Stigma Update

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Patient Experience with Stigma in NYS

According to the Medical Monitoring Project (MMP), a population-based surveillance system that assesses clinical outcomes and behaviors of PLWH receiving care in the US between 2009-2014, in NYS (excluding NYC) and NYC:

<table>
<thead>
<tr>
<th>MMP Statement</th>
<th>NYS (excluding NYC) (N=421)</th>
<th>NYC (N=1,577)</th>
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<tbody>
<tr>
<td><strong>Perceived Stigma</strong></td>
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<tr>
<td>“I hide my HIV status from others”</td>
<td>67%</td>
<td>47%</td>
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<tr>
<td>“It is difficult to tell people about my HIV infection”</td>
<td>74%</td>
<td>58%</td>
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<td><strong>Discrimination Experiences</strong></td>
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<td>Reported healthcare providers exhibited hostility or a lack of respect during</td>
<td>26%</td>
<td>13%</td>
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<td>a healthcare visit</td>
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<tr>
<td>Reported said discrimination occurred because of HIV infection</td>
<td>92%</td>
<td>69%</td>
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Source: NYSDOH Office of Public Health and NYC DOHMH HIV Epidemiology and Field Services Program
Internalized HIV-Related Stigma

Almost 8 in 10 HIV patients in the United States report feeling internalized HIV-related stigma.

What is internalized HIV-related stigma?

It is when a person living with HIV experiences negative feelings or thoughts about their HIV status. Here, it is defined as someone agreeing with one or more of the following statements:

- I am ashamed that I am HIV-positive.
- Being HIV-positive makes me feel dirty.
- I feel guilty that I am HIV-positive.
- I feel guilty that I am HIV-positive.
- I feel worthless because I have HIV.
- It is difficult to tell people about my HIV infection.
- I feel my HIV status from others.

Nearly 2 out of 3 say that it is difficult to tell others about their HIV infection. Roughly 1 out of 3 report feeling guilty or ashamed of their HIV status.

Nearly 1 in 4 say that being HIV-positive makes them feel dirty or worthless.

How can people living with HIV reduce internalized stigma?

There are several strategies you may want to consider:

- Take HIV medicine as prescribed to keep HIV undetectable and prevent transmission. This helps reduce internalized stigma by reducing the risk of spreading HIV.
- Find a community that can help you deal with stigma.
- Take a support group's or organization's advice on how to cope with living with HIV.
- Find support groups or organizations that help people living with HIV. These groups offer a safer environment and can help you overcome the challenges of living with HIV.

HIV TREATMENT CAN KEEP YOU HEALTHY AND PROTECT OTHERS

If you are being treated for HIV in care and taking treatment as soon as possible, you can receive the best possible care. Taking HIV medicine as prescribed can make the level of HIV in your blood very low and make it hard to transmit it to others. Getting and keeping an undetectable viral load is the best way you can do to stay healthy. Also, if you stay undetectable, you have virtually no risk of transmitting HIV to an HIV-infected partner through sex. Learn more about living with HIV at www.cdc.gov/hivtreatmentworks.

For More Information Call 1-800-CDC-INFO (232-4635)
Visit www.cdc.gov/hiv

Learn more about the Medical Monitoring Project:
www.cdc.gov/monitoring

SOURCE:


ADDITIONAL RESOURCES FOR REDUCING STIGMA:

- Let's Rise. HIV Together Campaign
  www.cdc.gov/together

- National Prevention Information Network (NPIN)
  http://npi.cdc.gov/search/alt stigma

- National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention
  Division of HIV/AIDS Prevention

- CDC Resources
At this time:
72 organizations participating in the QoC review have surveyed staff and received feedback from consumers
- ~3,032 staff members surveyed
- ~2,119 consumers surveyed
In general, survey respondents:

- Have not received training on HIV-related stigma and discrimination
- Did not have knowledge of policy against discrimination of key populations
- Agreed that infection occurs due to irresponsible behavior, and PLWH have had many sexual partners
- Observed people talking badly about:
  - Women
  - People of color
  - People with a mental health diagnosis
  - TG/GNC individuals
- Have lack of training:
  - Women's health
  - TG/GNC individuals
  - People with a mental health diagnosis
  - People who use drugs
In general, consumers:

- In the healthcare setting:
  - Have feelings of discomfort in waiting room/front desk area
    - Lack of welcoming environment
    - Staff behavior, intake forms, loud talking
  - Experienced stigma in other areas of healthcare center (ER, dental, specialty providers, inpatient units)
  - Experienced staff providing extra infection control procedures
  - Observed staff talking badly about PLWH, TGNC folks, and people with a mental health diagnosis
  - Clinic location and name cause for concern for confidentiality and privacy

- In the community and personally:
  - Experience more stigma in the community than in the healthcare setting
    - Have worries about telling others about HIV status, worries about discrimination, and hide their status from others
    - Lack of knowledge in the community
Stigma Reduction Action Plan

Themes

▪ Increasing staff education
  ▪ HIV-related stigma and discrimination trainings, key population trainings (TGNC, STI screening for LGBT population, mental health)
  ▪ Train staff outside of clinics

▪ Welcoming, inclusive environment
  ▪ Posters and resources for all populations (women, TGNC, PLWH), U=U

▪ Updating policies
  ▪ Stigma and discrimination, sexual orientation and gender identity (SOGI) use

▪ Creation of stigma reduction work groups (consumers and staff)

▪ Creation of support groups for key populations