immediately to one of the interviewers for further information or their permission was sought for contact details to be passed to the research team. They were then given more details about the study and written informed consent was obtained from all those who agreed to participate. Approximately 80% of women who were approached were willing to be part of the study and completed the interview. Those who declined cited fears over confidentiality, reluctance to discuss painful subjects or time pressure as reasons for not participating. Two women, who agreed initially, later withdrew as a result of pressure from a partner.

Before they were interviewed the women were asked to complete a written questionnaire containing 18 questions. These covered factual information such as age, length of stay in the UK, time of HIV diagnosis, housing conditions, number of children, current relationship status, and brief medical facts. The questionnaire was administered orally to women who had difficulties with the written version.

This was immediately followed by a semi-structured interview, which covered some of the main aspects of their daily lives. The women were asked to talk about their experiences of HIV in the broader context of their personal histories. Most appeared to experience this interview as a valuable opportunity to talk about their own situation and to be listened to. All participants expressed their willingness to be interviewed again should the study be taken further.

The sessions lasted from one to four hours with an average of about 90 minutes. Women themselves were given the choice of where to be interviewed and the majority (80%) chose to talk on hospital premises. Interviews were carried out between July and December 2001 by one of the authors (JA) and a female research assistant¹. Interviewers regularly exchanged schedules and transcripts with independent expert supervision to ensure consistency. Two women did not wish to be tape recorded and in these interviews extensive notes were taken. Travel and subsistence expenses were reimbursed for all participants.

¹ JA did not interview any women under her clinical care. 28

Finding from the survey: an overview

Sixty two women from 11 different countries completed the study. Their age ranged from 20 – 58 years with an average of 33. They were a well-educated group with 12% having finished primary school and 61% having completed secondary education. Twenty percent were university educated and 7% had postgraduate qualifications. Only 12 of the 62 women were working. Four were students and 46 were unemployed.

When asked why they had come to the UK, some women stressed the new challenges to be found in London. A number talked about poverty at home while others mentioned the pursuit of business opportunities. Only three identified the need for medical care as a reason for coming to the UK.

'We had family friends, people we know, and I had an uncle so I decided to come to London!' W20 Uganda

'I came to London searching for greener pastures!' W15 Nigeria

'I came on a holiday visa. I just liked the feel of London, I just liked everything about it, the people, there was just so much activity going on. I thought, oh well, maybe I might change my mind and I applied for a working visa. I thought I would stay only for a short time and go back.' W47 Zambia

A number of women from countries in East and Central Africa in particular mentioned political pressures at home which had pushed them towards the UK. The majority feared for their safety because of their own actions while the remainder felt they were in jeopardy because of the political activities of other family members, usually husbands or fathers.

'When I first came, I came seeking asylum. I had problems in my country. There was fighting and this guerrilla thing and ethnic tribes fighting each other, which I didn't know. I didn't know that my husband was involved somehow, somewhere, in those groups. So we were attacked and they tied him up and took him, so I ran for my life.' W2 Burundi

About a third of the women were asylum seekers at the time of interview. Sixteen had either compassionate or exceptional leave to remain for between one and five years, 12 had been granted indefinite leave to remain and a further six had British nationality. Two described themselves as illegal and one as a visitor. Most of the women (73%) had been in the UK for more than a year with around a third having arrived more than three years ago. Seventeen had been in the UK for less than 12 months and it was these women who were most likely to be currently asylum seekers.

Twenty eight were in a relationship with a male partner and 11 of these were cohabiting. About one third of the women had a family member in the UK, most commonly a sibling. Most also had family in Africa. The vast majority of the women (55) were mothers but only 39 had children living with them. Others had left their children in Africa in a variety of circumstances and some were unaware of what had become of them. Around half of the women had HIV negative children, 12 had at least one positive child and in 13 cases the HIV status of children was unknown.

A majority of the women had already experienced at least one profoundly traumatic life event. These included rape, murder of partners and family members and various other forms of persecution. 27 of the women spoke of direct experience of HIV related death and ill health in close relatives or friends and eight had experienced the death of at least one child from HIV.

'I wish they had shot me and killed me after raping me. They could have killed me straightaway – I had no family, I didn't know what had happened to my husband apart from seeing him being tied up and taken out of the house, I didn't know where my child, children were. All of them, I don't know where they are!' W10 Kenya

'I was raped – that's how I contracted it. When I was so young there was this political issue, that's when I was abused. I was detained for 30 days and every day raped by different men – I felt I was robbed of my life.' W62 Zimbabwe

'Things haven't been very easy ever since I knew I was HIV. Knowing that my husband had caught the illness from me, that was a really terrible suffering, I really suffered in my heart knowing that I had contaminated him with the illness and him being sick and him later dying was too much for me.' W27 Uganda

'When my son died my whole world like turned into dust before me, I was like, this is the end of me. It was like there is nothing.' W12 Malawi

Listening to the stories of these women, it was clear that many different factors were shaping their lives. First and foremost their potential fertility meant that they had to face a range of difficult decisions about sexuality, pregnancy and childbearing. At the same time their options were also constrained by their own and other people's expectations of how they should behave as female partners, wives and mothers. These women were also migrants, living with the challenges posed by a strange country. And finally they were HIV positive with all of the social and biological implications that come with such a diagnosis. In presenting the women's stories we begin by exploring the ways in which these different influences were interwoven in their lives.



