

‘Experts’, ‘partners’ and ‘fools’: exploring agency in HIV treatment seeking among African migrants in London

Abstract

In an attempt to promote patient agency and foster more egalitarian relationships between patients and doctors, discourse concerning health and wellbeing in the UK has increasingly centred around the notion of informed and ‘expert’ patients who are able to effectively input into the direction and management of their own health care and treatment. While the relationship between a patient and their doctor can play a vital role in influencing the treatment decisions and health-related outcomes of people living with long term illness, little is known about the ways in which people living with HIV actually perceive their relationship with their doctors, nor the implications this may have for the types of treatment they may seek to use and the related information that they share. Drawing on research undertaken amongst HIV positive migrants from southern Africa living in the UK, this paper argues that patient-doctor relationships can be heavily influenced by the perceived legitimacy of different forms of medical knowledge and treatments and by culturally influenced ideas regarding health, wellbeing and agency. Despite a desire amongst some migrants to use ‘traditional’ medicines from southern Africa as well as other non-biomedical treatments and therapies, the research found that the perceived lack of legitimacy associated with these treatments in the UK rendered their use a largely clandestine activity. At the same time, many patients made clear distinctions concerning issues affecting their immediate health and factors influencing their more general wellbeing, which in turn, impacted upon the information that they chose to share with, or conceal from, their doctors. Such findings challenge assumptions underpinning policy promoting patient agency and have significant and, in cases, potentially adverse implications

for the safety and effective administration and management of HIV treatments in African migrant populations and possibly more generally.

Introduction

For the last twenty years, sexual health promotion and HIV prevention in the UK has, in large part, been premised on the assumption that biomedical and science-based understandings of illness form the framework within which treatment seeking and treatment management decisions are made (Johnson, Mercer, & Cassell, 2006). Such approaches imply people will act in a rational and responsible manner to maximize their opportunities for securing effective biomedical treatment (Schoepf, 2004) whilst giving little recognition to the broader social, cultural and economic context within which treatment seeking and management decisions are made (Kesby, Fenton, Boyle, & Power, 2003; Imrie, Elford, Kippax, & Hart 2007). Recently however, attempts have been made within the UK health sector to move away from a purely science-based biomedical model of disease, to acknowledge and explore the more subjective, social and cultural dimensions of illness as they are experienced by people who are themselves living with ill health (Whelan, 2009). In seeking to better understand such experiences, particular attention has been paid to the role of ‘illness narratives’ (Kleinman, 1988; Garro & Mattingly, 2000) which reflect socio-cultural understandings and values and through which people can obtain or assert particular social identities, communicate what is significant in their lives, make sense of illness through a narrative structure (Mattingly, 1994) and, where necessary, re-establish some degree of order and continuity to the ‘biographical disruption’ which may be caused by ill health (Bury, 1982).

As Frank (1997) explains, different versions of the narratives of those living with ill health are influenced by who is being told, when and where, and what is or is not deemed appropriate to tell. Directly, inter-related with this, it is now well recognised that effective communication between patients and their doctors is fundamental in helping influence positive health outcomes (Ong, de Haes, Hoos, & Lammes, 1995; Charles, Gafni, & Whelan, 1997). In the

UK, the idea of ‘resourceful’ (Muir-Gray, 2001), ‘autonomous’ (Coulter, 2002) and ‘expert’ patients who are able to input effectively into the control and management of their own health care has been at the forefront of government policy on health since the late 1990s (cf. Department of Health 1999; 2001). Encouraging the promotion of patient-doctor ‘partnerships’, such approaches have played a key role in focusing attention on encouraging patient judgement, agency and empowerment in the health care process.

Such initiatives, in which patients are frequently recast as ‘service users’ or ‘clients’, undoubtedly appear to be well intentioned in reshaping power relations within the health care system. However, using research undertaken with migrants from southern Africa living with HIV in the UK, this paper seeks to add to debates regarding doctor-patient partnership models by exploring how multiple meanings and practices of health and treatment can shape communications within the clinic. The paper argues that patient agency can itself be heavily influenced by wider ideas about individual responsibility, the perceived legitimacy and effectiveness of different types of health care and treatment, and ideas about what kinds of information should or should not be shared with medical professionals. Placing particular focus upon medical knowledge, patient use of ‘traditional’ and ‘alternative’ medicines and treatments,ⁱ and ideas about health and wellbeing, it is argued that while patients are encouraged to ‘take control’ of their health care, wider structures and norms which govern dominant ideas about health and wellbeing can continue to both produce and constrain their actions and push less ‘acceptable’ and regulated ideas and behaviours underground. This not only calls into question the degree to which the promotion of patient agency reflects the empowerment or constraint of individual health care, but also highlights the potentially adverse implications which can result for individual and public health when the effective administration of life prolonging treatments are compromised by disjunctures between

individual beliefs and desires and pressures to be seen to be complying to wider and more 'acceptable' health care agendas.

