Knowledge of Legal Rights among Persons Living with HIV/AIDS in Puerto Rico: Implications for Stigma Management

Souhail Malavé-Rivera, PhD*; Blanca Ortiz-Torres, PhD, JD†; Nelson Varas-Díaz, PhD‡

Objective: To determine the level of understanding that people living with HIV/AIDS (PLWHA) in Puerto Rico have in terms of their own legal rights; to ascertain how the members of this population manage the violation/s of these rights in the event that such violations occurred.

Methods: A mixed-method design was used to accomplish our objectives. One hundred and three participants completed a questionnaire; an in-depth interview was also conducted with 10 members of the sample group.

Results: Quantitative results show that the most recognized rights among the participants were the right to have sex (n = 98; 95%) and the right to marry (n = 90; 87%). Most participants inaccurately indicated that PLWHA are forced by law to disclose their HIV serostatus both to their partners (n = 69; 67%) and to their physicians (n = 70; 68%). The results from qualitative analysis indicate that most of the participants had experienced discrimination, though none reported these occurrences to the legal authorities.

Conclusion: Findings suggest that there is a need to improve the implementation of the public policy that protects PLWHA who live in Puerto Rico from discrimination. Future interventions aimed at reducing HIV-related stigma should consider providing information about legal rights and strategies for managing stigma and discrimination. Healthcare professionals play an important role in the promotion of the rights of PLWHA in Puerto Rico. [P R Health Sci J 2012;3:130-137]

Key words: HIV, AIDS, Puerto Rico, Discrimination, Legal rights

The HIV/AIDS epidemic continues affecting many people around the world. One of the ancillary outcomes of this epidemic is that the rights of people living with HIV/AIDS (PLWHA) are violated on a regular basis. There is a call for a human rights approach that will reduce this rights violation (1, 2). Discrimination does not occur in a vacuum; for that reason, we have been attempting to better understand the manifestations and consequences of HIV stigmatization as they pertain to the violation of the rights of PLWHA.

Based on Goffman’s (3) conceptualization of stigma as a “deeply discrepable attribute of an individual or a group,” literature on HIV has operationalized the definition of the stigma related to HIV. HIV-related stigma refers to “all stigma directed at persons perceived to be infected with HIV, regardless of whether they are actually infected and of whether they manifest symptoms of AIDS or AIDS-related complex” (4). HIV-related stigma is often rooted in the lack of knowledge about HIV transmissibility, fear of contagion, and the association of HIV with socially devalued behaviors (e.g., promiscuity, drug use, homosexuality) (5, 6). Stigmatizing attitudes have been documented among family members of PLWHA (7, 8), employers of PLWHA (9), and healthcare professionals (10, 11). Some manifestations of stigmatizing behavior include avoiding physical contact with and resisting treating PLWHA. Both of these negative actions are considered to be discriminatory (12, 13), and these actions in turn can be the basis for the violation of rights (5, 12). Examples of discrimination that constitute violations of PLWHA’s rights have been widely documented in the literature and include refusal of employment (14), denial of healthcare services (15), restriction of liberty, and physical aggression (16). Discrimination against PLWHA can be detrimental to these individuals’ physical and emotional health, often resulting in symptoms of depression, delays in seeking health services, poor adherence to medication regimen, and poor quality of life (15,
In addition to the consequences of discrimination observed at the individual level, the public health implications of such discrimination are equally worrisome. Due to the negative consequences of HIV-related stigma, many people fear getting tested for HIV, and those who have already been diagnosed often refuse to participate in HIV-related programs or trials for treatment (19). Furthermore, PLWHA can experience poor adherence to treatment, which could lead to rapid viral replication and the development of drug-resistant strains (20).

Several qualitative studies have identified diverse strategies that PLWHA employ to manage HIV-related stigma, which strategies include voluntarily disclosing status, engaging in religious activities, avoiding any situation in which such stigma might arise, and/or confronting the stigmatizing individual or situation (21, 22, 23). In Puerto Rico, stigmatization has been documented in a number of contexts and settings. Familiar, professional, and even healthcare settings (8) have been environments in which stigmatizing events occur. Wherever and under whatever circumstances they occur, managing the stress resulting from stigmatization is critical for PLWHA.

