HIV/AIDS-related stigma and discrimination: Accounts of HIV-positive Caribbean people in the United Kingdom

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ABSTRACT

This paper explores the effects of HIV/AIDS-related stigma and discrimination (HASD) on HIV-positive Caribbean people in the Caribbean and the UK. In-depth, semi-structured interviews were held with a purposively selected group of 25 HIV-positive people of Caribbean origin, using primary selection criteria of sex, age, sexuality and country of birth. Interviews with respondents revealed that they are keenly aware of the stigma surrounding HIV/AIDS, which some attribute to a particularly Caribbean combination of fear of contamination, homophobia, and ignorance, reinforced by religious beliefs. In fact, religion serves a double role: underpinning stigma and assisting in coping with HIV. HASD has usually occurred where respondents have lost or do not have control over disclosure. Compared to UK-born respondents, the accounts of Caribbean-born respondents, most of whom were born in Jamaica, include more reports of severe HASD, particularly violence and employment discrimination. All respondents mobilise a variety of strategies in order to avoid HASD, which have implications for their social interactions and emotional well-being. While some manage to avoid the “spoiled identity” of the stigmatised, thereby creating their own understandings of HIV infection, these may remain individual-level negotiations. HASD affects HIV-positive Caribbean people at home and in the diaspora in a variety of ways: emotionally, mentally, financially, socially and physically. Interventions specifically addressing stigma and discrimination must be formulated for the UK’s Caribbean population. Tackling stigma and discrimination requires more than education; it requires “cultural work” to address deeply entrenched notions of sexuality.

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HIV/AIDS-related stigma and discrimination (HASD) has been deemed one of the greatest challenges to the fight against HIV infection (Aggleton, 2000; Mann, 1987). It is a worldwide phenomenon, with serious implications for both the HIV epidemic and the lives of people living with HIV/AIDS (PLWHA). HIV testing, HIV prevention (Brooks, Etzel, Hinojos, Henry, & Perez, 2005), access to treatment for HIV/AIDS (PLWHA), HIV testing, HIV prevention (Brooks, Etzel, Hinojos, Henry, & Perez, 2005), access to treatment for HIV/AIDS (PLWHA). HIV testing, HIV prevention (Brooks, Etzel, Hinojos, Henry, & Perez, 2005), access to treatment for HIV/AIDS (PLWHA).

The present research focuses on Caribbean PLWHA in the UK. This includes recent immigrants, and those who were born and raised in the UK and have at least one parent or grandparent of Caribbean descent. There is a relatively small body of literature on HASD in the Caribbean. Many accounts take the form of anecdote-informed speeches or declarations (Alleyne, 2004; Thomas, 2004), larger discussions on policy (Trotman, 2000), articles in or letters to newspapers (Blair, 2005; Jamaica Observer, 2005), or as part of behaviour surveillance surveys conducted by government ministries or regional organisations (e.g., CAREC & PAHO, 2006; Hope Enterprises, 2004). The relatively few studies that directly address HASD tend to focus on Jamaica: all agree that there is a high level of stigma in this country, and link this to what is also agreed to be a high level of homophobia in Jamaican society (Bain, 1998; Carr, 2002; Dinnall & Bain, 1994; Norman, Carr, & Jimenez, 2006; White & Carr 2005; Wickramasuriya, 1994). Important exceptions to this focus on Jamaica are Castro and Farmer’s (2005) work on Haiti, and Varas-Díaz, Serrano-García, and Toro-Alfonso’s (2005) study of Puerto Rican PLWHA. Castro and Farmer’s (2005) research took a different (critical medical anthropological) approach to HASD than most other studies, suggesting that HASD was less important than socioeconomic factors in hindering rural Haitians’ care-seeking behaviour. In Puerto Rico, HASD was found to result in the loss of social support, substitution to persecution, isolation, loss of employment and problems accessing health care (Varas-Díaz et al., 2005).

