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Experiences of stigma in healthcare settings by people living with HIV in Ireland: A qualitative study

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Abstract

Stigma in healthcare settings remains a barrier to accessing screening, treatment and care for HIV and is a driver of the global HIV epidemic. This study examined the stigma experiences in healthcare settings of people living with HIV (PLHIV) in Ireland. Semi-structured interviews were carried out with four women and ten men living with HIV. Data were analysed using a Directed Content Analysis approach to assess experiences of enacted, anticipated and internalised stigma. The findings indicate experiences of enacted, anticipated and internalised stigma were common. A further finding of spatial stigma was also uncovered. Analysis showed these experiences impacted participants' engagement with care and affected health-seeking behaviours and treatment adherence. The results suggest stigma experienced in healthcare settings may impact negatively on health outcomes.

Keywords: HIV, HIV-related stigma, stigma, health inequalities, qualitative health research

Background

HIV-related stigma remains a significant problem that creates barriers across all levels of the HIV care continuum (Gesese et al., 2017). For people living with HIV (PLHIV) stigma impacts negatively many aspects of health and well-being, including adverse mental health outcomes (Turan et al., 2017), reduced adherence to HIV medication (Turan et al., 2016) and lower quality of life (Nobre et al., 2018). Experiences of stigma in healthcare settings can have implications for onward transmission (Kinsler et al., 2007). Stigma is thus recognised as a social and structural determinant of health and a major driver of the HIV epidemic, with researchers specifically highlighting the need to reduce stigma in healthcare settings (Nyblade, 2019).

Approximately 7,200 people live with HIV in the Republic of Ireland (Health Protection Surveillance Centre [HPSC], 2019). Recent substantial increases in the rate of new diagnoses saw the highest number ever recorded in 2016 (HPSC, 2017). At present the notification rate is 11.0 per 100,000 of population, significantly higher than the EU average of 6.2 (European Centre for Disease Control, 2019; HPSC, 2019). These increases have occurred in the context of considerable social stigmatisation of HIV. A survey conducted in 2017 found that among PLHIV (n=168), 30% reported feeling stigmatised by family, 27% by health professionals and 23% by friends (HIV Ireland, 2017). Despite the relationship between stigma and the HIV epidemic, there is a paucity of research on HIV-related stigma in Ireland. Previous studies centred singularly on men who have sex with men (Murphy et al., 2015; Murphy et al., 2018) and internalised stigma (France et al., 2015; Murphy, & Hevey, 2013), while another study examined stigma experiences during hospitalisation (Surlis & Hyde, 2001). However, this was the first in-depth qualitative study on HIV-related stigma in Ireland that examined discrete stigma experiences of a heterogeneous group of PLHIV across a variety of healthcare services.

Methods

Participant recruitment

This study was part of a broader investigation that formed the basis of the lead author's doctoral research into HIV-related stigma in the Republic of Ireland. Participant recruitment and interviews were carried out between April 2016 and March 2017. A self-selecting convenience sample was recruited with the support of three HIV organisations located in three of Ireland's four provinces.

Inclusion criteria

Inclusion criteria stated participants must be over the age of 18, have proficiency in English and be living with HIV a minimum of 5 years. This minimum period was imposed because of concerns about the potential for post-traumatic stress disorder in newly diagnosed individuals (Martin & Kagee, 2011).

Sample size

The 'hard to reach' nature of this group proved a recruitment barrier. Much debate exists in qualitative research regarding appropriate sample size. Green (2004) asserts sample size should be "however many will be credible to the users of your research" (p. 102). Guest, Bunce and Johnson (2006) suggest little new data is generated after twelve interviews. With no new data being generated and the need to bring the research to a timely conclusion, recruitment was halted after fourteen interviews.