Being a woman with HIV

The lives of most women are heavily influenced by their capacity to become pregnant and give birth. However this raises additional problems for those who are HIV positive. Most of the women in this study stressed the importance of motherhood as a source of identity and legitimacy. Many pointed out that failure to have children can have profound economic and social consequences including divorce or desertion and a number were actively trying to conceive.

'If you have no children it means you are less of a woman.' W47 Zambia

But there was also a reluctance to bring a child who might be HIV positive into the world. For some this was compounded by anxiety that unsafe sex might put the potential father at risk as well as the fear that pregnancy might exacerbate their own disease.

'For me whose not got a child... I love kids and I can't wait to have a child... then knowing if you wait to have a child because I could pass it on to that child... and you can't give your child breast milk you know, we are women. I want to explain all these things as a woman you know, and you can't. It's very difficult.' W18 Tanzania

Most of the women had become mothers before their diagnosis and 39 had their children living with them. The majority of them acted as primary carers and their experiences of mothering with HIV were complex and contradictory. Many were raising their children in considerable poverty without the support of an extended family and often as single parents. The nature of their own illness made planning difficult yet they rarely got practical help with childcare and their own needs often went unmet.

'I just have to stand up for my kids so I'm the mum, I'm the dad, I'm the auntie, I'm everything.... so they need me.' W28 Uganda

For many, these responsibilities were made even more difficult by continuing concern about their children's health. Eleven of the women had children who were known to be infected and this naturally caused great distress.

'I had thought he was going to be born dead so I was delighted when he was alive but when I was told he was positive my world shattered.' W21 Uganda

'The worst days is when my boy is sick, 'cos I blame myself. I know it's my fault. If I had not brought him to this world he wouldn't be suffering, I think I've caused him a lot of pain.' W30 Uganda

Mothers are traditionally seen as the moral guardians of society. This meant that many of these HIV positive women were afraid of being stigmatised for not living up to these social expectations. This was reflected in the ways in which they told their stories. Most were anxious to show themselves as people leading blameless lives whose illness could be blamed on misfortune or on the actions of others. Though some said they had been half-expecting a positive result, most said that they were extremely shocked on receiving their diagnosis.

'When I gave out my blood I was very sure I was negative, because I was healthy and strong. But when I got the results I was shocked, I was shocked. I had to do another test, at least two tests to be sure that it's true that I'm HIV positive.' W9 Kenya

'You ask yourself, where did I go wrong? I was just a perfect, perfect lady. You know there are some ladies who go into the pub, they expose themselves to find men, but I wasn't the type of lady. I was the type of a lady who was so reserved. But well, there it is.' W57 Zimbabwe

'I still don't understand, they try to get it into my brain but I said I'm not ready now, because I don't accept the fact that I am HIV Positive.' W16 Nigeria

Guilt was often especially debilitating among those who were compelled to leave children behind in Africa. Changing circumstances meant that these children often had to be passed between carers and attempts to bring them to the UK were usually difficult and often unsuccessful. Many women were trying to support their children through sending money home from their own limited resources. But most found this (unavoidable) failure to fulfil what they and others saw as their maternal role deeply distressing.

'I'm supporting, I'm paying my son here and I'm paying for them in Africa, I'm paying the house they stay in, I'm paying for the food they eat.' W37 Uganda

'I wanted to bring my children over because that is the thing that is really eating me up, its still eating me up you see, because I am here and my children are on their own. They don't even have a father because he died a long time ago and they are living on their own.' W50 Zambia

For these women, the reality of motherhood brought both intense pleasure and also inevitable pain. Because of the supreme importance of motherhood in most African communities, the identities of the women were strongly shaped by their reproductive histories. The experience of parenting brought many burdens. But at the same time it gave many a reason to live and to survive the disease.

'He's eight and every time I think about him I just want to cry, forget the medicines and go, but then I don't know who is helping him when I'm dead. I'm trying to be strong for him.' W24 Uganda

'I had a strong will and I had to look on the children also, I thought that this little time that I had to live on this earth. I have to live for these children and be a strong person because of the children and that kept me going, and because I decided to be a full-time mother, I had also to do what a mother is supposed to do.' W9 Kenya

I am going to live for the sake of my baby. That's it.' W18 Tanzania



The impact of being a migrant on living with HIV

The women in the study were all living far from their countries of birth. Though many were financially better off in the UK than they would have been at home, they still had limited access to a range of economic, social and cultural resources. In addition, many had severe problems with their legal status that affected their capacity to make realistic choices about both the present and the future.

