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**Negotiating Access and Culture:
Organizational Responses to the Healthcare Needs of
Refugees and Asylum Seekers living with HIV in the UK**

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Informants

I conducted interviews with several key informants who are all engaged with the issue of access to healthcare for refugees and asylum seekers. I am extremely grateful for their willingness to speak with me despite their busy schedules. The following is a list of people with whom I spoke and their organizational affiliations. To preserve confidentiality, I will refer to them only as 'Informant' when referencing the conversations in the text.

Dr. Angela Burnett	Hackney Sanctuary Practice, NHS and Medical Foundation for the Care of Victims of Torture
Yohannes Fassil	North West London Strategic Health Authority, NHS
Victoria Field	Terrence Higgins Trust
Dr. Mary Haour-Knipe	International Organization for Migration and European Project on AIDS and Mobility
Rowan Harvey	Terrence Higgins Trust
Claire Loussouarn	Médecins du Monde UK
Rhon Reynolds	African HIV Policy Network
Moyra Rushby	Medact
Pete Westmore	Westminster Primary Care Trust, NHS

Abbreviations

The following is a list of the abbreviations used in this paper.

AHPN	African HIV Policy Network
ARV	Anti-retroviral medicine
BME	Black and minority ethnic
ECHR	European Charter of Human Rights
GP	General practitioner
GUM	Genito-urinary Medicine
MdM UK	Médecins du Monde, United Kingdom
NASS	National Asylum Support Service
NGO	Non-governmental organization
NHS	National Health Service
PCT	Primary Care Trust
RCO	Refugee Community Organization
STI	Sexually transmitted infection
THT	Terrence Higgins Trust

1. INTRODUCTION

1.1. Contexts

In the context of increasingly restrictive asylum systems across Europe, healthcare for refugees and asylum seekers presents a unique concern, as contrasted with other social benefits such as housing and access to employment. Logically speaking, an unhealthy population within the borders of a receiving country is not acceptable due to public health considerations regarding onward transmission of viruses such as HIV. From the public health standpoint, even staunch anti-asylum advocates would agree that healthcare must be legally available and practically accessible to all. While providing material welfare may arguably be ‘for’ the immigrant population, it is much easier to understand how access to healthcare for all is beneficial to both the immigrants and the host society, especially in the case of communicable diseases.

Nonetheless, problems with rights and access to healthcare for various migrant populations, particularly asylum seekers, have been reported throughout Europe. Inequalities in health indices between immigrant and ‘native’ populations persist even as availability of anti-retroviral (ARV) therapy has changed HIV/AIDS¹ into a manageable disease in the European context (del Amo et al. 2001). Migration is invariably an issue of contention, and HIV infection presents a further complicating factor in terms of discrimination and marginalization of the affected by both refugee communities and host societies (Bröring et al. 2003). Examination of access to healthcare for refugees and asylum seekers living with HIV reveals the interplay between public health and immigration discourses.

It is not surprising that the number of asylum seekers infected with HIV has risen as the global epidemic continues. Persons coming from high-prevalence countries, who have been targets of persecution and human rights violations, are undoubtedly at risk of contracting the virus as civilians living through conflict and displacement. The insecure and often impoverished position of refugees and asylum seekers places them at further risk within host societies. Across contexts, HIV predominantly affects the most marginalized populations; its spread is associated with poverty and inequality (Farmer 1995). Moreover, the fact of having been persecuted precludes most from travelling back to their countries of origin to seek family and social support.

In the UK, several Informants lamented the hostile environment created by the conflation of HIV and immigration in popular perception. Political discussions seeking to limit the influx of asylum seekers become yet more impassioned by the image of ‘dangerous’ carriers of HIV arriving at Britain’s shores (Flynn 2003). As such, refugees and asylum seekers living with HIV have become one of the most marginalized populations; they are ‘doubly stigmatized’ based on their HIV and immigration status (Dodds et al. 2004). While

¹ HIV, or Human Immunodeficiency Virus, is an infection that attacks the immune system. Prior to the advent of anti-retroviral therapy, when patients living with HIV presented with infections or cancers that had evidently damaged the immune system, they were said to have AIDS, or Acquired Immune Deficiency Syndrome. However, in countries such as the UK, where treatment to prevent such large-scale damage is widely available, the term AIDS is no longer widely used. Instead, patients are described as having early-stage or advanced HIV infection, depending on the strength of their immune system as measured by CD4, or white blood cells (Terrence Higgins Trust, cited in Gazzard et al. 2005). Thus, throughout this report the term HIV infection will be used to describe the disease.

the public health argument clearly supports providing healthcare to all members of society, anti-asylum discourse in recent years has worked against this assumption. Its proponents seek to limit the right to healthcare in order to avoid overburdening the system, and favour limitations targeted toward those infected by HIV in a backlash against ‘treatment tourism’ (All-Party Parliamentary Group on AIDS 2003). The goal of protection from disease has been eclipsed by the rationale of deterrence in restricting access to healthcare.

Due to regulations imposed in April 2004, the UK has moved from a system of universal rights-based healthcare provided by the state to a situation where most, but not all, are legally entitled to care. Asylum seekers who have failed in their claims are no longer entitled to secondary treatment without charge, as will be detailed below. Worse still, confusion regarding entitlement on the part of healthcare providers as well as refugee communities has complicated access for refugees and asylum seekers who continue to be eligible for free healthcare. While the ‘conventional wisdom is that immigrants, once legally accepted by a receiving country, have the same entitlement to social benefits, including health care, as the native population ... the granting of rights does not automatically mean full enjoyment’ (Bollini 1992: 103). In essence, a myth of the universality of UK healthcare is present in both policy and practice. While most NHS practitioners and users believe that the system exists to provide healthcare to all who need it, free of charge, the reality of availing oneself of services is complicated for certain groups of potential patients.

1.2. Access to healthcare

Despite the considerable amount of concern caused by limitations on the right to healthcare, the new policy legally affects only a small proportion of refugees and asylum seekers. However, in practice, utilization of health services among this population is fraught with difficulties. A commonly recognized result is that immigrants infected with HIV tend to present for testing at a later stage than members of other communities, often upon the onset of physical symptoms (Erwin and Peters 1999).

This paper examines possible explanations for difficulties that refugees and asylum seekers living with HIV have with accessing healthcare. It will argue that none of the candidate explanations suffices on its own, but that the complexity of the situation requires a multi-disciplinary view of both the problem and organizational responses to it. Such an analysis must consider the societal position of refugees and asylum seekers, which prevents them from being incorporated as ordinary healthcare ‘consumers’ (Obermeyer 2004).

One widely cited impediment is the intricacy of navigating Western-style healthcare services for someone coming from a different culture (e.g. del Amo et al. 2001). The lack of ‘cultural competency’ in service provision has been proposed as a reason for its inefficient utilization. The paper begins by considering the prominent notion of cultural competency and the imperative to improve cross-cultural understanding in doctor-patient interactions. However, it will show that cultural competency in itself is inadequate as a response to the challenges of access. The sections that follow illustrate shortcomings of a sole focus on cultural differences.

Undeniably, the pre-eminent characteristic of the lives of refugees, and especially asylum seekers, is their socio-economic and political marginalization in the UK. They

perceive the fundamental inequality of power between themselves as potential patients and the medical establishment; indeed this differential is not a mere perception but actually influences access realities. In this context, it is not difficult to imagine that recent legislative changes curtailing entitlement to care have a ‘soft effect’ of keeping many who remain legally entitled away from the NHS due to fear, uncertainty and confusion (Médecins du Monde (Mdm) UK 2004). Such responses are not unfounded, as the confusion extends to health practitioners and impacts the availability of healthcare options. Healthcare workers, in turn, rightfully complain that the system does not encourage proper consideration of the unique healthcare concerns of this population by ‘non-specialist’ practitioners. In fact, difficulties with healthcare access did not originate with the 2004 legislation; the altered regulations simply added to an already intricate situation in which actual and perceived marginalization provide the background to healthcare utilization.

Under these conditions, organizations conducting interventions to improve access to healthcare have a multifaceted task. Advocacy toward rights-based healthcare must address the recently imposed legal curtailments. At the same time, organizations must consider and attend to the cultural and pragmatic barriers to healthcare access. The paper will conclude by reviewing some of these efforts and the types of organizations engaged in this work. As increasing numbers of asylum seekers ‘fall through the cracks’ of the system and fail to receive any medical attention at all, these challenges are significant. The imperative posed by treatment and prevention of HIV in particular makes them even more so.

In sum, this paper seeks to illustrate the complexity of factors that influence healthcare decisions and opportunities for refugees and asylum seekers living with HIV. It reviews the cultural, social, legal, institutional and structural barriers that jointly prevent effective and successful healthcare utilization. It argues that *complexity* must be recognized as a central and defining feature of the situation, as it goes beyond any single explanation in offering a view of the realities of access to healthcare for this marginalized group.

2. BACKGROUND

Before delving into explanations of the difficulties that refugees and asylum seekers have with accessing healthcare, it is important to introduce the situation in more detail. I will first discuss characteristics of the population on which this analysis centres. Subsequently, I will present the controversy surrounding ‘treatment tourism’, which illustrates the political atmosphere of anti-asylum sentiment as it pertains to healthcare. Next, I will detail the revised entitlement regulations regarding HIV treatment.

2.1. The population in question

This paper considers access to healthcare particularly for refugees and asylum seekers in the UK. While recognizing that these issues affect other groups of migrants, and that migrant communities are often delineated by linguistic and ethnic cohesion rather than legal status, it nonetheless focuses on refugees and asylum seekers, aiming to explore the issues with reference to forced migration. It should also be noted that the different legal statuses of refugees as opposed to asylum seekers determine their rights to care; this will be discussed in more detail. Refugees and asylum seekers are considered together, in light of the

aforementioned vulnerabilities of forced migrants to HIV and their risk of marginalization within the UK. However, many studies of this topic consider migrants more broadly, and will nonetheless be referenced because of their pertinent contribution. Several of them acknowledge that a large proportion of respondents are, in fact, forced migrants (e.g. Dodds et al. 2004). In addition, many interventions focus on some portion of the 'BME', or 'black and minority ethnic' community, so named by the NHS funding structure that directs work in this field. According to several Informants, the term BME is irrelevant when applied to migrant communities, which are enormously diverse and are not uniformly different from the 'white British' majority, as the term implies (Davey Smith et al. 2001). Nonetheless, 'BME' will occasionally appear in this paper in describing some organizations' work.