Knowledge and legitimacy in health care encounters

In an age in which one in every three people in the UK is living with a chronic illness or disability (Wilson, 2001), and can only manage rather than cure their condition, the idea of developing patient resourcefulness and expertise seems logical. However, it is increasingly acknowledged that such approaches tend to overlook deep-rooted professional power and the structural constraints which govern resource accessibility (Tang & Anderson, 1999; Cant & Sharma, 1999; Wilson, 2001; Fox, Ward, & O'Rourke, 2005). Whilst asserting that those in positions of recognised expertise have the authority and power to regulate behaviour, a Foucauldian interpretation of power relations within medical encounters also recognises that self-surveillance carried out by individual patients as well as processes of socialisation which foster respect for the knowledge of those in positions of authority can influence individual health seeking behaviour (Wilson, 2001; Lupton, 2007). Perhaps paradoxically therefore, encouraging patient agency in health care assumes both a level of compliance to accepted (usually biomedical) agendas and a level of autonomy in the pursuit and management of health care and treatment, both of which can present particular challenges to patients and health practitioners.

One such challenge concerns decision making over treatment seeking and adherence and the information on this that patients are willing to share with health professionals. Despite the increasing popularity of alternative treatments and therapies in the UK in recent years, there remains a tendency for dominant health discourse to view the use of biomedical treatments as

constituting rational and responsible behaviour. As such, the use of non-biomedical treatments and therapies are reportedly viewed by some health professionals as somehow illogical and deviant, and as behaviour that still needs to be supervised and managed from within the biomedical sector (Cant & Sharma, 1999; Cohen, McCubbin, Collin, & Pérodeau, 2001; Keshet, 2009; Broom & Adams, 2009).

Research suggests that this is particularly apparent in relation to HIV, where the development and availability of potent anti-retroviral combination therapies has focused attention on the ‘technologization’ of HIV care and the ability of clinicians to manage the course of the infection (Yallop, Lowth, Fitzgerald, Reid, & Morelli, 2002; Gold & Ridge, 2001; Persson Race, & Wakeford, 2003; Rosengarten, Imrie, Flowers, Davis, & Hart, 2004; Davis, Frankis, & Flowers, 2006). With such significant biomedical advances being made in recent years, non-consistent use of anti-retroviral therapy (ART), and use of other forms of non-biomedical treatment can be interpreted from within the health sector as a combination of ‘incompetent’ doctors and ‘failing’ (Green & Smith, 2004) and ‘desperate’ (Broom & Adams, 2009) patients. However, such understandings overlook the broader socio-cultural contexts within which such treatments are used (Wong & Ussher, 2008; Schumaker & Bond, 2008), and the ways in which the meanings and values people invest in different treatments and medications can influence treatment uptake and consistency (Persson, 2003; Del Casino, 2004; Reynolds Whyte, van der Geest, & Hardon, 2007; Helman, 2007). As Van der Geest, Reynolds Whyte and Hardon (1996, 166) state, “rarely is noncompliance [with medications] the result of patients misunderstanding the doctor’s information, but it is the result of patients having different ideas and, in particular, different interests.” Such issues are perhaps particularly pertinent amongst migrants in the UK for whom understandings of health, illness and treatment may more commonly fall outside of the biomedical parameters which underpin the

National Health Service (NHS). Indeed, as Green, Bradby, Chan, and Lee (2006, 1499) explain, despite some efforts to make the NHS more equitable and inclusive, the promotion of different ideas about health have been sporadic and have often tended to “downplay or pathologise black people’s cultures whereby ethnic minorities are constructed as dangerous to their own health.”