The health problems experienced by many migrants coming to the UK are now well known. Both absolute and relative poverty can be very damaging and many experience mental health problems when deprived of familiar sources of support. For some these are exacerbated by previous trauma. The process of migration may be especially hazardous to the health of women who have to carry additional burdens in their role as carers.

Whatever their financial circumstances, all the women in this study were constrained by the fact that they were 'strangers'. But for those living on state benefits, economic problems were paramount. The support for asylum seekers is especially low with recipients given vouchers worth only 70% of the income support made available to other adults in financial need. Not surprisingly, many of the women talked about the difficulties they faced in making ends meet especially when their illness generated special needs.

'A freedom pass is from nine o'clock and maybe you want to go to hospital and you have an appointment at nine o'clock which means you have to start travelling early, travelling and you don't have money to pay for it... or maybe a child wants to go somewhere for a school trip, you have to pay for the school trip, you don't have money to pay, or a child wants some shoes or pocket money, you don't have any money, all you have is papers.' W9 Kenya

'I still want to buy my own country's food as well. But they decide they can only give me the £28 voucher and then if I'm lucky they might give me some which I don't know how much, then I will be able to buy my own stuff...£28 a week for me and the baby, 'cos his food if I have to buy it it's £7, yes £7, and Pampers about £6 so that's £13.' W16 Nigeria

'It is really horrible because you want to go and buy your African food from the African shop but you can't buy with the food vouchers.... you have to go to the supermarket.' B13 Kenya

'Once in a while you want to eat something good but you can't... and with children you can't say that because I am taking this medication this special meal will be for me, this is for mummy.' W2 Burundi

Housing conditions too were frequently inadequate. Prior to resolution of their immigration status, many of the women had lived in multiple occupancy properties often with small children. Their anxieties were often compounded by the constant fear of deportation.

'It was difficult because of the nine year old in a single room....and then having to share a bath and toilet with strangers and we shared with one person who was a drug user, every time you get in the bathroom there was syringes everywhere.' W9 Kenya

'You are living without knowing when or who is coming to knock on your door, maybe the police are coming to deport you, and that is the type of life I lived till the year 2000.' W9 Kenya

'Every ring of the doorbell, they've come to deport me, that's what it feels like, the sight of a police car, are they looking for me, you know; that's the kind of life you have to live and definitely with the virus you don't need that.' W38 Uganda

The impact of HIV status

The third element shaping the lives of these women was HIV infection itself. Not surprisingly many of the women reported that it led to feelings of depression and anxiety. Being HIV-positive inevitably involves high levels of insecurity since the course of the illness cannot be accurately predicted and medical knowledge itself is partial. These women have a potentially fatal disease and many have seen relatives and friends die from it. Most understand very clearly that they would die themselves without access to medication. For those whose legal status was in doubt this was an especially serious problem. Their access to drugs was experienced as highly uncertain and therefore their very survival was threatened.

'The just not knowing, you know, I mean, yes we're all going to die but just not knowing, you know, what will start it off, when it's cold you dress really, really warm... I'm just so scared of picking up anything that I will not go to a hospital, I just want to sort of stay clear of anything.' W23 Uganda

'It's difficult, imagining my young age and I have two children who maybe I might not see them, my grandchildren. These are the things that comes to me and I really feel sad for myself but again I put my heart at one and say, life must go on, take care of your body, you know, avoid stress.' W7 Kenya

Many women reported that they usually felt physically well. But about a third described physical symptoms, which limited their everyday life. They reported tiredness, side effects of medications and unpredictable periods of illness and disability including deteriorating sight and mobility problems. A number commented on the distress they felt when HIV affected their capacity to work.

'Its not an easy thing 'cos HIV robs you of a lot of things, it has robbed me of a lifestyle, cos now I sort of have to live in a different country where everything is quite different from what I am used to, and as if that wasn't enough I have to cope with not seeing.' W29 Uganda

'I want to try and do whatever I can to get my life back. I want to put my knowledge, the things I've studied and my skills into practice. I don't want to just sit there and be on benefits, I want to be useful.' W50 Zambia

'It's so difficult because I would like to go back to work but all days are not the same, sometimes you can work, you can't work... I would like to be working, because as well I need my freedom and I want to work freely.' W10 Kenya

Some women indicated that they had received more support than they had expected when disclosing their status. However most were afraid that they would be stigmatised. Drawing on their experiences both 'at home' and in African communities in the UK, the women talked about the extreme hostility often occasioned by a diagnosis.