This paper does not aim to examine any one group of forced migrants based on country of origin. However, due to high prevalence rates of HIV among persons from sub-Saharan Africa, with the majority of those affected by the epidemic concentrated in London, much of the work surrounding the issue has naturally focused on black African migrants in London. Estimates from 2003 indicate that 16,200 Africans were living with HIV in the UK; HIV infections believed to have been acquired in Africa constituted 72% (2,727) of all heterosexually transmitted infections diagnosed that year in the UK; and those acquired in Africa represent 90% of diagnosed infections acquired outside the UK (Sadler et al. 2005). Because many undocumented migrants fall entirely outside the authorities' radar, it is impossible to say what percentage of migrants overall are asylum seekers. With the advent of dispersal of asylum seekers as of the 1999 policy, the need to provide services and education in other regions of England has been recognized, but most organizations conducting this work remain in London. Approximately 60% of African-born people in England live in London, and approximately 75% of African-born people infected with HIV live in London (Weatherburn et al. 2003). This report is not limited to the black African migrant population in London, but will draw heavily on literature concerning this group, keeping in mind the significant gap in the literature regarding non-African forced migrants affected by HIV.

2.2. The social and political atmosphere: 'Treatment tourism'

Considerable media attention and public outcry recently focused on alleged 'treatment tourism' by persons diagnosed HIV positive in order to access UK health services free of charge. The purported 'treatment tourists' include asylum seekers and other migrants, such as students and those entering with work visas; asylum seekers are popularly thought to constitute the majority of this group. Only two studies documenting this phenomenon are known to exist. The Terrence Higgins Trust (2003) found that 75% of the migrants in their sample tested more than nine months subsequent to entering the UK, and that the most common reason for testing (58%) was onset of symptomatic HIV. Others tested as part of antenatal care, or as prompted by the death or diagnosis of a partner. Only two had been diagnosed prior to immigrating. Furthermore, only 22% had entered the UK to seek asylum. These data clearly contradict the myth of 'treatment tourism': perhaps if these persons had migrated solely to access healthcare, they would not have waited so long to begin treatment.

In a qualitative study, Barton (2004) found that all respondents whose decisions to migrate would have been influenced by knowledge of their HIV diagnosis prior to leaving would have stayed in the country of origin because of the availability of family support. In many countries, HIV is viewed as a 'death sentence' due to the unavailability of treatment,

and they likely would not have known of the possibility of treatment, a perception that is corroborated by other data in a discussion of the difficulties for those diagnosed in the UK to tell their families about the condition (Dodds et al. 2004). Of those in Barton's study whose decision to come to the UK would *not* have been influenced, all were asylum seekers who were forced to flee, and are unable to return due to safety considerations. For them, HIV status does not determine their continued presence in the UK. Barton concludes that for persons not seeking asylum, access to HIV treatment is not a 'pull factor' for migration to the UK, but it is a reason to stay; many felt 'trapped' in the UK, torn between a desire to return to their families and having access to life-saving HIV medication. Both studies note that a major obstacle for health promoters is that many migrants do not present for testing until they become symptomatic. Again, these data do not support the 'treatment tourism' myth.

Nonetheless, public pressure to limit accessibility of HIV treatment, built in part by playing upon fears of treatment tourism, resulted in new regulations effective from 1 April 2004 (Department of Health 2004a). Those termed 'Overseas Visitors' by the new regulations include asylum seekers whose applications have been rejected. While some asylum seekers are popularly believed to be 'treatment tourists', the data discussed above indicate that this is false, and furthermore that asylum seekers do not constitute the majority of migrants seeking HIV treatment. According to one estimate, 899 asylum applicants living with HIV (diagnosed or yet unknown) entered the country in 2003-2004, which represents 20% of all new HIV cases reported in the UK (Gazzard et al. 2005).

The focus on HIV particularly as the condition for which 'treatment tourists' seek UK medical care has led to its distinction from other STIs as a target for restrictions. The legislation regarding access to treatment exempts most STIs and certain other contagious infections, such as tuberculosis, polio, meningitis and hepatitis C: all patients affected by these diseases are treated free of charge, regardless of legal status. A recent Expert Panel's recommendations echo other advocates in suggesting that HIV be reclassified as an STI or as a blood-borne virus that poses a significant risk to public health, thereby permitting treatment to all those affected (Gazzard et al. 2005).

2.3. Regulatory framework: Entitlement to healthcare

All refugees and asylum seekers are entitled to primary, secondary and hospital care without charge within the NHS. As of 1 April 2004, the situation is more complicated for asylum seekers whose claims and appeals have been rejected (Department of Health 2004a). They are entitled to free emergency and primary care, but must pay for secondary care as Overseas Visitors. Secondary care includes drug therapy, hospital and antenatal treatment for those diagnosed HIV positive. The regulations specify that those who are deemed ineligible for free treatment must not be denied care; instead, clinic staff must explain liability for charges. Subsequent bills for service that a patient cannot pay may be accounted for by the local Primary Care Trust (PCT). Thus, according to several Informants, the policy does not entirely eliminate the possibility of care for 'Overseas Visitors'. Previously, all UK residents of longer than twelve months were entitled to all types of care without charge; eligibility was not determined by legal status.

Any person is entitled to free HIV testing and counselling regarding the results. However, free treatment is available only to asylum seekers whose claim has been

recognized, or not yet processed; treatment started prior to rejection of the asylum application may be continued until the applicant leaves the UK (Refugee Council 2004). According to two Informants, a recent supplementary letter to practitioners clarifying this policy stated that ‘treatment’ begun prior to the asylum decision does not necessarily mean administration of ARVs, but in fact denotes continuing observation by a physician on account of HIV diagnosis. This is in response to practitioners’ complaints that some patients do not require ARVs immediately upon diagnosis, as appropriate administration of ARVs varies according to a patient’s condition and with co-infections. Many practitioners had perceived a pressure to begin ARV therapy sooner than necessary so as to avoid having to charge for it in the event that asylum is denied. Other ethical considerations resulting from the amended regulations are discussed below.

Following the regulations of 1 April 2004, the Department of Health (2004b) issued a consultation in May 2004 proposing the withdrawal of free *primary* care for ‘Overseas Visitors’. The widespread and vocal opposition to the proposal on public health grounds, led by advocates such as the Entitlement Working Group of the Medact network, has so far been successful in preventing such legislation. Nonetheless, taken together, the amendments and the proposed changes have added a great deal of confusion to an already difficult situation, thereby complicating access to healthcare of all types for refugees and asylum seekers (Mdm UK 2004).

3. CULTURAL CONSIDERATIONS

Keeping in mind the background, I will now discuss some accounts that have been advanced toward an understanding of access to healthcare for refugees and asylum seekers who are legally entitled to it. One prominent explanation is that such patients have trouble ‘fitting’ with the healthcare system due to cultural differences. Indeed, it is important for doctors and patients to communicate across the cultural divide. This section explores conceptions of ‘cultural competency’ and its role in potentially increasing congruence between service users’ and healthcare providers’ views of the medical encounter.

3.1. Cultural competency

Medical anthropologists writing about cross-cultural medical encounters criticize the Western biomedical scientific paradigm for its reductionism and monotypic view of disease. Biomedicine’s focus solely on biological processes and the quest for the one correct answer to a malady based on physical explanations, lead to perpetuation of mind-body dualism and thus restrict the applicability of the biomedical framework across cultures. It simply does not allow for or recognize as legitimate ‘alternative’ attributions of etiology, such as witchcraft or spiritual contagion (Kagawa-Singer and Kassim-Lakha 2003; Kleinman 1995: 31). Cross-cultural differences crucial to the quality of a medical encounter, including such basic questions as who makes decisions on behalf of a patient and how much information is released to the patient and/or carer, are not thoroughly analysed within mainstream bioethics, which largely remains rooted in Western individualism (Kleinman 1995: 55). Thus, suffering often loses its value and meaning-making is ignored. In sum, ‘Medicine needs anthropology because the delivery of its benefits remains inefficient’ (Hemmings 2005).

In answer to these concerns, anthropologists have attempted to explain understandings of physical and mental illness and healing across cultures. Manderson (1998) analyses the underutilization of some healthcare efforts due to their cultural inappropriateness for the target population. Interpretations of disease and contagion often differ significantly from the Western model (Caprara 1998). Similarly, divergent perceptions of personal space and comfort with discussing personal details are important during routine medical assessment procedures (Helman 2001). Good and Good (1981) outline a culturally-based clinical model that includes the meaning of illness and the patient's experience as an integral part of the medical interview. Such a way of gathering information aids clinicians in assessing patients' assumptions.

The principles involved in making Western medicine more palatable and accessible to patients coming from other medical traditions, as well as recognizing the benefits of those traditions, are rightly of concern to medical anthropology. For instance, physicians must be aware of the possibility that a patient uses 'alternative' medicines, a widespread but often concealed practice (Erwin and Peters 1999). Anthropologists' role in promoting cultural competency has been recognized in the context of societies with large immigrant populations (Helman 2006). The UK clinic can be daunting for first-time patients. One Informant spoke of a frequent scenario, in which a patient is unable explain her ailment in a streamlined fashion to fit the ten-minute time slot scheduled by the over-booked general practitioner (GP). The patient prefers, instead, to talk around the issue, as is culturally appropriate in her society of origin. It is not difficult to envision how this encounter might be frustrating for both parties involved.

Koehn (2005) emphasizes the importance of 'transnational competence' on the part of health care providers. It includes such skills as the ability to understand 'the other's personal beliefs regarding the causes, treatment, and prevention of illness', to 'maintain personal interest in and concern about the other', and to 'use interpreters effectively when necessary', among others (Koehn 2005: 54; see also Koehn and Rosenau 2002). His study of medical encounters involving asylum seekers highlights the frequency of vast discrepancies between patients' and doctors' assessments of illness and treatment. It also indicates physicians' lack of awareness of post-migration stressors. Koehn notes that transnational competence maximizes trust and, from that, accuracy of diagnoses and adherence to treatment.

