HIV stigma: perceptions from HIV-positive and HIV-negative patients in a community dental clinic

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Abstract

Background. In the medical sense, stigma has been defined as the collection of negative attitudes and beliefs that are directed at people living with a particular condition or disease process. A cohort study was conducted to explore the HIV stigma that is perceived by HIV-positive individuals versus that perceived by the general population within a community-based dental clinic.

Methods. Two separate and independent cross-sectional surveys, the Berger Stigma Scale and the Rutgers-Modified Berger Stigma Scale, were employed in order to analyze the stigma factors of an HIV-positive population versus an HIV-negative general population, respectively. The HIV stigma factors studied included personalized stigma, disclosure concerns, negative self-image, and concern with public attitudes.

Results. The total stigma scale scores for the studied HIV-positive population were significantly lower than the total stigma scale scores for the studied HIV-negative population (P < 0.05).

Conclusion. Interestingly, there is a misplaced expectation by the general population that HIV-positive individuals experience more stigma than the HIV-positive population in the clinic actually reported. Interventions to reduce HIV stigma should be an integral component of comprehensive care for all patients.

Key words: Attitudes, HIV/AIDS, mental health, public health, self-perception, stigma.
agreed that a definite social stigma is still associated with the disease. The general population in the United States believes that stigma is still an issue for people living with HIV/AIDS, and the authors determined to test whether or not the HIV positive population feels the same way as the general public expects them to feel.

Methods have been developed to measure the stigma that is perceived by those infected with HIV, with the Berger Stigma Scale (BSS) being considered as one of the most effective and reliable. Separately, public reactions toward people infected with HIV have also been examined, leading to the understanding that a sizable portion of the general population still holds negative beliefs and preconceptions toward those with HIV/AIDS. Widespread studies have been conducted regarding the stigma perceived by HIV-positive individuals, as well as the stigma that the general population feels toward those with HIV/AIDS; nonetheless, limited studies have been carried out on the comparison between these two populations within the same geographic and demographic settings. Recognizing this disconnect, we sought to fill this gap by measuring the stigma perceived by people with HIV compared to the stigma projected by the general population. This was examined by employing the BSS for HIV-positive individuals and the Rutgers Modified Berger Stigma Scale (RMBSS) for the HIV-negative population. Since the BSS was designed specifically for persons infected with HIV, the RMBSS was created as its congruent analog, maintaining every question, modified only in language so as to reflect a non-infected individual’s opinion. Both tools measured stigma in four factors: personalized stigma, disclosure concerns, negative self-image, and concern with public attitudes and also assigned a total stigma score.

Methods

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1975 Helsinki Declaration and its later amendments. The protocol was approved by the UMDNJ-Stratford Campus/Rutgers Institutional Review Board.

Question development

The BSS was designed at the College of Nursing, University of Illinois in Chicago in 2001. The BSS is validated, standardized, and widely used to measure stigma in the HIV-positive population. It measures stigma perceived by people living with HIV, and was developed based on the literature on stigma and psychosocial aspects of having HIV. The 40 items of the BSS focus on experiences, feelings, and opinions as to how people living with HIV feel and how they are treated (Table 1). The person living with HIV responds to these items using a four-point Likert-type scale (strongly disagree, disagree, agree, strongly agree). Higher values indicate a greater level of agreement with each item. Rutgers School of Dental Medicine (RSDM) developed a derivative, Rutgers Modified Stigma Scale (RMBSS) in 2010, which was designed to measure stigma projected by people who do not have AIDS. The 40 items of the RMBSS focus on experience, feelings, and opinions as to how the general population perceive and treat those who are HIV-positive (Table 2). The person not living with HIV responds to these items using a four-point Likert-type scale (strongly disagree, disagree, agree, or strongly agree). Higher values indicate a greater level of agreement with each item. Test-retest correlation for the survey instruments were analyzed, measuring 0.92 for the BSS survey and 0.82 for the RMBSS survey. Both tools have the same score ranges. The total HIV score can range from 40 to 160, the personalized stigma score can range from 18 to 72, the disclosure concern score can range from 10 to 40, the negative self-image score can range from 13 to 52, and the public attitude score can range from 20 to 80; the higher the score, the higher and more severe the stigma.

