

HIV Futures surveys since 1997: an adaptable survey instrument continues to examine the problem of stigma.

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Background:

HIV Futures (HF) is the largest survey of people living with HIV (PLHIV) in Australia and one of the longest-running surveys of this population globally. In nine surveys, over two decades (1997-2019), PLHIV have been asked questions regarding their experience of HIV-related stigma and discrimination. Here we review findings from HF surveys to describe change in relation to: experiences of stigma, sites of stigmatizing practice, and the differential impact of stigma on diverse populations.

Methods:

A desktop review of findings from published HF reports was conducted to document and compare results over time.

Results:

The first two iterations (HF1-HF2, 1997- 2000), only asked about instances of workplace discrimination, reflecting the extent to which illness and the visible impact of treatment (eg. the effects of lipodystrophy) negatively affected workplace experiences of many PLHIV. In 2000, 21% reported experiences of workplace discrimination, 13% in 2019. From HF3-HF7 (2002-2013), participants were asked to identify forms of stigma experienced in healthcare setting including avoidance (39%), confidentiality breaches (38%) and increased infection control (34%) (average response across 5 surveys). HF8-HF9 documented the negative impact of stigma on QoL among PLHIV, focusing on the ways fear of discrimination or fear of rejection has a negative impact on wellbeing. HF9 (2018), adopted the National Stigma Audit, showing a greater impact of stigma on women, bisexual men, and gender-diverse PLHIV.

Conclusion:

Despite improvements in legislation to protect against discrimination, PLHIV continue to experience less favourable treatment in a range of settings including medical care and workplaces. More recent research, however, has demonstrated more far-reaching impacts of stigma, including the ways stigma is experienced as an ongoing fear, vigilance or loss of confidence among PLHIV. Future research needs to focus on improving understanding of strategies that can alleviate the negative impact of stigma.

Disclosure of Interest Statement:

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