Erwin and Peters (1999) found that some African-born persons living with HIV in London complained of having been left out of the decision-making process regarding treatment. While it is difficult to thoroughly explain uncertainties and limitations inherent in HIV therapy, an effort by the physician to do so may increase confidence in the recommended treatment. In sum, the outcome indicators of a culturally competent approach include 'better adherence to medical care, follow-up appointments, health care utilization patterns, modification of high-risk health behaviours, promotion of culturally-based health protective behaviours, and reductions in disparities of health outcomes across culturally diverse groups' (Kagawa-Singer and Kassim-Lakha 2003: 585).

Essentially, cultural competency is a lens through which healthcare workers may gain deeper understanding of their patients' perceptions regarding health, and also a way of service provision that systematically incorporates cross-cultural sensitivity (Brach and Fraser 2000). It is a method of bridging different traditions to improve the quality of care, not a way of bringing the patient into line with the biomedical model. It is important to remember that

'culture' is not to be understood as a monolithic, homogenous concept and to avoid genetic explanations of ailments affecting certain racial/ethnic groups (Kagawa-Singer and Kassim-Lakha 2003: 580). As such, cultural competency is an approach to listening, rather than a method of healthcare provision pre-fabricated to target certain groups. This view is especially salient to healthcare provision in societies with populations from different regions. The competency of healthcare personnel working with diverse groups should be developed. Studies have found that the way doctors perceive their patients impacts on the quality of care (van Ryn and Burke 2000). One Informant outlined a holistic approach to address special needs without making assumptions about patients based on their cultural background.

3.2. Making mainstream health services accessible

On the European level, calls for cultural competency in healthcare provision lament that 'few countries have seen fit to ensure migrants with the type of socially and culturally tailored services they need, and in many parts of Europe there are migrants who are falling outside the scope of existing health and social services' (Committee on Migration 2000: 13). According to several authors, not only healthcare workers but medical institutions themselves should incorporate cultural competency (Kagawa-Singer and Kassim-Lakha 2003). Many writing in the UK with regard to refugees and asylum seekers express similar sentiments (Burnett and Peel 2001; Lynch 2001). A survey of medical practices found frustrations and lack of shared understanding between practitioners and patients, particularly concerning preventative health and continuity of care (Trafford and Winkler 2000). The source of these frustrations often had as much to do with such practical matters as advance registration as with discrepant understandings of treatment.

Undeniably, the 'lack of understanding is exacerbated by not sharing a language' (Trafford and Winkler 2000: 27). The literature regarding service provision to refugees and asylum seekers highlights the lack of availability of interpreter services (Trafford and Winkler 2000; Wasp et al. 2004). Good quality interpretation, unsurprisingly, is a key component of culturally competent practice (Koehn 2005). Best practice states that family members, particularly children, should not be interpreters because they are often not equipped to handle potentially embarrassing conversations, especially regarding sexual health, and may not accurately translate all that is said (Burnett and Fassil 2002: 16). However, one Informant noted that when the patient expresses a preference to use her child as an interpreter to the often only available alternative of a telephone service, it is difficult for a practitioner to insist on the latter.² In addition, members of a patient's linguistic community might have a politically problematic relationship with the patient due to events that transpired in the country of origin (Tribe 1999). Avoiding the aforementioned pitfalls by utilizing trusted interpreters with whom practitioners are familiar and comfortable is often impossible due to limited human and financial resources.

Informative manuals for healthcare providers have been published outlining the particular healthcare needs of refugees and asylum seekers, and the difficulties of providing effective healthcare for this group (British Medical Association 2002; Burnett 2002; Burnett

² One available and widely used telephone interpretation service in London is Language Line. In addition, HARP (Health for Asylum seekers and Refugees Portal) Website offers multi-lingual resources along with a wealth of information for medical practitioners.

and Fassil 2002; Trafford and Winkler 2000). A list of health problems considered prevalent among refugees and asylum seekers advises doctors to be alert for physical and psychological effects of war and torture (British Medical Association 2002: 7). Burnett notes factors that might influence the health and well-being of forced migrants, including 'multiple loss and bereavement, separation from family, exile, loss of identity and status, poor access to education, unemployment, poor housing, racism, discrimination and isolation' (2002: 6). She also describes conditions resulting from mental distress that are prevalent among this population, and advises sensitive ways to apprehend and then address them. Similarly, Burnett and Fassil (2002) remark that the health practice could be an important referral point for other needs.

3.3. Particular vulnerabilities related to HIV

The issue of HIV engages cultural competency and holistic care tailored to refugees and asylum seekers as a population with specific needs. The psychosocial and cultural component of HIV treatment and prevention has long been recognized (Obbo 1995; Schoepf 1995). The disease has no cure, treatment is prohibitively expensive for the vast majority of sufferers, and thus prevention and education efforts have been paramount in the struggle to contain the epidemic. Both education and access to treatment are complicated by the taboo status in most cultures of the virus's modes of transmission. This allows for the unquestioned persistence of 'unorthodox' beliefs such as that prayer is more effective than ARVs in 'curing' HIV (Erwin and Peters 1999).

In addition, risky *behaviour* has been conflated with risky *groups*, such as drug-users or sex workers, further stifling open conversation about the illness (Clatts 1995). Refugees and asylum seekers have become known as such a high-risk group. They often face double stigmatization with regard to HIV status: from within their ethnic communities and from the host society. Both see those who are HIV positive as a dangerous, shamed 'other', leading to extreme marginalization. Concomitantly, their isolation may result in lowered utilization of early treatment as well as refusal to access the social and emotional support networks offered by community groups. Obstacles to effective prevention work within refugee communities often originate in traditional restrictions on publicly acceptable discussions of sexual behaviour (Shtarkshall and Soskolne 2000). The ways in which stigmatization operates among refugee communities in London will be discussed in more detail below.

3.4. Explanatory value

It is clear from the above discussion that greater attention to cultural considerations would improve the quality of medical encounters. However, specific dynamics of cultural competency are as yet open to debate. Namely, 'Poor communication could account for both high and low levels of consultation with a GP. For example, the initial experience may discourage the patient from future attendance, or difficulties in communication may mean that they need to make several repeat visits to resolve their problem' (Arora et al. 2001: 145). Evidently, further research is needed to elucidate the details of this approach.

Furthermore, while cultural competency is important, it is mainly concerned with the actual medical encounter. It often does not extend to problems of access due to 'external'

factors, such as the adverse environment effected by legislated regulations. It is hard-pressed to include the fear and insecurity that restrictions instill among refugee communities. The cultural aspects of healthcare are crucial, but the explanatory value of an exclusively anthropological approach is limited by its failure to incorporate power dynamics experienced by refugee communities contending with the NHS as a system of the host society. Cultural competency may not take into account that healthcare is one aspect of daily realities overwhelmingly influenced by the asylum system and concurrent anti-immigrant sentiment in the public arena. The following section attempts to widen the discussion by analysing power discrepancies between refugees and asylum seekers and the setting in which they attempt to access healthcare.

4. QUESTIONS OF POWER

As discussed above, medical anthropology often does not tell the whole story. Before any problems do or do not arise during a medical encounter, the consultation itself has to be allowed to *happen* in the first place. This raises the broader question of opportunity to access services, which for refugees and asylum seekers often entails barriers arising from the experience of living with marginalization. Perhaps ‘culture’ is not the only constraint to utilizing healthcare effectively. This section will discuss the condition of real and perceived powerlessness of forced migrants in the UK.

4.1. Relevance of ‘cultural’ analysis

As acknowledged by the advocates of cultural competency, it is unclear whether attempts to truly learn others’ cultures are fruitful. Gathering enough cultural knowledge for it to be useful in a medical encounter is simply impossible for the multitude of cultures in a host society such as the UK. Conversely, scant information may lead to nothing more than stereotyping. It might be useful to remember that ‘culture’ is no more than a paradigm of norms, and that each person lives out cultural prescriptions in her own way. This perspective is salient for migration, a process characterized by cultural interaction. As such, it is not only unfeasible to expect health practitioners to learn about so many cultures, but such a task is made all the more difficult by the process of integration or acculturation affecting patients’ worldviews (Lambert and Sevak 1996). But to take it one step further, what proponents of cross-cultural sensitivity often fail to emphasize is that the reification of ‘culture’ and cultural differences obscures the fact that it is the medical establishment of the host society that has the power to *define* norms to which immigrants are compared when analysing ‘appropriate’ patient behaviours (Jöhncke 1996: 173). While some medical anthropologists are concerned about whether the discipline’s methods produce relevant knowledge for medicine, they often do not focus on the legal, structural and institutional aspects impacting their work (Hemmings 2005; Lambert 1998).

‘Insisting that only more knowledge of immigrants’ culture can solve the present problems is also a good way of doing nothing at all. ... A focus on “cultural background” systematically places the roots of all problems with the immigrants’ (Jöhncke 1996: 175). While it is important to consider the sense of support and community derived from identifying with an ethnic or cultural group, it is equally important not to forget that emphasizing ‘cultural’ difference often becomes a way to deny racism and inequality

(Kelleher 1996). The adverse socio-economic circumstances in which refugees and asylum seekers live may be as definitive of their perspective as cultural considerations in interacting with healthcare provision. Perhaps forced migrants' belonging to a 'culture' of marginalization due to their current situation is stronger than similarities within ethnic groups of people who migrated at different time periods and under diverse circumstances (Davey Smith et al. 2001). Thus, a broader analysis than one solely focused on cultural background is required to truly understand difficulties that some face in accessing healthcare. One might examine policies and bureaucratic structures, along with the racism and xenophobia that perpetuate marginalization.