This is of considerable significance in the case of HIV, since it affects a disproportionate number of black African migrants in relation to the white population of the UK, and requires adherence to carefully monitored and individualised anti-retroviral treatment regimens in order to help prevent the development of drug resistant strains and ultimately, death. At the same time, delays in getting affordable and consistent sources of ART to many parts of Africa have meant that historically, relatively few people from affected countries have been able to rely upon such forms of biomedicine and have been placed in situations in which it is arguably entirely rational to seek out alternative forms of treatments. Indeed, such treatments are often integral to African cosmologiesⁱⁱ which regard many types of ill health as having environmental or spiritual, rather than purely biomedical aetiologies, and many of which have been found to be effective in peoples’ own or shared experiences via the provision of physical and/or psychological relief. As Kremer and Ironson (2006, 520) state, “Writing prescriptions is easy but in the end, regardless of what the physician wants, the patient makes the ultimate decision whether or not to take ART.” This paper argues that such factors are influenced by a constellation of discourses and practices which shape migrants’ agency in health seeking. The paper thus seeks to examine the factors which influence the relationship between HIV positive migrants from southern Africa and their doctors, and to provide insight into the potential implications of these relationships for treatment seeking and consumption.

Methodology

This research was undertaken as part of a larger study on treatment seeking and treatment management amongst migrants from southern Africa living in London. Ethical approval for the study was obtained from the East London and The City Research Ethics Committee and the Institute of Education, University of London, and informed consent was obtained from all informants prior to participation. This paper draws upon data obtained through eleven focus group discussions held with seventy migrants from Zimbabwe (n=39), Zambia (10) and South Africa (21), thirty nine of whom were women and thirty one men, and twenty repeat interviews (a total of forty interviews) held with migrants from these countries (twelve women and eight men). At the time of the study, interview participants were accessing HIV services at a London hospital.

The aim of the focus group discussions was to gain insight into people's understandings and experiences of health care services in the UK and in their home country, and their access to, and use of, biomedical, alternative, and traditional sources of treatment. Selection criteria for participation included coming to the UK as a migrant from Zimbabwe, Zambia or South Africa, living in London and being aged over 18. Five of the groups were single gender, and six were mixed, according to participants' preferences. The location of each discussion was decided upon by group participants and included community group centres, peoples' homes and rooms within the university in which the lead researcher was based. Each discussion took between two and five hours, was tape recorded (with permission) and transcribed verbatim.

Most participants from Zimbabwe and Zambia were accessed via community support groups and had arrived in the UK within the past decade. Those from South Africa and those who had been in the UK for longer time periods and were not making use of community groups

were accessed via more informal social networks e.g. via friends of key contacts. Many of those who had arrived in the UK from Zimbabwe in the past decade had applied for asylum in the UK. A number of the Zambians and South Africans had applied for leave to remain on compassionate grounds, having first arrived in the UK on study or work visas.

At a later stage of the research, repeat interviews were undertaken with twenty migrants from Zimbabwe (n=10), Zambia (n=8) and South Africa (n=2) who were accessing HIV support services via a major London hospital.ⁱⁱⁱ Participation was on a voluntary basis and interviews were undertaken in a location of the participant's choice (usually in a non-clinical setting in the hospital, at the person's home or at the university). An interview guide approach (see Kitchen and Tate, 2000) was used, enabling flexibility in wording and ordering of questions, a more conversational form than that offered by structured interviews, and the possibility of following up new issues as they were raised. Interviews were tape recorded (with permission) and transcribed verbatim by the lead author. The purpose of these interviews was to gain insight into the ways in which social, cultural and economic factors had influenced people's understandings of their health prior to, and since their HIV diagnosis, and how such factors had oriented them towards seeking particular types of treatment. Particular focus was placed upon the relationship that patients held with health providers such as HIV clinicians and GPs and the ways in which these relationships influenced the kind of treatment that people sought, and the kind of information that they chose to disclose to them.

It is likely that the lead researcher's previous experience of working in southern Africa and with migrants in the UK played a role in facilitating the discussions. However, the fact that she also had non-clinical status and was able to ask questions which drew upon peoples'

experiences beyond their encounters with biomedicine are likely to have helped to open up spaces for discussion on what are, potentially, sensitive issues.

Communicating with HIV clinicians

Almost all of the participants involved in interviews in this study commented on the high level of trust and respect that they held for their HIV clinicians. In most cases, people had been seeing the same doctor since their initial diagnosis, a factor that had helped them to build up a relationship that they regarded as solid and dependable. As has been reported elsewhere (cf. Horne, Cooper, & Fisher, 2008), a number of patients felt that the expertise and experience of their physicians made them best placed to advise them on their treatment, and as such, they were happy to take their recommendations with little question. This was most often the case amongst those who had come from relatively ‘westernised’ backgrounds and had primarily used biomedical treatments for illness whilst in Africa. However, it was also reported amongst several people who, at HIV diagnosis, were already extremely sick with an AIDS-defining illness. In these cases, individuals felt that the knowledge, expertise and care provided by their doctors had been the major factor in their survival, and as such, they reported placing ultimate faith in them. The competence of doctors was also judged by the perceived quality of their technical and inter-personal skills, with those seen to be commanding respect from other health workers viewed as being the most capable.