Recruitment and consent

During the course of routine dental visits, active patients of the Rutgers extramural dental clinics in Galloway and Somerdale, New Jersey, were invited to participate. At the time of data collection, 18% of the active patient pool of these clinics were HIV-positive. Within this patient pool, two populations were identified. The first consisted of patients aged 25 through 64, who were HIV-positive, and the second consisted of patients from the general population, aged 25 through 64, who were HIV-negative. All the participants gave informed consent in this institutional review board-approved project. Any patient under the age of 25 or over the age of 65 was ineligible to participate. Additionally, any patient aged 25 through 65 that could not read English was also excluded.

Procedure

A cross-sectional study was conducted in the two RSDM extramural clinics. Both of these clinics have been providing oral health services for individuals
infected with HIV and have received Ryan White Funding for over 25 years. Intake receptionists distributed the appropriate surveys to patients based on their medical history as they checked in for their appointments. Data was collected for both populations via the surveys. Surveys were completed voluntarily and anonymously, placed in sealed envelopes, and dropped into a secured receptacle in the dental clinic waiting room.

**Analysis**

A total enrollment of 200 participants (100 HIV-positive patients and 100 HIV-negative patients) provided a 95±9% CI based upon the number of active unduplicated AIDS patients enrolled in the extramural clinics.

Mean scores, standard deviations, medians, variances, and averages of absolute deviations were calculated for each of the four stigma factors (personalized stigma, disclosure concerns, negative self-image, and concern with public attitudes) and the total HIV stigma score for both AIDS and non-AIDS populations. The primary analysis compared results from the BSS to the RMBSS.

**Results**

**Participant characteristics**

Population analysis of the two enrolled cohorts reflected the demographic profile of the local populations of both groups, and illustrated significant differences between the HIV-positive and HIV-negative groups. Of the 100 enrolled HIV-infected participants, those with self-reported race/ethnicity as Black/African American constituted nearly half of the received surveys (45%) (Table 3). Three quarters of this cohort’s respondents were male (72%) and...
A clear majority of the 100 enrolled non-HIV-infected cohort self-reported race/ethnicity as Caucasian (81%) (Table 3). The non-AIDS cohort was evenly split between male and female respondents (49% and 50%, respectively), with one transgender participant. Two thirds of both groups reported to be between the ages of 44 and 64 years.

**Stigma scale results**

The stigma scale scores of the two cohorts, with the Berger Stigma Scale used for the HIV-positive population and the Rutgers-Modified Stigma Scale used for the HIV-negative population were tabulated and analyzed (Tables 4 and 5). The difference between the average Total HIV Stigma Score for the HIV-negative cohort using the RMBSS and HIV-positive cohort using the BSS was statistically significant (P < 0.05), scoring 110.5 versus 97.2, respectively. Additionally, all individual stigma factors were higher in the HIV-negative cohort, including personalized stigma, disclosure concerns, negative self-image, as well as public attitudes. The disclosure concern subscale represented the most significant deviation between the two groups scoring 60.1 versus 28.0 for the HIV-negative and HIV-positive cohorts, respectively.

**Discussion**

There is an exaggerated expectation in the general population that HIV-positive individuals experience a certain degree of stigma. To remedy this, there must be interventions to prevent HIV-related stigma. Community-based organizations can take steps to improve the public’s lack of understanding of HIV.
and increase acceptance of HIV-positive individuals. Through education, we have a responsibility to decrease the public’s rejection of people with HIV (personalized stigma), foster a community of unconditional regard for an individual’s status (disclosure concerns), eliminate any projection of inferiority towards HIV-positive individuals (negative self-image), and change the public’s preconceptions about people with HIV (concern with public attitudes).

This study entirely relied on self-reported survey—a type of instrument known to have inherent limitations with regards to accuracy and reliability. The results are dependent upon the honesty of respondents, their objective introspective ability, as well as their response bias. To minimize this limitation, surveys were completed anonymously and privately. It might be surmised that the HIV-positive participants that took part in this study did not experience a significant degree of stigma. However, it can be noted that this cohort might have been biased towards a sense of approval and acceptance—the community-based dental clinic that disseminated this study takes steps to minimize stigma perceptions among its patients. Support group presentations, literature distribution, poster presentations, and open dialogue and discussion about HIV are pillars of the clinics. The lower stigma perception of participants in this dental clinic might bias results.

Although the samples differed in their demographic makeup, the populations studied were representative of the New Jersey demographic profiles for each group surveyed: New Jersey’s HIV-positive and HIV-negative populations. Further studies and analyses could be considered to rule out possible demographic skewing of our results to minimize the impact that New Jersey’s HIV-positive population is more demographically diverse than its general population.

