

## **HIV stigma: health care professionals' views from the Brighton bubble and the South African frontline**

Rebecca Godfrey<sup>1</sup>, Bobbie Farsides<sup>1</sup>  
<sup>1</sup>(Brighton & Sussex Medical School, England)

**Abstract:** This descriptive comparative case study explored Health Care Professionals' beliefs about if and how a person living with HIV/AIDS's experience and/or perception of stigma is influenced by their experiences in hospital. Data collection was through semi-structured interviews with Health Care Professionals at two inpatient sites in Brighton, England and Tygerberg, South Africa. The data was analysed using thematic content analysis. In Brighton, HIV care is tailored towards men who have sex with men, and Health Care Professionals suggested that patients outside this demographic may be more likely to experience or perceive stigma. Outside of specialist services, participants highlighted lingering 'curiosity' and 'judgment' around transmission. Contrastingly, HIV is so prevalent in Tygerberg that curiosity around transmission was reportedly rare. In Brighton, within specialist HIV care, there was a definite sense that Health Care Professionals can significantly alter a patient's experience of stigma by shaping the patient's own perception of their condition. In Tygerberg, fatalism prevailed with HIV continuing to be viewed as poorly prognostic. This case study is valuable in highlighting the unique nature of HIV care and stigma in the Brighton bubble. It has also provided an insight into fundamental issues related to HIV stigma on the South African frontline.

**Keywords -** health care professional, HIV/AIDS, perception, qualitative, stigma

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### **I. INTRODUCTION**

Over recent decades, the physical burden and prognosis of Human Immunodeficiency Virus [HIV]/Acquired Immunodeficiency Syndrome [AIDS] has been dramatically altered for HIV positive patients [1]. However, despite the introduction of highly active antiretroviral therapy [HAART], in the UK in 1996 and South Africa in 2004, a strong case can be made for the continuing psychological burden of stigma for person[s] living with HIV/AIDS [PLWHA] [2-4]. Stigma experienced by PLWHA is defined by the Joint United Nations Programme on HIV/AIDS as: "a process of devaluation of people living with HIV and AIDS" (UNAIDS, 2005). The effects of stigma are well documented [5-8], and the fear of prejudice continues to dominate patient accounts of living with HIV in both nations [1, 4, 9-10]. Health Care Professionals' [HCPs] witness and in turn influence the stigma that PLWHA face [11-13]. However, HCPs' views are not well explored, particularly in the inpatient setting. This descriptive comparative case study sought to consult HCPs working at hospitals in two very different settings. Outside London, Brighton has the highest rate of HIV infection in the UK, with a prevalence of 7.7/1000 [14]. HIV care is provided by a specialist team, and geared towards the predominant demographic of men who have sex with men [MSM]. In South Africa, HIV prevalence is estimated to be 12.2% in the general population, and Tygerberg hospital sees a racially and sexually diverse HIV population [15]. Existing literature around HIV stigma in South Africa emphasises how discrimination is driven by resource constraints in hospitals, and hostility in communities [4-5, 16-19].

### **II. AIM & OBJECTIVES**

Through investigating HCPs' views in these two very different contexts, the study sought to meet the following aim and objectives:

Aim:

To explore HCPs' beliefs about if and how HIV stigma is influenced by patients' experiences in hospital

Objectives:

To offer a descriptive comparative case study of health care professionals' views on HIV stigma

To investigate the dominant issues that HCPs in the hospital setting identify as relevant to a PLWHA's experience and/or perception of stigma

### III. METHODS

Empirical work was preceded with an in depth literature review of relevant databases. Following ethical approval in both study sites, participants were recruited from hospitals in Brighton, England and Tygerberg, South Africa. Table 1 illustrates participant characteristics.

Table 1: Participant characteristics

<b>Brighton</b>		<b>Code</b>
3 doctors	1 HIV specialist	HIVdocB1
	1 non-HIV specialist working in the Medical Admissions Unit	MAUdocB2
	1 non-HIV specialist acting as the HIV liaison or lead in their field	GENdocB3
3 nurses	1 working on the infectious disease ward [where patients under the HIV team are admitted]	IDnurseB1
	1 working in the Medical Admissions Unit	MAUnurseB2
	1 acting as the HIV liaison or lead in their field	GENnurseB3
3 HCPs involved in maternal HIV care	Further details omitted to avoid compromising anonymity	OBSHCPB1 OBSHCPB2 OBSHCPB3
3 HIV pharmacists		HIVpharmB1 HIVpharmB2 HIVpharmB3
<b>Tygerberg</b>		<b>Code</b>
4 doctors	1 HIV registrar	HIVdocT1
	3 internal medicine registrars [includes work in the Medical Admissions Unit]	MAUdocT2 MAUdocT3 MAUdocT4
	3 nurses	1 working on the Medical Admissions Unit 2 working on internal medicine wards
3 nurses working on the delivery ward		OBSnurseT1 OBSnurseT2 OBSnurseT3