While some people were willing to follow their doctor’s advice with little question, most of those interviewed were keen to take a considerable level of responsibility for their health care and treatment. Indeed, some people reported that their HIV clinician had actually made a point of emphasising that they, as patients, played the most important role in the success of their own treatment and health since they were the only ones who could guarantee that they

would take their anti-retroviral medications as they should. For some people, this also involved proactively seeking information on biomedical treatments that they had been prescribed, and taking the initiative to discuss biomedical treatment options with their doctors whenever the opportunity arose.^{iv} However, others cited a number of factors which constrained their ability and willingness to share their thoughts over, and experiences of, treatment taking with their doctors.

One such issue was the reported tendency amongst some doctors to use medical terminology that was considered too complicated or inaccessible to understand. Talking about encounters with his HIV doctor when he started taking ART, a Zambian man^v explained how confusing he had found the experience and how he did not feel that he was in a position to make a fully informed decision over the treatment.

There was a language that they were speaking that I didn't understand – the viral load, CD4 count – these were things that they could understand but I couldn't understand. So it's like what is a CD4 count, what is a viral load, how do the two behave? They were saying this is too low, this is too high – but they were speaking a language I couldn't understand.....I've had a choice [over treatments] but to be quite honest it's quite difficult to make the choices because the language that is spoken with the treatment is a new language. Even though they say you can try this or this, they are talking about M1, M4, M25 – you feel like saying 'just tell me what I've got'.....even the leaflets, there are certain words in there that you have to go in a dictionary to find to understand it.....They won't come to do it in a language that you can understand because that is the language that they know.....that medical language defeats you. I'm lucky, I'm only on two tablets, but

for people who are on more, to explain to them what each tablet does to you – you can say ‘yes, yes’, but to be honest, I might have understood, but not fully.

(M7, Zambian)

When asked why he had not requested that the doctor explain his treatment in a more accessible manner, the informant’s response was typical of the majority of those interviewed who felt that the doctors had too many other important issues to attend to, to have to answer ‘foolish’ questions from patients.

If someone is telling you this is A, B, C, and you keep asking the same questions, you will feel a fool. I’d love to ask questions but I don’t want to bore someone in trying to learn. I’m not a doctor and I haven’t reached that level where there will be a language they will speak that I will really understand.

(M7, Zambian)

Partly as a result of these gaps in communication, tensions in the patient-doctor relationship were also reported when doctors were keen to move patients on to different treatments. In all such cases, patients acknowledged that the new medications they were being transferred to were considered by health professionals to be more advanced than their existing treatments. However, several people commented that they did not feel that it was necessarily in their best interests to change treatments, but that they had not had the opportunity to discuss the options fully with their doctor. F8 (a Zambian woman) for example, had been put onto a combination therapy which meant that she only had to take one, rather than two tablets each day. However, she reported feeling much more comfortable taking the tablets separately since she felt better able to monitor the effects of each drug individually. Similarly, M5, a Zimbabwean man, was

particularly aggrieved to find that his treatments had been changed without, he felt, him giving his consent. In this case, he commented that the desires of the doctors to pursue more advanced medications and make the treatment ‘easier’ to take had taken precedence over his own wishes and his knowledge of the way that his body worked.

I’m a bit angry because when I spoke to my consultants last year, they said they were going to keep me on the existing drugs but add another one. And my viral load was undetectable. But when the new consultants came in, they said they wanted to change them to make my treatment easier. But I said ‘I’m not complaining’ – but they kept saying ‘easier, easier’. ...Now they are telling me that they want to make it easier because it has worked for other patients – I am not those other patients.

(M5, Zimbabwean)

Although almost all of those interviewed placed faith in their HIV doctor as an individual, a number of people raised more fundamental concerns regarding the intentions of the health service more broadly. Some participants felt that their status as migrants made them particularly vulnerable to exploitation by the health sector and voiced their suspicions that they were being used as guinea pigs in biomedical trials. This was particularly evident amongst participants from South Africa, where health issues have historically been strongly associated with apartheid, exploitation and exclusion. As the following discussion demonstrates, it was apparent that such perceptions could directly influence the way that people related to health professionals, the information that they were willing to share with them and the repercussions of this for treatment adherence and treatment seeking outside the biomedical sector.