Efforts to reduce HIV-related stigma advocate capacity building among PLWHA to confront stigmatization and identify legal support, when such support is available (1). Even in areas (e.g., Puerto Rico) where there are specific laws to protect PLWHA, there is evidence of stigma and discrimination (8, 10, 24). The violation of PLWHA's rights could be partially attributed to the lack of knowledge of those rights. A formative study on stigma and discrimination identified a lack of knowledge about the rights of PLWHA, not only among themselves but also among healthcare professionals, people who work in the media, lawyers, and politicians (2). Combining education with the active support of the rights of PLWHA might be an effective strategy for decreasing HIV-related stigma and discrimination.

In Puerto Rico, protective legislation was not approved until 2000, when the legislature passed law no. 349 (for the purposes of this paper, we will use “law 349” when referring to this law), which is entitled "Bill of Rights of People Carrying the HIV/AIDS Virus" (Carta de Derechos de las Personas Portadoras del Virus del VIH/SIDA in Spanish) (25). Not until almost 20 years after the first case of HIV was diagnosed in Puerto Rico was a comprehensive law protecting PLWHA from discrimination passed (26). This law establishes the responsibilities of the government, assuring that PLWHA are granted all civil and constitutional rights. The following are some excerpts:

- **Article 3: The Rights of People with HIV/AIDS in Puerto Rico.** This article establishes the protection of specific rights, including the right to have access to services and information related to HIV/AIDS; the respect of the individual rights of PLWHA; the liberty of the individual won’t be restricted, the right to the confidentiality of one’s HIV status; and the right to have a civil, professional, and sexual life.

- **Article 4: The Responsibilities of the Department of Health.** To advocate this law and generate mechanisms to educate healthcare professionals, patients, and the general public. The establishment of this law is an important step in the protection of the rights of PLWHA. Despite this official policy, Puerto Rican PLWHA still struggle with HIV-related stigma and discrimination (2, 8, 25–27). Research conducted among PLWHA in Puerto Rico confirms that stigma and discrimination occur constantly (8). However, no previous studies have explored either the knowledge of legal rights among PLWHA in Puerto Rico or the strategies these individuals employ to manage stigma and discrimination.

Considering that efforts in other countries focus on disseminating the knowledge of legal rights as a strategy for reducing stigma and discrimination (1, 2), the main objectives of this study were 1) to assess the knowledge of their own rights in a sample of PLWHA in Puerto Rico and 2) to explore the strategies that they use to manage stigma and discrimination.

### Methods

#### Participants

A total of 103 participants completed a self-administered questionnaire. The majority of these participants were Puerto Rican (n = 95; 92%) and had a mean age of 48 years (ranging from 19 to 72). Fifty-eight percent (n = 60) were male, and 41% (n = 42) were female. Most identified themselves as being heterosexual (n = 71; 74%) and single (n = 68; 66%), and 85% (n = 88) lived in San Juan, the capital city of the island. We present a detailed description of the participants’ socio-demographic data in Table 1.

#### Selection and screening

A study staff member recruited all of the participants at two healthcare centers for PLWHA in San Juan, Puerto Rico, from August to October of 2009. This person approached potential participants individually, inviting them to complete a self-administered questionnaire while they were in the waiting area. We screened prospective participants to establish eligibility. The inclusion criteria were 1) being HIV positive, 2) being 21 years or older at the moment of participation, 3) being able to consent for participation, and 4) being willing to participate.

#### Measures

We developed a self-administered Spanish-language questionnaire. The questionnaire was used to do the following: 1) to ascertain socio-demographic information, 2) to assess each participant’s level of knowledge concerning law 349, 3) to...
encourage each participant to relate his or her experiences of discrimination, and 4) to ascertain the strategies used to manage such experiences, when they existed. Completion time was approximately 25 minutes. We describe each topic below.