There is no research on black Caribbeans’ experiences of HASD in the UK. What there is concerning the UK’s ethnic minorities focuses on Africans (Anderson & Doyal, 2004; Dodds et al., 2004; Erwin, Morgan, Britten, Gray, Peters, 2002; Erwin & Peters, 1999; Flowers et al., 2006; McMunn, Mwanje, & Pozniak, 1997), due to their disproportionate representation among the ranks of the HIV+ in the country (UK Collaborative Group for HIV and STI Surveillance, 2006). Research on this population confirms findings elsewhere: for example, Dodds et al. (2004) report the link between HIV status and immorality. They also find HASD against Africans at the state and institutional levels, as well as at the community, family and individual levels.

Methodology

MA conducted in-depth, semi-structured interviews with 25 of 250 HIV+ participants in the LIVITY Research Project. A quota-based sample was used, with the primary selection criteria being sex, age, sexuality and country of birth. After filling out the main study instrument—an 11-part questionnaire seeking information on pre- and post-diagnosis sexual behaviour and condom use, travel and sex in the Caribbean, HIV knowledge, and STI history, among other things—patients were invited to participate in an in-depth interview. Researchers (MA and IS) helped participants to fill out the questionnaire if respondents requested assistance. Roughly two-thirds of the patients asked to participate were willing to do so. The sample size (25) was deemed appropriate to reach saturation.

Patients gave informed consent and were compensated for their time. Interviews were tape-recorded, lasted
between two and three hours, and were later transcribed by a professional with full adherence to patient confidentiality. The topic guide covered the issues in the questionnaire with an emphasis on ascertaining patients’ motivations and beliefs behind their (sexual) behaviour. Important additions to the quantitative arm of the study in the in-depth interview were stigma and discrimination and coping strategies. In particular, respondents were asked to describe their knowledge of HIV-related stigma prior to diagnosis and the reasons for it; their reactions to their diagnosis; decision-making around disclosure of their status; stigma and discrimination they may have experienced; how they felt HASD affected their lives; and how and how well they believed they were coping with their illness.

In the course of recruiting patients for the quantitative component of the LIVITY Research Project (i.e., the questionnaire), more information was gained on patients’ experiences of stigma and discrimination (among other issues) through their comments in response to the questions or issues brought up by the questionnaire. These data are also included in this paper.

Transcribed interviews were analysed using the qualitative analysis software ATLAS.ti. Interviews were analysed for recurrent themes in relation to levels of stigmatisation, the degree of felt and enacted stigma, and the impact of HASD on their lives and identities.

Of the 25 patients, 10 were homosexual or bisexual men, five heterosexual men, and 10 heterosexual women. Two-thirds of patients were born in the Caribbean. Of the 16 patients born in the Caribbean, most (10) were born in Jamaica. The proportion of Caribbean-born vs. UK-born patients, and of Jamaican-born vs. the rest of the Caribbean-born patients approximates the proportions found in the larger sample of 250 patients. Patients’ ages ranged from 19 to 72. Four patients were diagnosed in the Caribbean. Thirteen believed they had acquired their infection in the Caribbean. Respondents had been living with HIV for between nine months and 13 years. (See Table 1 for selected characteristics of the sample.)

The LIVITY Research Project was approved by the North West Research Ethics Committee, United Kingdom.

**Results**

We first explore respondents’ views on the reasons for HASD, as these impact on their negotiation of and experience(s) of stigma. This latter is addressed in the two subsequent sections, which are divided into “felt stigma” (their feelings about being HIV positive and the reactions they fear from others) and “enacted stigma” (the actual experience[s] of HASD) (Jacoby, 1994). We then discuss how respondents avoid HASD, while the final section considers the positive outcomes of respondents’ diagnosis.

**Reasons for stigma**

Respondents linked the stigmatising attitudes and behaviour of others to fear of contamination, HIV’s association with immoral behaviour, and ignorance. All respondents spoke of others’ fears of catching the disease, based on perceptions of the ease of transmission.