In certain circumstances, they [people with HIV] know that they are being put on trials without anyone talking to them. Because when they go out and they say at a support group which medicines they are taking – and they are the only one taking this, then they will be asking ‘why?’ Then they think they are on trials because when it happens it brings a question mark. The other thing is that when people are on medication they are listening to their bodies, and you go to the doctor and say this is what is happening –some doctors don’t listen. The patient will tell them this is how I am feeling, can I change the regime and they will say ‘no, no, no’ and they will insist that you stay on that. Now if that person goes home a lot of things are going on in their heads. They think; I am telling my doctor but he is not listening to what I am saying. Maybe that person is an asylum seeker so he can’t stand and fight with the doctor. So, what he will do is maybe he will stop [the treatment] or maybe start looking for alternatives. But meanwhile, when they go to the hospital they will keep quiet and the hospital will keep recording false data because that person is not taking the medication. So, that way the trust between the patient and the doctor comes under quite a big question mark because the doctor is not really listening to the patient.

(South African man, mixed gender focus group)

Some people felt that a further obstacle to effective communication could occur when doctors were caught up in wider health care agendas which promoted certain types of medications in the interests of the pharmaceutical industry. For a number of people (particularly people from South Africa and some Zimbabweans), this was interlinked with an underlying belief in conspiracy theories in which the transmission of HIV and the testing of drugs were seen as part of a ‘western’ agenda to control and exploit people in developing countries (for a more detailed discussion of these issues see Niehaus with Jonsson, 2005). For others such as M1, a Zimbabwean man, it was also considered to result from an attitude amongst health providers

in the UK that continues to treat biomedical knowledge as superior to other forms of understanding such as traditional treatments from Africa.

The NHS, it's okay. But they are in a situation where they believe that only one type of medication works because they can define it themselves. It's a sort of unidirectional way that somehow they have convinced themselves that what they don't understand is wrong. And then they define normality in terms of what they themselves understand. Which is nonsensical because actually, these people who are using these other things [other forms of medication], they lived for millennia without the medications that you are using over here and they didn't suddenly die, they are not extinct.

(M1, Zimbabwean)

Use of non-biomedical treatment

It is increasingly recognised that some non-biomedical treatments can provide physical and psychological benefits in terms of health and wellbeing. However, it is also acknowledged that the interactions between some types of herbal and pharmaceutical medicines can have significant, and potentially adverse repercussions for the health outcomes of people taking HIV anti-retroviral treatments (Schumaker & Bond, 2008; Mills, Montori, Perri, Phillips, & Koren, 2005a) and indeed, that the claims supporting some such 'remedies' are highly debatable. Research has found that a significant proportion of people use traditional and/or alternative treatments for HIV either instead of, or in combination with anti-retroviral medications (Pawluch, Cain, & Gillett, 2000; Owen-Smith, Diclemente, & Wingood, 2007; Littlewood & Venable, 2008). In the present study, forty five per cent (45%) of those participating in interviews reported using some form of non-biomedical treatment before they

had started taking, and/or in combination with, their anti-retroviral treatment (ART). In addition, 75% claimed that they would like to use non-biomedical treatments either in combination with, or as alternatives to ART if they were able to access them.

All of those concerned were keen to try other treatments to improve their health status. However, as has been reported elsewhere (cf. Doyal and Anderson 2005; Doyal, Anderson and Papparini, 2009), reliance upon ART was also found to lead to some people feeling that they were ‘trapped’ in the UK. Many people interviewed were therefore keen to try other treatments which, if successful, would enable them to return to their home country. More women than men reported having used such treatments, although similar proportions of men and women expressed a wish to use them. The desire to use such treatments did not appear to be heavily influenced by age, level of education or time spent in the UK.^{vi} However, it was more commonly felt (in both interviews and focus groups) amongst those who had grown up in families which had used such treatments (often ‘traditional’ African treatments), the majority of whom had been based in rural areas. Although people from all three countries reported using, or wishing to use, non-biomedical treatments, it was particularly evident amongst those from the Kwa Zulu Natal area of South Africa and the Matabeleland area of Zimbabwe, where such practices were reported to play an important role in health seeking culture.

