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# ORIGINAL PAPER

# **Experiences of African Immigrant Women Living with HIV in the U.K.: Implications for Health Professionals**

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**Abstract** In the U.K. immigrant women from Africa constitute an increasingly large proportion of newly diagnosed cases of HIV. A significant minority of these are refugees and asylum seekers. Very little is known about their experiences of living with HIV/AIDS, their psychosocial needs or their views of health care provision. This paper reports the results of a qualitative study that explored these issues by interviewing eight African women living with HIV in the British city of Nottingham. Women's ability to live positively with HIV was found to be strongly shaped by their migration history, their legal status, their experience of AIDS-related stigma and their Christian faith. Significantly, health services were represented as a safe social space, and were highly valued as a source of advice and support. The findings indicate that non-judgemental, personalised health care plays a key role in encouraging migrant African women to access psychosocial support and appropriate HIV services.

**Keywords** African women · HIV/AIDS · Migration · Migrant · U.K. · Nottingham

# Introduction

Globally, sub-Saharan Africa is the region most severely affected by the HIV pandemic [1]. As a consequence,

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immigrants from sub-Saharan African countries constitute an increasingly large group of those affected by HIV in the countries where they settle. In the U.K. for example, African immigrants make up 36% of those living with HIV (12,558 out of 34,689) despite the fact that they constitute less than 1% of the population [2, 3]. In contexts of increasing migration, health professionals are called upon to recognise the diverse cultural, social, economic and political histories of their patients, and to understand how these interface with their current living situation, including their HIV-related health and treatment needs [4].

Relatively little research has been conducted to investigate the health experiences of migrant populations living with HIV in the U.K., or on their patterns of access to, and utilisation of, HIV treatment and care [5]. Findings from the limited available studies indicate that African migrants tend to present later than other population groups for HIV testing and treatment [6]. This is attributed to a number of obstacles to seeking or accessing care, including individual/community characteristics (such as AIDS-associated stigma, lack of perceived risk and denial), and factors associated with service and welfare provision in the host country (such as perceived discrimination, language and cultural differences, financial constraints and uncertain legal status) [6, 7]. For a significant minority of migrants who are refugees or asylum seekers, their legal status in the country is a key concern. In the U.K. all documented migrants, refugees and asylum seekers are entitled to free medical treatment and limited social welfare benefits, including housing. These services are withdrawn however if an asylum application is rejected, and such HIV positive migrants face the prospect of deportation to countries where HIV treatment may not be easily accessible [8].

Migrant African communities in the U.K. traditionally congregate in London, where a large range of specialist

medical and community-based services are available, and where there are dense social networks through which material and social resources can be accessed [3]. Since 1999 however, the Government has instituted a policy of 'dispersal' which aims to ease the pressure on services in the capital by sending refugees and asylum seekers to alternative locations all over the country. Questions have been raised as to whether HIV services outside the capital are able to provide specialist care that is appropriate and accessible for African migrant groups. Very little research has been done however to explore the experiences of HIV positive Africans living outside London [8, 9].

In the U.K. women accounted for 65% of new HIV diagnoses made in 2003, of which more than 70% were black African [2]. Most of the research on HIV and migrant African communities in the U.K. however has focused upon men, or has utilised mixed-gender samples [7, 10]. Only one study by Doyal & Anderson (2004, 2005) has explicitly focused on African women and it drew its sample exclusively from London [11, 12]. This study showed that, though not a homogeneous group, African women's experiences of living with HIV were shaped heavily by their socio-economic circumstances, by the responsibilities of motherhood and by their immigration status. In situations where women were living in relative poverty and where their immigration status was insecure, health concerns were overshadowed by more immediate survival concerns. In addition, given the limited treatment availability in African countries, for many women, staying in the U.K. represented their only opportunity of access to HIV treatment. Thus, some women appeared trapped in a catch-22—even when life in the U.K. was difficult, going back home was no longer an option. Doyal and Anderson's study also highlighted the fact that HIV/AIDS remains a heavily stigmatised disease, and that fear of HIV-related stigma affected women's ability to access social support both from family, friends or from the voluntary sector [11, 12].

In order to ensure equity of access to health care based on gender and on locality, there is a need for more research to examine the experience of African women living with HIV in the U.K. and, in particular, to consider the nature of this experience for those living in areas that are less well served with specialist HIV statutory and voluntary services. This study set out to investigate these issues in the English city of Nottingham. The study aimed (i) to explore African women's experiences of coping with HIV, and, (ii) to explore their views on the city's HIV services.