'Even now it is very hard to tell somebody I am sick, because like our community they take it as a curse, or like you misbehaved or went out with somebody, like they take you as a prostitute, it is an attitude which is very bad that we have.' W47 Zambia

'Mostly people say that its witchcraft, that's what they believe.' W7 Kenya

'If you had AIDS that means you know it was surrounded by that immorality you know, that means you are immoral.' W12 Malawi

Like people from back home, they can make you die when the time is not yet.' W3 Cameroon

About a third of the women reported direct experience of HIV related stigmatisation such as rejection by husbands or partners, eviction from their home and refusal to allow contact with children. When this was combined with the hostility many experienced as black migrants in the host community, the impact on mental health was often profound.

'I thought we were so close, when I was diagnosed I told her I was and then after some time she's like oh please don't come near because it will catch me, so her attitude changed from completely, completely, and then the way she acted it really told me that you don't have to come here, go away I don't want you, and I read the body language, I knew that was it, and I say ok.' W35 Uganda

'My sister, they have kids. Immediately I go there he starts putting something in the toilet, if I want to touch the children they are telling me no, no, leave him alone, leave him alone, he don't want, so I was just surprised I say hey, I eat something, the kid he want to take it, they say no don't take, go and take another one in the fridge.' W44 Zambia

'I was chucked out of the house. Well, we just differed, because she kept on – even the cup, she'd mark it, this is the cup you should use, she would just put them in a separate corner.' W49 Zambia

'When my father rejected me, as I told him I was positive and stopped my mother, my mother was also being stopped from being to come to my house, my sisters when they come to my house they have to use this and that, so when they went back they were stopped not to come to my house at all, so that threw me away, it was so hard, it was so hard.' W21 Uganda

'I don't think you can ever come to terms with it, with HIV. Because in yourself you can come to terms with it but society doesn't allow you to, its like society is fighting you all the time from all kinds of directions.' W34 Uganda

Many of the women reported that their sense of themselves was radically changed by the reality of their illness. Not surprisingly, the experience was often a negative one with the diagnosis seeming like an immediate death sentence.

'I've seen so many people at home die of HIV. I have on my mother's side about five people died of HIV and I saw them wasting away, so it's like death.' W24 Uganda

'It's really changed my life. I don't know how to say it, it's amazing, there's never a day that I don't cry you know.' W3 Cameroon

'It's more than a shock to know you have HIV. You feel that life has come to an end and yet you are still breathing.' W3 Cameroo

But the shock of diagnosis could have good as well as bad consequences. For many the diagnosis led them to re-evaluate their lives. A number of women said that they had asked themselves questions about who they really were and what was important in their lives. They thought hard about their priorities and about how best to use the time and energies remaining to them.

'What I used to take for granted I don't take for granted anymore. If I'm doing something I always think oh maybe this is the last time I will be doing this. Let me do it properly.' W61 Zimbabwe

Managing life with HIV

One of the main themes explored in this study was the management of daily life. How do these women look after themselves when they are far from 'home' with a life threatening disease and often with major responsibility for the care and support of others? From the women's own accounts of their coping strategies four main themes emerged: the management of information, use of medical services, participating in voluntary organisations; and reliance on religious faith.

Management of information

All the women in the study were concerned about how to control information about their HIV status. For many of them this represented the single most important challenge in their daily lives. They needed some people to know but not others and were always scared of the response. Ten of the women had told no one at all outside the health care team about their diagnosis. Ten had told at least one close friend and 19 had told a family member, usually a sibling.

'I was having problems, it was like I had something here on my heart and I really need to tell someone, so it's fine I'm getting the treatment and doing well. The doctor is telling me every day you are doing well, you are alright, but still I was saying to myself I need one member of my family to know.' W58 Zimbabwe

'You see if you tell your brother he will want to tell his wife, he tells his wife, his wife is going to tell her sister, the wife tells her sister, the sister wants to tell her friend. Before you know it the whole community has talked of it.' W15 Nigeria

Six reported that they had made a conscious choice not to disclose their status to past or present sexual partners. The main reason given was the need to protect themselves from being abandoned or from physical or verbal abuse. Many reported that their male partners were extremely unwilling to discuss HIV-related issues and several believed that the men they were with had deceived them about their own status.