Table 1. Characteristics of participants (N=14)			
		Mean (SD) or N (%)	
Age		46	(SD 8.6)
Gender	Male	10	71%
	Female	4	29%
Full-time employment or education	Yes	6	43%
	No	8	57%
Current relationship status	Single	9	64%
	In a relationship	2	15%
	Married	3	21%
Years living with HIV		13.8	(SD 6.8)
Years on treatment		11.7	(SD 5.8)
Sexuality	Homosexual	6	43%
	Heterosexual	7	50%
	Undeclared	1	7%
Nationality	Irish	11	79%
	British	1	7%
	American	1	7%
	Zimbabwean	1	7%

Table 1: Characteristics of participants

Ethics statement

All participants were provided with participant information sheets, and gave written informed consent. All data was anonymised and transcripts and recordings were held in encrypted files. Ethical approval was granted by a university research ethics committee.

Data collection and interview procedures

Interviews took place in private spaces facilitated by support organisations in the east, south and west of Ireland. All interviews were conducted by the lead author, who has prior experience of working with and supporting people living with HIV. A semi-structured interview schedule was developed, piloted and refined following a review of the literature. Interviews began by asking participants to recount their experiences of being diagnosed with HIV. This provided a segue into a question about the first person to whom they disclosed their status, followed by questions about their experiences disclosing their status in other settings, including healthcare settings. Questions were framed open-endedly to avoid pre-

empting responses. Interviews lasted approximately an hour, were digitally recorded, and transcribed for uploading to NVivo for organisation and analysis.

Analytical procedures

Transcripts were analysed using Directed Content Analysis, a method in which a defined conceptual framework is used to guide analysis in order to elaborate on existing theory (Hsieh & Shannon, 2005). In this instance analysis was informed by the HIV stigma framework which differentiates between discrete stigma mechanisms such as enacted, anticipated and internalised stigma (Earnshaw & Chaudoir, 2009). Enacted stigma refers to explicit experiences of discrimination; anticipated stigma refers to the expectation of differential treatment based on one's status; and internalised stigma refers to an endorsement of the negative feelings/beliefs about HIV in relation to oneself. Based on these categories, a priori codes were created; an inductive approach was also facilitated and new codes were generated as analysis progressed. The constant comparison technique was used to assure consistency of coding (Corbin & Strauss, 1990) and technique triangulation was used to increase validity (Humble, 2009). Coding sheets (nodes) were exported from NVivo to Word documents where further analysis was performed. Memos were made in the margins to track interpretation and observations. Initial analyses were performed by the lead author and reviewed by and discussed with the second author. Following review and agreement among researchers, codes were re-examined and interpreted within the context of the theoretical framework.

Results

While there was a general sense of satisfaction with care received by medical personnel in HIV clinics, issues of stigma and discrimination arose for participants in healthcare settings outside of this context, with all but two participants reporting experiences. Enacted stigma

and anticipated stigma were most common, while internalised stigma was rarer. Participants also alluded to the concept of spatial stigma.

Enacted stigma

Enacted stigma experiences were the most common, with 11 of 14 participants reporting such experiences in healthcare settings, including in dental care, general practitioner care, and hospitalisation. A frequently reported complaint was being asked inappropriate questions regarding mode of transmission. Such questions were considered objectionable on the basis that they were medically irrelevant and assumed to contain a value judgement:

The doctor would be like, ‘Oh, you're HIV positive... how did you get that like?’ And I'd just say, ‘Does it matter how I got it?’ [Female, 50].

So the consultant came in and she said, ‘I see you're HIV positive – how did you get it?’ And it threw me...because the minute you tell somebody how you got it, there's a judgement made [Male, 59].

Another commonly encountered issue was healthcare professionals (HCPs) implementing precautionary measures in excess of standard protocols. This included the practice of “double gloving,” which was described as “degrading” [Female, 41]. Similarly, another participant – a trained nurse – recalled undergoing a scoping procedure in which the procedure room was “all covered in plastic” [Male, 49]. He considered this an unusual and discriminatory practice.

