

Measuring and reflecting a complex understanding of stigma in research over time: examining the role of HIV Futures surveys since 1997

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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 an evolving set of questions regarding their experience of HIV-related stigma and discrimination. Here, we look at the ways in which the concept of stigma has developed over time.

Methods:

A desktop review of findings from published HF reports was conducted to critically appraise the ways in which questions about stigma and discrimination were posed and presented in reporting.

Results: Up until 2015, HF aim to document the frequency of discrimination experiences in a range of settings. More recent iterations have included comprehensive questions aiming to increase understanding of the extent to which PLHIV hold fears of discrimination, experience of internalized stigma and the impact of this on lives and relationships. This change reflects advances in treatment and legislative reform between 1997 and 2015, which has led to improved health and reduced experiences of overt discrimination, but paradoxically more sharply revealed the subtle and relational nature of stigma. Analysis of HF findings has been intended to document relationships between stigma and social factors, such as peer connectedness. A focus on the ways PLHIV perceive stigma also allowed for more attention on differential impacts of stigma between population groups.

Conclusion:

HIV-related stigma is a life stressor that can affect confidence, engagement with social life and relationships, for PLHIV. The role of HIV social research is increasingly to identify the ways in which system and service-level responses can create a buffer against ongoing, and often hidden, impacts of stigma. This requires a complex understanding of how material factors (e.g. poverty alleviation), and community, peer and sexual relationships can alleviate the negative impact of stigma.

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