Socio-demographic data: Respondents answered questions regarding age, sex, current residence, and monthly income.

Knowledge-of-Rights Index: This 11-item index (see Table 2) included statements based on the contents of law 349. Stating the premise “People living with HIV...,” items included the following: “can get married”, “are not forced by law to disclose their HIV status to their partners”. Respondents had to choose either 1 (yes) or 0 (no) to indicate which statements they believed were rights for PLWHA and which were not.

Experiences-of-Stigma-and-Discrimination Index: This 13-item index inquired about experiences of HIV-related stigma at any point after their diagnosis and included the following statements: “I have been placed in isolation” and “I have been denied service at a healthcare center”.

Table 1. Socio-demographic description of participants

<table>
<thead>
<tr>
<th></th>
<th>n</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>60</td>
<td>58</td>
</tr>
<tr>
<td>Female</td>
<td>42</td>
<td>41</td>
</tr>
<tr>
<td>Transgender</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td><strong>Mean age</strong></td>
<td>48 y/o</td>
<td></td>
</tr>
<tr>
<td><strong>Sexual orientation</strong></td>
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<td></td>
</tr>
<tr>
<td>Heterosexual</td>
<td>71</td>
<td>75</td>
</tr>
<tr>
<td>Homosexual</td>
<td>17</td>
<td>18</td>
</tr>
<tr>
<td>Lesbian</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Bisexual</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>12</td>
<td>12</td>
</tr>
<tr>
<td>Single</td>
<td>68</td>
<td>66</td>
</tr>
<tr>
<td>Separated</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Divorced</td>
<td>10</td>
<td>9</td>
</tr>
<tr>
<td>Widowed</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td><strong>Level of education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than high school</td>
<td>19</td>
<td>19</td>
</tr>
<tr>
<td>High school</td>
<td>43</td>
<td>42</td>
</tr>
<tr>
<td>Vocational or technician</td>
<td>14</td>
<td>14</td>
</tr>
<tr>
<td>Some college</td>
<td>18</td>
<td>18</td>
</tr>
<tr>
<td>Undergraduate degree</td>
<td>8</td>
<td>7</td>
</tr>
<tr>
<td><strong>Source of income</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full-time job</td>
<td>8</td>
<td>7</td>
</tr>
<tr>
<td>Part-time job</td>
<td>7</td>
<td>6</td>
</tr>
<tr>
<td>Social Security</td>
<td>25</td>
<td>24</td>
</tr>
<tr>
<td>Unemployment</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Disability</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Welfare</td>
<td>61</td>
<td>59</td>
</tr>
<tr>
<td><strong>Monthly income (approx.)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;$500</td>
<td>63</td>
<td>65</td>
</tr>
<tr>
<td>$501-1,000</td>
<td>15</td>
<td>16</td>
</tr>
<tr>
<td>&gt;$1,001</td>
<td>18</td>
<td>19</td>
</tr>
</tbody>
</table>

*Some participants did not answer the question. The reported percentage was calculated using the available data. **Some participants reported having more than one source of income. The reported percentage was calculated using the total number of the sample (n = 103).