Inclusion criteria specify that participants must have worked in their institution for at least five years, regularly providing care for PLWHA thereby ensuring expertise and experience over time. Purposive selection was used to identify HCPs from a range of cadres and inpatient settings. Participants were then randomly selected from a list of all eligible candidates in each identified participant group, using a random number generator. The number of participants was chosen with the goal of theoretical saturation. There were no incentives or remunerations for participation.

Data collection was through semi-structured interviews with the lead researcher following a question guide developed from a question matrix, and lasting 30-60 minutes. Pilot interviews allowed the question guide to be refined.

Interviews were audio-recorded and transcribed by independent transcribers using verbatim transcription. The data were analysed using thematic content analysis, and independently coded and discussed by the lead researcher and project supervisor.

Study limitations relate to the fact that some professional groups are not included in the study despite having day to day contact with PLWHA, and, due to time limitations accompanying ethnographic observation was minimal. Findings were not designed to be generalizable.

## IV. RESULTS

### 4.1 Changing attitudes: "I don't know if we're winning really" [MAUdocT2]

Given the experience of participants, it was possible to capture a sense of change over time, particularly following the introduction of HAART: "It was no longer seen as just as a death sentence" [HIVpharmB1]. HCPs in Brighton described a gradual change in attitudes: "There are two very clear times: before 1996 and after 1996... you were going to die and probably fairly soon... and then that changed. There was a sort of fairly gradual change over a few years" [HIVdocB1]. "...before you were like a hand grenade with the pin out" [HIVdocB1].

In Tygerberg however, HCPs felt that HIV continues to be seen as poorly prognostic: "some of the older generation doctors still feel quite strongly that HIV patients tend to do much worse than non-HIV patients" [MAUdocT2]. "I don't know if we're winning really. They [PLWHA] usually already have a poor prognosis going into intensive care. If they get out, then they usually still have a poor prognosis... then all the workload was essentially for nothing" [MAUdocT2]. This has important implications in the resource-poor setting: "we sometimes end up having to withdraw treatments or not give treatments, because you can't commit that much of your resources to the patient" [HIVdocT1].

### 4.2 'Curiosity' or 'judgement' regarding how a patient acquired HIV: "I always look in the notes" [OBShCPB1]

Participants suggest that HCPs in Brighton might be more open or non-judgemental than elsewhere in the UK:

"Brighton is kind of an unusual place isn't it? It's not like if you were working in Sheffield or something like that. A lot of the healthcare staff here are gay, a lot of them have friends who are HIV-positive so it's kind of a slightly false environment. I'd imagine the patients who are HIV positive have less problems in Brighton than they would anywhere else in Britain" [MAUdocB2].

However, HCPs were also very honest about a lingering curiosity around HIV and, in particular, transmission: "I'm as guilty of that as anybody else... I always look in the notes" [OBShCPB1]. HCPs acknowledged the potential for judgement: "they associate it [HIV] with gay men and people having reckless sex" [HIVpharmB2]. One doctor described asking a patient early in his career: "did you get HIV because you're gay?" The patient replied: "I didn't get HIV because I'm gay, I got it because I had sex with somebody else who had HIV", and the doctor commented that "it just reminded me that it was related to his sexual behaviour, rather than his sexual orientation" [HIVdocB1].

In Tygerberg, HIV prevalence is high, with individuals from many different backgrounds represented amongst PLWHA. HIV is described as almost usual rather than unusual, with very little space for curiosity. One doctor was not alone in explaining that he often feels: "we've all heard many, many stories where it's like yeah that could have been me and so I think how you said how you got the virus it's not important" [MAUdocT4]. HCPs unanimously agreed that is unusual to think about how their patients acquired the virus:

"I can't remember the last time I've thought about how a patient actually acquired HIV. It's not that I just don't care anymore, it's just that we see so many patients with HIV I just really don't think about how they acquired it" [MAUdocT3].