'It took me about 11 months to tell him. I had prepared myself in case he throws me out of the house.' W9 Kenya

'I looked to his face and there wasn't any kind of like shock ... When I first heard I was nearly fainting you know. But there wasn't any shock and I thought maybe he is aware [of HIV].' W39 Nigeria

'Well the problem was he never said anything, he never mentioned anything to me and that is very, very bad, very, very bad.' W26 Uganda

'My husband didn't want me to set out to get the information, he didn't want anything to do with HIV discussion, if there was a programme on the television he just wouldn't want to watch it or thing like that. There was a time when I just wanted to get out and go and have myself tested, but he discouraged me – "what is it going to help you if you go" – "what is the test going to do?"' W33 Uganda

'After I tested positive that was the end of everything, because I knew, he knew long time ago that he was but he could not tell me. Well I didn't want to blame him very much but I wanted him to be honest with me and then tell me.' W31 Uganda

Most women faced particular problems in deciding what to tell their families. Telling parents was seen as especially difficult since most were back home in Africa. Imparting the news on the phone was often said to be impossible yet travel constraints meant they were unable to do it face to face. The anxiety about parents finding out also placed limits on who could be told in the UK.

'If today I tell my mum I'm HIV positive within one week my mum would die.' W8 Kenya

'If my passport comes back I think I will go back home for a holiday, then come back, maybe that's when I will tell him and my mum.' W55 Zimbabwe

'If it's people from my country and maybe they know my family you have to make it a secret because they tell them, they won't keep quiet, it would go straight to Africa.' W17 Tanzania

Disclosure to children was always a matter of great concern and most tried to avoid it as long as possible. But it was generally agreed that at a certain age children had not only a right but also a need to know.

'I told my mum and she said for god's sake spare that boy, he's a very sensitive boy, so I would advise you not to tell this boy at the moment, let him grow up and then he grows up and you are still alive then maybe one day you sit him down and tell him.' W31 Uganda

'I remember my child one time came to me in the kitchen when I was taking my medication and he asked me mummy why are you taking medicine and you are not sick and I couldn't reply. I just kept quiet but as time went on I felt no, he's becoming a teenager and very soon maybe he will start moving with girls... so at the age of 14 I decided to tell him.' W9 Kenya

Some women managed to sustain very full social lives despite the diagnosis and friends were very important to them. But they also talked about the need to compartmentalise friendships between those who were positive and those who were not.

'I have two groups of friends - the ones who are positive and the ones who aren't - I have to be different with each.' W34 Uganda

'My life has changed since I found out I was HIV positive. I have very few friends now and the friends I have are also HIV positive... I don't feel comfortable sitting in the company of somebody who doesn't understand what I'm going through and hiding medication because you don't know who is coming to your house and what that person is going to think of you.' W9 Kenya

'It's not so easy to have friends in your place who are not positive... maybe they might see something, you see, maybe they might see something that is going to tell them a story about you so you don't like really, really, feel free.' W50 Zambia

But for many the protection of themselves and their family could only be achieved through keeping their status secret. They found it hard to sustain close relationships, which were based in part on a lie and hence preferred to retain a degree of separateness.

'I have to keep a distance because I have to watch what I say, sometimes I might say something which would push my friend out, away, so I have to like be very careful.' W27 Uganda

'I do have friends, but at the end of the day you have to cope and struggle on your own.' W19 Uganda

'Sometimes friends come round and they talk about it, you know, and I just laugh and I'm like, oh, but you know people can still survive it, inside I'm like, I can't even share this with my friends, you know, I can't share it with my family, so that's it.' W39 Nigeria

Many of the women said that the lack of a male partner was one of the most difficult things they had to face. They wanted to be in an intimate relationship but perceived the obstacles to achieving this to be very great. For many, the lack of friends and of a partner resulted in physical and emotional isolation that was very difficult to bear.

'I'm HIV positive. Some men who are not HIV positive might be interested in me but I will not, I don't want to know, to risk somebody's life, and to find a man who is positive to be your partner or your friend is not easy, yeah, it's not easy, I've just decided to remain the way I am.' W51 Zambia

'Men they think that they are doing us a favour to fall in love with us because we are HIV positive, yeah, so you are HIV positive if you don't love me, if you don't go to bed with me nobody will go to bed with you because you are HIV positive.' W2 Burund

'He didn't create Adam with a man, a man has to be with a wife, with a woman, sometimes you feel that emptiness and that loneliness, that lonely part comes once in a while and you see people moving together and you say I was there, it was good, those days, now it's history. I don't want to be a pensioner in my house alone.' W30 Uganda

'If I have to be in an affair, a relationship, I don't want a positive person, I want a person who's well, but the disclosure, to tell somebody that, I don't want to be heartbroken, I've been heartbroken, so my fear is to fall in love again.' W30 Uganda

'Being brave it damages something inside because my heart is loaded, I'm too stressed, I find some time I can't talk nice to people, to people, to my children, because I have a lot to do... I have nobody to turn to, it's my own problem and being my own problem I have to work hard to solve it, there's no way.' W37 Uganda

'I can't bear this cross all alone. I need to share it with somebody... Most of the time you are the only one that knows your problem and that drives you crazy at times.' W15 Nigeria

Using health services

The women in this study described the health care they received as a major resource in their survival strategy. Of course the picture might well have been different outside London where few specialist services are available. But for these women at least, the NHS was a vital source of support and many contrasted the right to treatment in the UK with lack of care in their own country. Some did find the clinic environment depressing, saying that frequent visits reminded them of their diagnosis. Several reported that doctors tried to explain aspects of care, which they did not want to hear and some were afraid of being recognised. However most rated the HIV services they received very highly and many travelled long distances to stick with familiar clinical teams.

