

“If I cannot access services, then there is no reason for me to test”: the impacts of health service charges on HIV testing and treatment amongst migrants in England

Abstract

Policy governing entitlement to access government health care for foreign nationals in England is a subject of debate, controversy and confusion. Of particular concern to health providers has been the impact of National Health Service charges on delaying HIV testing and anti-retroviral treatment uptake and adherence amongst certain migrant groups. Data obtained through focus groups with seventy migrants from southern Africa, suggests that confusion over health care entitlements exists amongst those seeking health care and is reported amongst health service providers. This confusion, as well as financial difficulties and fears over deportation facing some migrants, can in turn be a factor influencing their decisions to avoid formal health services, resort to alternative and often ineffective or potentially adverse forms of therapy, and delay HIV testing and treatment uptake.

Introduction

Recent data suggest the percentage of late HIV diagnoses in the UK is highest amongst black Africans (Chadborn, Delpech, Sabin, Sinka & Evans, 2006). Whilst overall numbers of HIV infections are reported to be going down, 10% of black Africans receiving an HIV positive result in 2007 were diagnosed with HIV and AIDS at the same time (Health Protection Agency, 2008a).

A number of factors help explain late HIV diagnosis and inconsistency in treatment seeking amongst migrant communities. These include constraints associated with insecure immigration status (Körner, 2007), high levels of AIDS-related stigma and associated fear of rejection from community support networks (Dodds, 2006; Doyal & Anderson, 2005), traditional health seeking norms and a lack of familiarity with health care services (Kang, Rapkin, Springer & Kim, 2003) and structural barriers to accessing health services (Burns, Imrie, Nazroo, Johnson & Fenton, 2007).

Within the UK, structural constraints to accessing health care have received attention within the past decade as a result of frequent and often confusing policy changes relating to health care entitlements for foreign nationals (cf. Kelley & Stevenson, 2006; Yates, Crane & Burnett, 2007). While it is generally reported that such policy is impacting adversely on particular migrant groups, relatively little is known about the implications of such policy on the health seeking options that remain available to migrants, nor the consequences of this for late HIV testing and treatment. Drawing upon data collected through focus group discussions with migrants from southern Africa, this paper aims to shed light on the impact of recent government policy on health seeking and HIV testing in England. Focus is placed on examining the alternative – and often adverse health seeking options available to those without access to National Health Service (NHS) healthcare entitlement¹ and the implications of this for individual and public health.

Policy context

The UK government played a key role in the development of United Nations policy to ensure universal access to HIV prevention, treatment and care by 2010. Paradoxically however,

pressures from the domestic tabloid press concerning issues of immigration, asylum and fears of 'health tourism' have played a significant role in influencing the UK government's own policy regarding secondary health care entitlements for foreign nationals (Cole 2007; Ingram 2008)² and in 2004, the Department of Health set out new guidelines laying down NHS procedures for identifying and charging those deemed ineligible for free treatment.

As part of this new policy, those living lawfully in the UK for at least twelve months before requiring treatment and asylum seekers whose asylum claim or appeal remained outstanding were deemed exempt from charges. However, the case remained less clear for undocumented migrants, refused asylum seekers and visa over-stayers, resulting in reports of widespread confusion amongst NHS clinicians and management and, in cases, the enforcement of substantial charges on vulnerable and often destitute people (Hargreaves, Holmes, Saxena, Le Feuvre, Farah, Shafi et al. 2008).

The 2004 regulations set out the types of treatment for which people in England could be charged.³ Whilst people with serious communicable diseases such as tuberculosis and sexually transmitted infections were not liable to NHS charges, HIV was specifically excluded from this exemption. At the same time, all people treated for life threatening conditions in an Accident and Emergency (A and E) department were exempt from charges (Cole, 2007). Thus, as Ingram (2008) explains, a paradoxical situation was created in which people were entitled to life-saving treatment for AIDS-defining illnesses, yet refused asylum seekers, visa over-stayers and undocumented migrants were not entitled to treatment for the condition (HIV) causing this illness in the first place. As a result, many thousands of people cannot access NHS health care, yet also cannot work legally to pay for their health care costs (Hall, 2006).

