Combination antiretroviral therapy among immigrant and indigenous HIV infected patients: quality of life and treatment adherence

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Personalized stigma and disclosure concerns among HIV-infected non-indigenous and indigenous patients in the Netherlands

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Submitted
Abstract

This study examines stigmatization among non-indigenous and indigenous HIV-infected patients in the Netherlands. We interviewed 90 indigenous and 112 non-indigenous HIV-infected patients using the subscales personalized stigma and disclosure concerns of the Berger HIV stigma scale. Use of these scales among HIV-infected non-indigenous patients was feasible. In multivariate analyses, being non-indigenous contributed to personalized stigma and having an HIV transmission route other than homosexual contributed to disclosure concerns. Future studies should explore the mechanisms underlying stigmatization in the different subgroups so interventions to decrease stigmatization can be developed and examined.

Key-words: HIV; Personalized stigma; Disclosure concerns; Non-indigenous patients

Introduction

Stigmatization is a crucial problem among HIV-infected patients. Stigmatization may lead to increased stress, depression, poorer quality of life and life satisfaction among HIV-infected individuals. It may also prevent HIV-infected patients to engage in health seeking behaviours. Due to stigmatization HIV-infected patients may be reluctant to disclose their HIV-status, which may negatively affect adherence to highly active antiretroviral therapy (HAART). Failure to engage in other health seeking behaviours, such as seeking HIV-testing and practising safe sex, could even affect public health.

Increased recognition of stigmatization being a major problem led to a growing interest in how HIV-infected patients experience or perceive HIV-stigma. To date, the most widely used measure to assess HIV-stigma perceived or experienced by HIV-infected individuals is the HIV-stigma scale. This scale has demonstrated adequate levels of reliability and validity when applied among HIV-infected patients differing in age, HIV-transmission route and ethnic background across various countries, including the USA, Peru, India, and South Africa.

Although stigmatization is seen in all groups of HIV-infected patients, some HIV-infected patients may be more likely to encounter HIV-stigma. Previous studies conducted in Western Europe and the USA showed that indigenous HIV-infected men-having-sex-with-men (MSM) are often part of supportive networks within the gay community with a relative HIV tolerant attitude, and consequently experience or perceive less stigma than HIV-infected patients outside such supportive networks, such as persons with a heterosexual HIV-transmission route. Studies conducted in Western Europe and the USA showed that non-indigenous HIV-infected patients or patients from ethnic minority groups experience consistently more HIV-stigma than indigenous HIV-infected patients.

In the Netherlands, as in most Western European countries, the HIV-infected population has evolved from being predominantly composed of indigenous MSM to a population of which patients with a heterosexual HIV-transmission route and non-indigenous patients form a substantial part. As of June 2009, 16,129 patients with a HIV diagnosis were registered in the Netherlands of which 4,861 acquired HIV heterosexually. Of those, 39% was of Dutch origin, 34% of Sub Sahara African origin, 10% of Latin American origin including Suriname and 5% of Caribbean origin. Compared to other Western European countries, the percentage of intravenous drug users (<5%) is small. The Netherlands are known for their relatively tolerant attitude towards MSM. The attitude towards HIV-infected patients within immigrant communities in the Netherlands is generally negative and they are often excluded from their own community. Non-indigenous HIV-infected patients are generally younger and have been HIV positive for a shorter period of time. Living with HIV for a longer time may probably help patients to adapt and to perceive or experience less stigmatization.

To our best knowledge, no quantitative studies about perceived or experienced HIV-stigma among non-indigenous HIV-infected patients have been conducted in Europe, to date. Our first aim was to investigate whether non-indigenous HIV-infected patients perceive or experience more HIV-stigma than indigenous HIV-infected patients in the Netherlands. Our second aim
was to investigate to what extent HIV-transmission route, sex, age, and numbers of years being HIV-positive were associated with HIV-stigma. Before answering these questions, we examined the feasibility of administering the English- or Dutch version of the HIV-stigma scale among non-indigenous HIV-infected patients in the Netherlands. This is highly relevant, because most of the non-indigenous patients are not native English or Dutch speakers.

**Methods**

**Patients and procedures**

Adult HIV-infected patients receiving HAART at the HIV outpatient clinic of the Academic Medical Centre (AMC) in Amsterdam between January 2008 and June 2009 were eligible for participation when they had sufficient fluency in English or Dutch to participate in an interview, had a HIV-transmission route other than homosexual and belonged to one of the following groups: Dutch indigenous patients and non-indigenous patients from Sub Sahara Africa, Surinam or the Dutch Antilles. In addition, a group of Dutch men with homosexual HIV transmission route was included. For this group, a random selection of patients was asked for participation to prevent oversampling of patients coming more often to the clinic due to more health problems and of patients more willing to participate. We could not include non-indigenous men with a homosexual HIV transmission route because the group registered as such is very small. During consultation, the HIV treating physicians and/or a HIV counselors asked eligible patients to participate. Because the present study was part of a larger study about adherence and virologic response to HAART, pregnant women and patients who started HAART before 1998 were excluded. We aimed to include 90 non-indigenous patients and 90 indigenous patients. After signing informed consent, an English or Dutch questionnaire was administered in an interview format, depending on the preferred language of the patient. After the interview, patients received an incentive of €7.50 for participation. This was not announced in the patient information that participants received prior to the interview. The study was approved by the institutional review board of the AMC Amsterdam.