Table 2. Results of the knowledge-of-rights index

<table>
<thead>
<tr>
<th>Items</th>
<th>Answered correctly</th>
<th>Answered incorrectly</th>
</tr>
</thead>
<tbody>
<tr>
<td>People with HIV/AIDS...</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. are allowed to have sexual relations</td>
<td>95% (n = 98)</td>
<td>5% (n = 5)</td>
</tr>
<tr>
<td>2. are allowed to get married</td>
<td>87% (n = 90)</td>
<td>10% (n = 10)</td>
</tr>
<tr>
<td>3. are not forced by law to disclose their HIV status to their bosses</td>
<td>87% (n = 90)</td>
<td>11% (n = 11)</td>
</tr>
<tr>
<td>4. cannot be fired from their jobs if they don’t inform their bosses of their HIV status</td>
<td>86% (n = 89)</td>
<td>11% (n = 11)</td>
</tr>
<tr>
<td>5. are permitted drink water from the same glass of a person who is not HIV positive</td>
<td>79% (n = 81)</td>
<td>20% (n = 21)</td>
</tr>
<tr>
<td>6. have the same (constitutional) rights as people who don’t have HIV/AIDS have</td>
<td>79% (n = 81)</td>
<td>17% (n = 18)</td>
</tr>
<tr>
<td>7. are allowed to have children</td>
<td>77% (n = 79)</td>
<td>20% (n = 21)</td>
</tr>
<tr>
<td>8. are allowed to work in hospitals or health centers</td>
<td>73% (n = 75)</td>
<td>23% (n = 24)</td>
</tr>
<tr>
<td>9. are allowed to make decisions about their own treatment (e.g., which medications to take)</td>
<td>52% (n = 54)</td>
<td>45% (n = 46)</td>
</tr>
<tr>
<td>10. are forced by law to disclose their status to their partners</td>
<td>32% (n = 33)</td>
<td>67% (n = 69)</td>
</tr>
<tr>
<td>11. are forced by law to disclose their status to physicians</td>
<td>29% (n = 30)</td>
<td>68% (n = 70)</td>
</tr>
</tbody>
</table>

Stigma-and-Discrimination-Management Questions: This section consisted of closed- and open-ended questions regarding strategies participants might have used to manage stigma. Questions included Have you ever sought psychological help after a stigmatizing event? and Have you ever sought legal help after a stigmatizing event?

In-Depth—Interview Guide: The guide included 11 questions that addressed each respondent’s experiences of HIV-related stigma and discrimination and delineated the strategies he or she used to manage those experiences as well as the strategies needed in order to prevent the occurrence of those rights violations in PLWHA in Puerto Rico or—if such occurrences cannot be prevented—deal with the results after they have occurred.

Procedure

At the time of the study, no instrument had been developed that explored the knowledge of rights among PLWHA in Puerto Rico. Given that limitation, and because the nature of the proposed objective was so specific to the Puerto Rican context, we developed a questionnaire to meet our proposed objectives.

A panel of experts on HIV/AIDS (two experts) and civil law (one expert) evaluated the instrument for content validity (28), and we incorporated their recommendations. We conducted a pilot study to ensure that participants could understand the content of the instrument. Ten participants who met the inclusion criteria completed the questionnaire, and we included their suggestions in the final version.
We also developed an interview guide to gather information about stigma management. Two experts in psychology who had experience in HIV/AIDS research reviewed the guide and provided feedback for the final version.

Following the pilot phase, we started the recruitment phase. A staff member screened participants, and those who met all of the inclusion criteria were asked to join the staff member in a private office space in each center. This procedure increased privacy and confidentiality during the process. The staff member explained the consent form in detail and obtained consent from each participant before providing the self-administered questionnaire. If a person had a physical condition preventing their being able to read and/or answer the questionnaire or if there were literacy issues, the staff member provided assistance, reading all of the questions and writing down the participant’s answers.

After completing the questionnaire, the staff member invited every 10th participant to take part in an in-depth interview. If that individual declined, the next participant who completed the questionnaire was invited. Based on the exploratory nature of the study, we determined a sample size of n = 10 to be adequate for this phase. Those participants who agreed to continue chose the date and time of their interview. Participants were interviewed individually in the same private offices where they filled in the questionnaire. Each interview lasted approximately one hour. A study staff member transcribed each interview for further analysis. The protocol of the study was approved by the Institutional Review Board (IRB) of the University of Puerto Rico, Rio Piedras Campus (#0809-142).

Analysis

We carried out a descriptive analysis of the quantitative data using SPSS (version 17.0). We used frequencies and percentages to present the results for the socio-demographic data, both indexes (Knowledge of Rights and Experiences of Stigma and Discrimination), and closed-ended questions.

