Avoiding Disclosure of HIV Status Leads to Greater Isolation and Depression Among HIV-Infected Individuals in Southern India
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Background
• Stigma reduces willingness to disclose HIV infection
• In Southern India, we previously found that HIV-infected individuals employed various strategies to avoid disclosure, such as:
  - Stating that one’s symptoms are due to a different disease
  - Seeking treatment away from home
• Hiding one’s HIV infection was often motivated by a fear of hostility or prejudice
• But limiting disclosure may come with consequences:
  - Psychological distress caused by social isolation
  - Limited access to social support and needed resources
• In this analysis, we examined the longitudinal effects of efforts to avoid HIV status disclosure:
  - Specifically, we looked at whether limiting HIV disclosure led to:
    - Actual reductions in subsequent enactments of stigma
    - Changes in endorsements of HIV-related stigmatizing beliefs
    - Changes in psychological distress (e.g., depression)

Methods
• Longitudinal cohort study of HIV-infected individuals on ART medications
• 229 individuals in southern India enrolled
  - 198 completed assessments at baseline (t = 0 months),
  - 6-month (t = 6 months), and 12-month follow-up (t = 12 months)
  - 135 men; 63 women
  - Analyses include only the participants who completed all three sessions

Measures
Disclosure Avoidance Scale (α = 82): 14 items assessing the frequency of employing techniques to avoid disclosure of HIV infection. Items averaged for scale score, e.g., “How often have you described your illness as tuberculosis instead of HIV?” (0 = no, 3 = often)

Actual disclosure to others: 12 items assessing whether or not participant had disclosed HIV status to specific family, friends or coworkers. Items averaged for an overall score, e.g., “Have you told your mother that you have HIV?” (0 = no, 1 = yes)

Enacted stigma: 10 items assessing prior experiences of discrimination. Items summed for total score, e.g., “Has a hospital worker mistreated you because of HIV?” (0 = no, 1 = yes)

Vicarious stigma: (α = .88) 10 items assessing the frequency with which participants heard stories about people being mistreated because of their HIV infection, e.g., “You have heard stories about families avoiding any relative who has HIV?” (0 = no, 3 = frequently)

Internalized stigma (α = .83): 10 items assessing extent to which participants endorsed HIV-stigmatizing attitudes. Items averaged for scale score, e.g., “How much do you feel that you should avoid feeding children because of your HIV?” (0 = not at all, 3 = a great deal)

Beck Depression Inventory (α = .90): Variant of BDI Version 1 previously validated in India; 21 items assessing symptoms of depression. Items summed for scale score.

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Results
• Little change over time in disclosure avoidance, actual disclosure, enacted stigma, or vicarious stigma.

Greater disclosure avoidance at t = 0 months associated with:
At t = 6 months:
  - Higher actual disclosure (r = -0.26, p < .01)
  - Higher internalized stigma (r = 0.23, p < .01)

At t = 12 months:
  - Lower actual disclosure (r = -0.16, p < .05)
  - Higher internalized stigma (r = 0.17, p < .05)

No differences in vicarious stigma (r = 0.09, p = .19)
No differences in enacted stigma (r = -0.06, p = .38)

Greater disclosure avoidance at t = 6 months associated with:
  - No differences in enacted stigma (r = -0.02, p = .84)
  - No differences in depression (r = 0.09, p = .19)

Greater disclosure avoidance at t = 12 months associated with:
  - No differences in enacted stigma (r = -0.01, p = .90)
  - No differences in depression (r = -0.09, p = .18)

Greater disclosure avoidance at t = 0 months was associated with lower actual disclosure at t = 6 months (r = -0.30, p < .01) and t = 12 months (r = -0.22, p < .01).

Greater disclosure avoidance at t = 0 months was associated with differences in actual disclosure at t = 6 months (r = 0.14, p = .22) at t = 12 months (r = 0.08, p = .95)

Greater disclosure avoidance at t = 0 months was associated with differences in depression at t = 0 months (r = 0.07, p = .61) at t = 6 months (r = 0.02, p = .86)

Summary/Conclusions
• Disclosure avoidance results in greater social isolation, poorer mental health, & continuing endorsement of HIV stigmatizing attitudes.
• By contrast, disclosure avoidance does not lead to fewer enactments of stigma, nor does it shield one from hearing stories about discrimination against others with HIV.
• Programs are urgently needed to support people living with HIV/AIDS in identifying and disclosing their infection to sympathetic friends and family.