To compound this situation, confusion and inconsistencies in policy implementation by health care providers have been reported (BMA, 2006; Hargreaves et al., 2008). This has led to patients with serious health conditions being turned away from some hospital and GP services, a situation often supported by health service managers trying to control budgets (Cassidy, 2008).

Following a challenge against the 2004 ruling in the High Court in April 2008, a refused asylum seeker who had been in the UK for six months and could prove temporary admission was, in theory at least, eligible for free treatment in England. This more liberal stance was, however, short lived, with the Court of Appeal overturning this decision in March 2009, effectively reverting the situation to pre-2008 charging rules. While it is not yet possible to report on the direct impacts of such recent policy, this research examines the repercussions of such policy on migrants' understandings and experiences of the NHS. Research data suggest that confusion over health care entitlements and the imposition of charges can not only impact adversely upon individual well-being, but may have serious implications for the transmission of HIV and associated opportunistic infections.

Methodology

This research was undertaken as part of a study of the socio-cultural and structural factors influencing HIV testing and treatment seeking amongst migrants living in London. Ethical approval was obtained from the East London and The City Research Ethics Committee and the Institute of Education, University of London, and informed consent sought from informants prior to participation. This paper draws upon data obtained through eleven focus

group discussions held with seventy participants from Zimbabwe, Zambia and South Africa to gain insight into people's understandings and experiences of health care services in the UK. Relatively high numbers of migrants from these countries are known to be living with HIV. Thirty nine participants came from Zimbabwe, 21 from South Africa and 10 from Zambia. The higher number of Zimbabwean participants and the fact most experienced a lengthy asylum application process is reflected in the predominance of quotes cited here from this community. As an explorative study focusing on relatively poorly understood issues, participants were recruited to provide an illustrative rather than a representative sample (cf. Valentine 2001). Being in the UK as a migrant, living in London and being aged over 18 were the selection criteria for participation in focus groups. In total, 30 men and 40 women participated. Because this part of the study aimed to elicit insight into migrants' experiences of health seeking in general, HIV status did not influence selection criteria for participation in focus groups. As a result, some of the findings reported here are likely to also apply to health conditions besides HIV. However, participants in seven of the focus groups were accessed via community groups supporting people living with HIV, and participant's personal experiences of seeking HIV-related health care services in England framed the focus of their discussions. Discussions were digitally recorded and transcribed. A grounded theory approach enabled data to be coded and analysed as themes emerged from the data.

Results

The majority of participants expressed their appreciation of the health care they had received via national health services in the UK⁴. However, many participants reported experiencing difficulties accessing free health care in England. Two of the main difficulties faced concerned their ability to register with a GP, and the charges that they feared, and, in cases, had experienced, accessing healthcare.

Accessing health care

While GPs have discretion over registering an individual at their practice, those with an open list can only refuse someone with ‘reasonable grounds’ to do so and treatment deemed to be ‘immediately necessary’ must be given regardless of registration. Despite policy upholding free primary health care for all, documentation requested by frontline staff in order to register someone with a GP was cited as a barrier in many practices as the following experience demonstrates.

For six weeks I was bedridden and I couldn’t get a GP. I have been to so many but they all say they are full, they are not taking new patients....I have so many documents from this country supporting my temporary admission, I have a letter from my consultant, I have tax exemption certificate, social services documents – I tell them that my passport has been at the Home Office for four years, what am I supposed to do now? (Joyce⁵, Zambian woman seeking discretionary leave to remain).

NHS charges

For some people, personal experiences of being charged for health services had left a marked impact on their feelings towards health providers. While some reported experiencing relatively small charges to see a GP, others reported charges of thousands of pounds for hospital admissions, surgery and treatment. Legal guidelines state that treatment deemed immediately necessary must be given regardless of whether the patient has been informed of, and agreed to pay, any charges⁶, leaving often already vulnerable people in difficult financial circumstances. One man for example, reported being aggressively pursued for £38,000 after

receiving emergency treatment for an HIV-related condition, despite never having consented to the treatment charges.