4.2. Analysing inequality

Some anthropologists do, indeed, call for a broader approach. Kleinman observes that, 'It is utopian ... to apply the remote principles of justice and beneficence to ordinary clinical problems, unless we first take into account the brutal reality of the unjust worlds in which illness is systematically distributed along socio-economic lines and in which access to and quality of care are cruelly constrained by the political economy' (1995: 48). In his analysis of the transmission of HIV in Haiti, Farmer remarks that prominent risk factors include poverty, sexism, traditional and emergent patterns of sexual union due to rural-urban migration, lack of access to treatment for STIs, lack of timely response by public health authorities, lack of culturally appropriate prevention tools, and political upheaval (1995: 23). Examining the preceding list, it is difficult to ignore the structural inequalities that provide the background to transmission of HIV; while these factors are not determinants of HIV transmission independently of individual behaviour, they exacerbate certain individuals' risk. In the context of the UK, forced migration might be added to the list. Because HIV disproportionately affects the marginalized sectors of a society, such as refugees and asylum seekers, it is an illustrative lens through which to view the relationship between socio-economic conditions and health (Carballo and Siem 1996).

In the UK, refugees and asylum seekers constitute a population marginalized both economically and politically. Conditions of life for forced migrants are such that conventional indices of socio-economic differences are often inapplicable because they ignore basic realities such as, for example, the fact that educational level often does not translate to employment at a comparable level to that among the majority British population due to the role of racism in hiring practices (Davey Smith et al. 2001). From the point of view of refugees and asylum seekers, marginalization is confirmed by the lack of voice afforded to them in national discourse. Particularly for the latter, the oppressive presence of the government, in the form of the asylum system, weighs heavily. As one African man living with HIV noted, 'Everything depends on immigration – health and happiness, no medication, no employment – everything depends on it. Because the law is changing every minute, you never know where you stand' (Respondent cited in Dodds et al. 2004: 12). In the face of a pervasive sense of powerlessness resulting from social inequalities, 'Many report a quiet sense of defeat, which can be a rational strategy for those who see little capacity for personal or even collective action' (Dodds et al. 2004: 13). As such, few are inclined to directly challenge the structural inequalities that delineate their access to health services. Some of the ways that inequality, insecurity and stigmatization exacerbate vulnerabilities to acquiring illness as well as difficulties in accessing healthcare are examined in the next section.

According to several Informants, many problems arise with access to treatment because patients are expected to conform to the healthcare system, but the system largely does not see the need to accommodate marginalized groups. The dynamics of HIV transmission and treatment illustrate the socio-economic determinants of poor health and health management among persons whose greatest need is practical supports with daily survival. While ‘cultural difference’ in interacting with healthcare services should not be overlooked, perhaps it constitutes a secondary consideration to the immense practical barriers resulting from powerlessness and inequality that mediate access to care.

5. BARRIERS TO HEALTHCARE ACCESS

This section will examine some of the ways in which power functions in the process of accessing healthcare. First, I will review structural barriers resulting from the legislative framework and, more importantly, misinterpretation of legislation. This entails access barriers for all refugees and asylum seekers, as well as referencing the case of those living with HIV. The second part will look at characteristics of daily life as a forced migrant. It will consider vulnerabilities to contracting HIV as well as factors of refugee life that contribute to difficulties in seeking out healthcare, and certainly to the disinclination to assertively pursue care that one is entitled to once it has been denied.

5.1. Structural barriers to accessing healthcare

5.1.1. Adverse effects of legislation

The regulations regarding Overseas Visitors of 1 April 2004, introduced above, are part of a series of measures regarding welfare benefits for asylum seekers. As a result of constantly changing legislation, some GPs are confused about refugees’ and asylum seekers’ entitlement to NHS treatment, and patients often encounter problems when trying to register with a GP.³ Asylum seekers are most affected by this lack of clarity, since policies do not change as frequently regarding refugees, and refugees are generally more aware of welfare regulations and more likely to challenge registration problems when they occur because they are more secure in their legal status. Several Informants mentioned that one of their most important tasks is disseminating information about access rights to healthcare providers. A widespread misconception among providers is that asylum seekers whose claims are still pending are not entitled to healthcare. This had been a problem even before the most recent legislative changes (Carlowe 2001; Dar 2000). Dispelling these myths involves a huge education effort undertaken by networks of voluntary organizations, aimed at administrative staff such as receptionists, practice managers and Overseas Managers at hospitals.

The most common manifestation of the confusion is that healthcare providers ask potential patients for documentation, such as a passport or other identity papers; neither refugees nor asylum seekers should be required to show such documentation, and most do not possess this paperwork (Refugee Council 2003). One Informant said that in some London

³ While most persons diagnosed and undergoing treatment for HIV utilize the services of a Genito-urinary Medicine (GUM) clinic for their needs, many who have not found out about their infection first enter into the healthcare system through visiting a GP or through antenatal care. In addition, many prevention efforts aim to reach people through GPs (Erwin et al. 2002). Therefore, it is crucial that general practices are aware of the entitlement regulations and healthcare needs of refugees and asylum seekers.

boroughs, documentation requests are as strict as two forms of personal identification and two forms of proof of address. Demands for documentation have a disturbing consequence: another Informant noted that many potential patients are deterred from trying to register⁴. Refugees' and asylum seekers' lack of knowledge about entitlement regulations, combined with some GPs' reluctance to accept their registration, produce the unfortunate result that many fail to access primary care.

The situation for asylum seekers is especially difficult, as their constant worry about uncertain immigration status causes wariness and avoidance of any scenario that involves paperwork. Many believe that any contact with 'official' matters could impact their asylum claim. Thus, opportunities for preventative care are often missed, and many asylum seekers later present at the emergency ward with acute illness, according to several Informants. Clearly, this is an especially worrying state of affairs for those infected with HIV (Pollard and Savulescu 2004). In addition, Dodds et al. (2004) describe patients who sensed racism and stereotyping by health practitioners when trying to register; this sometimes impedes access to services and further exacerbates communication difficulties. They mention one asylum seeker living with HIV who found herself in the midst of an institutional disagreement on whether she was entitled to emergency care. When she was subsequently given the option to lodge a discrimination complaint against the hospital, she refused, because 'she had no desire to seek compensation or to draw further attention to her situation, she only wanted access to the emergency care and treatment to which she had a right' (Dodds et al. 2004: 12).

The end result of registration difficulties is that some fail to access care at all, while others resort to informal sources. 'Unofficial' doctors in refugee communities, who often combine non-Western medical approaches with Western ones, provide such care. According to one Informant, these may be medical professionals who have not officially transferred their qualifications in the UK, and thus practice on a private basis. In some cases, they are persons without medical qualifications. While many appreciate such 'alternative' modes of care because these doctors are embedded in the patients' communities and are receptive to their needs, this system is not without its pitfalls. The financial expense of visiting private doctors might be considerable. Furthermore, these doctors often do not have a wide range of medical equipment and testing supplies, and are unable to make referrals for secondary care. In the case of persons living with undetected HIV, seeing these doctors might delay testing for the infection. The Refugee Council (2004) is concerned that the new legislation will result in increased use of informal sources of care.

5.1.2. Unfair 'burden'

The unclear situation regarding entitlement, coupled with a reluctance to take on 'difficult' cases, results in unwillingness by some GPs to register refugees and asylum seekers despite extra financial support offered to those who do (Carlowe 2001). Thus, while some practices are open to registering refugees, others are not, 'creating neighbouring practices with very different demographic profiles and unequal needs' (Jones and Gill 1998: 1445). When asked about advocacy in such a situation, one Informant responded that it is not easy to suggest that an asylum seeker be treated by an unsympathetic GP, given the high potential of difficulties in a medical encounter even with a compassionate doctor. Thus,

⁴ After a third failed attempt to register with a GP, patients may contact the local PCT, which has the power to allocate them to a GP (Refugee Council 2003). However, many refugees and asylum seekers are unaware of this recourse, and may be reluctant to utilize it even if they know about it.

though she recognizes the overall unequal distribution of refugees and asylum seekers across GPs, in individual cases she is reluctant to recommend that a patient try to overcome unwillingness to treat. However, another Informant pointed out that the percentage of GPs who are actually antagonistic to asylum seekers is quite small: most difficulties with registration originate in confusion regarding legislation.

Communication is constantly cited by health practices as an obstacle to providing quality care to refugees and asylum seekers, and is a major reason why they are labelled difficult cases (Jones and Gill 1998; Trafford and Winkler 2000). Interpreter services are found lacking by many (Montgomery and Le Feuvre 2000). Problems with communication lengthen consultations; one Informant mentioned that it is not unusual for a morning surgery schedule to last until well into the afternoon at a practice that specializes in treating refugees. In addition to a reluctance to conduct time-consuming consultations, some GPs also seek to avoid having to contend with asylum seekers' complex health needs, often because they do not have the resources for such 'specialist' work (Carlowe 2001). Practitioners sometimes encounter refugees and asylum seekers who ask for non-health related advice, on topics such as filling out forms, housing and employment; given that they are not prepared to speak about such topics, some GPs are overwhelmed by these requests. Patients' inadequate access to information regarding the NHS, coupled with a scarcity of quality interpretation services, together result in, at best, inefficient use of the system (Wasp et al. 2002). The experience is of a 'Lack of a shared understanding of health and health care between practices and refugees' (Trafford and Winkler 2000: 20).

According to two GPs, 'The main obstacles to providing appropriate care are the inflexibility of the NHS and the delays and bureaucracy inherent in the arrangements for the support of asylum seekers' (Montgomery and Le Feuvre 2000: 893). Though they are aware of certain entitlements to benefits for asylum seekers, they find that these benefits are not quickly forthcoming. For example, the HC1 form needed to obtain help with health costs, such as free prescriptions and travel to and from hospital, is sixteen pages long and only available in English (Refugee Council 2003). Practitioners' time is often spent battling bureaucracy on behalf of their patients. Clearly, a lesser administrative burden imposed by the NHS would improve the situation.

Due to the many hindrances to treating such patients, and the commonly held perception that refugees and asylum seekers are a highly mobile population, some GPs register them as 'temporary' patients. This perception is not unfounded in the case of asylum seekers who have recently submitted their applications, who are liable to dispersal. With temporary patients, GPs often do not perform comprehensive health checks, do not keep complete medical records, and have no financial incentives to conduct immunization or cervical smear tests (Jones and Gill 1998).