<table>
<thead>
<tr>
<th>Table 1</th>
<th>Sample characteristics&lt;sup&gt;a&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male</td>
</tr>
<tr>
<td>Sexuality</td>
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</tr>
<tr>
<td>Heterosexual</td>
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</tr>
<tr>
<td>Homosexual/bisexual</td>
<td>10</td>
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<tr>
<td>Age (years)</td>
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<td>45+</td>
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<tr>
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<td>5</td>
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<td>Caribbean</td>
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<tr>
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<tr>
<td>Trinidad &amp; Tobago</td>
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<tr>
<td>Grenada</td>
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<tr>
<td>Barbados</td>
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<td>Guyana</td>
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<td>St. Lucia</td>
<td>1</td>
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<tr>
<td>Place of infection&lt;sup&gt;b&lt;/sup&gt;</td>
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<tr>
<td>UK</td>
<td>6</td>
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<tr>
<td>Caribbean</td>
<td>9</td>
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<td>Place of diagnosis</td>
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<td>Caribbean</td>
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<tr>
<td>Total</td>
<td>15</td>
</tr>
</tbody>
</table>

<sup>a</sup> Values are crude numbers.

<sup>b</sup> According to respondent.

They...don’t want to have nothing to do with you, because they...think if you’ve got it and you sit beside them, you can pass it on to them some way or the other. (Jamaican-born woman)

HIV acquisition was associated with sexual behaviours and identities that were regarded as immoral. While women included promiscuity in their description of immoral behaviour, and there was some mention of prostitution, it was HIV’s link with homosexuality that dominated respondents’ accounts, particularly those of Caribbean-born respondents.

I think that the stigma is more around sexuality, how HIV ties in with the homosexuality. So HIV is linked to homosexuality and because homosexuality is stigmatised, then HIV gets stigmatised. I suppose HIV is seen as a by-product of being gay in Jamaica. (Homosexual Jamaican-born man)

Religion was a key factor in the link between immoral behaviour and HIV: many respondents had heard the view that only “sinners” contracted HIV, and that the epidemic was a means of being “punished for your sins,” as a Barbadian-born man put it. Women repeated variations of a morality tale told by their pastors in which a woman was infected by a man she had met on holiday. The tale laid the blame at the feet of the woman, not the man who infected her, for having sex outside the context of a committed relationship:

Because the way that [the preacher told the morality tale], the way [he] describe the [woman in the tale]...a very spiritual and holy person, who you wouldn’t think that that person would do that sort of thing, they’d
wait until probably they're in a marriage or something like that. But it was she went out there and all this holiness went out the window, and she got this venom. (Trinidadian-born woman)

Ignorance is understood as a general lack of awareness of HIV/AIDS, which is blamed in part on the influence of religion, lack of health promotion especially in the Caribbean, and the refusal of parents to discuss sexual issues with their children. There was also, however, in respondents’ opinions, a refusal to learn about HIV, which they believed was a peculiarly Caribbean phenomenon.

Setting on a bus sometimes conversations will come up and the things that they say, it’s ignorance. And how do you teach a person who doesn’t know to be tolerant? I mean it’s there, you get it from books, television, in the soaps, they put it in everything, they inform you. But yet people, they don’t see that. Most Caribbean people, they don’t take time to understand. They would beat something, but they don’t take the time to understand what they read. (Trinidadian-born woman)

A Jamaican woman called this “ignorance” the Jamaican “mentality” and linked it to homophobia as well:

Q: Do you have any idea why there’s so much stigma? A: We’ve got this mentality which is just … look at their mentality towards gays. Willing to take out a gun and shoot you if you are gay. I don’t even think it’s even education, because by now we should know that HIV and AIDS is not passable through [physical contact], but it’s our mentality I think. (Jamaican-born woman)

Most respondents believed that this “mentality” rendered HASD higher in the Caribbean and among members of its diaspora than among British people.