Others reported experiencing intrusive visits from immigration officials and Overseas Visitors' Managers, even, in cases, when the person had legitimate immigration status in the UK. One Zimbabwean woman who had been in hospital with a recently diagnosed HIV-related illness had been charged £4000 for her treatment. She recounted how stressful her experience had been.

I was worried how am I going to pay this £4000? So what kills you first is the stress and worry ...I found myself thinking if I did not have indefinite leave to remain in this country then what would I do? Just imagine, at this time I was suffering from depression and they add insult to injury by bringing in an immigration officer. I had my leave to remain, I was just comfortable. But just imagine someone who doesn't have this – you'd just try to go away, you'd remove the drip and run away from there before immigration got there. (Emily, Zimbabwean woman with indefinite leave to remain)

Although HIV testing in the UK is free regardless of immigration status, the prohibitive costs of accessing treatment, fears of deportation and uncertainties over their future in the UK acted as disincentives for many migrants without legal immigration status to test for HIV. The following comment was typical of this attitude and highlights how such considerations are taken into account when deciding whether or not to undertake a potentially life changing medical test.

There are a number of people without papers, so they cannot access services. So if I cannot access services, then there is no reason for me to test – if I test and I know I'm HIV positive, I

know it will be very difficult to access [treatment]. (Vincent, Zimbabwean man, asylum status undisclosed)

Self-medication and alternative therapies

For those unable to access free health services, self-medicating was common. While some medications were sought from pharmacies, prescription drugs were more difficult to obtain, and could result in people sending for medications from their home country, which in turn, were often reported as being administered incorrectly and thus relatively ineffective.

Now you see that DHL is available they will send for tetracycline....there in Zimbabwe you can buy it from the counter and use the tetracycline and if you have a sore you just put it on there and it can heal. We are using medications the wrong way. We don't have the proper dosages and we are making the infection just stay there.....If a man has an STI he is only half-treating it so he is spreading it (Agnes, Zimbabwean woman, awaiting asylum decision)

A significant number of people chose to use 'African treatments' (usually of herbal or spiritual nature) because they placed faith in their healing properties. However, as the following statements make clear, these were also used out of necessity by people unable to access NHS care and treatment and by those who feared exposing themselves to the immigration authorities if they did so.

There are some people who do not have papers in this country, who can't have access to a GP or a hospital and they have to rely a lot on the traditional medicines.....All they can do is to rely on the traditional (Greta, Zimbabwean woman awaiting asylum decision)

There are some people like me who grew up with tree leaves and roots – and for them to think of a GP – it's when they might be exposed that they don't have papers, they might be deported. So they will rely on the traditional things. (Robert, Zimbabwean man with recently granted leave to remain)

You know, GPs can be very expensive.....that's when you start thinking about this man who is a spiritual healer, that's when this option comes in.....Because when you go to a GP you are talking about no less than £100 – I know because that happened when I first came here. Just to see him cost £40 and the test was £90. (Kenneth, Zimbabwean man appealing refused asylum claim)

As with other forms of self-medication, use of African treatments could provide welcome pain relief and help ease various health conditions. However, research participants repeatedly stated that they, and/or people they knew were often not sure how much of the medication they should take, for how long, nor how it might interact with any other treatments they used or other health conditions they had. In addition, a number of people reported that this kind of self-medication had played a significant role in them delaying their HIV test and waiting until they were extremely sick before seeking 'formal' health care.

Using false identity

Although not widespread, it was claimed that using false identity to access health services was not uncommon amongst migrants unable to access free health care. While none of the participants in this research claimed to have done this themselves, a significant proportion reported being aware of such cases within their community. Most cases involved undertaking blood tests using another person's identity, which in turn, enabled the person without legal

status to access medications including anti-retroviral drugs. The following statement reveals how easy this was deemed to be.

I come from Zimbabwe – you are my brother and you know I can't access a GP because I don't have papers – but I need treatment. So I wear your jacket, I go to an A and E, I say your date of birth, your name, your address, then I'm admitted. Everything I produce, the National Insurance number – it is there. But the person receiving treatment is me but I'm using your documents. But this is because you are forced because you are in this situation. (Robert, Zimbabwean man appealing refused asylum claim)

It was reported that such practices were mainly done for relatives or close friends. However, some people claimed to have heard of people charging for this service, knowing they had a ready market amongst those unable to use their own identity.