5.1.3. Dispersal of asylum seekers

The 1999 Immigration and Asylum Act instituted a dispersal policy in the asylum reception process. Persons who submit asylum applications and are deemed eligible for welfare support services enter the system, administered by the newly created National Asylum Support Service (NASS), which operates outside mainstream welfare provision. Asylum seekers entering the NASS system are dispersed to regions north of London, to areas that do not have high concentrations of asylum seekers, and must remain there while they

await decision on their applications. As instituted, the purposes of dispersal were to distribute welfare costs away from London and southeastern England and to minimize attractiveness of the UK for ‘bogus’ asylum seekers, presuming that they would be deterred by the inability to settle where they choose. While asylum seekers were supposed to have been dispersed to areas of matched linguistic concentration and ethnic composition, in practice the location of dispersal tends to depend on availability of low-cost housing. Many critique the way the policy is carried out. Centralized management at NASS results in a lack of communication with and funding of service providers in the regions, and hence inadequate service provision (Griffiths et al. 2005: 46).

According to one Informant, while some sceptics of the dispersal policy initially conceded that it might do well to reduce the pressure on London based healthcare providers and that asylum seekers might find better quality care in the regions, its implementation leaves much to be desired. The All-Party Parliamentary Group on AIDS (APPG) notes ‘the degree to which the current nationality and immigration system forces individuals to live in abject poverty, thereby undermining clinical efforts to maintain good health’ (2003: 6). Asylum seekers have been relocated to areas with a dearth of voluntary agencies to support their access to statutory services by providing interpreters and support in navigating the healthcare system. This has left an even greater gap in the possibility of accessing healthcare, and greater dependence on ‘sympathetic’ health practitioners. Many GPs outside London are faced with the healthcare needs of asylum seekers for the first time (Dar 2000). Furthermore, inadequate support from NASS for capacity building both in the voluntary and statutory sectors has inhibited the acquisition of ‘cultural competency’. While many new refugee community organizations (RCOs) have been established in the regions, they are largely under-funded and staffed by volunteers with high turnover rates (Griffiths et al. 2005: 61).

The way the system has functioned for asylum seekers living with diagnosed HIV is that frequently their course of treatment is disrupted by dispersal (APPG 2003; Gazzard et al. 2005). They are often uprooted quite suddenly; some are given as little as forty-eight hours’ notice prior to dispersal, and risk losing all support benefits if they do not comply. A survey of physicians found many instances of dispersal of HIV positive patients without consultation of the treating physician prior to the move (Creighton et al. 2004). Negative consequences are dire, and have included interruption of ARV therapy, mother to child transmission of HIV infection, and HIV related death. A main concern is that medical records do not follow asylum seekers to the dispersal destination and crucial information is lost because of communication difficulties (Murshali 2005). Furthermore, for those who have ‘suffered painful experiences it is not therapeutic ... to have to repeatedly rehearse their life history with a series of different health care providers’ (Weston 2003). An initiative to provide patients with handheld medical records to take along when they are dispersed is slowly being taken up by practitioners, according to one Informant.

5.2. Vulnerabilities due to the experience of forced migration

5.2.1. Contracting HIV

One reason that refugees and asylum seekers are categorized as a high-risk group for HIV infection is that many come from countries where HIV infection is especially prevalent. However, the particular vulnerabilities associated with persecution, the very reason that these persons seek asylum, are often overlooked. Certain aspects of conflict expose civilians to the

possibility of contracting HIV, the incidence of which is often high among combatants who perpetrate sexual violence (Weston 2003: 141). Refugees and asylum seekers may have been through situations of massive human rights abuses, including rape with the specific intention of transmitting HIV (Carlowe 2001). During generalized violence and flight, awareness of HIV transmission may not be a prominent consideration.

Being a forced migrant entails vulnerabilities in itself. For many in this situation, health is not the prioritized concern; poverty, unemployment, uncertain immigration status, and lack of sufficient housing often trump health considerations, especially when it comes to preventative care (Louhenapessy 1996). Faced with poor living conditions and lack of protection, and prohibited from working to support oneself, some may enter into sex work. The psychological stress, isolation and anxiety that often characterize the process of seeking asylum may result in lowered self-esteem and consequent increases in sexual risk taking (Weston 2003: 141). Many authors emphasize the need to recognize the *current* stresses in the lives of refugees and asylum seekers, and to avoid focusing only on pre-flight experiences. Burnett and Thompson (2005) point out the many aspects of the life of an asylum seeker that may contribute to poor mental health outcomes. It is not difficult to imagine how the asylum process can exacerbate feelings of insecurity and helplessness, as those in the application stage have little control over the outcome of the asylum claim and their lives in the meantime. The dispersal scheme does not permit asylum seekers a choice in where to live, and the prohibition against working leaves them dependent on scant welfare provision. Moreover, those who suspect that they are infected with HIV but have not been tested may fear that a positive test could lead to deportation (Burnett 2002: 13; Gardner 2000).

Understandably, while dealing with such immense pressures, refugees, and particularly asylum seekers are unlikely to try to articulate their rights in order to overcome barriers to accessing healthcare. As outlined above, the more likely scenario is that they simply will not access care, and will ‘disappear’ until such time as they require emergency treatment. In the case of HIV, it means that many will present only once they experience symptoms of the infection (Erwin and Peters 1999).

5.2.2. *Living with HIV*

For those who have been diagnosed with HIV, managing physical illness as well as the societal stigma associated with it is complicated by their precarious circumstances. For asylum seekers waiting for a decision regarding legal status, the uncertainty of staying in the UK and continuing treatment constitutes a major focus of anxiety, especially for persons who come from countries where ARV therapy is largely unavailable (Doyal et al. 2005; Doyal and Anderson 2003). Meanwhile, basic economic problems preoccupy many who live in inadequate housing and have trouble subsisting on the meagre income support. Life in shared accommodation with limited access to cooking facilities often means difficulties with concealing medications and preparing meals to accompany medications as required (Doyal and Anderson 2003; Weston 2003). The psychological distress of trying to cope with health status along with social and economic marginalization may be severe. Weatherburn et al. (2003) found that African migrants living with HIV experienced problems managing their condition much more frequently than white British people living with HIV, due to the challenges of life as forced migrants.

5.2.3. Confidentiality and stigma

By far the most pervasive issue present in accounts of refugees and asylum seekers living with HIV is the struggle to contain disclosure of their diagnosis due to the desire to avoid stigmatization (Dodds et al. 2004). The association of HIV transmission with shameful behaviour can result in an oppressive sense of fear that one will be discovered and subsequently ostracized from the community. Paradoxically, this may lead to pre-emptive self-isolation to prevent discovery by friends and family members (Kang et al. 2003). Needless to say, linguistic and social barriers stand in the way of seeking and receiving support from outside the refugee community. Erwin et al. (2002) note that patients' unwillingness to disclose their status to family and friends raises concerns that they are less likely to access informal support networks. Most African migrants in London worry about the likelihood that news regarding their diagnosis would travel through networks not only in the community but also to their families in Africa; the stigma involved would outweigh any psychological benefits of disclosure. Many reported that community support gives them strength in the face of the inequality and deprivation they face as immigrants, and to disclose would mean a risk of losing their place in the community (Dodds et al. 2004).

Such fears are not unrealistic, as many who have disclosed report rejection and ostracism even by close family members (Doyal and Anderson 2003). Many are reluctant to access services for fear that their HIV status will become known to their communities (Erwin and Peters 1999; Gardner 2000). Some patients report struggling to hide medications, travelling to distant clinics to avoid being seen receiving treatment for HIV in their neighbourhood, and keeping clinic visits as short as possible, thereby precluding informational discussions (Erwin and Peters 1999). As such, the fear of stigmatization inhibits benefiting from practical and psychosocial support.

Stigma from outside the community acts as yet another barrier to effective prevention and access to care. Too often, refugees and asylum seekers are depicted in the public consciousness as dangerous to public health because they are carriers of infectious diseases, and at the same time as a drain on the health system's resources. Implicit and explicit racism, anti-immigration sentiment and stereotyping of African-born people in particular as 'threatening' transmitters of HIV are psychologically debilitating for persons living with HIV (Dodds et al. 2004). Caution of such stigma affects the conduct of prevention and advocacy activities; one Informant spoke of the '*Daily Mail* factor', referring to this newspaper's reputation for particularly inflammatory statements regarding asylum seekers. Unfortunately, such 'Stigmatization and shunning can increase the tendency of the immigrant community to deny the issue and, in some cases, can alienate people with HIV/AIDS ... and drive them into hiding' (Shtarkshall and Soskolne 2000: 5). Perhaps this alienation is a factor in some refugees' failure to seek out care until later stages in the disease. Moreover, perceptions of being the subjects of discrimination contribute to distrust of health services (Erwin and Peters 1999). In sum, marginalization and stigmatization result in an overwhelming feeling of powerlessness among persons living with HIV and impact their healthcare options and behaviours.

5.2.4. Being informed

The persistence of stigmatization is, of course, related to commonly held misperceptions regarding HIV infection both within and outside the African refugee community. Unfortunately, few studies with non-African born participants are available on

these issues (Naz Project London 2002). African immigrant respondents felt that because of media attention on the HIV epidemic exclusively among African-born people, the ‘majority of the British population believed that all African people have HIV or AIDS’ (Dodds et al. 2004: 15). Furthermore, black African people are stereotyped as hyper-sexualized, irresponsible and threatening to public health. Persons living with HIV, who ‘confirm’ this stereotype, must struggle with the daily burden of these perceptions, which they believe are quite present in the minds of British individuals (Dodds et al. 2004). It would be informative to examine how issues of stigma play out in other refugee communities, where HIV infection is not as prevalent and does not comprise a stereotype held by outsiders.

Concomitantly, discussions of sexuality and sexual health are unacceptable in many refugee communities (Naz Project London 2002). Within the pan-African community, stigma leads to an absence of realistic discussions regarding HIV prevalence and transmission (Dodds et al. 2004). The widely held belief that casual contact and the sharing of dishes and utensils will result in transmission of HIV results in ostracism of many, and unsurprisingly has damaging effects on their morale. Instead of direct conversations about HIV, it is often brought up in the pan-African community as an affliction of people from other regions of Africa. In this way, stigma and misinformation are perpetuated. Moreover, many black Africans expressed a fear of imminent death, which indicates that their information regarding HIV is grounded in the African context, where it is largely not a manageable disease (Erwin et al. 2002).