Felt stigma

PLWHA’s expectations about others’ reactions to them were dominated by worries about ostracism and disdain (“scorn,” as Caribbean respondents put it), violence, blame, and uncontrolled, malicious disclosure (“scandal” as a verb in Caribbean vernacular; or gossip) in response to people’s fear of contamination arising from the twin associations of HIV with imminent death and ease of transmission and a tendency for communities to blame HIV acquisition on immoral behaviour.

And if you have it, they think you’re nobody and they’ll scandal you all over the place. They will tell everybody. (Bisexual Jamaican-born man)

So it’s like they scorned [a PLWHA], they don’t eat with him. You know, he can’t cook for them. They cleaned down the whole house with bleach, Dettol and everything. (Homosexual UK-born man)

The use of the word “leper” when referring to the feared reaction encapsulates the relationship between fear of transmission and ostracism. In the words of one man:

I notice before this happened to me, that people who’ve got HIV and tell their friends, their friends sort of number them like, er, leper… [whispers] “They’re HIV, keep away from them.” (Grenadian-born heterosexual man)

Caribbean-born women and gay UK-born men in particular worried about being blamed for their illness. The women’s fear seems justified in light of the morality tales told in church.

Jamaican people, they get confused that dirty people have AIDS. Jamaican people make you feel it—I’m the cause of this. (Jamaican-born woman)

Some compared HIV/AIDS with other diseases, especially cancer, to highlight the particular stigmatisation and blame associated with HIV.

If you’ve got cancer or some other illness like that, people are like, “Ahhhh,” and all the rest of it. The minute they hear HIV, “It’s his own fault, he should have been using protection!” (Homosexual UK-born man)

Women in particular said that words like “dirty,” “nasty” and “bad” were used to describe PLWHA. These words point to behaviour as well as physicality: a “dirty” person is someone who infringes moral boundaries, is thus contaminated and can contaminate others.

Some bisexual and heterosexual men in particular were afraid of being labelled homosexual:

People ask “How did you get it?” and people think in Jamaica that you have to be a batty-man: “well, you must be gay.” (Bisexual Jamaican-born man)

Respondents also expected violent reactions from the community, especially Caribbean-born respondents, who shared more reports of violent incidents than UK-born PLWHA: “Nothing can take gunshot,” said one Jamaican-born woman explaining why she had not disclosed her status to a sexual partner. Caribbean-born respondents reported hearing of HIV+ people’s houses being stoned, burned down (as an act of purification as well as violence), beaten up, killed, and of communities ejecting PLWHA from their neighbourhoods.

Feelings about HIV

Respondents’ feelings about their condition were characterised by depression, alcoholism and suicidal ideation, arising from the association of HIV with likely death and social vilification. While many were better able to control these feelings/urges with time, one man still considered suicide an option 12 years after diagnosis:

[Suicide] is still there for me; I’m still getting counselling for it. I’m not where I was two years ago, but it’s still there and I think for me now it will always be there; I’ve made my peace with suicide. (UK-born homosexual man)

Some respondents, particularly women, fought with internalisation of stigma.

When I was first diagnosed I felt like… oh don’t drink from my cup, or, I didn’t want to kiss my son.” (UK-born woman)

Heterosexual men seemed to be the most affected psychologically. One Jamaican-born man said, “I can’t be happy,
I can’t be focused.’’ Another’s health (physical and psychological) was too fragile for him to commit to employment.

Because for instance I tried having a job and living a normal life, [but] it’s on and off ... something will happen and I don’t even feel like getting out of bed, and that disturbs everything at work. (Jamaican-born heterosexual man)

Enacted stigma

The above fears (“felt” stigma) mobilise stigma avoidance strategies, which will be discussed in the next section. As a result, there has been little “enacted” stigma. Enacted stigma was driven by a fear of contamination, arising from association with social transmission and death, and driven by immorality. The most notable difference among patients’ experiences is their variation by region. The most severe examples of HASD occurred in Jamaica, as verbal abuse, employment discrimination and community-level HASD. Family-level stigmatisation in either region was rare, and in some cases (in both regions) was corrected when the respondent explained routes of transmission. There are accounts of discrimination within both the Jamaican and UK health care systems.

