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HIV stigma is a barrier to achieving 90-90-90 in India

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UNAIDS has set an ambitious target for all countries to scale up testing and treatment so that by 2020, 90% of people living with HIV will know their status, 90% of those diagnosed will be on antiretroviral treatment, and 90% of those receiving antiretroviral medications will be virally suppressed. Many countries are making good progress and in 2017, UNAIDS published a progress report indicating that the global community had reached 70-77-82 of the individuals in each category.¹ To reach the target, it is crucial that we understand country-specific challenges and barriers to these goals. In India, stigma is a barrier to the achievement of the 90-90-90 goals.

HIV testing is the first crucial step in learning one's HIV status and getting linked to care and treatment services. Although India's National AIDS Control Organisation is committed to ensuring that 90% of all people with HIV will become aware of their status, the gap between ambition and reality remains substantial with an estimated 26% not knowing their status.² Research on barriers to testing repeatedly identifies stigma and discriminatory laws^{3–5} to be important factors, especially among key populations, who fear that identification as a member of a stigmatised group will lead to additional discrimination and intersectional stigma, which occurs when an individual experiences multiple stigmas. Key populations have reported labelling and mistreatment by health staff at public health facilities, including inadequate cultural competence to counsel clients from marginalised communities on same-sex behaviour, transactional sex, or injection drug use and absence of peer counsellors in the system owing to a policy of only hiring counsellors who have formal education.⁵ By contrast, providing peer counsellors and peer outreach programmes through HIV services operated by community-based organisations or non-governmental organisations increases uptake of testing services and should be scaled up.⁵

In light of India's recent adoption of the test-and-treat model, people newly diagnosed with HIV should be linked immediately to treatment services in private or government antiretroviral clinics. In addition to providing these facilities in convenient locations, barriers to engagement must be identified and overcome. Before the introduction of test and treat, UNAIDS estimated that only 50% of people were successfully linked to treatment,¹ and several studies have found that stigma is significantly associated with delay in seeking care, with patients often expressing fears about insufficient protection of confidentiality.^{6,7}

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Although overt acts of discrimination are less common than subtle cues and hearing about discrimination of others (partly because of lack of disclosure by people with HIV), these experiences result in avoidance of status disclosure and delays in treatment seeking.^{8,9} For instance, experience or fears of discrimination has led pregnant women in Kolkata to avoid using services for prevention of parent-to-child transmission of HIV.¹⁰ Internalised stigma is also associated with depressive symptoms, and the relation is likely to be bidirectional, with care-seeking delays being more common among people who report higher levels of both internalised stigma and depression.⁶ Among injection drug users, fear of rejection by families and negative attitudes of healthcare professionals add to perceived stigma and treatment delays. Studies have documented reluctance of doctors to start people who inject drugs on antiretroviral treatment because they perceive these people to be non-adherent.¹¹

HIV stigma fears have also been reported to lead to suboptimal adherence, missed appointments, and delays in getting prescriptions refilled, thereby interfering with viral suppression. Patients have reported fear of taking their pills in front of family members, of asking for transport to clinics, or of being seen refilling prescriptions at their local pharmacy. ^{12,13} A study of rural mothers with HIV found that the association between internalised stigma and adherence was mediated by the women's use of stigma-avoidant coping strategies, suggesting that keeping one's diagnosis a secret might make it more difficult to take one's medications.¹⁴ Unfortunately, disclosure avoidance often results in a loss of social support and lower quality of life.¹⁵ Fear of stigma and discrimination also affects the ability of young people to manage their own regimen, by discouraging caregivers from informing them about their infections.¹⁶ Finally, fear of disclosure and subsequent stigma can interfere with adherence intervention efforts, such as phone reminders with patients or use of pre-exposure prophylaxis among Indian men who have sex with men.¹⁷

Given the pervasive effects of HIV stigma on all aspects of the HIV treatment cascade, a comprehensive stigma reduction response is needed on multiple levels, including policy, community, health-care institutions, and the family, as well as interventions that can help people with HIV to access testing and treatment and to remain in treatment without fear. The current Indian AIDS Control Programme strategy has made the elimination of stigma and discrimination a major focus, and a bill submitted in 2006 to prohibit discrimination in employment, education, health care, travel, and insurance on the basis of HIV status was finally passed in early 2014. This bill also recognises that a person living with HIV has the right to privacy and confidentiality about their HIV status. In addition, improving self-worth through reflections of personal experiences can reduce internalised stigma and depressive symptoms,⁷ and participation in positive networks and living in joint family are associated with less stigma among individuals with HIV.¹⁸ An ongoing randomised clinical trial is using a partly computer-administered intervention in health-care settings to address fear of HIV transmission and improve universal precaution skills.¹⁹ Such programmes need to be scaled up and should involve people living with HIV at all stages to reduce stigma associated with membership in at-risk populations and ensure that relevant skills for interaction with patients are taught.¹⁹

India has made some progress toward the UNAIDS target with regards to the provision of testing and treatment;^{1,2} however, stigma continues to pose a major challenge, particularly

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among members of already marginalised communities, who are also targets of additional intersectional stigma. Existing policies must therefore be enforced, and additional stigma reduction strategies need to be funded and integrated into media, school curriculums, and the education and training of future health-care professionals to eliminate this barrier to reaching the 90-90-90 goals.