Precisely due to the stigma issues discussed above, refugee communities are difficult to reach with HIV prevention efforts. Fenton et al. (2002) found a tendency toward high-risk sexual behaviour and low rates of HIV testing among African migrant communities in London.⁵ The study did not find an association between length of residency in the UK and the uptake of testing for HIV, which ‘suggests that more work needs to be done to dispel the stigma associated with HIV testing’ (Fenton et al. 2002: 244). HIV testing was most common among those who had previously been diagnosed with an STI and thus perceived themselves at risk. Furthermore, Sadler et al. (2005) report that stigma, discrimination and fear of deportation, have a pervasive effect on the lives of African respondents in their community sample; they influence the decision to be tested, uptake of services, and risk behaviours.

Assessing knowledge and behaviour among Africans living with HIV, Chinouya and Davidson (2004) report an alarming amount of risky sexual behaviour, like not using a condom, but note that its incidence is lower than in community based samples of African-born people with unknown HIV status. They also found inaccurate HIV-related knowledge among a small percentage of their sample.⁶ Moreover, Weatherburn et al. (2003) encountered a desire for more information regarding HIV treatment among their sample of African people living with HIV. Thus, not even those diagnosed with HIV always have accurate information at their disposal.

⁵ The rate of testing among African migrants, at about 30-35%, is higher than that of the general population, at about 13%, but the authors deemed it low considering the elevated risk in this population (Fenton et al. 2002). More recently, Sadler et al. (2005) found a higher rate of testing, with 50.9% of men and 42.9% of women in their African community based sample reporting having been tested. However, 66% (93 of 141) of the respondents with an HIV positive oral fluid sample had not previously been diagnosed.

⁶ For instance, 16% believed that ‘one can get cured of HIV in the UK’ and 10% were not sure whether that was true; 7% believed that ‘resistance means my partner cannot catch HIV from me’ and 10% were not sure; and 21% believed that ‘prayer can cure HIV’ and 13% were not sure (Chinouya and Davidson 2004: 20).

5.3. Explanatory value

This section has considered aspects of forced migrants' lives that influence their access to healthcare opportunities and information. It has reviewed vulnerabilities to contracting and living with HIV. It has also analysed possible reasons for reluctance to engage with the healthcare system and challenge instances of service refusal. As such, it has presented examples of the pervasive nature of marginalization and power inequality. While keeping in mind the lack of cultural competency within the NHS as a valid explanation of complications in accessing healthcare, it is also crucial to consider the above manifestations of structural and institutional obstacles.

When looking at the situation from the 'practical' point of view of a forced migrant, it is not difficult to comprehend instances of failure to access services, and even less difficult to imagine how informational interventions might miss their target audience. A deep understanding of the intricacies of how this population engages with the healthcare system is therefore necessary for conducting effective interventions. This requires awareness of the legal, institutional and societal barriers to access described above, in addition to cultural sensitivity. The following section will examine some interventions currently ongoing in this field. It will consider different types of organizations, referring to how each is best suited to operate within the complexity of healthcare access.

6. INTERVENTIONS

In considering interventions to address some of the many issues raised above, it is helpful to think about two dimensions that may be important to organizations' effectiveness: legitimacy and capacity. Problems with access to healthcare stem from a variety of sources involving both cultural and structural barriers. Pervasive stigma impacts refugees' and asylum seekers' interactions with statutory services and with interventions that aim to facilitate access to healthcare. The ways in which interventions address these difficulties will be examined in this section.⁷

6.1. Addressing HIV in a culturally competent way

The issues raised thus far highlight the caution and sensitivity necessary for conducting programming in this field, and the type of organization involved makes a difference. Voluntary sector RCOs serve small communities based on ethnic, linguistic, or country of origin ties, and have proliferated as refugee communities become established in the UK.⁸ The need for social support and inclusion has spurred the creation of many RCOs, such as the African People's Link, among the African-born population (Chinouya and

⁷ The interventions mentioned here are just several examples of the numerous initiatives currently ongoing in London; they were chosen in the hopes that they are fairly representative of the *types* of interventions. Much of the information regarding these initiatives clearly comes from the interviews conducted with Informants. However, the opinions expressed are not those of the Informants, unless clearly indicated. Unfortunately, information was not gathered regarding initiatives outside London due to time constraints.

⁸ Estimates state that 500-600 RCOs operate in London alone, while numbers outside London are much lower but as yet unknown (Griffiths et al. 2005: 102). It is unclear how many of these work on access to healthcare.

Reynolds 2001). While Griffiths et al. (2005: 20) caution against assuming that RCOs are unproblematic representatives of their communities, their culturally-grounded contact with service users is indispensable. Several Informants commented that RCOs are well positioned because of their proximity to service users' cultural background. In their study of the Afghan, Iranian and Somali refugee communities in Harrow, Wasp et al. (2002) found that people relied on RCOs and informal networks as a first source of advice regarding registration with a GP. RCOs are often asked to engage in 'cultural brokerage' between patients and healthcare providers, acting as sources of information as well as interpreting. Wasp et al. (2002) express concern about the possible lack of information available to members of more recent immigrant groups that have not yet established RCOs.

RCOs constitute an important vehicle for informational interventions to raise awareness of HIV and condom use. Information and direct support services are also provided by NGOs geared toward various BME communities, such as Naz Project London. Some organizations utilize their deep knowledge of communities to conduct HIV prevention by means of workshops and social marketing (Chinouya 2001). Despite the challenges of initiating conversations regarding 'taboo' health issues, those who engage with this task find that their efforts result in fruitful discussions (Akpan 2004).

Furthermore, RCOs' familiarity with culturally appropriate means of social support is helpful for persons living with HIV. Sometimes their legitimacy derives from the fact that staff are from the communities and may be affected by HIV themselves (Haour-Knipe 2005). While many are quite reluctant to participate in programming with general purpose RCOs for fear of disclosure of their HIV status and subsequent stigmatization within the community, they often find that self-help groups composed solely of refugees and asylum seekers living with HIV provide their chief means of social support. They perceive such RCO initiatives as more useful than similar projects by larger organizations focused on HIV because those do not always address refugees' concerns (Dodds et al. 2004).

RCOs may also be connected with religious institutions; one Informant mentioned the great importance of faith-based organizations in helping refugees with healthcare, and these organizations' potential for dissemination of prevention materials. Several studies also note the significance of spiritual and practical support that many refugees receive from churches or other religious institutions (e.g. Erwin and Peters 1999). Some persons living with HIV mentioned the comfort of faith as a coping mechanism, but conversely, acknowledged the need to conceal their condition from the congregation for fear of stigmatization (Doyal and Anderson 2003).

6.2. The limitations of 'cultural brokers'

The importance of RCOs in bridging the 'culture' gaps left by healthcare services should not be understated. According to one study, RCOs' self-identified greatest resource is cultural competency (Chinouya 2001). Many statutory health practitioners without special training or interest in the particular vulnerabilities of refugees and asylum seekers find the extent of these issues beyond the scope of their work and do not feel equipped to deal with these extra challenges (Kang et al. 2003). For them, networking with the voluntary sector can contribute to holistic approaches. Wasp et al. (2002) are concerned about the scarcity of links among health providers and RCOs, and recommend that more links be established to increase

practitioners' understanding of the communities. However, RCO support to statutory services may sometimes be an unsustainable endeavour. Trafford and Winkler (2000) mention a general practice in London that had instituted a twice-weekly refugee clinic that included consultations with Social Services and voluntary organizations. Apparently, the purpose of this initiative was 'to ease the burden on the practice' and the clinic 'had too little involvement from the general practitioner' in order to be useful for the practice as a whole (Trafford and Winkler 2000: 29). In this situation, the 'burden' was shifted from the GP rather than being incorporated into the activities of the statutory practice.

In addition, education and prevention should not be the exclusive responsibility of RCOs, as some evidence suggests a need for health promotion activities to be channelled through GPs. Fear of stigmatization often causes patients to seek HIV-related services outside their communities, altogether avoiding RCOs (Erwin et al. 2002; McMunn et al. 1998). While there is great potential for RCOs to disseminate culturally appropriate educational materials regarding HIV transmission and general information regarding the NHS, they cannot act as 'cultural brokers' in each medical encounter. The work of RCOs is not a substitute for culturally competent approaches to care by health practitioners themselves (Arora et al. 2001).

Other limitations of RCOs include inconsistent funding and the resultant lack of organizational capacity for a broad range of service provision. The limited capacity also restricts their engagement in lobbying and advocacy work, except as part of larger networks.

6.3. Initiatives within the NHS

Overall, evidence suggests that Genito-urinary Medicine (GUM) clinics are well suited to attend to the needs of refugees and asylum seekers living with HIV, even in dispersal areas (Allan and Clarke 2005). Specialist GUM services received widespread approval as a source not only of treatment but also emotional support by the women in Doyal and Anderson's (2003) study. Conversely, many complain about discriminatory attitudes encountered from GPs and hospitals, especially regarding registration, as discussed above. Some attempt to circumvent this discrepancy by utilizing GUM clinics for all healthcare needs (Dodds et al. 2004: 32). However, this is evidently not the clinics' intended purpose. In addition, because GPs are the gateway to primary care access, positive reception by GPs is crucial to promote early testing and HIV prevention. GPs are often where one might learn of GUM clinics in the first place (Gardner 2000). Thus, it is crucial that all statutory NHS services, including GPs and hospitals, are trained in receiving refugee and asylum seeker patients.

As an example of 'best practice', certain London PCTs are known for their highly trained refugee/asylum Health Support Teams, who are aware of issues in accessing care and serve as integrated mediators. They also advocate on behalf of patients on a case-by-case basis in the event of registration difficulties. Such teams are a much-appreciated effort on the part of the NHS, according to one Informant, and clearly evidence the capacity of statutory services to address these 'specialist' needs. One prominent example is the Health First team of Lambeth, Southwark and Lewisham PCTs in London. However, not all PCTs include such comprehensive teams, and some do not have them at all (Le Feuvre 2001). Many hospitals lack a sufficient number of culturally competent personnel. And many PCTs have recently

become aware that they are failing to reach certain groups. Ultimately, community organizations and statutory health authorities must share the challenges of service provision (Van Duifhuizen 1996).