HASD in the Caribbean

The only respondents diagnosed in the Caribbean were diagnosed in Jamaica. Community-level HASD was experienced in the form of disclosure of HIV status against the will of PLWHA and verbal abuse in the neighbourhood:

People were saying I’ve got AIDS where I was living, throwing abuse at me... calling me “AIDS Woman.” (Jamaican-born woman)

Employment discrimination could follow diagnosis in Jamaica:

You have to have a medical and as soon as they see you’re positive, then they don’t take you. I started the training and everything, passed the test and passed the physical, but they did a blood test as part of the physical, and they found I was positive and stopped me ...I went by the office and they said to me that they had stopped me because of medical reasons...I might die in their system, or something. (Jamaican-born woman)

A teacher was fired as the news of her status spread:

Parents were streaming in now [saying] they don’t want no AIDS teacher teaching their kids. “AIDS Miss [her name]”... The principal called me, she said, “There’s rumours going around that you’ve got AIDS!” She didn’t say HIV! She said, “You’ve got AIDS. I don’t want nobody to come and burn my school down, so it’s best if you leave.” (Jamaican-born woman)

These women felt that HASD had forced them out of the country.

Stigma in the family

Stigmatisation by family members was rarely reported. Family members, usually mothers, aunts, and sisters, made their opinions on PLWHA known in a variety of ways, from “cleansing” to separation to outright rejection.

[When my mother does my laundry she] disinfects my clothes...because she thinks that my clothes are probably soiled or whatever, because I have a disease. (Homosexual UK-born man)

But then after that I noticed this cup was mine, and that plate was mine; before nothing was mine. I noticed this blanket is mine...[nervous laugh] So my things were segregated now. (Jamaican-born woman)

One woman’s parents and one man’s sister refused to allow them into their homes.

[My sister asked] me, “What these tablets for?” and I tell her. She said, “Oh!” and she had two young kids, she tell me I can’t stay in the house with her. I feel bad. Up till now, I don’t even ... do much well with her now. I had to go and live with another sister. (St Lucia-born heterosexual man)

All family members eventually accepted the respondents back into their family, after the former allayed their fears about onward transmission.

Healthcare discrimination

In both Jamaica and the UK, respondents had been treated with insensitivity by members of the medical profession.

He said, “You’re HIV positive and you’ve got something like three months to live. And looking at you now, I think you haven’t even got that much!”...In Jamaica, the doctors, they just treat you like you’re second class...the way they talk to you... you know it’s because of your status. (Jamaican-born woman)

Some, as the woman above states, treat PLWHA with contempt. Others have tried to avoid contact: through refusing to see HIV+ patients; perceived excessive prophylactic measures, such as putting on gloves; or neglecting to conduct physical examinations.

Respondents complained also of breaches of confidentiality in both parts of the world, with a man stating, for example, that doctors discussed his status loudly on a non-HIV ward. They said also that doctors in the UK treated their HIV status as the sole cause of any other symptoms. Apart from one instance, complaints are reserved for doctors who are not HIV specialists. This HASD can have consequences for access to health care services. One woman, for example, delayed her dental appointment for several months out of her conviction that her dentist was discriminating against her.

Stigma avoidance

Limited disclosure

This was the most sure-fire way to avoid stigma. Patients made very careful calculations about who they would tell their status to. They employed passive and active assessment strategies (which some called “research”: observation and questioning) to decide on potential disclosees:
I don’t know if my friends or some of my family, if that’s the way they’re going to look on me. But I think I sort of like need to do research on them without saying I am, so I can sort of have the knowledge to know what level they are, what they can deal with, what they can’t deal with. (Gay UK-born man)

The most important factor in these decisions was trust: trust that the disclosee would not scandal him/her; that the person would offer support; that the disclosee would not treat the person any differently, and that their role within the family or friendship would not change. Women seemed to be particularly concerned about the effect of disclosure on their children:

Do you know, it’s not even so much about me. I wouldn’t want [my son] to be stigmatised. Because I’m an adult, I can defend myself; he’s a child. It’s not so much for me, it’s him. (UK-born woman)

Deception

When the victim of uncontrolled disclosure, patients tended to lie if confronted:

She said, “Is it true?” I said, “No it’s a lie.” Well, I lied. (Jamaican-born woman)

One woman subjected to uncontrolled disclosure depended on the perceived physicality of HIV/AIDS to convince others that she was not in fact HIV+:

Because like nobody’s ever really seen me like what they’re saying, skinny or … I always make sure that if I’m like going out and what not, I’m well dressed and like if I’m leaving the area, I’m well dressed and put together, with my hair combed and then they’ll look at me and say, “No, it’s all lies. Look at her, look at her.” So, a lot of people now have started to think, no it’s not true. (UK-born woman)

Relationships I: Refusal to enter relationships. This was most likely among older Caribbean-born women (i.e., past child-bearing age). While most patients felt that disclosure to sexual partners was important, these women felt that it was a necessary condition and thus would not enter into a relationship without doing so.

I’m not ready to have a relationship with anybody. I mean, I do go out with friends. But to get physical with anybody, no, I can’t see that. Sex is an important part of my life and it’s a bond, and honesty—I cannot now sleep with a person and not be honest with them. And I think if I tell anyone, what if he reacts badly? That would be too much for me to take. So to avoid that just no. (Trinadian-born woman)

Relationships II: Casual/doomed relationships. Gay and bisexual men were most likely to say that disclosure to a casual partner was less important, as no relationship of trust had been or would be established. Lack of disclosure to a regular sexual partner could cause tension in a relationship, and lead to its premature end.

I’ve been in a few relationships, but then I think I have a problem because of my situation. I think I haven’t been honest because I can’t say, and with me, I try to be as honest as I can, that’s who I am and if I can’t be, then it is a problem. So at some stage, I just phase it out because of it. (Jamaican-born bisexual man)

Relationships III: Relationships without disclosure. In those few situations in which the respondent had been unable to disclose to a regular sexual partner unaware of their status, there were feelings of guilt and attempts at safer sex. However, respondents reported situations where they felt unable to disclose their status and had attempted to insist on safer sex, but were repeatedly met with refusal to use condoms by their partners.

Limited social interaction

Primarily those respondents suffering severe emotional distress believed that rather than open themselves up to the possibility of betraying their illness to others, they would restrict their social activities, out of shame and fear that others would discover they were ill. With time they usually re-entered their social world, determined to keep their secret. However, a Jamaican-born man who had only known for nine months of his diagnosis said, “I try to live a more simple and boring life right now, which is hard.”

The summary of findings shown in Table 2 below demonstrates the different impacts of the various roots of stigma. It reveals also that similar types of felt and enacted stigma can have different origins.

Positive positive stories

For all these tales of fear and worry, there are important positive stories to tell as well. For example, a UK-born woman disclosed to her Jamaican boyfriend, and he responded sympathetically: they subsequently married.

I was crying by this time and everything, and he was like… he took my face, he wiped my face clean, he hugged me and he kissed me and he was like, “You know what? It doesn’t matter. I love you for you.” (UK-born woman)

As well, there were respondents who felt that the disease has had positive effects. A small minority believed that HIV had imbued them with a stronger sense of self by forcing them to find reserves of strength in order to cope with their infection.

I feel that being positive might have been a blessing in disguise, in the sense that it’s made me the person that I am: stronger. I look at it as HIV can either make you or break you, and it didn’t break me, it made me the strong person that I am today. So, trying to picture my life adjusting without HIV, I just can’t—it’s been so long. Because having to deal with this over the years has made me stronger, so I wonder if I didn’t have to deal with this, if I would be this strong person that I am today. (Jamaican-born homosexual man)

Even the young woman who felt that she had been forced out of Jamaica believed that her infection had forced
positive behaviour change. She still felt guilt over cheating on her boyfriend, and suspected that that man had been the one to infect her.