We conducted a content analysis of the qualitative data, using Nudist NVivo (version 2) to store and organize the data. A panel of three researchers categorized all of the interviews and developed a list of 31 categories (serving as units of analysis) that emerged from the interviews. The coding of each category of information required the consensus of the three panel members. For the purposes of this paper, we are presenting results from the following analytic categories: experiences of discrimination, consequences of discrimination, strategies used to face discrimination, seeking help, don’t know where to go for help, and alternatives to discrimination.

Results

Quantitative results

The majority of the participants recognized that they had the right to have sexual relations (n = 98; 95%), the right to get married (n = 90; 87%), and the right not to be forced by law to disclose their HIV status to their bosses (n = 90; 87%). The least recognized right was that the law did not obligate them to disclose their status to their partners (n = 33; 32%) or to physicians (n = 30; 29%). We present the scores for this index in detail in Table 2. One-third (n = 30; 29%) of respondents expressed knowing about law 349, while 66% (n = 68) reported not so knowing.

Sixty-two percent (n = 64) of the participants acknowledged having been discriminated against at least once. The most common experience, shared by 33% (n = 34) of the participants, was that of “being placed in isolation.” Others mentioned that “someone had solicited information about my HIV status in a non–health-related context” (n = 20; 19%), and that “I’ve been denied health services” (n = 14; 14%).

A few respondents (n = 5; 5%) complained or reported a discriminatory event to an authority; only one participant reported having made a legal complaint, a case which, in fact, won.

Some participants (n = 29; 28%) indicated their reasons for not complaining about discrimination, which reasons included the following: “it wasn’t necessary” (n = 9; 31%), “I didn’t know what to do or where to go” (n = 9; 31%), and “I’m not sure of what my rights are” (n = 3; 10%).

Qualitative results

Throughout the interview, participants were asked about their experiences of discrimination and their reactions to those experiences. They were also asked about their own perceptions of PLWHA’s rights, and about their ideas of possible ways to reduce HIV stigma and discrimination. The following is a sample of the categories that were included in the analysis to describe the participants’ experiences of discrimination and their reactions to such experiences.

Experiences of Discrimination: All 10 participants had experienced HIV-related discrimination in settings that included, among others, healthcare centers, academic and workplace environments, and familial, social, or romantic relationships. The following quotes show how HIV-related stigmatizing attitudes can lead to discriminatory actions. The association of HIV with imminent death is one of the reasons that people hold stigmatizing attitudes. The following example describes a healthcare professional telling an HIV-positive patient that it did not matter whether she decided to have surgery since death was inevitable for all PLWHA.

The first hematologist recommended that I not have my spleen removed because surgery would be dangerous for me. But when I got here, I continued the treatment with this other doctor, and one time he told me, “I think we have to remove your spleen.” I replied, “I don’t have any problem with that, but the other doctor recommended not doing it because of the high risk.” And then he [the second doctor] said, “After
Consequences of Discrimination: The fear of being identified by others as a person living with HIV was a salient outcome among the participants. Some participants mentioned hiding from those who might recognize them as HIV patients when seeking health services, even using the strategy of going to another municipality to receive services. Others reported that the fear of disclosing their HIV status was an obstacle to their being able to defend themselves from discrimination.

Three participants looked for professional help in which they complained after having been discriminated against.

I went to other hospitals to get treatment. I was going to Bayamón [the city] to get treatment. I told them, "I want to get services here because I have family over there, and I don’t want them to find out." (Male participant #3)

When I came here, I came through the back door. I didn’t want anybody to see me! I think that if I had entered and seen a person who knew me, I would have turned back and not entered. (Female participant #5)

Other participants mentioned that some PLWHA don’t want to seek healthcare services at all out of fear of being recognized by others, which avoidance of treatment can—and sometimes does—have fatal consequences.

I know of people who have died because of not telling others they have HIV. Here in [name of place of residence], a man had it [HIV], and he died because he did not seek treatment, because he didn’t want to tell. (Male participant #1)

Some participants preferred not to seek legal services to defend their rights so that they would not have to publicly disclose their status.