#### **Research Setting**

Nottingham is the economic and cultural capital of the East-Midlands area of the U.K. and has a population of

approximately 625,000 people of whom 81.1% are classified as white-British and 15.1% are from other ethnic groups. It is well known for its legendary hero—Robin Hood—but is also known for high crime levels and relatively high levels of social and economic deprivation in its inner city neighbourhoods [13].

According to the latest available cumulative figures, 428 people in Nottingham have been diagnosed with HIV or AIDS, of whom 49% are African. Forty five percent of people living with HIV/AIDS are female, of whom seventy one percent (n=89) are African [14].

HIV services in Nottingham are delivered through hospital-based clinics based in Infectious Diseases and Genito-Urinary Medicine Units. These services are supported by a multi-disciplinary, community-based 'Positive Care Team' (comprising a specialist nurse, a social worker, a dietician, a community care officer and a befriending service coordinator). The Positive Care Team runs a weekly drop-in centre where people living with HIV/AIDS (PLWHA) can come to socialise and access professional help on an informal basis. The voluntary sector in Nottingham is small, comprising two refugee support groups and one PLWHA support group that is run by non-Africans. There are no African focused HIV-related community organisations.

# Methodology

The research adopted a qualitative approach in which semistructured interviews were conducted with HIV positive migrant African women living in Nottingham [15]. Interview guides were constructed to cover the following broad topic areas: experiences of coming to the U.K., the impact of HIV/AIDS, sources of support, coping with everyday life and views on health services. Data was collected in 2005.

The study's inclusion criteria were that women must be aged between 18 and 50 years and must be able to speak English. The sample was recruited opportunistically via the hospital or drop-in centre with the help of the Positive Care Team, and consisted of 8 African women from 3 different countries; Congo (n = 1), Malawi (n = 2) and Zimbabwe (n = 5). This represented approximately 10% of Nottingham's female African PLWHA population.

The interviews were conducted by the first author (a nurse from sub-Saharan Africa). All interviews were audiotaped and transcribed by the first author. Some interviews took place in women's homes, and some were held in the hospital. Ethical approval was obtained from the local National Health Service Research and Ethics Committee. Great care was taken to ensure that participants understood the nature of the study. They were assured that their participation was entirely voluntary, that it would not affect



their care in any way, and that their views would remain strictly anonymous. Arrangements were made for psychological care in case any one became distressed, however recourse to this provision was not required.

Data was analysed thematically using framework analysis [15, 16]. This method consists of a number of steps (familiarisation, identifying a thematic framework, indexing, charting, mapping and interpretation) in which the data is initially ordered according to an emerging thematic framework. This is then reviewed to identify patterns, associations and concepts that can provide explanations for the findings [17]. A sub-sample of transcripts and the coding framework were checked with another researcher (the 2nd author), and the main findings were cross-checked with the Nottingham Positive Care Team. Key themes were: 'being a migrant', 'facing HIV', 'living with HIV/ AIDS', and 'using health services'. A number of cross cutting sub-themes were identified that were found to strongly affect women's ability to cope positively with their diagnosis and to access social support. These were the role of religion, legal/migration status and HIV-related stigma.

# Socio-Demographic Profile of the Sample

Two participants were students, 4 were asylum seekers and 2 had 'indefinite leave to remain' (i.e. they were entitled to settle permanently in the U.K.) All were aged between 30 and 50 years. The group was fairly well educated, with 5 members having studied to secondary school level. The students were in part-time employment and one participant was in full time work. The asylum seekers were barred from working and had to rely on state benefits which (as will be described below) were judged insufficient. Women gave a variety of reasons for migration, including fleeing from war (n = 1), political insecurities (n = 2), pursuit of work (n = 1), visiting relatives (n = 2) and education (n = 2). All participants had been in the U.K. for a relatively short period of time (between 1 and 5 years) and were still trying to adjust to the new environment. The majority of the participants had initially come to the U.K. alone, though a few of the women were later joined by some or all of their children or a husband. Nonetheless, they found themselves without the close social and family networks that are characteristic of the African setting.

The majority of women (n = 7) had children. Four of these had children living in the U.K., whereas those of the other 3 were still in Africa living with relatives, but were depending upon the participants for financial help. The majority of the women were the main providers and care givers for their children, both in the U.K. and back home. Half of the women had been divorced prior to coming to

the U.K., 2 participants were single and had never been married, whereas 1 was widowed. Thus most of the women were single parents with no informal psychosocial support from a partner.