**HIV-stigma**

The HIV stigma scale consists of 40 items comprising four subscales: personalized stigma, disclosure concerns, negative self-image and concern with public attitudes.[4] The scale has demonstrated adequate levels of reliability and validity.[4,10] The HIV stigma scale was administered as part of a larger questionnaire. To minimize patient burden, we only used the factors personalized stigma (18 items) and disclosure concerns (10 items). Examples of items are ‘People avoid touching me if they know I have HIV’ for the personalized stigma scale and ‘In many areas of my life, no one knows that I have HIV’ for the disclosure concerns scale. A four-point Likert-scale was employed, ranging from 1='strongly disagree' to 4='strongly agree'. For each subscale, item scores were summed to yield a personalized stigma score ranging from 18 to 72 and a disclosure concerns score ranging from 10 to 40.

A number of items ask patients who have not disclosed their HIV status, to imagine that they did, and to answer the items based on how the patients think they would feel or how they think others would react. During the interviews, we noticed many patients had difficulties in answering these items. For further exploration of these items, we made a distinction of items that could be hypothetical. This resulted in 17 hypothetical items out of 28 items. Hypothetical items were present among both subscales of stigma.

Questions were independently translated into Dutch by two bilingual native Dutch researchers. After discussion of minor discrepancies between the two versions, agreement was reached and a final version was devised. In each interview, we registered which items needed additional clarification. For clarification, a standardized text was developed. Interviewers were physicians in training not involved in the treatment of the participants, or researchers. All interviewers were trained by the coordinating investigator of the study.

**Analyses**

**Feasibility of the HIV stigma scale.** We conducted χ²-tests to investigate the difference in percentage of missing items and the percentage of needed explanation among the four subgroups. Cronbach’s alpha coefficients were calculated for the two subscales per subgroup and per language version.

**Difference in mean stigma scores.** When subjects missed less than 10% of items within the personalized stigma scale, or the disclosure concerns stigma scale, scores were imputed using the mean scores of the completed items of the scales. We investigated differences in mean scores on the two stigma subscales among the four subgroups, using ANOVA with post-hoc Tukey-test.

**Factors affecting stigma.** We conducted linear regression analyses to investigate if sex, age, number of years being HIV positive, non-indigenous status (Sub Sahara African or Surinamese/Antillean), heterosexual HIV-transmission route (yes/no) and language version were associated with personalized stigma and disclosure concerns. All variables were included in a multivariate analysis. All analyses were conducted using SAS version 9.0.

**Results**

**Patient characteristics**

A total of 333 eligible patients were asked for participation of which 202 participated (response=61%). The most important reason for non-response was that patients did not know about the study beforehand and consequently had no time for an extra interview following consultation with the physician. Patient characteristics are shown in Table 1.
Forty-seven patients (23%) missed one or more items on the personalized stigma scale and 64 patients (32%) for disclosure concerns items. This percentage differed among subgroups (\(\chi^2=2.5; p=0.48\); see Table 1). Thirty-three percent of patients who completed the Dutch version needed explanation for personalized stigma items compared to 51% of those who completed the English version (\(\chi^2=5.2; p=0.02\)). There was no significant difference between language versions for the disclosure concerns scale (\(\chi^2=0.3; p=0.59\)).

Cronbach's alpha coefficients were 0.94 and 0.85 for the personalized stigma scale and the disclosure concerns scale, respectively. The Cronbach's alpha coefficients for the different subgroups ranged from 0.71 to 0.94 indicating adequate internal consistency (>0.70).