'Here they treat you good, in our country they can't even touch you, they do like this, no go there, they shout at you and make you feel bad, but here they don't do that they talk to you nice.' W49 Zambia

'They give you all the support when something is going wrong, they tell you something is wrong they don't like just write your notes and chuck you the medicine. No they will explain to you.' W35 Uganda

'They [HIV clinic staff] are very kind. They have feelings towards us, very kind people. Sometimes you will see people [in other departments] even the doctor will not want to touch you or the nurse will not want to touch you or talk to you, but when you come here they welcome you. You know you mix with them and they have a chat and joke around, and that makes you feel at home.' W31 Uganda

'I cope from the information that I get from medical staff.' W55 Zimbabwe

'I find it very comforting when I'm coming here, you know.' W57 Zimbabwe

Two thirds of the women interviewed had experience of anti-retroviral therapy (ARV). Most were fearful of side effects prior to initiating the drugs and many had experienced problems at the beginning. But in most cases, these had gradually improved. A number of women pointed out that their living conditions sometimes made adherence with drug regimes difficult. Those living in shared accommodation described the difficulties of concealing medicines and the need to avoid taking them in public. For women with limited access to food or cooking facilities drugs requiring dietary manipulation were especially difficult to manage.

'It was horrible... I got side effects, diarrhoea and vomiting....so I had to be really strong, you know, really, really persevere I was just so determined I wasn't going to change... I knew my body would adjust. I just had this strong feeling that it would adjust and it did.' W23 Uganda

'I had to go on medication immediately and it was very hard because you are living with somebody whom you haven't told and to have to take this medication either with meals or after meals and some have to be kept in the fridge, so I felt, no it was too much for me. But I managed to do it.' W9 Kenya

'It is horrible, it is horrible to medicate yourself all the time, it is, not vitamins but medicine something you're hiding, it's very, very uncomfortable, to always have something that you're hiding.' W30 Uganda

'The very first days I had to take about 18 tablets, but they were reduced so now it's just something which you be used to it, it's just like drinking water now to me, I just it's easy, it goes easy, it, but first days it was so difficult, I had to, those days I had to take them three times a day, three times a day.' W58 Zimbabwe

Despite their difficulties, most of the women remained extremely committed to these drugs. Indeed many pointed out the huge sacrifices they had made in order to continue them. Unless they gave up the treatment, most would be unable to return to their home country and the families they had left behind. Hence the drugs enabled them to survive but not in circumstances of their own choosing.

'I've been like cut off you know. It would have been really nice for me to go back and get back my job, go back to my family, go back to my friends....my home, the sunshine.' W50 Zambia

Participating in voluntary organisations

Many of the women talked very positively about voluntary sector services and the important role they played in their lives. About half reported that they were a major source of social, emotional and practical support. Friendships were formed and fostered and women found a place in which it was safe to talk about their status and its implications.

'These organisations, apart from giving me a carer they have also made sure that my children are comfortable and they have also made sure I am comfortable by coming to visit me in hospital, and even talking to me on the phone, and that is very good, it just made me very happy.' W9 Kenya

'I gained strength from other people because I'm not alone, there are others, African women going through what I'm going through.' W30 Uganda

'I, actually most of the time I miss the home food, that's why I usually go maybe to support groups, I find that they prepare there the African food, just try to, to go in and then have something.' W49 Zambia

'It makes me feel that I'm not alone, for a long time I felt I was, it makes me feel so like I'm in family, they are very good people, they are very friendly, supportive, they are good people.' W24 Uganda

'It's a totally different picture I saw when I went there, people are putting on music, dancing; some of them are dancing; and they are talking about their difficulties.' W19 Uganda

'It was like a miracle to me... When I went to Positively Women they gave me some clothes, there's a woman brought me full bag like this... another one brought me a very big quilt to cover myself because it was winter.' W2 Burundi

'What makes it useful for when only women meet, all women who are HIV positive is that you share experiences, you learn and come to know that there are some women who have been worse than me, who have experienced harder times, have gone through what I have not gone through myself, you really learn and hear different experiences from different women.' W51 Zambia

However about a third of the women reported that they did not use these groups at all. Some had gone along once or twice and had not continued. Others had never attended. Several said they were too busy or too tired and some worried about gossip and information being passed on around the community. A number of women said that seeing people who were sick or remembering people who had died made them feel more vulnerable.

