

SHORT REPORT

Pathways to HIV testing and care by black African and white patients in London

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Objective: To examine factors associated with uptake of HIV clinic services by black African HIV positive people living in London.

Design: Questionnaire survey of patients attending study clinic.

Setting: HIV outpatient clinic in south London, UK.

Subjects: All HIV positive patients attending the clinic between July 1999 and March 2000.

Main outcome measures: Use of health services, delay in seeking HIV test, pre-HIV test concerns, delay in uptake of HIV care, barriers to clinic use, disclosure, sources of support.

Results: 392 questionnaires were completed. Respondents were 64% white, 26% black African, and 10% from other ethnic groups. Twenty eight per cent of black Africans suspected they were HIV positive before diagnosis (white patients 45% ($p < 0.01$)). Before testing 11% of black Africans had previously attended a genitourinary medicine clinic, 80% had consulted a GP. Twenty per cent of black Africans expressed concern over entitlement to care and where to get an HIV test. The majority of black Africans (66%) received HIV care within 1 month of their diagnosis. They were significantly ($p < 0.01$) less likely than white patients to disclose their HIV status to family and friends.

Conclusion: This study suggests that although black Africans are a high risk group for HIV infection they generally do not suspect their status. While they may delay testing, their uptake of HIV clinic care and use of statutory and voluntary support services after diagnosis is similar to their white counterparts. However, they lack informal support networks. This study highlights the continuing need for health promotion work among London's African communities, to reduce the stigma surrounding HIV/AIDS and to raise awareness of the benefits of testing.

It has been a consistent finding that black Africans with HIV/AIDS living in London present to outpatient clinics at a more advanced stage of disease compared with white patients.^{1,4} However, there have been very few studies in the United Kingdom examining ethnic differences in the use of medical care in relation to HIV/AIDS.^{3–9} The aim of this study was to examine black African HIV patients' pathways to hospital services, factors affecting access to these services, use of support services, and disclosure of HIV status and, where appropriate, to compare this with the experiences of white patients. This observational study describes the experiences of patients attending the HIV outpatient clinic at St Thomas's Hospital where over a quarter of all new patients registered annually are black African.³

METHODS

A total of 608 new and existing patients who attended the St Thomas's clinic in the period July 1999 to March 2000 and

who were able to read and write were invited to take part in the study. An anonymous questionnaire, available in English, French, Spanish, and Portuguese, was distributed by a non-clinical researcher to patients in the clinic for self completion. Data analysis was performed using SPSS for Windows, version 7.5.2. Univariate analyses of associations between patient variables were conducted using χ^2 tests.

RESULTS

Characteristics of respondents

In all, 392 questionnaires were completed with no ethnic differences in the refusal/non-return rate of 35.5%. Respondents were 64% white, 26% black African, and 10% from black Caribbean and other ethnic groups, the latter were excluded from analysis. Ninety two per cent of white patients and 40% of black Africans were male, the median age for black Africans was 34 (range 21–60 years) and for white patients 38 years (range 20–76 years). Black African respondents were from Uganda (36%), Zimbabwe (14%), Zambia (12%), and 14 other African countries, 21% had been in the United Kingdom less than 5 years and 59% less than 10 years. Although having very similar education levels to white patients, black Africans were more likely to be unemployed (49% compared with 19%). Seventy five per cent of black African respondents had children.

Experience of health service

Of respondents living in the United Kingdom for 5 years or more, 11% of black Africans had attended a genitourinary medicine clinic before their positive diagnosis and 18% had had a previous HIV test. Eighty one per cent of black African men and 71% of black African women had ever consulted a general practitioner.

Testing for HIV

One quarter of black Africans were first diagnosed on a hospital ward and 53% first tested positive at a genitourinary medicine clinic. Other test sites included other hospital departments, GP, private, and antenatal clinics. The reasons most frequently cited by black Africans for having an HIV test were illness and/or symptoms (40%), the advice of doctors or nurses (29%), feeling at risk (16%), and having a positive partner or child (16%).

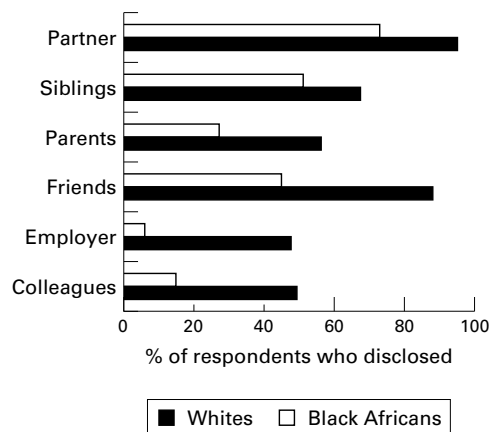
Twenty eight per cent of black Africans suspected they were HIV positive before testing compared with 45% of white patients ($p < 0.01$). Of those black Africans who did suspect, 62% waited 12 months or more before testing compared with 31% of white patients ($p < 0.01$). Presented with a list of possible pretest concerns black Africans reported being very worried about a range of practical, social, and emotional issues relating to HIV (see table 1).