6.4. Advocacy by NGOs

Advocacy efforts in this field generally take two forms: direct, case-by-case advocacy for patients to access care, and lobbying efforts directed toward policy makers. Advocacy is generally conducted by larger NGOs that target their activities toward refugees (such as the Refugee Council) and those that aim at prevention and treatment of HIV (such as the Terrence Higgins Trust (THT)). Recently, groups of clinicians have spearheaded efforts, supported by some parliamentarians. In addition, advocacy work is often the product of network-wide efforts among the aforementioned groups.

Direct advocacy is carried out on behalf of patients who have trouble registering with a GP or accessing hospital care. As previously mentioned, the major obstacle in direct advocacy is confusion on the part of health practitioners regarding entitlement regulations. Vast inconsistencies exist across London; several Informants mentioned that since registration for primary care is at each GP's discretion, receptiveness varies by borough. In certain overloaded boroughs demands for documentation and other obstacles are greater because practitioners are reluctant to take on yet more patients whose entitlement status is unclear. Some NGOs and RCOs have initiated programmes for helping clients to register with the NHS. Medact facilitates access through its network of 250 healthcare providers by seeking out information regarding where particular patients may turn for their healthcare needs. Medact also educates network members as to changes in entitlement legislation and immigration more generally. Médecins du Monde's newly established Project London operates a part-time clinic to address patients' immediate healthcare needs while staff engage in direct advocacy by telephone to ask London providers to register the patients despite their lack of documentation.

Both aforementioned projects also incorporate a longer-term lobbying component, aimed at improved access and against curtailments of the right to healthcare. Lobbying most often entails advancing the public health rationale for expanding access. Moreover, the THT and the African HIV Policy Network (AHPN) argue that universal treatment is financially pragmatic. For instance, it is not cost-effective to treat the numerous TB cases that result from co-infection with HIV without treating HIV as well; these organizations have argued that repeated treatment of TB is expensive as well as dangerous, as it increases the spread of multi-drug resistant TB.⁹ And HIV treatment in itself is cost-effective; since all persons are eligible for Accident and Emergency treatment, many who do not access regular treatment subsequently end up in the emergency wards of hospitals, a costly encounter for the NHS.

Yet more frightening is the fact that many refuse to test for HIV because they see diagnosis as useless if they are unable to access free treatment; this is compounded with fears of the effect of a positive diagnosis on the asylum claim. The consequence is even later presentation for treatment (Power et al. 2004). Advocates collect case information of instances when patients have been unable to receive services and compile them as evidence to

⁹ Presently, TB treatment is free and accessible to all, regardless of legal status.

be presented to the government by, for example, the Entitlement Working Group of the Medact network. They also support the advocacy of the National AIDS Trust, which has recently campaigned to ensure care for all persons who test HIV positive, regardless of legal status (Power et al. 2004). One Informant observed that key to such advocacy is that it does not pronounce itself on immigration policy; it is solely presented as a health issue.

In the area of prevention, although healthcare advocates recognize the importance of HIV education targeted for certain groups such as sub-Saharan Africans, due to high prevalence of the infection among them, they also understand the need to avoid arousing yet more public outcry and discrimination against asylum seekers. Thus, while RCOs' culturally tailored education interventions are necessarily aimed at specific groups, broader advocacy initiatives must steer clear of perpetuating stigmatization and stereotyping.

6.5. Clinician reactions

Some practitioners have responded to the April 2004 legislation on entitlement with strong disapproval. As previously mentioned, while some physicians shy away from registering and treating refugee and asylum seeker patients, others go so far as to embrace advocacy efforts to improve such services. On the part of the government, the All-Party Parliamentary Group on AIDS has been particularly receptive to working in concert with physicians as well as NGO advocates (APPG 2003; Gazzard et al. 2005). Healthcare practitioners have lobbied on the grounds that they do not wish to become enforcers of the immigration system, according to several Informants. One Informant noted that physicians would prefer to stick with the Hippocratic oath as a guide to practice, rather than the ever-changing legislative environment. Many wish to work under the assumption that the right to healthcare should be universal for all persons living in the UK (Robinson 2003). Physicians who are informed by clinic managers that care to a certain patient will be chargeable, and that the patient might not return for fear of being forced to pay, find themselves unable to carry out their duties as medical professionals.

The medical ethical considerations at the heart of clinicians' advocacy efforts constitute an important source of legitimacy, especially in making the public health case for better access to care (Gazzard et al. 2005). For example, healthcare practitioners have argued that abruptly stopping ARV treatments can be a risk to individual health and can cause drug resistance. Furthermore, the disinclination to test because of no prospect for free treatment perpetuates unawareness of one's status and thus a failure to change one's behaviour to prevent onward transmission of HIV (Granville-Chapman 2004). Worse still, cases have been reported of expectant mothers infected with HIV being refused free antenatal care to inhibit transmission of the infection¹⁰ (Power et al. 2004).

6.6. Right to healthcare

A major point on the agenda of advocates has been the recent curtailments on the *right* to healthcare. In effect, until April 2004 the UK had a system whereby persons considered 'residents' and thereby eligible for healthcare because of their 'belonging' were

¹⁰ Antenatal care is considered secondary care, while care during childbirth itself remains free to all.

defined by length of stay (twelve months). The amended regulations call into question the universality of healthcare provision in the UK; entitlement has been altered so that secondary healthcare is now dependent upon one's *legal* right to remain, as defined by the asylum system. Rejected asylum seekers are no longer considered eligible for certain benefits due to their 'non-belonging' to the community regardless of length of stay.¹¹ As such, healthcare has been further intertwined with immigration regulations.

The debate regarding whether there is a right to lifesaving treatment has invoked Article 3 of the European Charter of Human Rights (ECHR), which prohibits torture and inhuman or degrading treatment. It has been argued that denying healthcare to persons affected by HIV constitutes a form of inhuman treatment. Previously, it had been possible for asylum seekers living with HIV who had failed in their asylum claims to appeal for special Humanitarian Protection status based on their condition in order to stay in the UK and access healthcare, but increasingly they are refused this status (Dodds et al. 2004). In the May 2005 decision regarding the case of *N*,¹² a woman who had been refused asylum and was ill with HIV was to be deported back to Uganda despite doctors' warnings that she would live less than one year if medications were withdrawn, which they likely would be upon return to Uganda (UK AIDS and Human Rights Project 2005). The court argued that because *some* treatment for HIV was available in Uganda, *N* would have the possibility of receiving treatment, and therefore the UK was not responsible for a breach of Article 3 of the ECHR; that is, *N* could theoretically access care in Uganda, and was therefore not being sent to a situation of inhuman suffering.¹³ Thus, *any* available treatment in the country, even if it is geographically or financially inaccessible to the patient, was deemed sufficient to counteract the severity of inhuman treatment that would result from sending someone to a country where no treatment was available at all.

Though this case is most directly relevant to deportation, according to some it raises the issue of 'whether or not article 3 impose[s] obligations on states to provide medical treatment to non-nationals' (English et al. 2005). The unsuccessful appeal of *N* to stay in the UK was a setback for those arguing for humanitarian leave on medical grounds for rejected asylum seekers diagnosed with HIV. Perhaps more importantly, it contributed to the feeling among asylum seekers of a beleaguered situation with regard to accessing services and has encouraged abstention from healthcare. According to one Informant, this development has not had the desired effect of coercing such persons into leaving the UK, but instead has exacerbated destitution and street sex work, which undoubtedly raises public health concerns.

6.7. Networking

Many of the organizations mentioned above also actively involve themselves in multi-sectoral networking to enhance cultural competency of services as well as advocacy efforts.

¹¹ Processing of an asylum claim can often take longer than one year due to backlogs.

¹² *N v. Secretary of State for the Home Department* [2005] UKHL 31, on appeal from [2003] EWCA CIV 1369.

¹³ This is in contrast to the case of *D v. United Kingdom* [1997] 24 EHRR 425, in which the European Court of Human Rights ruled that *D*, who was in the advanced stages of AIDS, if returned to his native St. Kitts would have *no* recourse to treatment because it is completely unavailable there, and would also not be able to access family support because his family had left St. Kitts. The ruling in the case of *D* was that he should be allowed to stay in the UK and access medical treatment. In the case of *N* the court specifically mentioned *D v. United Kingdom*, referring to his exceptional situation (English et al. 2005).

Several Informants mentioned the value of both formal and informal networking and coordination efforts. An example of a broad network composed of health practitioners, NGOs and RCOs is the North West London HIV and Sexual Health BME Network, which was recently established to address issues of sexual health promotion in BME communities such as late-stage HIV testing and low uptake of health promotion messages channelled through GPs.¹⁴ The network provides training opportunities and education of its partners regarding BME health needs and healthcare entitlements. One of its key functions is to facilitate outreach and contact in both directions, between BME communities and service providers (Fassil 2005). On a more specific level, the AHPN coordinates the lobbying efforts of small African RCOs; it is linked with African-led forums through its advisory group. In addition, it conducts capacity building for health promoters and ‘cultural brokers’ to more effectively engage in direct advocacy.

Several Informants mentioned that RCOs’ in-depth knowledge of forced migrants’ experiences in accessing healthcare and living with stigma lends considerable legitimacy to lobbying efforts. At the same time, RCOs often lack capacity to mount full-fledged advocacy initiatives. Thus, collaborations between NGOs that engage in such large-scale advocacy and RCOs strengthen the positions of each. Partnership between NGOs and RCOs is also crucial in direct advocacy efforts. Just as many health practitioners are unclear about entitlement regulations, so refugee communities are confused about their healthcare rights. Several network-wide efforts disseminate knowledge about regulations. For example, the THT employs ‘cultural brokers’ to conduct education campaigns through RCOs regarding entitlement regulations and inform financially disadvantaged patients that if they are charged for healthcare, these charges can be disputed and annulled through the PCT accounting system. By and large, these are measures to build confidence among refugee communities so that they are not deterred from accessing services. At the same time, the THT and the AHPN collect case information on persons who are charged as much as £20,000 for care, aiming to illustrate the confusion caused by the new regulations and the reality of patients ‘disappearing’ from treatment because they fear financial liability.