### 4.3 Confidentiality: "not even their husbands know" [OBsnurseT1]

Patients closely relate confidentiality to stigma. This was well recognised in Brighton, where confidentiality issues were described as rare, with HIV specialists and patients advocating for the right to privacy: "once it's out it's out" [HIVdocB1]. The maintenance of confidentiality was one of the reasons given for valuing the specialist service.

In Tygerberg, participants described real issues with confidentiality on the wards: "sometimes doctors disclose there in front of six other patients in the ward" [GENnurseT2]. "I mean you just mention 'ARVs' [anti-retroviral drugs] and everyone knows what ARVs mean" [MAUdocT4]. Whilst HCPs in the UK have a clear public health responsibility to ensure partners are informed about HIV, this is a grey area in terms of policy in South Africa. South African doctors manage the adverse consequences of non-disclosure, frequently treating partners of known HIV positive individuals. Doctors felt strongly that partners should be informed: "if they don't use their opportunity to tell spouses, I would go ahead and tell them ...because I have seen when their spouse dies eventually, the one that was uninformed" [MAUdocT2]. South African nurses highlighted the risks of disclosure, describing discrimination in their communities. Nurses felt that partners should not be informed without patient consent: "not even their husbands or boyfriends know, there's nothing that you can do except talk to the patient" [OBsnurseT1]. Doctors ultimately make this decision, and carry the psychological burden of choosing between disclosing a patient's HIV status and exposing their partners to infection.

### 4.4 How a patient perceives HIV and how they feel about their own diagnosis: "It's very hard to be all things to all people" [HIVdocB1]

Participants highlighted dramatic differences in how PLWHA in Brighton feel about stigma: "There are some people who are much more up front about their HIV ...there are others who are incredibly isolated and won't allow us to share information with other HCPs" [HIVdocB1]. In Brighton there was a definite sense that

how a patient perceives HIV and how they feel about their own diagnosis is a key influence on their lifelong experience of stigma. Participants felt that men that have sex with men [MSM] are well supported by their communities and local health services, which are used to seeing & accepting gay men with HIV: “because we’re in Brighton there’s so much support for MSM” [GENurseB3]. “Our demographic of patients is predominantly white, gay men. I would say that they are less likely to experience stigma because the gay population is a lot more educated about it, a lot more accepting about it, they almost definitely know somebody with it” [HIVpharmB2]. One doctor acknowledged that services are tailored towards MSM: “we have relatively few people from ethnic minorities, we have relatively few heterosexuals, and people from those groups may feel relatively isolated. It’s very hard to be all things to all people” [HIVdocB1]. HIV specialist staff felt that African patients and HIV positive women in Brighton are more likely to feel isolation or stigma. Participants described how African patients can be stigmatised by their communities: “to have HIV in Africa is a death sentence... they still experience stigma from the community and from their churches... and the way they get exposed is usually inadvertent... there’s rumours go round, which can be very damaging’ [OBShCPB2]. HCPs described how Caucasian women can also be vulnerable to feeling stigmatised:

“I think she doesn't feel she fits in anywhere. She doesn't feel she fits in with the women's group at the Beacon because they are mainly African women. But she doesn't fit in with her normal friends, because all she's thinking about is, I've got HIV and they haven't. I've got a secret they are not aware of” [OBShCPB3].

In Tygerberg there was a feeling that the patient’s own views are eclipsed by the discriminatory attitudes and behaviour of others, which are perpetuated by the media: “in communities of poverty, there’s no understanding, so people are scared they might get the disease from them” [MAUdocT4].

“Why are so many of them getting murdered, why are they still malnourished, why can’t they get work? If we really go into it with every patient, you will be overwhelmed pretty soon because there’s some harsh life stories... you have to understand your limitations, you have to learn this early” [HIVdocT1].

However, several nurses highlighted the potential for HCPs to strengthen resilience to stigma: “Obviously the way they see the disease themselves, I think that plays a role. If you’re straightforward with them, informing them about the disease, they would be more empowered to feel less stigmatised” [MAUdocT2].

4.5 HIV specialist versus ‘generalist’ care: “I don’t want to go to the AIDS ward” [HIVdocB1] Specialist care in Brighton almost creates a bubble around PLWHA. Some participants described how patients can worry about being identified within this bubble: “we whisk you away to the unit which identifies you as having HIV, at least in the eyes of some – ‘I don’t want to go to the AIDS ward’” [HIVdocB1]. Others felt that PLWHA might be concerned about being treated outside of the specialist bubble: “they are used to a very high level of service in the HIV department... And I think they would be concerned that there wasn't the expertise in the room generally, to understand their condition [in a non-specialist clinic]” [GENdocB3]. However, several HCPs felt that PLWHA would be best managed according to their presenting complaint: “patients generally do better in the relevant specialist areas: so stroke patients do better on stroke wards... I think there's a lot to be said by the whole team being au fait with HIV” [GENdocB3]. The same doctor voiced concern that HCPs working outside the bubble of HIV specialist care may lack experience with PLWHA: “because HIV has been so specialised in the past, there is a risk that other people are a little deskilled” [GENdocB3].

