

Critical Review of HIV-related Stigma Literature in India: Insights and Recommendations

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Introduction

In India, HIV-related stigma poses major challenge to the national efforts on HIV prevention, treatment and care.

There is a growing body of India-specific research on stigma and discrimination towards people living with HIV and marginalised groups associated with the epidemic, but its use for drawing policy and programme implications is negligible due to a lack of synthesis of available evidence.

We conducted a systematic literature review to serve as an evidence-base to inform effective national response to stigma and discrimination against people living with HIV (PLHIV), men who have sex with men, transgender people, sex workers and drug users; and to guide future research based on existing gaps.

Materials and Methods

Peer-reviewed literature on HIV-related stigma in India was systematically searched through academic databases (such as PubMed/Medline, PsycINFO and Sociological Abstracts). Grey literature search included reports from Indian government, UN agencies, PLHIV networks, and non-governmental organisations.

42 peer-reviewed articles and 14 grey literature articles were critically evaluated. Literature search retrieved articles that were available as of January 2012.

Inclusion criteria: Article or report should significantly focus on any or more of these aspects:

- prevalence of HIV-related stigma and discrimination;
- the types of stigma experienced by people living with HIV and marginalized groups at risk for HIV;
- stigma measurement tools;
- stigma conceptualization, and
- description or evaluation/assessment of interventions to reduce stigma and discrimination.

Exclusion criteria:

We excluded literature that was directed at measuring knowledge, attitude and practices (KAP studies) towards HIV or towards people living with HIV if they had no major input on stigma conceptualisation and measurement; and descriptive anecdotal articles on stigma faced by people living with HIV. Additional exclusion criteria included: newspaper articles, letters to editor in peer-reviewed journals, articles not in the English language, and conference abstracts.

Figure 1: Category of peer-reviewed articles accessed through Medline and PsycINFO databases

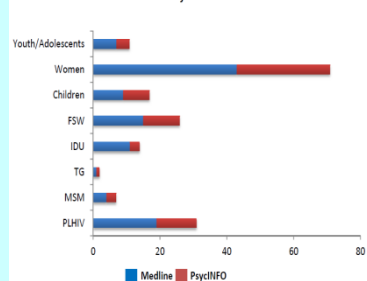
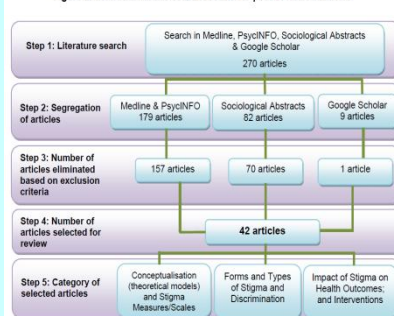


Figure 2: Flowchart of the search results for peer-reviewed articles



Results

Research synthesis revealed:

- Various forms of stigma and discrimination toward PLHIV and marginalised groups are reported in multiple settings in India.
- Women, feminine MSM and hijras/TG people face disproportionate burden of HIV-related stigma. Gender dimension is critical to understand HIV-related stigma faced by Indian women and by feminine MSM and hijras.
- Limited research exists on conceptualising HIV-related stigma (including stigma related to sex work, same-sex sexualities and drug use) from a cultural perspective.
- Limited evidence is available on the impact of stigma on health outcomes such as access to HIV prevention/treatment, quality of life, sexual risk behaviours and mental health.
- Only a few studies have focused on developing and testing culturally-relevant stigma measures and scales for use in India, and
- Limited studies are available on evaluating stigma reduction interventions.

Conclusions

To fill research and programme gaps, there is a need for:

- Developing and testing theoretical models and constructs on AIDS stigma for use in India.
- Studies that capture stigma experiences of people in rural settings, marginalised communities, and various subgroups of people living with HIV.
- Development of culturally-sensitive stigma measures.
- Well-designed single and multi-level interventions among various populations that measure both stigma reduction and their impact.
- Scaling-up of effective stigma reduction interventions among people living with HIV, marginalised communities and health care providers; and
- Structural interventions to protect the human and legal rights of PLHIV and marginalised communities.