MIGRANTS AND HIV STIGMA: FINDINGS FROM THE STIGMA INDEX STUDY (UK)

AUTHORS:

MARTHA JUDITH CHINOUYA; ANTHONY HILDRETH; DEBORAH GOODALL

NORTHUMBRIA UNIVERSITY, COMMUNITY, HEALTH & EDUCATION STUDIES RESEARCH CENTRE

And DIANA INEGBENEBOR AFRICAN HEALTH POLICY NETWORK

EXECUTIVE SUMMARY

The Human Immune Deficiency Virus (HIV) has affected families and individuals for over three decades. Despite developments in the clinical and social care of people living with HIV, 'stigma' remains one of the areas where it is complex to measure progress. The Stigma Index is an international action research intervention assessing experiences of stigma by people living with HIV. This report is based on results of the migrant sub-sample of the UK Stigma Index Survey questionnaire respondents. Key findings include:

- 276 survey participants described themselves as 'migrants': 195 women and 81 men. All women and 74 men reported heterosexual identities. They were 7 gay or bisexual men. Most participants were above 40 years of age, reflecting the ageing profile of people living with HIV in the UK.
- Most participants lived in major cities including London, Manchester and Leeds, with a few in rural areas.
- Deprivation was a key theme, reflecting research findings from other studies amongst HIV-affected immigrants in the UK. Most participants reported that they were unemployed. A fifth reported that they had experienced episodes of food insufficiency in the past year.
- Survey respondents reported other stigmatised chronic conditions and physical disabilities that compounded their experiences of living with HIV-related stigma.
- Control of information about a positive diagnosis is critically managed by persons living with HIV. More than half the survey participants reported that they had personally disclosed to family members. Ten percent reported a breach in confidence where members of their families had been informed about their HIV status without participants' consent.
- 40 men and 90 women reported that they had personally told their sexual partners that they were living with HIV. In 12 cases participants reported that they gave consent for someone else to inform their partners. As above, in some cases, disclosure to sexual partners, presumably by a third party occurred without the participants' consent.
- Felt stigma was common. Over half of the survey participants reported feeling ashamed because they were living with HIV. There were concerns about breaches of confidentiality, as some participants perceived that others were 'gossiping' about their positive HIV diagnosis.

- Felt stigma increased anxieties about personal safety, particularly amongst men. Male survey participants were three times more fearful than women of being insulted, physically harassed and/or assaulted. Depression was also reported. Nearly half the number of men and a third of the women reported that they felt suicidal.
- Personal strategies for safeguarding against the negative impact of stigma included avoiding social gatherings, friends, intimacy, clinical and social care settings.
- Participants believed that stigma arose through ignorance about HIV and how HIV was transmitted.
- Most participants were unaware of policies and declarations that protected them as persons living with HIV. Although some participants believed that their human rights had been violated, they were unlikely to seek legal redress.

KEY RECOMMENDATIONS

The involvement of people living with and affected by HIV is important in designing anti-stigma interventions as this gives HIV a 'human face' and increases the cultural relevancy of such interventions. Anti-HIV stigma campaigns embedded in human-rights approaches may help fight the discrimination experienced by people living with HIV. Based on experiences reported by the UK Index Study migrant sub-sample it is recommended that:

- Efforts to fight stigma must recognize the social determinants of health, that is, the individual cultures interacting with wider social and political factors to impact on health and wellbeing of migrants living with HIV. Such efforts should take account of discourses emanating from, for example, race, racism, migration. Efforts to fight stigma amongst migrants should utilize orchestrated efforts and collaborative partnerships between policy makers, HIV activists, academics, health planners and individuals living with HIV.
- Efforts to fight stigma must seek to build capacity in human rights approaches amongst
 migrant community groups, policy makers and individuals. This can be achieved
 through training, skills building and increasing networking opportunities amongst
 various stakeholders. Initiating such cultural shifts in the workforce, will enable
 workers and people living with HIV to incorporate human rights approaches in antistigma campaigns.
- Efforts to fight stigma must seek to increase mentoring opportunities amongst migrant communities living with HIV so as to fight stigma' from within'.
- Efforts to fight stigma must extend HIV awareness campaigns beyond the 'suspect high risk groups' that have historically included gay men and African communities.