However, networking among RCOs, NGOs and the statutory sector is not without its problems. While such networks may connect RCOs with other service providers, the larger actors invariably set the parameters of such partnerships. Some RCOs do not formalize as organizations and network members because they wish to avoid perpetuating their communities’ position of marginality (Griffiths et al. 2005: 202). According to an Informant, in the eyes of many service users, RCOs should avoid collaborating with the statutory sector because the RCOs’ role includes supporting communities that wish to remain invisible from the government. RCOs must strike a balance in order to remain sufficiently outside of ‘official’ partnerships so as to retain legitimacy and accountability with the communities.

¹⁴ As discussed above, BME, or black and minority ethnic, is an uninformative term to describe refugee communities. While members of the Northwest London HIV and Sexual Health BME Network agree as to the ambiguity of this term and acknowledge the need to tailor culturally appropriate services to small segments of the ‘BME’ population, the funding structure necessitates continued use of this category (Fassil 2005).

7. CONCLUSION

7.1. Breaking the cycle of stigmatization

When studying healthcare utilization among refugees and asylum seekers, as in many other contexts involving marginalized groups, it is evident that demographic categorizations based on socio-economic characteristics commonly employed in public health do not apply (Obermeyer 2004). It is not possible to anticipate such patients' behaviours in seeking healthcare and health-related information without delving into an analysis of cultural, social, and structural factors that contribute to such decisions. These considerations are likely to differ substantially from those pertaining to other population groups for the reasons discussed above, though it is as important not to essentialize a monolithic 'native British' population as it is to keep in mind the diversity among refugee communities (Davey Smith et al. 2001). The barriers to accessing healthcare for refugees and asylum seekers living with HIV in the UK are extensive. An adverse socio-economic situation is compounded by precarious legal status, and associated reluctance to assert the right to healthcare. In addition, community stigmatization and discrimination from outside the community exert a strong psychological pressure on persons living with HIV, and in some cases prevent those undiagnosed from testing. The manifestations of power inequality and marginalization go beyond the issue of cultural difference in illustrating the reasons that many have trouble accessing healthcare.

Many of the difficulties with accessing care existed prior to 2004, but the situation has deteriorated due to the newly instituted entitlement limitations for rejected asylum seekers, which have impacted the wider refugee community. The regulations have exacerbated confusion regarding the right to healthcare. Again, few of those to whom the regulations do not technically apply are in a position to contest the situation. Overwhelmingly, refugees and asylum seekers prefer to stay away from what they experience as the capriciousness of the 'authorities'. What this means for public health is an elevated potential for the spread of HIV as it goes undiagnosed and as communities retreat further from the 'spotlight' of anti-asylum discourse and become harder to reach with prevention messages. In turn, stigma flourishes as the ideas that allow it to continue remain unrefuted (Dodds et al. 2004).

Indeed, a vicious cycle emerges: statistics and public perceptions signalling high HIV prevalence among certain groups fuel stigmatization of these groups, persons living with HIV continue to conceal their status and do not engage in efforts to dispel myths regarding the illness within their communities, and simultaneously the real and potential difficulties with accessing healthcare prevent those living with undiagnosed HIV from testing and detecting the virus early. Meanwhile, groups working to disseminate accurate information regarding HIV transmission are reluctant to target it toward high-prevalence groups, fearing a surge in further stigmatization, just as they are concerned with constructing culturally appropriate tools to minimize stigma-borne resistance to information. As such, public recognition of the vulnerabilities of forced migrants to contract HIV due to their position of social inequality is obscured (Dodds et al. 2004). The unfortunate end result of these structural barriers to healthcare access, combined with informational juggling, is increased onward transmission of the virus and late presentation of those infected to healthcare services.

The above discussion has involved two interrelated types of healthcare. Primary care, prevention and testing for HIV are meant to be conducted through the GP; treatment for

diagnosed HIV is meant to be accessed through the GUM clinic. Thus, the emphasis on GPs' awareness of the issues regarding refugee and asylum seeker patients originates due to their role as the first point of contact with the NHS. However, both GPs' and GUM clinics' functions are often bypassed by persons infected with HIV who present to emergency wards with acute physical symptoms. In such cases, it is clear that the usual steps in accessing the system have not been taken; some reasons for these failures have been discussed. One prominent reality of service provision is inconsistent receptiveness across PCTs. Unfortunately, 'sympathetic' GPs cannot treat every refugee or asylum seeker, and there is a need for more awareness of the issues and adherence to culturally competent approaches throughout the system. Taking advantage of the inconsistencies shifts focus away from the structural obstacles to accessing care. According to one Informant, non-'specialist' health practitioners should be responsible for knowing about these issues simply because the general population they treat includes refugees and asylum seekers. Large-scale advocacy efforts are crucial in working toward such changes. If the UK remains committed to rights-based healthcare provision, there is clearly a need to improve the opportunity for articulation of this right for those who encounter problems with doing so within the current system. Though a reversal of the policy of excluding rejected asylum seekers from HIV treatment would be a welcome step, it is evident that more than just legal barriers to healthcare utilization persist. As some Informants stated, both refugee communities and healthcare practitioners have to be 'convinced' to engage in the medical encounter; often this involves explaining entitlement regulations and PCT accounting procedures.

An overarching concern, present throughout the literature and across all conversations with Informants, is the regrettable conflation of HIV and immigration in public discourse. The need to address public stereotypes, and break the 'vicious cycle' described above, is apparent as part of the effort to reduce stigmatization. While it is a topic of concern throughout the field, it is unclear how such pervasive attitudes might be counteracted. Recent government policies regarding welfare provision for asylum seekers are in part a reaction to the growing anti-asylum stance among the public, which is compounded by the outcry against 'treatment tourism'. Conversely, it is possible that the legislation in turn legitimates and encourages those same attitudes of stigma, xenophobia and racism. Perhaps a reversal of government policy away from seemingly lending support to the 'treatment tourism' hypothesis may lessen these sentiments. It may be that the best-suited actors to mitigate the immense obstacle of stigmatization are, in fact, policy makers. Perhaps the universality of healthcare is their domain to protect, both in actuality and in perception.

The conflation of immigration and HIV discourses in the UK is not unique. In fact, 'Press and political discourse in many countries have headlined the association between migrants and the spread of HIV/AIDS, although in reality their vulnerability results from their limited or non-access to prevention and education, and to detection and treatment for those who are infected' (Taran 2002). Initiatives such as the European Project on AIDS and Mobility illustrate the similarities regarding this issue across Europe and the increasing importance of networking and knowledge sharing among service providers to collaborate on policy development (del Amo et al. 2001). On a global level, several Informants mentioned that one point in the advocacy discourse is the contradiction between the UK's professed commitment to combating the spread of HIV in the 'developing world' and its failure to provide for adequate care and prevention for the same persons in Britain. In the eyes of immigration opponents, asylum seekers in the UK are somehow different from the now-ubiquitous images of 'AIDS orphans' shown as part of funding appeals for interventions in

Africa. However, due to the global nature of forced migration, persons suffering from HIV in other parts of the world are, in actuality, part of the same population and affected by the same epidemic as those who reach the UK after fleeing persecution and armed conflict. Thus far, this interesting realization has only been made by NGO advocates; it has yet to penetrate the public discourse on HIV and immigration.

7.2. Limitations

This paper draws on secondary literature and interviews with several Informants involved in interventions to facilitate access to healthcare and health-related information. Due to timeframe limitations, I have not incorporated any direct data collection component with forced migrants affected by HIV; some of their views have been gleaned from other publications. The ethical constraints against one-off research encounters with marginalized groups were also taken into account. As mentioned previously, the literature is heavily influenced by studies of African-born immigrants, and information on non-Africans was difficult to find. This is a major limitation of the current paper. Also because of space and scope limitations, it does not detail certain aspects of the issue, such as the controversy regarding routine testing of all asylum seekers for HIV upon entry into the UK, healthcare in detention centres and accommodation centres, the existence of one-stop services that include medical care, and, in the realm of intervention, dynamics of project funding.

Most importantly, by focusing on forced migrants, it omits consideration of certain other populations that are yet more invisible and marginalized, and are similarly affected by barriers to accessing healthcare. Of these groups, the most relevant to the current analysis are undocumented migrants and visa ‘overstayers’. While not officially categorized as forced migrants, some of them may be described as such. According to several Informants, they continue to be the most difficult to reach population due to their even greater reluctance to appear before not only government authorities but also community organizations. Few studies exist that attempt to isolate undocumented migrants; as increasing numbers of asylum seekers whose applications are rejected ‘disappear’ into the parallel economy, the issues discussed above as concerning this group increase in relevance.

7.3. Further directions

The current analysis has revealed some of the numerous issues involved in forced migrants’ access to healthcare; indeed, the situation is defined by complexity. The paper has shown that no single approach to explaining access and utilization of healthcare is sufficient. Cultural considerations have to be taken into account alongside legal, institutional and societal constraints. For example, stigmatization surrounding transmission of HIV and entitlement changes in response to outcry about ‘treatment tourism’ should be regarded in tandem. And the systemic impact of dispersal must be analysed in light of availability of services as well as xenophobic attitudes outside of London. In sum, a multi-disciplinary, multi-perspectival approach is necessary in order to adequately address the complex interplay of relevant factors.

As previously stated, this is a preliminary study based mainly on secondary literature. Further multi-disciplinary and empirical research is needed. One starting point for enquiry

might be identification of individuals who have succeeded in accessing healthcare despite the significant barriers, and have also overcome the societal pressures of stigmatization to become HIV educators and advocates within refugee communities. Perhaps it would be instructive to examine the ways in which they are empowered to do so. Another direction for further research is to conduct systemic studies of organizational networks and their interventions in this field, some of which have been introduced above. The majority of programming evaluation focuses on interventions in isolation. However, as this paper has shown, the strengths and weaknesses of many actors in different aspects of the situation influence the capacity and relevance of their work. It would be helpful to look at the network of interventions and the extent to which members fill each others' gaps in addressing the set of issues described above.

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