In line with previous research, (cf. Kremer & Ironson, 2006; Peltzer Friend-du-Preez, Ramlagan, & Fomundam, 2008), few people had fully disclosed to their doctors their use of, or intentions to use other treatments. A number of key reasons were given for this. First, some respondents stated simply that they did not recall their doctor ever asking them about their use of other treatments, or that they had only done so when they had first started taking ART.

Secondly, it was generally felt by both focus group and interview participants, that using non-biomedical treatments – particularly those which had been sourced from Africa, would be frowned upon by HIV doctors in the UK, and would open the patient up to a level of shame, embarrassment and rebuke. It was common for people to comment that openly using such treatments when access to more advanced biomedicine was freely available would be interpreted as foolish, naïve, and irresponsible, even when they themselves placed considerable faith in non-biomedical treatments that they had used whilst in Africa. Rather than risk this humiliation, some people had decided that they would not broach the subject with their doctor. F7, a Zimbabwean woman, for example, had been taking a series of different herbal medicines which had been sent to her by a traditional healer in Zimbabwe. Although she reported becoming increasingly unwell as a result of using these treatments, she did not report this to her doctor, stating

I didn't talk to them about what I had been taking because I was so embarrassed.....I believe that if you are talking to someone who is educated medically, they won't understand – 'you are using herbs, what do you need to use herbs for?' So I thought they wouldn't understand why I wanted to use the herbs, what I was going to use them for. So that's why I didn't tell them.

(F7, Zimbabwean)

A major issue raised by respondents was their inability to 'prove' to doctors that treatments that they obtained from Africa were effective. However, it was frequently commented that unlike Chinese medicine which was well documented and as such, relatively well accepted, treatments from Africa were rarely researched, resulting in ill informed preconceptions regarding their safety and utility.

A further reason for not discussing the use of such treatments was the fear that doctors would attempt to stop the person from taking them even though the patient themselves felt that they were of benefit to their health. In order not to upset or offend their doctor by going against their wishes, therefore, a number of people felt that it was best just not to mention such things in the first place. Other informants such as F4 and M4, explained that if they ever did discuss their use of, or intentions to use, non-biomedical treatments, they would first gauge the mood of their doctor and then wait to broach the issue when the doctor appeared to be in a receptive frame of mind. In addition, they commented that they would read up on the treatments that they wished to take so that they could go to their doctor fully armed with evidence supporting its efficacy. This was considered especially important when dealing with those doctors who were reputed to be particularly disapproving of non-biomedical treatments.

You know, I like the doctor very much, but I have to find ways to get to her – I don't just bring things up – I have to see her state of mind that day, and if she is happy and chatty then I can bring up the situation with her and we can talk about it. If she is in a bad mood, I save it for another time.

(F4, Zimbabwean)

Normally I'd research it first and before I saw the doctor I would print off information written by other doctors and then ask him what he thinks about it.

(M4, Zambian)

With most patients only attending appointments with their HIV doctor every three months, however, there was often a considerable time lag between people trying new treatments and

finding an opportunity to discuss this with their doctor and in some cases, it is possible that this may have risked compromising the effective use of their anti-retroviral treatments.

The uptake of non-biomedical treatments was also not generally discussed when patients did not feel that it was necessary to inform their doctors of their use. This was usually the case when people were taking various types of non-prescription supplements and immunity boosters that they had purchased in the UK or via websites, or when products such as Aloe Vera were deemed by informants to be so ‘natural’ that they could not pose any form of health risk. In such cases, most people concerned felt that because these treatments had come from the UK or via ‘official’ websites, they were more likely to be acceptable to their doctors than ‘traditional’ treatments sourced from Africa. The fact that many of these treatments were also available in tablet or bottled form (rather than as raw or semi-processed herbs) also helped people to legitimise their use, since it implied that they had been ‘measured’ and were regulated by officially ‘approved’ health professionals. As such, a number of people explained that they had not felt that these products were likely to interact negatively with their ART and that it had not occurred to them to discuss the use of these products with their doctors.

At the same time however, some people felt that the legitimate nature of these treatments meant that it would be easier to discuss their use with a doctor should they ever feel it necessary to do so. One woman patient on ART for example, explained that she was seeking to also use Mariandina, a herbal product that its makers claim helps maintain good general health, boosts immunity and can help treat certain HIV-related conditions such as tuberculosis, herpes zoster and Karposi’s Sarcoma (see Mariandina Nutritional Health Products 2009).^{vii} In this case, the patient felt that she might discuss with her doctor her

intentions to use this product because Mariandina was itself made by a medical doctor (albeit a controversial one^{viii}).