'I feel I don't really need to be reminded of the HIV in me and things like that, I feel if I'm outside that setting of the support group, I cope much better.' W47 Zambia

'I went there but when I come from there I feel bad, I was feeling sick because when I go there, there is some people if you look, you have to think oh maybe tomorrow I'm gonna die and when you go there every time they put that a candle it means someone died there, so when I go there I was thinking, oh maybe it's me now.' W44 Zambia

'Oh I don't need the crowds to understand what happening around me, I mean ok find me here, ok it's supposed to make you stronger but then what makes you stronger is who you are as an individual and I'm just a strong person.' W52 Zimbabwe

Turning to God

Finally the vast majority of the women in this study talked about their religious faith as a major source of support in coping with their difficulties. Apart from one Muslim woman, those in the sample were all Christian, with Pentecostal, Catholic and Anglican affiliation being most common.

'It is only in church that I feel really integrated, because you know there is one common ground for girls and boys that have problems. I feel good about myself for a change. It makes me feel better.' W15 Nigeria

'My priest knows about it, so, I always, when I'm stressed or when I'm low he comes along and pray and something, and it helps.' W31 Uganda

'Since I started going there my faith has gone so high, and um there is a lot of joy in the Christian church, singing, dancing, and all that.' W21 Uganda

It is significant, however, that a number of the women feared rejection by other members of their congregation. Several reported that moral judgements against HIV positive people were especially strong within the church and this made them reluctant to reveal their status. Hence they attended services but were unable to get the personal support that could only come after disclosure. Several also reported being afraid that information given in church might get back to family members.

'The man told his wife and his wife told one of the elders in the church and they asked us to leave the church because of the problem.' W13 Nigeria

'I used to go to church and I told the pastor about my diagnosis. I told a few people about my diagnosis, within no time the whole church knew about it and whenever there were big crusades they would call me in front...' W34 Uganda

These women relied mainly on their own spiritual beliefs rather than direct support from their church. The healing potential of religious faith was mentioned by many, either through the power of prayer or by laying on of hands. It was said to give inner strength both to the women themselves and to those involved in their care. Many of the women seemed to see medicine and religion as complementary and both were called upon in the struggle for survival.

'I have turned to God, I have really got to know more about God now, I know God exists, I know everything, God is in control, I know there is an afterlife after here.' W27 Uganda

'I would pray, I say God please heal me through this medication.' W12 Malawi.

'So I always speak to my body, I say you AIDS you are not in my body, you are not here, because Jesus carried my disease, and when I'm taking this medication I always say heal me through this tablets, if these tablets were made to make me feel well, you know heal me through them.' W27 Uganda

'I wanted to stand on that word that I am healed without taking the tablets. But again you say to yourself, God helps the ones who help themselves, so if I help myself by taking the tablets, God is going to help me in other ways to keep healthy and not getting sick.' W45 Zambia



Looking Towards the Future

At the end of the interviews we asked the women what would improve their situation – what would make life easier. Some of the women were understandably depressed and found it hard to envision the future. However the most common theme to emerge was the desire to do something active which would allow them greater control over their own lives. Asylum seekers in particular desperately wanted the opportunity to use their skills. The desire for greater economic security was also mentioned very frequently while that legal status remained ambiguous longed for greater certainty. Despite the huge difficulties they faced, many of the women showed great determination and considerable optimism about new treatment possibilities. They were still looking towards the future and showed considerable resilience in trying to shape the best possible options for themselves and their families.

'I'm not gonna let this wear me down, I'm not gonna let it kill my spirit, or stop me from doing what I have to do, I just have to move on, you know.' W39 Nigeria

'I would like to go back to work. Any work, anything, just to set up really a life for my kids, to leave them something you know, for them to remember me, our mum used to do this, or our mum was this... I don't want them to grow seeing mum is sleeping all day, mum has spent all her time in hospital.' W28 Uganda

'I don't think of death, I'm planning, I'm planning to study to get my degree, I'm planning to start to get a job.' W30 Uganda

'I just pray I just get a small place to myself, maybe when I sit there alone and put my HIV in perspective, when I'm alone I will be able to plan the future.' W24 Uganda

'I want to get my life back and try and do whatever I can to get my life back and get a job. Yeah, if I have to get out of that flat I have to go to work, I want to put my knowledge, the things I've studied and my skills in practice, I don't want to just sit there and be on benefits, I want to be useful. I just want to be what I was before.' W50 Zambia

'I want to live, life is sweet, you know, I want to live just like everybody else, get better and feel strong within myself, go to work you know, stay with my husband.' W56 Zimbabwe

'I'm looking the rest of my life, I don't know where, where is the end of my life or what, I don't know, but I just say, when I wake up in the morning I say, oh yes, thank you Lord I'm here.' W60 Zimbabwe

Recommendations

The report highlights some striking features of the lives of African women with HIV in the UK which are rarely incorporated into policy or service design. The following recommendations have been made to help policy makers and service planners align their planning and delivery to the expressed needs of these women.