The majority of the group had been HIV positive for a period of 1–4 years.

#### **Results: Women's Stories**

Being a Migrant

The impact of migration on women's health varied according to their individual circumstances, particularly whether their legal right to remain in the U.K. was assured or not. For those participants seeking asylum, the complex, unpredictable and lengthy process of obtaining a secure legal status was a constant source of stress. Moreover, in a context where being sent back home would potentially mean losing access to life saving treatment, obtaining asylum was a matter of life or death:

My head is not well. I am not thinking properly because of problems of immigration (P5)

The issue of treatment access was a predominant concern for all women however, placing a constraint on their ability to make life choices:

If I had a choice I wouldn't be here – I can't go back home because where will I get medication from if I go back home? What will happen to my daughter? (P6)

Participants had varied views on life in the U.K. Those who had left difficult circumstances behind were grateful for the basic security they now had. However, the asylum seekers in particular were struggling financially and were often carrying the additional burden of trying to make already meagre state welfare benefits stretch to support kin in Africa. Their situation especially was characterised by great anxiety. Moreover, for the asylum seekers, not being able to work reinforced a feeling of uselessness and sickness. In their view, work was an important means to improve their economic situation but was also central to their identity as mothers and providers, and represented a 'normalising' activity that would have given access to social resources and provided a feeling of structure and purpose to their day:

You have to just sit like I am sitting - you know back home we work, we work very hard (P3)

Thus the experience of migration shaped women's experiences of HIV in complex and inter-dependent ways.



#### Facing HIV

In many African settings, AIDS is framed within a judgmental and moralising discourse that condemns women for perceived 'sexual promiscuity' whilst tacitly accepting a sexual double standard for men [18]. All the participants expressed the view that society considered women with HIV to be 'immoral' or 'prostitutes' and that AIDS was 'their fault':

They think that maybe you used to go around with many men – you see they will think that and won't think of anything else – they will think you are a prostitute (P5)

In spite of coming from high HIV prevalence countries, all the women had presented late for HIV testing, having been diagnosed only once in the U.K. and only upon the advice of health care professionals. Three of the participants admitted that they had previously suspected that they may have been HIV positive (due to a boyfriend/husband's illness or obvious multi-partner sexual behaviour), but, in a context where treatment was not available and where AIDS is so heavily stigmatised, they had been unable to contemplate getting tested themselves:

When I was married, my husband was having girlfriends here and there so I couldn't say I was free from this thing. I was just praying I won't catch it but you know, you see people dying. And then you think mine goes here and there and that will be the end of me (P3)

Upon diagnosis, some participants expressed sentiments akin to a sense of relief at finally knowing, or at being diagnosed in a setting where help and treatment was available:

Because I knew that in this country they, they control the disease so I was happy because back home by this time I would be 6 feet down (P1)

Others however were extremely shocked and had clearly gone through periods of severe depression:

Ooh – the first days I am crying when I get illness, oh my Lord, my children (P8)

For many women, their child care responsibilities and love for their children were cited as a key factor that kept them going in difficult times:

Everything is for the children, the children you know, I haven't got time for myself really, when they told me – since then, I do not feel well – sometimes I think to myself to drink all the medicine and die, but when I look at my children there, I know it's worth it (P5)

In sum, the social context of stigma and the social responsibilities of motherhood were major factors affecting women's decision making around HIV testing and subsequent care-seeking.

#### Living with HIV/AIDS

For the participants, accessing help to cope with their diagnosis was shaped by fear of AIDS-related stigma. Thus, management of information around their diagnosis was one of the most difficult aspects of living with HIV. All but one of the women had disclosed their diagnosis to at least one other person—either an immediate family member or a good friend. The decision to disclose however was undertaken with great trepidation and only after careful deliberation on the extent to which they could trust the other person and whether confidentiality would be maintained. One participant, for example, recalled telling a friend about her illness and being thrown out of her house:

I, I remember when I was in [name of town] I tell my first friend and she said to me 'I don't want to see you, I don't want talking to you, do not come to my house'. You don't know if you tell another it will be the same. You think it will be the same like that person. That is why I look, this one I tell no problem, this person not (P2)

Participants reported great anxiety about family in Africa finding out. Given the dense and over-lapping social networks that characterise African kin circles, women were extremely cautious about revealing their diagnosis to others in the U.K.:

No I didn't tell anyone. Because who can I tell? I will tell my friend, then they will tell another one. You know different people, one you can tell is normal and another will speak too much. Then all the people from your country will know she is sick. Then they will start to talk about you, then you will feel bad. So that is why I do not tell anyone (P4)

Some of the asylum seekers in particular seemed extremely lonely and socially isolated, having been housed in 'rough' neighbourhoods, and having limited opportunities to make friends. The other participants reported having at least a few friends in Nottingham, but, due to lack of disclosure about their HIV status, this did not necessarily translate into psychosocial support for their illness. In fact, one major impact of women's concern around disclosure is that they seemed extremely reluctant to openly socialise with other African women living with HIV/AIDS. For example, when the participants were asked in interviews how they would feel about attending a peer support group just for African women, they all rejected the idea.

All the participants attended church and indicated that their faith was a major source of comfort in dealing with their diagnosis. Indeed, the majority of the participants had disclosed their diagnosis to a church pastor:



In church, you know, I just trust that in church. My testimony is to tell to those who are there - not to anybody outside, you know that is it (P3)

These findings demonstrate that, although most had women developed strategies to obtain social support while living in a new city, stigma was a major barrier that prevented them from accessing support specific to coping with HIV.

# Support from Health Care Services

The participants unanimously cited the HIV services as their most commonly sought out source of support, advice and care for their illness. The majority were extremely complimentary about the care they received, and two explicitly preferred these services to those obtained from their General Practitioners:

Because they [at GP's] don't care about people, sometimes I see like that but at [the hospital], I talk with the doctor nicely. But at GP's sometimes they look at you as somebody who is just like that (P5)

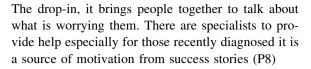
This negative experience was represented as a need to feel accepted and treated like 'normal' people with a 'normal' illness. Thus, many participants noted appreciation of even the smallest gestures like a smile:

Every time I go to the hospital when I go to the receptionist to see my doctor she quickly gets my card, comforts me, tells me to go and sit there, greets me and says hello. Then with time the doctor calls me, then I go see my doctor and my doctor comforts me smiling at me, writing me blood tests or prescription to take the medicine, then I go to make another appointment. Everything is good (P2)

Women's expressed satisfaction with their health care appeared to be reinforced by the obvious contrast in health services between their country of origin and the U.K. The participants reported coming from situations where there is a lack of resources and where they have experienced stigma and discrimination—especially from healthcare workers. For example, one participant described the care her boyfriend had received in Africa:

In Africa there is no medication and they are not too good in hospitals. They won't treat you very well. Here doctors are very careful, yes they I don't know what to say, each time you go for check up. But back home check up is on your first day, that's it until you die (P1)

Interestingly, the drop in centre was particularly valued by some respondents, being seen to offer a chance to meet other PLWHA and to share and learn more from them:



Thus, some participants appeared to value the drop in as an informal space for sharing and expert in-put, although, as described above, they did not appear keen on a service specifically for African women.

#### Discussion

The research findings indicate that African women living with HIV/AIDS in Nottingham face similar issues in coping with HIV to those reported in other studies—particularly regarding migration status, stigma and limited social support [11, 12, 19]. Likewise, the study confirms a commonly reported finding that an HIV diagnosis constitutes a profound 'biographical disruption', including the disruption of one's former assumptions and behaviours, changes in self-concept and in the mobilisation of helping networks [20]. Migrants living with HIV however face a dual challenge in terms of coping with a life threatening chronic illness and adjusting to a new country [21].

The context of stigma clearly impeded women's ability to come for HIV testing, and, subsequent to diagnosis, to access social support [22, 23]. According to Goffman [24] stigma is both a social and an individual process in which individuals may stigmatise themselves (felt stigma) as well as being stigmatised by others (enacted stigma). The women in the sample clearly expressed a significant degree of felt stigma, and some had experienced overt discrimination. The study showed that HIV positive African migrant women (especially those whose immigration status is insecure) found themselves in a precarious social situation that may have exacerbated their sense of felt stigma, and inhibited their ability to challenge it. In the U.K. (as in Europe more generally), immigration is a highly contested political issue and society may appear hostile to immigrants. Indeed, in some public fora, migrants are explicitly represented as potential vectors of disease and contamination [25, 26]. In such a hostile social climate and in situations where migrant African women have little social power, it is perhaps unsurprising that migrant groups will cling all the more to a 'known' moral/social order rather than develop strategies of resistance [27]. Thus, women's subjective experience of stigma did not appear to have been significantly altered by the fact that they were living in the U.K.