Maybe because it was invented by a medical doctor they [her doctor] will understand what I am saying about it. It's different from me coming in with a package with some powder in it [i.e. herbal medicines from Africa] which no-one will understand. Maybe they will think that it was invented by a medical doctor, he knows what he is doing.

(F4, Zimbabwean)

Distinctions drawn by patients regarding issues affecting their health and issues affecting their more general well-being were also found to influence the kind of information that was shared with their treating HIV physician, and demonstrate that dominant cultural ideas and expectations regarding gender and identity are key components which need consideration when exploring the constitution of patient agency. One woman, for example, had been using a range of herbal medicines from Zimbabwe and from African markets in London to try to make herself more fertile. While she reported that she had found these medicines helpful in 'washing out' her stomach and her blood by bringing on diarrhoea and vomiting, she said that it had not occurred to her to discuss their use and the potential for negative interaction with her HIV treatments with her doctor because she viewed her fertility as a private issue, rather than an issue that was directly connected to her health status.

Similarly, a significant proportion of focus group participants and a number of those interviewed reported using herbal 'love potions' sent from southern Africa to attract partners and to enhance their sex drive and performance. Such potions are usually ingested and taken on a regular basis and as such, have the potential to interact with biomedical HIV treatments.

However, none of the people who reported taking them had discussed their use with their doctor, seeing this as an issue that fell firmly outside the bounds of what could or should be discussed with a health practitioner. When asked whether he would talk about his use of love potions with his doctor, M4 stated,

It's a hard question because this is about someone's feelings. If you get a woman and you feel you are not performing well sexually and you want to make this lady happy, I don't think that you are going to think first, well let me talk to my doctor! Because if they stop you and you really want this lady – that's a big question mark.

(M4, Zambian)

None of the research participants claimed to know exactly what was in these substances, and the present study did not involve any form of scientific analysis of their content. The potential for adverse interactions between such 'treatments' and ART is not therefore known. However, a number of participants themselves acknowledged their concerns over the use of such potions, stating that there was a temptation to take them in large and unregulated amounts to ensure their efficacy.

We tend to use these things in greater quantities to make sure it works. You might take it every day and you'd use a tablespoon instead of a teaspoon. All we might know is that it has come from this tree – but a tree has so many properties in it that you don't know what you are taking.....It's not as if you actually see someone going to the tree to get this thing – so it could be anyone getting anything from any tree. These things are not done out in the open so that's another reason why people don't talk about these things with their doctor – its something they would do in private.

Conclusions

For the past decade, health care policy in the UK has made steps to promote patient agency and to reshape the power relations between doctors and patients. Ideas inherently linked to the notion of patient-doctor partnerships clearly imply the need for a significant level of mutual respect, openness, trust and good communication between both parties in the health care process. However, the findings from this study challenge the extent to which such restructuring is achievable or necessarily desirable when prevailing ideas about agency, medical knowledge and the legitimacy of various types of treatment continue to be perceived by patients as endorsing the dominant position of biomedicine.

In the research reported here, such perceptions were found to place major constraints on the ways that some patients viewed their relationship with their doctors, and the type of information that they were willing to share with them regarding their decisions over treatment seeking and consumption. A major issue for patients seeking HIV treatment was the difficulty they faced in understanding the treatment choices that were available to them, and their lack of confidence in asking doctors who they perceived to have more important issues to attend to, to provide information in a language that was more accessible to them. At the same time, such difficulties in effective communication were found to lead to confusion and anxiety when people did not understand why their treatment was being changed, or when they felt that the wishes of their doctors – often assumed to be in concordance with wider biomedical health agendas - were being prioritised over their own understandings and health care needs.

Although some people reported that they willingly chose to conform to the advice of their doctor, a significant proportion of people felt that their actions – or at least those actions undertaken in public – were constrained by the need to be seen by doctors and other people in their community to be acting ‘responsibly’ and adhering to the scientifically advanced treatment opportunities afforded by western biomedicine. While most people expressed their faith in ART, the research found that a significant proportion had used, or expressed a wish to use, ‘alternative; or ‘traditional’ treatments, and as such, sought ways to circumvent the monopoly of biomedicine. However, the stigma and secrecy associated with these treatments, particularly those obtained from Africa, meant that their use was often surreptitious and was rarely discussed openly with health care practitioners. Additionally, for some patients, various forms of treatments were considered too natural to be of any possible harm either taken alone or with ART, or were considered to be safe because they came in a processed form and/or were considered to originate from sources that patients felt that their doctors would find reputable. Information shared with health practitioners was also found to be restricted by patients when they did not consider the (usually herbal) substances that they were taking for issues related to aspects of their wellbeing to be of direct consequence to their HIV-related health outcomes.

