

Student: Anna Brinsdon

Project: I am HIV but I am not a patient - Managing marginalised identities in health interactions

Supervisors: Associate Professor Gillian Abel and Mrs Jen Desrosiers

Sponsor: Canterbury Medical Research Foundation

Introduction:

Despite international efforts, stigma is still a significant issue for people living with HIV/AIDS (PLWHA). Even within health services, it is experienced to a surprising extent. This stigma can negatively impact the health and wellbeing of PLWHA by affecting not only the immediate practitioner-patient relationship but also future health seeking behaviour. Although many studies have documented the persistence of stigma in healthcare, few have focused from the perspective of PLWHA on how they attempt to manage this stigma.

Aim:

To explore the strategies that PLWHA use to manage stigmatisation in their health interactions.

Method:

The data for this project was drawn from a small qualitative study looking at the lived experience of HIV in Canterbury. Fourteen participants took part in face to face interviews in 2013 and 11 were interviewed again in 2014. I familiarised myself with the participants' descriptions of their experiences and analysed the transcripts for relevant themes.

Next, I conducted a review of the relevant literature, focusing on how PLWHA manage stigma in both health and social settings. After completing this, I helped to prepare a paper discussing our findings.

Results:

While the majority of experiences were positive, nearly all participants had at some point encountered stigma or discrimination during their healthcare interactions. These experiences occurred with a wide range of health providers including hospitals, general practices, dental services, optometrists, physiotherapist clinics, pharmacies and sexual health clinics. The two most common sources of stigma were healthcare practitioners holding exaggerated fears of HIV transmission or not maintaining confidentiality and privacy. Transmission fears led healthcare workers to sometimes take extreme precautions when treating PLWHA. For example, one optometrist refused to clean a participant's contact lenses as she was afraid that her technicians would become infected. Another participant had a GP leave the consultation room to get a different ear thermometer, as she was concerned about using her regular one with a patient who was HIV positive. Breaches of confidentiality also made participants feel vulnerable to stigma. One participant was given her initial HIV diagnosis, without warning, while family and friends were present in the room. Another participant heard his HIV status being discussed loudly between staff on the ward.

In addition to this, some interactions were affected by stigma due to other characteristics such as sexual orientation and also by participants' own internalised stigma.

When exploring how people with HIV acted to resist and manage stigma in their health interactions, the overarching theme that emerged was seeking control. Three main techniques were used by PLWHA to increase control: selective disclosure, self-advocacy and improving their knowledge of HIV. Selective disclosure was used by participants to carefully manage which healthcare staff were made aware of their HIV status. Some participants chose to disclose upfront before they were even asked. This pre-emptive disclosure put them in charge of when, where and how much healthcare workers found out. It also allowed participants to gauge practitioners' attitudes at the beginning of the interaction. Other participants chose to avoid stigma by not disclosing their HIV status at all to some providers.

In our study this strategy was seen occasionally with interactions at dental services. The second method used to resist stigma and seek control was self-advocacy. Our results show that most people living with HIV actively challenged the stigma they experienced and some lodged formal complaints after being discriminated against. The final strategy used by PLWHA to reduce stigma was to develop their knowledge of HIV. Many participants had attended courses and seminars as well as completing their own research into HIV. They were generally well informed about cell counts, viral loads and different medications. This allowed participants to have more control in their interactions with health professionals and increased their decision making power. It also worked hand in hand with the strategy of self-advocacy by helping PLWHA respond to stigma based on misinformation and fear.

Conclusion:

Our findings highlight that HIV related stigma is still an important issue in healthcare interactions. We show that people living with HIV attempt to resist stigma by seeking control through selective disclosure, self-advocacy and improving their HIV knowledge. These findings hold the potential to improve future health interactions by adding a depth of understanding to the practitioner-patient relationship. Our results draw attention to stigmatising attitudes and give valuable insight into a patient group that previously may have just been labelled as 'difficult'. The results also suggest that more education may be necessary for healthcare providers to better understand HIV transmission.

In a situation where there is no evidence base for these extra protections, all that over cautiousness achieves is maintaining stigma and fear.

Further research is required to explore these strategies and determine whether they are replicated by other PLWHA both nationally and internationally. Research into the effects of these stigma management strategies would also be worthwhile to see if they effect health access or outcomes.