Use of clinic services

Sixty seven per cent of black Africans and 78% of white patients received HIV care within 1 month of diagnosis and over 85% of all patients had received care within 6 months. Twenty three out of 32 black Africans who reported not

Table 1 Pre-HIV test concerns of black African patients

Statement	% Very worried
Effects on your family if you were HIV positive	74
Discrimination if you were HIV positive	68
Fear of dying	66
Not being able to make plans for the future if you were HIV positive	64
Not being able to have children if you were HIV positive	60
Effects on your work if you were HIV positive	55
Partner's reaction if you were HIV positive	49
Bumping into someone you knew at the HIV clinic	48
What the Home Office might do if they found out you were HIV positive	40
That your children might be taken away if you were HIV positive	32
Whether you were entitled to medical care	28
Where to go for an HIV test	20
The attitudes of the clinic staff	13
How to communicate with clinic staff	12

**Figure 1** Disclosure of HIV status by black African and white patients to friends, family, and colleagues.

receiving care within 1 month gave reasons for the delay which included denial, coming to terms with diagnosis, not knowing where to go, feeling well/no symptoms, stigma and discrimination associated with HIV, and fear of medication.

Approximately 20% of all respondents received free travel. Forty two per cent of black African reported that cost of travel sometimes made it difficult to come to the clinic (compared with 2% of white patients ($p < 0.001$)). Fifteen per cent of black Africans had to arrange childcare in order to come to the clinic, two thirds of these patients reported that it was difficult to arrange such care. Thirty five per cent of all patients took time off work in order to attend clinic appointments, 54% of black Africans reported that this presented difficulties (compared with 36% of white respondents).

Disclosure and support

Among patients diagnosed after 1994, black Africans were significantly ($p < 0.01$) less likely than white patients to disclose their HIV status to siblings, friends, parents, partner or work colleagues (see fig 1). Fifteen per cent of black Africans and 3% of white patients had not disclosed their status to any family or friends including their partners.

There were no ethnic differences in the use of housing support (74%), social services (68%), and telephone helplines (14%) over the previous 12 months. Eighteen per cent of black Africans had used legal services perhaps because of immigration issues. In the previous 12 months HIV organisations were

used by 40% of all patients. However, black African men were significantly less likely than black African women to have used these services, 29% versus 50% ($p < 0.05$). Within the clinic black African men were less likely than women to have consulted the African liaison nurse or the health advisers.

DISCUSSION

Black Africans in the United Kingdom face an HIV diagnosis in a different context from that experienced by their white counterparts and have different use of health services. Those who test positive are often recent immigrants to the United Kingdom and face uncertainties over housing and employment. Although general practitioners are widely used, other sources of health care are less likely to be accessed. This may reflect a lack of knowledge of these services and how to access them. This is supported by the fact that over 20% of black African respondents reported pretest concerns about entitlement to care and where to go for an HIV test.

The level of concern about a range of practical, social, and emotional issues relating to HIV testing is high among black African patients. As parents many have to worry about the consequences of their diagnosis for their family and whether they will be able to have children. The fear of dying expressed by two thirds of black Africans suggests that they are interpreting their diagnosis in terms of the African context. Whereas in the United Kingdom HIV/AIDS is now a manageable disease, in Africa few have access to treatment and survival times are much shorter.

The considerable stigma attached to HIV/AIDS in African communities in the United Kingdom¹⁰⁻¹² is reflected in the importance placed on confidentiality. Worries about confidentiality, and the unwillingness to disclose their status to family and friends, means that African patients are much less likely to have informal support networks. Although the use of statutory and voluntary support services are comparable with white patients, black African patients' need for support may in fact be greater. This may be particularly true of black African men who tend not to use HIV support services.

This study cannot inform us about those who do not access services, whose concerns are likely to be greater than those reported here—speakers of minority languages may also have been excluded. The study was conducted in a clinic which has a designated African liaison nurse whose major role is to act as a link between patients and outside support organisations. Hence, the study may overestimate the use of these services by black African patients living with HIV/AIDS in London.

This study highlights access to care by black Africans, prevention, and denial of diagnosis as important issues for further research. It emphasises the continuing need for health promotion work among London's African communities to reduce the stigma surrounding HIV/AIDS and to raise awareness of the benefits of testing. As the majority of black Africans access and receive health promotion from general practitioners⁹ there may be a wider role for primary care physicians and community health workers in promoting awareness of HIV/AIDS in these high risk communities and facilitating access to HIV testing and care.

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CONTRIBUTORS

JE was responsible for study design, study supervision, statistical analysis, interpretation of results, and preparation of the manuscript; MM contributed to study design, interpretation of results and preparation of the manuscript; KG was responsible for data collection and contributed to data analysis and interpretation; NB contributed to study design, interpretation of results, and preparation of the manuscript; BP contributed to preparation of the manuscript.

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