On the South African frontline, HIV is so prevalent that all health workers regularly care for patients with HIV: “now it’s one in three patients perhaps that are HIV positive” [HIVdocT1]. Several participants highlighted a role for other members of the multi-disciplinary team: “when I got to this hospital I am physician, primary care giver, social worker, pre-[HIV]test consent taker and post-test counsellor” [MAUdocT3]

## V. DISCUSSION

This study highlights how HCPs perceive the experience of PLWHA as having changed dramatically over a relatively short period of time. In the UK, the introduction of HAART in 1996 radically improved prognosis. This has contributed to a more gradual reduction in stigma, with the condition increasingly viewed as chronic and treatable, rather than life-threatening and highly-infectious. In Tygerberg, HCPs have also witnessed a change over time. Despite significant improvements in treatment, HIV is still viewed as poorly prognostic. Limited availability of, and adherence to, HAART is likely to contribute to the fact that patients with HIV still appear to do less well. Unfortunately, resource constraints necessitate investment in patients that are most likely to benefit. Hence beliefs relating to poor outcome have practical implications for care in PLWHA. Furthermore valued interventions such as counselling are not readily available despite HCPs (particularly nurses) being convinced of their value.

In Brighton ‘curiosity’, ‘judgement’, and assumptions around how HIV was transmitted still exist and potentially contribute to the stigmatising view that HIV is acquired through irresponsible sexual behaviour. Interestingly, HIV is so prevalent at Tygerberg that all HCPs are so used to managing PLWHA, and it is rare for staff to feel curious about transmission, or to have the time to dwell on individual circumstances.

In Brighton there is a definite sense that HCPs can significantly alter a PLWHA's experience of stigma by shaping the patient's own perception of their condition. This was seen as an advantage of being cared for by a specialist team as outside specialist care, this concept is perhaps under-recognised. It is arguably best demonstrated in the difference in perceived stigma between gay men, who are surrounded by communities and health services that reinforce acceptance, and women from minority ethnic or Caucasian communities, who can feel alone and stigmatised in their everyday lives and also in the hospital setting. In South Africa, the data was striking in its sense of fatalism. There is a perception that the HCP's role is purely medical, because the tremendous psychological burden that PLWHA face is simply insurmountable. Sociocultural issues driving stigma are ingrained in local communities, and have devastating consequences. Whilst nurses recognise that hospital counselling may alter a patient's perception of stigma, and build resilience to discrimination, resourcing is once again an issue. There are also real issues with confidentiality on the wards, despite potentially dire consequences for PLWHA returning to their families and communities. These issues resonate with existing findings in the literature.

This data highlights some important avenues for further work. Brighton is arguably more liberal than elsewhere in the UK, with a particularly high HIV prevalence, and specialist HIV care, tailored towards MSM. Further research into HIV stigma in other areas of the UK might add an interesting perspective. In Tygerberg, some themes might be consistent with trends at other South African health facilities with a comparatively high HIV burden and high cultural diversity. However, there are clearly differences, for example in the provision of HIV counselling and testing. The findings from this study should not be generalised. However, interesting concepts have been raised, and their relevance should be considered elsewhere, taking into account similar and contrasting features in the local context. It is important to make a distinction between HCPs' views of what is happening and what PLWHAs are actually experiencing. The value in talking to HCPs has been highlighted. Certainly it would be interesting to build on this work by talking directly to PLWHA about their experiences of stigma.

## VI. CONCLUSION

The way in which HCPs perceive the issue of HIV stigma is interesting and relevant. It is essential that HCPs are involved in the growing body of research which seeks to acknowledge, understand, and address an issue as ethically sensitive as HIV stigma. Despite reported limitations, this case study is valuable in highlighting HCPs' views on the unique nature of HIV care and stigma in the Brighton bubble. It has also provided an insight into the fundamental issues related to HIV stigma identified by HCPs on the South African frontline, with detailed analysis at a micro-level.

## VII. ACKNOWLEDGEMENTS

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