Many of the issues raised in the present research were undoubtedly influenced to varying degrees by respondents’ status as migrants in the UK. While this, and the relatively small sample size precludes the generalisation of findings to a wider population, the ease with which processes of globalisation now enable people to maintain close social and material links with their home countries suggest that some of the findings may have wider relevance. Findings indicate that understandings over what constitutes reputable medical knowledge and the perceived legitimacy of different types of treatments can play a potentially important role

in influencing the information that patients choose to share with, or conceal from their doctors. In the case of HIV-related health care where certain herbal treatments have been found to have the potential to interact negatively with anti-retroviral treatments, such obstacles to effective communication between patients and doctors may have adverse implications for both individual and public health.

Although it was beyond the remit of this study to explore the views of healthcare providers, it is clear that their perceptions of the patient-doctor relationship must be central to any further research in this area, so that ways of initiating more effective channels of communication are established. Of key importance here is the need to find ways of ensuring that the ‘right’ kinds of questions can be asked, which, through recognising the very real discourses and practices that influence people’s every day lives, draw upon wider interpretations of health and wellbeing than only those contained within biomedical models of understanding. Central to this is the need for health care providers to more openly acknowledge the wide array of treatments that exist outside of the parameters of biomedical science, to recognise not only their limitations, but also their potential physiological and psychological benefits to individual users, and to proactively seek to ensure that patients are provided with opportunities, and feel able, to discuss their use of such treatments without fear of criticism or rebuke.

At the same time, this paper has demonstrated that agency in health seeking has many, often conflicting, dimensions beyond those of the biomedical frameworks within which current policy is drawn up. As such, it is important that health workers and policy makers do not assume that all patients construct their agency only via the discourse and practices of modern biomedicine and that they are able to look beyond viewing people and their bodies in purely

medical terms, to foster a wider and more flexible understanding of the ways in which people shape their agency and decision making over their health and treatment.

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ⁱ It is recognised that terms and categories such as ‘alternative’ and ‘traditional’ can be seen as problematic since in their very nature, they normalise and give precedence to biomedicine. While recognising the heterogeneous, fluctuating and overlapping nature of such categories, they are used in this paper as they have become conventionally used terms in the UK.

ⁱⁱ Whilst recognising the wide range of cosmologies which exist across and within different countries and regions of Africa.

ⁱⁱⁱ Focus groups participants were recruited from community groups and contacts across London, whilst interview participants were recruited from one London hospital. There was no overlap between the two groups.

^{iv} Such actions are linked to the relatively high levels of treatment activism associated with the field of HIV.

^v Interview codes are used here to protect participant identity. M refers to male respondents, F to female respondents.

^{vi} A small number of the youngest focus group participants who had migrated to the UK whilst still children were however, less likely to use or want to use African treatments.

^{vii} Although the makers of Mariandina do not claim to be able to cure people of HIV, there was a common perception amongst research informants that its use could significantly reduce the likelihood and effects of various HIV-related conditions. Testimonies posted at <http://www.mariandina.com/index2.htm#> also attest such claims. While the author of this paper does not know if or how Mariandina products interact with various forms of ART, some of the ingredients listed in the products e.g. St. John’s Wort, have been reported to have potentially adverse impacts on the effectiveness of certain HIV medications (cf. Mills, Foster, van Heeswijk, Phillips, Wilson, Leonard et al. 2005b).

^{viii} Mariandina was first produced by a Ugandan doctor, Charles Ssali. A controversial figure, Charles Ssali was suspended from the Royal College of Surgeons of Edinburgh in 1992 and publicly rebuked for his claims to have found a cure for AIDS (Laurance, 1998). Questions over the efficacy of Mariandina also led to the drugs being banned from sale in Uganda although they were later licensed for sale as nutritional supplements (Ariko, 2005). Despite such controversy, Ssali remained a popular figure in some quarters until his death, and is still hailed by some as a crusader against the monopoly of the pharmaceutical industry.