1. HIV service policy and planning needs to take into account an understanding of the complex interplay between the three key tenets which underpin the experience of many women across the diverse range of African communities in the UK: gender; faith & religion; and stigma. All of these, in varying degrees, form a thread through the lives of most African women with HIV with whom we spoke.
2. The wide range of difference and diversity within African communities in the UK should be more readily acknowledged and worked with. It is no longer adequate simply to consider 'African communities' as a generic target group, or provide one set of services and expect it to be appropriate or even accessible to all women. Services should be targeted more specially at communities based on such factors as nationality, tribal background & religion.
3. Consideration should be given to the differences in needs of settled and evolving communities. Communities that have been resident in the UK for a number of years will be fully or partially integrated into UK society. Those where people have recently arrived in the country, however, are more likely to face considerable barriers both in accessing HIV treatment and support and integrating into civil society. The needs of the two types of community are significantly different and will require different services and support.
4. Services should be respectful of the autonomy that many women have shown in their physical and psychological journey to this point in their lives, and recognise that autonomy is crucial to physical and mental well being. This could take the form of something as simple as listening to a woman's story of how she arrived where she is today, to taking active steps or devising programmes that build on women's ability to survive and turning them into skills that facilitate integration into UK society.
5. Services should be gender sensitive and demonstrate an understanding of and respect for the position of women, and especially mothers, in many African communities.
6. Service delivery should be flexible and reactive to the needs of service users, especially for women who have responsibilities to fulfil as mothers, carers or workers. Flexible working practices and opening hours may be one way to approach this.
7. Services should actively tackle the HIV related stigma that is rife within many African communities.
8. Maximising integration into society and encouraging full participation in civil society should be a main aim of all services working with African women. The inability of many women to achieve integration is a prime reason for feelings of isolation and depression and a major barrier to building fulfilling lives in the UK.
9. Service provision should be linked into integrated pathways of care with other clinical and social care services. This will help to ensure that all service users are able to access the full range of appropriate services.
10. Service design should build in capacity to support staff in coping with the extreme pressures which many face when dealing with diverse and complex client loads. This includes both training in understanding the legal and social constraints which face people seeking services, and emotional support to manage work with people who may have undergone extreme trauma and/or be facing difficult and threatening choices.

Organisations working with HIV positive African people in London

African Community Involvement Association

Eagle Court, 224 London Road, Mitcham CR4 3HD
Tel. 020 8687 2400

African HIV Policy Network

New City Cloisters, 96 Old Street, London EC1V 9FR
Tel. +44 (0)20 7017 8912 Fax. +44 (0)20 7017 8919
Email: info@AHPN.org

Body and Soul

9 Tavistock Place, London WC1H 9SN
Tel. 020 7383 7678 Email. paula_harrowing@hotmail.com

Globe Centre

159 Mile End Road, London E1 4AQ Tel. 020 7791 2855

HIV/AIDS Association of Zambia

Suite 53 Chancel House, Neasden Lane, London NW10 2TU
Tel. 0208 214 1475/1476 Email. admin@haaz.org.uk

Lighthouse Kings

Unit 2, Empress Mews, Kenbury Street London SE5 9BT
Tel. 0207 737 9740

Lighthouse South London

14-15 Lower Marsh, London SE1 7RJ
Tel. 0207 816 4720

Lighthouse West London

111-117 Lancaster Road, London W11 1QT
Tel. 0207 792 1200

London East AIDS Network

35 Romford Road, London E15 4LY
Tel. 0208 519 9545

Muslim HIV/AIDS Support Service

6 Stoughton Close, London SE10 8JL
Tel. 020 7564 4949

National AIDS Trust

New City Cloisters, 196 Old Street, London EC1V 9FR
Tel. 020 7814 6767 Email. info@nat.org.uk

NAZ Project

Palingswick House, 241 King Street, London W6 9LP
Tel. 020 8741 1879 Email. naz@naz.org.uk

Positively Women

347-349 City Road, London EC1V 1LR
Administration: 020 7713 0444
Helpline (staffed by HIV positive women:10am-4pm Monday to Friday) Tel. 020 7713 1020

South London Congolese Association

Unit 103 Croydon House, 1 Peall Road, Croydon CR0 3EX
Tel. 020 8664 9580

THT Direct

For advice and referral to all HIV services including your nearest centre Tel. 0845 12 21 200

Ugandan AIDS Action Fund

Unit 333, Great Guildford Business Square,
30 Great Guildford Street, London SE1 OHS
Tel. 020 7928 3275 (office) 020 7928 9583 (helpline)

Zimbabwean HIV/AIDS Forum

PO Box 10047, London SE15 2LY
Tel. 020 7732 0604

Further Reading

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