I wouldn’t take it to court. You know why? I would feel bad having to appear in court where other people are listening… Just thinking that I would have to say, “I am a patient of this and that” … It is better not to go to court. I would rather remain quiet. (Female participant #8)

These examples are evidence of how HIV-related stigma is preventing many PLWHA from accessing healthcare services and seeking help when facing discrimination.

Strategies Used When Facing Discrimination: Some participants acted against discrimination, driven mostly by their not wanting others to have to go through the same things that they had had to go through. Others did not confront the situation and chose to retreat out of their fear of negative repercussions.

Confront the situation: Two participants shared experiences in which they complained after having been discriminated against.

[Aafter being threatened to give back a bed that was given to him by a religious organization] I did complain. I said, “To me it seems this is discrimination.” I talked with a social worker, and she said, “I will give you the authorization to keep the bed. Just in case, I’ll refer you to a lawyer, and then we’ll refer you to legal assistance, because they can’t take that bed away from you.” (Male participant #9)

In this case, although there was no reference to knowledge of specific rights, the participant was able identify that he was being discriminated against, which led him to seek help.

Avoid the situation: To avoid possible negative repercussions, four participants chose not to complain about discriminatory behavior.

[Aafter a discriminatory experience with a nurse] Because if one starts trouble, they would deny you services [in the clinics] because they’re all friends [healthcare professionals]. (Male participant #1)

[Talking about other PLWHA] Because it may be that they don’t want trouble; they don’t want to get into trouble if they think they’re gonna be affected. (Female participant #4)

Besides the fear of revealing their HIV-positive status to others, the fear of being mistreated was a significant motive for not reporting or complaining about discrimination.

Seeking help: Three participants looked for professional help to manage their situations.

I started seeing a psychologist. It was helpful. But she recommended that I see a psychiatrist for treatment for depression. (Female participant #5)
Now I go to some support groups where they guide us; they tell us we have rights, that we can defend ourselves. (Female participant #10)

Although not many participants claimed to have sought help after having experienced discrimination, those who did agreed that it was helpful to them.

Don’t know where to go for help: Three participants mentioned that they did not know what to do or where to go to denounce discrimination. What follows are the comments from two of those participants:

No, the majority [of PLWHA] don’t know [where to go]. I don’t know where to go. Because they [the pertinent agencies] don’t say: “You have rights.” (Male participant #1)

I am about to seek legal advice because of many situations I have gone through. Some people do nothing because they don’t know a lawyer or of a governmental institution to which they can go to file a claim. (Male participant #9)

Alternative ways to reduce discrimination: Ten participants made suggestions on how to reduce HIV stigma and discrimination. They stressed the need to educate people, particularly “healthcare providers,” on how to not stigmatize PLWHA.

Educate providers to be more sensitive so that they won’t hurt others. One can notice when they look at you. If one says, “I’m HIV positive,” they make a gesture. (Male participant #1)

I think that there should be more orientation through radio and television. (Female participant #5)

In all ten interviews, participants indicated there is a need to protect the rights of PLWHA through the enforcement of the policy established by the Puerto Rican government.

Discussion

Results from this study indicate there is a general knowledge of the legal rights being discussed in this manuscript among this sample of PLWHA. Whether this knowledge was derived from the sample members’ familiarity with law 349 remains questionable since most of the participants professed being unaware of this law. If such knowledge could not be attributed to familiarity with the law in question, it could potentially be a product of the informal transmission of information through social networks.

The inaccurate notions about being legally forced to disclose HIV status to healthcare professionals shared by most participants are worrisome since previous studies in Puerto Rico have evidenced stigmatizing attitudes among those professionals (8, 10). Yet, a small number of participants reported being informed about law 349 by healthcare professionals. This finding suggests the potential role of healthcare professionals in educating the public about the rights of PLWHA. Nevertheless, our results further imply that in order to assume this role, healthcare professionals require additional education, especially that which involves the development of interventions to reduce stigma and discrimination. These efforts should also focus on the role of these professionals as educators of the population they serve. If such were to be done, more healthcare professionals would be able help disseminate information about the rights of PLWHA and thereby contribute to the decrease of discrimination.