Reliance on A and E Departments

Despite research suggesting that costs of emergency treatment outweigh those incurred through effective preventive and primary health care (Yates, Crane & Rushby, 2007), a commonly raised theme was the widespread reliance of migrants – particularly those without documents or secure immigration status – on hospital A and E Departments. This was partly due to difficulties people faced registering with GPs, whilst fewer questions were reported to be asked of those presenting for emergency treatment.

Although treatment deemed by a clinician as 'immediately necessary' is not automatically free at the point of access⁷, hospitals are currently unable to charge for treatment undergone in an A and E department. This was well known to many participants in this research, and

people commonly reported that they had delayed seeking health care until their condition was so serious that they could call an ambulance and be taken straight to A and E.

It [HIV-related illness] got worse and I couldn't eat – and one day I just said to my sister it's either now you call an ambulance or I just go out on the street and get run over. I think I would have been better off in Zimbabwe where at least I could have found some treatment. Here it looks like it is inaccessible to me. (Lucas, Zimbabwean man with recently granted leave to remain)

You would rather wait for a situation where you get taken to hospital by ambulance because even if you walk in they want to know who is your GP. And if you don't have one they become very suspicious. (Jack, Zimbabwean man, asylum status undisclosed)

In the majority of such cases, the person's condition was by then so serious that they had been diagnosed with an HIV or AIDS related condition requiring immediate treatment and a lengthy stay in hospital.

Conclusions

Knowledge of HIV status can help people make informed decisions about their – and other's, health and well-being, whilst anti-retroviral therapy can decrease viral load, HIV infectiousness, and chances of vertical transmission. However, policies which make – or are perceived to make – health care difficult and prohibitively expensive to access have been found to act as barriers to HIV testing and treatment uptake in England. This is reported to be a particular issue amongst refused asylum seekers, visa over-stayers and undocumented

migrants who have been at the centre of recent government policy changes on health care access.

While charging policies may help the government appease more protectionist elements of UK society, data reported here suggest they can undermine domestic strategies on reducing HIV, STIs and associated conditions such as TB (Department of Health, 2001; 2004), as well as undermining government commitment to universal access to HIV treatment. Although it must be acknowledged that migrants face a range of obstacles in accessing health services, constraining access to free health care has been shown to be one factor which can result in people resorting to other, potentially ineffective or adverse forms of treatment, and to reliance upon A and E services once their health has deteriorated to a condition in which emergency treatment is necessary. The results also suggest that some people use false identities to access health services and treatment (although further research could usefully be undertaken to examine the true extent of this phenomena), in turn, potentially raising the possibility of misdiagnosis and treatment of both the migrant and the person whose identity is being used.

Such scenarios have been reported to influence late HIV testing and treatment uptake, and thus, have adverse implications for individual health and well-being and the transmission of HIV and related conditions. If the government is serious in its stated intentions to reduce the transmission of HIV and other communicable health conditions in England and the UK, findings suggest the need to reconsider the implementation of NHS charging regulations. Given that such changes are likely to take time, this research also suggests that clearer guidelines and information on health care entitlements be made available to both health workers and to migrants, and that more needs to be known about the health care options that

are available to migrants unable to access free health care, and the potential for assistance and/or harm that may result from their use.

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¹ Most health care provided via the NHS is free at the point of delivery.

² Primary health care, e.g. access to a GP, is available free at point of delivery for all people at the discretion of the provider.

³ Responsibility for health policy is devolved in Wales, Scotland and Northern Ireland where implementation of rules on healthcare entitlements are slightly different. This paper focuses on the situation in England.

⁴ A few were sceptical of the NHS and preferred to use African treatments.

⁵ All names have been changed to protect participant identity.

⁶ Not to do so is considered to risk breaching the Human Rights Act 1998.

⁷ The Court of Appeal decision ruled that patients may be able to access treatment by arguing that it is urgent or immediately necessary and that they cannot return home at present to seek treatment there. They are still liable to be charged, but treatment cannot be refused if they cannot pay (Hundt, 2009).