Some women in the sample therefore, appeared to lack psychosocial support that may have helped them to cope better with their illness (and with the insecurities of their migration status). Although Nottingham lacks community



based and voluntary sector activities for this specific group of women, even if they did exist, it is not clear that they would be well-used for HIV support purposes given the great anxiety around disclosure and stigma. Concerns around stigma appeared to put women off the idea of an African women's peer support group. However, the positive value that some women attached to the drop-in centre implies that some women did appreciate a place to go where they could meet others and learn more about their condition. It may well be that if concerns around stigma could be overcome, and if trust could be established, women may find that a peer support group was extremely useful. Health professionals could play a role in establishing such a group. Furthermore, starting such an activity under the auspices of the relatively well trusted health services may enhance its acceptability.

Many women in the study had sought solace in their personal faith and in the wider church community. Some had disclosed their status to their pastors, primarily in order to receive prayer. The extent to which women were able to seek support around their illness from fellow church goers was unclear however—as reported in similar studies [28]. Nonetheless, health professionals could consider establishing links with local churches to support them in conducting health promotion or social activities.

As noted in other studies, immigration issues loomed large for some women in this study, and were all the more critical given their link with access to HIV treatment [29]. The issue of whether potential lack of access to HIV treatment in African countries entitles asylum seekers to be given legal permission to stay in the U.K. is highly contested however, and is unlikely to be resolved in the near future [8].

Significantly, the health service was represented as the only safe social space in which women could access non-judgemental care and support. Indeed the health care team was viewed as a critical source of help and advice. Similar findings have been reported in other studies [9, 12, 29]. Although women presented late to health services, once contact had been made, they appeared to be extremely satisfied with the care they received, and did not report any significant barriers to accessing care. This is undoubtedly partly due to the multi-disciplinary nature of service provision in which specialised medical, social welfare and nursing support was available in one location. The dedication of the Positive Care Team and the drop-in facility was also recognised.

# Limitations of the Study

This was a small study but the findings are consistent with those reported elsewhere, lending weight to their validity. The sample was accessed via the health service, thus is it is not clear to what extent the views expressed are representative of African migrant women in Nottingham per se, or of those that are not in regular contact with the local HIV care team. A community-based sample may have yielded a more representative picture, but, in the absence of African HIV organisations in Nottingham, it would have been difficult to access such a sample. The researcher (1st author) was a Kenyan nurse who was herself a migrant to the U.K. She felt this enabled her to establish good rapport with the participants, whilst still recognising the many differences in their experiences that nonetheless existed.

# **Study Implications**

The study has a number of implications for HIV health workers. Firstly, it illustrates the value of exploratory research in assisting practitioners to understand the needs and social context of different migrant groups vis a vis AIDS prevention, treatment and care. This goes beyond a simplistic documentation of culture as a 'variable' of health behaviour, and, rather, illustrates the need to understand how the socio-economic and policy context in which migrant women live, has a defining role in structuring their ability to deal with HIV/AIDS [4, 11]. In this case, dealing with issues such as migration status goes beyond a health workers' remit. However health workers need to be aware of the broader context in which their patients are managing their health, and they can play a key role in referring women to appropriate institutions, or, as in the Nottingham case, by setting up comprehensive and multi-disciplinary services.

Second, in a context where AIDS is heavily stigmatised, the findings indicate that women particularly valued care that was non-judgmental, personalised and kind. It is clear that health workers' own attitudes to HIV and to their patients will critically determine patients' subsequent use of health services [10, 29]. Women indicated that expectations of judgmental or discriminatory treatment put them off seeking help—a finding reported in a number of other studies [30]. Given current global policy imperatives to encourage people to come early for testing and treatment, it is important that health workers are trained and supported to develop appropriate attitudes and non-discriminatory behaviour [2].

Third, it remains unclear how health workers can best help HIV positive African migrant women to access psychosocial care outside the realm of formal services. This is an area where more research is required.

Finally, it is clear that health interventions alone will not eliminate inequalities in access to HIV care and treatment, or the availability of psychosocial support in African migrant groups in the U.K. Ongoing work is needed to enhance our understanding of the health experience of HIV positive migrants. As concluded by Amo et al. [5]



however, it may be that strengthening liaisons between HIV clinical care settings, researchers and communities is the best way to achieve this goal.

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