Although most participants indicated that they had been discriminated against at least once, quantitative and qualitative results showed a lack of initiative in these same participants when it came to complaining after such events. Withdrawal and avoidance of confrontation were the most common reactions to discrimination. According to the quantitative responses, the two main reasons that participants gave for not complaining or otherwise seeking redress after having experienced discrimination were that they thought it was “unnecessary” and they “did not know what to do.” On the other hand, qualitative responses evidenced fear of disclosing HIV serostatus in a public context (e.g., in a courtroom) and fear of reprisals when later seeking healthcare services as the primary reasons for maintaining silence after experiencing discrimination. Keeping one’s HIV status secret seems to result in contradictory outcomes: doing so 1) functions as a strategy for protecting oneself from stigmatization and discrimination and 2) becomes a barrier to confronting such acts. A lack of strategies for managing discrimination was evident among participants: Only a few sought help after having been discriminated against. Quantitative and qualitative results reveal that the number of participants who sought professional help to manage an experience of discrimination was low. However, those individuals who received professional help found it to be helpful. Although not explored in this study, this outcome suggests that seeking help to manage events of discrimination could have a positive impact by reducing negative outcomes of HIV-related stigma. Further studies can explore the relationship between receiving professional help after experiencing HIV-related stigma and health outcomes.

We recognize that these findings are specific to the Puerto Rican context and are not representative of all PLWHA in Puerto Rico. The individual characteristics of the members of the sample population could have skewed the results of the study, as these people tended to have relatively low levels of education. Results about the knowledge of rights could have been influenced by the fact that the respondents were presented with the rights for PLWHA in the Knowledge-of-Rights Index, which could facilitate their being recognized.

Establishing rights for PLWHA is a step towards HIV-related stigma reduction; however, public policy aimed
at protecting the rights of PLWHA must transcend the approval of legislature and pay attention to such policy’s implementation, as well. The Puerto Rico Department of Health must encourage capacity building at the institutional and community levels, strengthening the implementation of policy by facilitating access to information and resources. The promotion of accurate information in conjunction with practical educational experiences contributes to reducing negative attitudes towards HIV (30, 31). Results from this study should be interpreted as a call to action, stimulating those in the health sciences to contribute to the promotion of rights of PLWHA among healthcare professionals and healthcare professionals in training. Future interventions to reduce HIV-related stigma should include strategies for managing stigma and discrimination and information on legal rights, how to identify the violation of these rights, and how to identify resources for assistance.

Resumen

Objetivo: Determinar el nivel de comprensión que las personas que viven con el VIH/SIDA (PVVS) en Puerto Rico tienen en términos de sus propios derechos legales y cómo los miembros de esta población maneján la/s violación/es de estos derechos en caso de que tales violaciones ocurran. Métodos: Un diseño de método mixto fue utilizado para lograr nuestros objetivos. Ciento tres participantes completaron un cuestionario, además se llevó a cabo una entrevista en profundidad con 10 miembros del grupo estudiado. Resultados: Los resultados cuantitativos muestran que los derechos más reconocidos fueron el derecho a tener sexo (n = 98; 95%) y el derecho a casarse (n = 90; 87%). La mayoría de los participantes indicó erróneamente que las PVVS están obligadas por ley a revelar su estatus serológico a parejas (n = 69; 67%) y a médicos (n = 70; 68%). Los resultados del análisis cualitativo indican que la mayoría de los participantes identificó haber experimentado eventos de discriminación, pero no los reportaron a ninguna autoridad legal. Conclusión: Los resultados sugieren que existe una necesidad de mejorar la implementación de la política pública que proteja contra la discriminación a las PVVS que viven en Puerto Rico. Futuras intervenciones para la reducción del estigma relacionado al VIH/SIDA deben incluir información sobre los derechos de las PVVS. Los profesionales de la salud tienen un rol importante en la promoción de los derechos de las PVVS en Puerto Rico.

References