If I wasn’t HIV positive, I’d still probably have multiple partners now. I’d still be sexually careless. I don’t think I’d be the type of mother I am to my child, with me setting an example for him; he’s never seen me being careless with men or nothing. He’d have probably seen men in and out of my house and that wouldn’t be a good example, I think. It’s made my life better as a person. (Jamaican-born woman)

Other patients with strong religious beliefs denied feelings of depression due to their faith in the support, and in some cases, the healing potential, of God.

I feel good about me. I feel good about me... I am of the firm belief that healing is possible, through my faith in God and Jesus, as a healer, he heals absolutely everything. It’s possible. (Trinidadian-born woman)

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Respondents who were coping well claimed that their family and their faith were instrumental in this process. Having this support, as well as being convinced of their own longevity (that HIV was not indeed, the “death sentence” many called it upon learning of their diagnosis) seemed to be keys to good coping. However, many of these respondents, including some of those who claimed they were better off now, also said that they had “ups and downs”: the woman who felt she had become a better example for her son said there were days when she felt she was “losing it...especially when you’ll think what’s going to happen.”

Table 2
Key dimensions of stigma

<table>
<thead>
<tr>
<th>Reasons for stigma</th>
<th>Felt stigma</th>
<th>Enacted stigma</th>
<th>Stigma avoidance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fear of contamination</td>
<td>Expectations of being ostracised; Internalised fear of transmission; Isolation</td>
<td>Community: Employment discrimination; Healthcare discrimination; Gossip</td>
<td>Seclusion; Limited disclosure; Casual/doomed relationships; No relationships; Deception</td>
</tr>
<tr>
<td>Association with immorality (religious reinforcement); e.g., homosexuality, promiscuity</td>
<td>Blame: Fear of being labelled homosexual or promiscuous and of having sexuality revealed; Shame; Depression; Suicidal ideation; Low self-esteem</td>
<td>Community: Scorn and scandal; Physical violence; Verbal abuse; Gossip; Disclosure Familial: Rejection (by partner); Ejection (from home)</td>
<td>Non-disclosure; Deception</td>
</tr>
<tr>
<td>Ignorance</td>
<td>Otherness (misunderstood); Low self-esteem</td>
<td>Community: Negative attitudes towards PLWHA; Scorn and gossip (disclosure); Verbal abuse; Second-class citizen; Expectation of death</td>
<td>Seclusion; Limit social interactions; Educate or test views about HIV/AIDS; Deception</td>
</tr>
</tbody>
</table>

Discussion

This paper confirms that HASD serves to reinforce the marginalisation of previously stigmatised groups (Aggleton, 2000; Aggleton et al., 2005). This follows Goffman, who conceptualised stigmatisation—the discrediting of an individual or group—as a defence against a perceived threat, a means of social control over undesirable elements in society through marginalisation and exclusion (Goffman, 1963). The findings of this study show that HIV+ Caribbean people are keenly aware of the stigma surrounding HIV/AIDS, and believe it is based on a particularly Caribbean cocktail of fear of contamination, homophobia, religious beliefs and ignorance. Whether or not they are right that the Caribbean and its diaspora have higher levels of stigmatisation than the UK, the perception that this is the case mitigates against disclosure and openness.