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References

- 1. UNAIDS. Ending AIDS: progress towards the 90-90-90 targets. Geneva: UNAIDS, 2017.
- National AIDS Control Organisation. Integrated counselling and testing centre. 2016 http:// naco.gov.in/integrated-counselling-and-testing-centre (accessed Dec 8, 2016).
- Panditrao M, Darak S, Jori V, Kulkarni S, Kulkarni V. Barriers associated with the utilization of continued care among HIV-infected women who had previously enrolled in a private sector PMTCT program in Maharashtra, India. AIDS Care 2015; 27: 642–48. [PubMed: 25559362]
- Rogers A, Meundi A, Amma A, et al. HIV-related knowledge, attitudes, perceived benefits, and risks of HIV testing among pregnant women in rural southern India. AIDS Patient Care STDS 2006; 20: 803–11. [PubMed: 17134354]
- 5. Woodford MR, Chakrapani V, Newman PA, Shunmugam M. Barriers and facilitators to voluntary HIV testing uptake among communities at high risk of HIV exposure in Chennai, India. Glob Public Health 2016 11: 363–79.
- Steward WT, Bharat S, Ramakrishna J, Heylen E, Ekstrand ML. Stigma is associated with delays in seeking care among HIV-infected people in India. J Int Assoc Provid AIDS Care 2013; 12: 103–09. [PubMed: 22282878]
- 7. Steward WT, Chandy S, Singh G, et al. Depression is not an inevitable outcome of disclosure avoidance: HIV stigma and mental health in a cohort of HIV-infected individuals from southern India. Psychol Health Med 2011; 16: 74–85. [PubMed: 21218366]
- Chandra PS, Deepthivarma S, Manjula V. Disclosure of HIV infection in south India: patterns, reasons and reactions. AIDS Care 2003; 15: 207–15. [PubMed: 12856342]
- 9. Steward WT, Herek GM, Ramakrishna J, et al. HIV-related stigma: adapting a theoretical framework for use in India. Soc Sci Med 2008; 67: 1225–35. [PubMed: 18599171]
- Rahangdale L, Banandur P, Sreenivas A, Turan JM, Washington R, Cohen CR. Stigma as experienced by women accessing prevention of parent-to-child transmission of HIV services in Karnataka, India. AIDS Care 2010; 22: 836–42. [PubMed: 20635247]
- Chakrapani V, Velayudham J, Shunmugam M, Newman PA, Dubrow R. Barriers to antiretroviral treatment access for injecting drug users living with HIV in Chennai, south India. AIDS Care 2014; 26: 835–41. [PubMed: 24283220]
- Achappa B, Madi D, Bhaskaran U, Ramapuram JT, Rao S, Mahalingam S. Adherence to antiretroviral therapy among people living with HIV. N Am J Med Sci 2013; 5: 220–23. [PubMed: 23626959]
- Vallabhaneni S, Chandy S, Heylen E, Ekstrand M. Reasons for and correlates of antiretroviral treatment interruptions in a cohort of patients from public and private clinics in southern India. AIDS Care 2012; 24: 687–94. [PubMed: 22107044]
- Ekstrand ML, Heylen E, Mazur A, et al. The role of HIV stigma in ART adherence and quality of life among rural women living with HIV in India. AIDS Behav 2018; published online May 22. 10.1007/s10461-018-2157-7.
- Garrido-Hernansaiz H, Heylen E, Bharat S, Ramakrishna J, Ekstrand ML. Stigmas, symptom severity and perceived social support predict quality of life for PLHIV in urban Indian context. Health Qual Life Outcomes 2016; 14: 152. [PubMed: 27809839]

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- Ekstrand ML, Heylen E, Mehta K, Sanjeeva GN, Shet A. Disclosure of HIV status to infected children in south India: perspectives of caregivers. J Trop Pediatr 2018; 64: 342–47. [PubMed: 29092080]
- Chakrapani V, Newman PA, Shunmugam M, et al. Acceptability of HIV pre-exposure prophylaxis (PrEP) and implementation challenges among men who have sex with men in India: a qualitative investigation. AIDS Patient Care STDS 2015; 29: 569–77. [PubMed: 26348459]
- Kumar S, Mohanraj R, Rao D, Murray KR, Manhart LE. Positive coping strategies and HIV-related stigma in south India. AIDS Patient Care STDS 2015; 29: 157–63. [PubMed: 25612135]
- Nyblade L, Srinivasan K, Mazur A, et al. HIV stigma reduction for health facility staff: development of a blended-learning intervention. Front Public Health 2018; 6: 165. [PubMed: 29977887]