Some interviewees experienced difficulties obtaining appointments after disclosing their status. In a very small number of cases, participants were denied service outright. One participant recounted how she was obliged to wait until the end of the day for another doctor to perform an endoscopy after the attending physician refused to treat her:

He went through my chart and he sat there and he just went, ‘Oh, you're HIV positive, I didn't know that.’ ‘Oh I can't do you,’ he says straight out. ‘I wouldn't be able to deal with you.’ And he walked out of the room and I never saw him again [Female, 50].

An additional issue was a lack of knowledge amongst clinical staff:

The first time I ever came here (support service) was I wanted a GP where I wouldn't have to explain what HIV was. Some people tell their doctor and it turns out they know more than their doctor [Male, 49].

I applied to one GP and I mentioned the HIV on the form...and when I went back the receptionist said that the doctors wouldn't take me on because they felt they wouldn't have the specialist knowledge [Male, 46].

Similarly, another participant recounted his family doctor appeared “relieved” when he requested to switch to another physician, saying it was his “first encounter with, that whole area of stigma kind of thing.” The same participant reported he was satisfied with the reception he received at his subsequent GP, but noted the physician admitted “he knew very little about it, but we'd work together between me, him and the clinic” [Male, 59]. For many, this was simply part of the reality of living with HIV and was tacitly accepted. However, others alluded to the need for training, education and professionalism to counter the problem. One participant, for instance, remarked on this after relaying a story about a nurse that refused to attend to a severe laceration when he presented at an accident and emergency department:

If I didn't have HIV I would be a bit cautious as well. But I think if they are trained to do that job, they shouldn't worry about that [Male, 40].

A number of participant accounts suggested the potential for such experiences to affect health

seeking behaviours. One participant described initially being told by a dentist that “he did not deal” [Male, 59] with HIV patients, before ultimately offering him the final appointment of the day, which was declined. Such experiences often encouraged avoidance behaviours, with one participant claiming he refused to see a dentist for over sixteen years, saying “I’d go nowhere near it” [Male, 49]. This issue was further highlighted by another participant who reported being charged a ‘hazard’ fee:

The dentist charged me a €100 more for their own ‘protection.’ I was so taken aback by it that I never really looked in to it. I just said I'm never going there again [Female, 48].

Two participants’ accounts underscored the compound stigma that can be experienced by people who use drugs (PWUD), and the additional barrier this can create. Specific concerns included hostile treatment and attitudes of distrust and scepticism. One participant, for instance, related two separate occasions during which nursing staff had been dismissive of his complaints of pain:

I was really sick and it was really painful. And I felt I wasn't being listened to or believed. That I was just a guy that had issues around drugs who was just looking for pain medication, you know? Which wasn't the case [Male, 54].

I went to the A&E and your one says to me in A&E, the staff nurse...she says, ‘There's more people here that has more issues than you’ [Male, 54].

Both participants that were PWUD reported encountering similar behaviour from staff at different hospitals, and speculated the stigma they experienced was due to a combination of their HIV status and their drug addiction. One outlined forcefully how stigma often occurred in healthcare settings, and was significantly compounded by his status as a person who uses

drugs:

Once they hear drug addict...they look at you like you've ten heads. They treat you differently, you know? ... Half of the time it's the people that are looking after you that are fucking stigmatising you. The people that are looking after you that are making you feel fucking, you know, two inches tall [Male, 42].

Anticipated stigma

The fear, expectation or perception that one would be stigmatised was often a source of particular anxiety when accessing healthcare and often led interviewees to refrain from disclosing their status to HCPs:

Speaking to people who are positive now, some people just wouldn't tell their doctor [Male, 49].

Often such fears revolved around potential breaches of confidentiality:

I didn't trust the receptionist. So...I deliberately didn't tell the doctor – which I think is mad now – because, you know, what if the receptionist said it to one of the mothers in the school? [Female, 54].

Another participant outlined that as he had an undetectable viral load, and was therefore non-infectious, he had taken the decision not to disclose his status in certain contexts:

I don't disclose just to avoid any unnecessary uncomfortableness on anybody's part [Male, 51].