**Conclusion**

This study demonstrates that decades into the HIV epidemic, there is still a misplaced stigma projected towards individuals with HIV by the general population. Our findings reaffirm the need to educate the

<table>
<thead>
<tr>
<th>Age</th>
<th>Number of HIV+ Respondents</th>
<th>Number of HIV- Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>25–34</td>
<td>16</td>
<td>23</td>
</tr>
<tr>
<td>35–44</td>
<td>21</td>
<td>19</td>
</tr>
<tr>
<td>45–55</td>
<td>42</td>
<td>34</td>
</tr>
<tr>
<td>56–64</td>
<td>21</td>
<td>24</td>
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</table>

<table>
<thead>
<tr>
<th>Gender</th>
<th>Male</th>
<th>Female</th>
<th>Transgender</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>72</td>
<td>27</td>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>White</th>
<th>African American</th>
<th>Hispanic</th>
<th>Asian</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>34</td>
<td>45</td>
<td>16</td>
<td>5</td>
</tr>
</tbody>
</table>

The demographic profiles of survey participants reflect the demographic profiles of the local community. Minorities are represented more heavily in the HIV infected cohort.

<table>
<thead>
<tr>
<th>Analysis</th>
<th>Personalized Stigma</th>
<th>Disclosure Concerns</th>
<th>Negative Self-image</th>
<th>Concern with Public Attitudes about People with HIV</th>
<th>Total HIV Stigma Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean Scores</td>
<td>41.0</td>
<td>28.0</td>
<td>29.4</td>
<td>48.5</td>
<td>97.2</td>
</tr>
<tr>
<td>Standard Deviation</td>
<td>12.1</td>
<td>5.9</td>
<td>813</td>
<td>12.4</td>
<td>23.2</td>
</tr>
<tr>
<td>Median</td>
<td>40.0</td>
<td>28.0</td>
<td>29.0</td>
<td>48.0</td>
<td>95.0</td>
</tr>
<tr>
<td>Variance</td>
<td>145.8</td>
<td>34.7</td>
<td>66.1</td>
<td>154.9</td>
<td>535.7</td>
</tr>
<tr>
<td>Avg of Abs. Dev.</td>
<td>8.9</td>
<td>4.7</td>
<td>6.0</td>
<td>9.6</td>
<td>17.4</td>
</tr>
</tbody>
</table>

The four stigma subscales and total stigma scores of the HIV infected population as recorded from the Berger Stigma Scale.

<table>
<thead>
<tr>
<th>Analysis</th>
<th>Personalized Stigma</th>
<th>Disclosure Concerns</th>
<th>Negative Self-image</th>
<th>Concern with Public Attitudes about People with HIV</th>
<th>Total HIV Stigma Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean Scores</td>
<td>49.3</td>
<td>60.1</td>
<td>34.9</td>
<td>53.9</td>
<td>110.5</td>
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<tr>
<td>Standard Deviation</td>
<td>7.4</td>
<td>4.1</td>
<td>5.0</td>
<td>8.5</td>
<td>15.6</td>
</tr>
<tr>
<td>Median</td>
<td>49.0</td>
<td>29.0</td>
<td>34.0</td>
<td>54.0</td>
<td>108.0</td>
</tr>
<tr>
<td>Variance</td>
<td>54.8</td>
<td>16.9</td>
<td>25.0</td>
<td>72.3</td>
<td>246.9</td>
</tr>
<tr>
<td>Avg of Abs. Dev.</td>
<td>5.6</td>
<td>3.1</td>
<td>3.9</td>
<td>6.6</td>
<td>12.1</td>
</tr>
</tbody>
</table>

The four stigma subscales and total stigma scores of the general population as recorded from the Rutgers Modified Berger Stigma Scale and their associated analysis.
public about minimizing projected stigma in all its forms: personalized stigma, disclosure concerns, negative self-image, and concern with public perceptions. To that end, community dental clinics must open a dialogue about HIV with all patients, not just those infected with HIV. Doing so will bring HIV out in the public consciousness and reduce the negative beliefs and preconceptions aimed at people living with HIV.

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Authors’ contributions

ST was responsible for the study conception and design, data collection and analysis, and drafting and revision of the manuscript. JY was responsible for the study conception and design, data collection and analysis, and drafting and revision of the manuscript. ND was responsible for the study conception and design, data collection and analysis, and drafting and revision of the manuscript. All of the authors have read and approved the final manuscript.

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Competing interests

The authors declare no competing interests with regards to the authorship and/or publication of this article.

Ethical approval

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1975 Helsinki Declaration and its later amendments. The protocol was approved by the UMDNJ-Stratford Campus/Rutgers Institutional Review Board.

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