In his study of HIV+ Jamaicans, Carr also found that fear of contamination was a key feature of HASD. Carr and others have found a clear association between HASD and what he calls “sex/gender transgressors” (Carr, 2002). Dinall and Bain (1994), in one of the earliest studies on stigmatisation in the Caribbean, found in the Jamaican church community what later researchers would confirm in other spheres of Jamaican and Caribbean life: stigmatisation of PLWHA was apparently particularly high when directed at male homosexuals and female prostitutes. This focus on “transgressors” was confirmed by subsequent studies of (prospective) members of the health care profession: Bain’s study of health care workers in Jamaica, and studies of medical students in Barbados and Jamaica (Bain, 1998; Norman, Carr, & Jimenez, 2006; Norman, Carr, & Uche, 2006; Wickramasuriya, 1994).
Felt stigma is strong and has, as previously noted (Aggleton, 2000), worked to limit enacted stigma, where patients have been able to control disclosure of their infection. For the most part, their disclosure decisions have been sound ones: instances of stigmatisation and discrimination have usually occurred where respondents have lost or do not have control over disclosure. Compared to their UK-born counterparts, Jamaican-born respondents’ accounts of HASD include more reports of overt or severe HASD, particularly violence and employment discrimination. Respondents mobilise a variety of strategies in order to avoid stigma, which have implications for their social interactions and emotional well being.

This study suggests that HASD can undermine care and treatment of PLWHA, and limit opportunities for integration into society and economic independence. As Varas-Díaz et al. (2005) also found in their study of Puerto Rican PLWHA, employment and health care are particularly at risk. Although there was little indication here that respondents neglected their HIV-related care as a result of HASD, they may miss or delay other medical appointments, as well as be unable to work due to outright discrimination, or their psychological or physical health, and may therefore have to rely on social services for survival.

The examples of “successful” negotiation of stigma are instructive. Even with the full knowledge and, in some cases, the experience of HASD, respondents managed to avoid the “spoiled identity” of victims of stigma (Goffman, 1963). This information is important for revealing that while stigma is an oppressive reality for PLWHA, there is some scope for negotiation, for creating their own mitigation strategies and their own understandings, meanings, and implications of HIV infection. At the same time, it is important to note that most of the respondents who reported positive self-image were still unwilling to disclose their status widely. As well, emotional well being is not necessarily a constant: those “ups and downs” have to be negotiated and counteracted.

Carr’s (2002) finding that Jamaican PLWHA find solace in religion is reinforced by this work, as well as that of research in other contexts (also Kaplan, Marks, & Mertens, 1997; Moneyham et al., 1998; Tuck, McCain, & Elswick, 2001). In this way, the positive stories also show us religion’s double potential (as noted by Carr, 2002): while it can be used to condemn PLWHA, it can also be an important source of strength. Family support too is key (see also Carr, 2002; Dodds et al., 2004; Li et al., 2006; Serovich, Kimberly, Mosack, & Lewis, 2001). It seems that the belief that one has many years to live is an important aid to coping (Schwartzberg, 1994).

The gendered nature of HASD has been noted by many researchers (Aggleton, 2000; Carr, 2002; Rankin, Brennan, Schell, Laviwa, & Rankin, 2005; White & Carr, 2005). The primary culprits of HIV, as we have seen, were believed to be promiscuous women and homosexual men. This presumption reinforced the existing gender order dominated by a culturally determined masculinity—heterosexual, with multiple partners—and femininity—monogamous and sexually restricted.

Conclusions

These results of the qualitative arm of the LIVITY Research Project fill a gap in the literature on HASD by providing valuable understanding of the experiences and perspectives of PLWHA both in the Caribbean and in the Caribbean diaspora. They reveal the importance of addressing stigma both in the Caribbean and among British Caribbean people in the UK. And indeed, public health experts in the Caribbean are well aware of this and have implemented nationwide strategies to this end (e.g., the Jamaican Ministry of Health’s anti-stigma campaign, launched in September 2006 [Ministry of Health, 2006]). HIV/AIDS-related stigma and discrimination is a real issue for Caribbean people living with HIV at home and in the diaspora, affecting PLWHA’s lives in a variety of ways: emotionally, mentally, financially, socially and physically. Certainly in the UK, there is a need to create interventions specifically addressing stigma and discrimination in the UK’s Caribbean population. It seems clear that education alone is insufficient: just as Carr noted in his study of stigma in Jamaica (2002), the results of this paper suggest that tackling stigma and discrimination requires “cultural work” to address deeply entrenched notions of sexuality and understandings of HIV transmission and treatment.

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