Such fears were of acute concern to participants living in smaller communities. This underscored the added burden created by stigma in accessing services. One participant spoke

of a friend from a support group who travelled from “somewhere godforsaken” to attend a clinic and support services “because his sister and his aunt worked in the local health centre” [Male, 49].

Spatial stigma

Three participants, all attending separate clinics, alluded to the concept of spatial stigma. One observed the clinic he attended was located to the hospital’s rear – something he felt reflected HIV as a “hidden illness,” remarking “it is very dirty, not very welcoming” [Male, 50].

Another reported his clinic experiences were “awful” and “like a conveyer belt” [Male, 49].

One participant expressed frustration his clinic would not give permission to display posters advertising a HIV support group, because of the “ethos” of the hospital. He noted this was at odds with the hospital’s willingness to display information related to other conditions:

Even last week I just noticed there's a poster, ‘If you're living with gout’ (*laughs*). I was looking around and saying, ‘Jesus! Not one!’ They wouldn't put up the poster [Male, 59].

Internalised stigma

Internalised fears of vectorisation, particularly at the early stages of diagnosis, were not uncommon. One participant recalled her anxiety as she was tended to by a nurse at her clinic:

I remember thinking, ‘Jesus you're pregnant – are you going to be alright? Even with your gloves and – are you ok?’ And she said no, she'd be fine. But I remember thinking, ‘Oh my god – this poor girl, she's going to get something from me’ [Female, 54].

Another participant highlighted the potential for internalised stigma to elicit avoidant coping behaviours:

I like to forget I have it. Do you know what I mean? Like I even stopped taking my therapy for a while, you know? Because I wanted to put it in the back of me (sic) mind. And forget it was there. I even put off getting tested, you know? Because I was afraid of the result [Male, 42].

Discussion

The similarity of participant experiences across a variety of healthcare settings in disparate geographic locations indicates stigma remains a significant issue for many PLHIV in the Republic of Ireland. Experiences of anticipated and internalised stigma were associated with health avoidance behaviours affecting disclosure, engagement with services, accessing testing and medication adherence (Turan et al., 2017). Enacted stigma created explicit barriers as healthcare professionals refused treatment, offered diminished conditions of service and referred patients to other services (Nair et al., 2019). This aligns with studies and conceptual frameworks that have highlighted the mediating effects of stigma in healthcare settings on health outcomes (Earnshaw & Quinn, 2012; Nyblade et al., 2019). Consequently, HCPs should be mindful of the potential effects of stigma in respect of health behaviours and the additional impact on those experiencing intersecting stigmas (Stangl et al., 2019a).

Of interest in this study were participants' observations on clinic environments and the description of spatialised stigma (Wacquant, 2007). Unwelcoming environments were interpreted as an implicit exercise of power and a signal to stay "down, in or away" (Link & Phelan, 2014, p. 24). This compounded the sense of social elision experienced by participants and further contributed to the construction of a stigmatised subjectivity (Scambler, 2006). Clinicians and HCPs should be cognisant of the potential of spatial stigma to marginalise their patients and impact negatively on health behaviours and outcomes. This latter effect is well documented by associations between patient experiences of hospital environments and

clinical effectiveness outcomes, including medication adherence (Doyle, Lennox, & Bell, 2013).

The results highlight the need to implement effective stigma interventions to mitigate the health impacts of HIV-related stigma and reduce associated health inequalities. Such interventions should adopt a complex multi-component approach addressing policy and practice at the organisational level, in addition to individual level interventions aimed at increasing HCP knowledge and awareness, and empowering PLHIV (Nyblade et al., 2009). Comparable rights-based approaches have proven effective elsewhere (Stangl et al., 2019b).

Limitations

The study sample is relatively small and consisted mainly of heterosexual Irish adults. The sample was self-selecting and thus the potential for selection bias is noted. The study was limited to residents of the Republic of Ireland only. Consequently, the findings may not be generalisable to other settings.

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No potential conflict of interest is reported by the authors.

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