### Table 1. Characteristics of HIV-infected patients and interviews

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>Male (%)</th>
<th>Mean age (SD)</th>
<th>Mean number of years HIV positive (SD)</th>
<th>Dutch version (%)</th>
<th>Missed items on PS (%)</th>
<th>Missed items on DC (%)</th>
<th>Needed explanation on PS (%)</th>
<th>Needed explanation on DC (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>202</td>
<td>110 (54)</td>
<td>43.3 (10.9)</td>
<td>7.1 (4.5)</td>
<td>147 (73)</td>
<td>47 (22)</td>
<td>13 (6)</td>
<td>77 (38)</td>
<td>64 (32)</td>
</tr>
<tr>
<td>Dutch HIV transmission route homosexual</td>
<td>45</td>
<td>45 (100)</td>
<td>51.6 (9.7)</td>
<td>8.1 (5.1)</td>
<td>45 (100)</td>
<td>15 (33)</td>
<td>5 (11)</td>
<td>12 (27)</td>
<td>15 (33)</td>
</tr>
<tr>
<td>Dutch HIV transmission route other*</td>
<td>45</td>
<td>28 (62)</td>
<td>46.7 (11.7)</td>
<td>8.3 (5.5)</td>
<td>45 (100)</td>
<td>7 (16)</td>
<td>0 (0)</td>
<td>11 (24)</td>
<td>10 (22)</td>
</tr>
<tr>
<td>Surinamese/Antillean HIV transmission route other*</td>
<td>27</td>
<td>16 (59)</td>
<td>42.9 (10.2)</td>
<td>6.6 (4.2)</td>
<td>26 (96)</td>
<td>1 (4)</td>
<td>1 (4)</td>
<td>13 (48)</td>
<td>9 (33)</td>
</tr>
<tr>
<td>Sub Sahara African HIV transmission route other*</td>
<td>85</td>
<td>21 (25)</td>
<td>37.3 (7.3)</td>
<td>6.1 (3.5)</td>
<td>31 (36)</td>
<td>24 (28)</td>
<td>7 (8)</td>
<td>41 (48)</td>
<td>30 (35)</td>
</tr>
</tbody>
</table>

*Other HIV transmission route than homosexual HIV transmission route: heterosexual HIV transmission route, injecting drug use, blood transfusion, and other
PS: personalized stigma
DC: disclosure concerns

### Table 2. Stigma scores in different groups of HIV-infected patients

<table>
<thead>
<tr>
<th></th>
<th>Personalized stigma (SD)</th>
<th>Disclosure concerns (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>42.4 (9.2)</td>
<td>28.0 (4.6)</td>
</tr>
<tr>
<td>Dutch HIV transmission route homosexual</td>
<td>36.2 (6.4)</td>
<td>25.1 (4.3)</td>
</tr>
<tr>
<td>Dutch HIV transmission route other*</td>
<td>38.5 (9.3)</td>
<td>28.1 (5.4)</td>
</tr>
<tr>
<td>Surinamese/Antillean HIV transmission route other*</td>
<td>43.9 (9.5)</td>
<td>29.3 (4.9)</td>
</tr>
<tr>
<td>Sub Sahara African HIV transmission route other*</td>
<td>47.1 (7.5)</td>
<td>29.1 (3.3)</td>
</tr>
</tbody>
</table>

*Other HIV transmission route than homosexual HIV transmission route: heterosexual HIV transmission route, injecting drug use, blood transfusion, and other
Values are means (standard deviation); Higher scores indicate more stigma

### Feasibility of the HIV stigma scale

Forty-seven patients (23%) missed one or more items on the personalized stigma scale and thirteen patients (6%) missed one or more items on the disclosure concerns scale. The percentage of patients that missed items on the personalized stigma scale was highest among Dutch men with homosexual HIV transmission route (33%) and Sub Sahara African patients (28%; \(\chi^2=11.0; p=0.01\)). The percentage of missing items for the disclosure concerns scale did not differ among subgroups (\(\chi^2=5.5; p=0.14\)). There were no differences between language versions in missing items on both subscales.

When exploring the items in detail, more patients had missing items on the hypothetical items (23%) than on non-hypothetical items (6%). The items that were most often missing were ‘Most people with HIV are rejected when others learn’ (11%) and ‘Some people act as though it is my fault I have HIV’ (7%).

Seventy-seven patients (38%) needed explanation for one or more of the personalized stigma items and 64 patients (32%) for disclosure concerns items. This percentage differed among subgroups for the personalized stigma scale (\(\chi^2=10.9; p=0.01\)) but not for disclosure concerns (\(\chi^2=2.5; p=0.48\); see Table 1). Thirty-three percent of patients who completed the Dutch version needed explanation for personalized stigma items compared to 51% of those who

### Disclosure concerns

Disclosure concerns differed significantly across the four subgroups (\(F=9.1; p<0.01\)). Disclosure concerns scores were significantly lower among Dutch men with a homosexual transmission route (table 3) compared to all groups with HIV transmission route other than homosexual.
Table 3. Mean differences among the four subgroups in personalized stigma (PS) and disclosure concerns (DC), established by post-hoc Tukey-test.

<table>
<thead>
<tr>
<th>Relative to:</th>
<th>Dutch MSM</th>
<th>Dutch heterosexual</th>
<th>Surinamese / Antillean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dutch heterosexual</td>
<td>PS: 2.3</td>
<td>DC: 3.0***</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Surinamese/Antillean</td>
<td>PS: 7.7***</td>
<td>DC: 5.4***</td>
<td></td>
</tr>
<tr>
<td>Sub Sahara Africa</td>
<td>PS: 10.9***</td>
<td>DC: 8.6***</td>
<td>PS: 3.2***</td>
</tr>
<tr>
<td></td>
<td>DC: 4.0***</td>
<td>DC: 1.0</td>
<td>DC: -0.2***</td>
</tr>
</tbody>
</table>

***P<0.05

Factors affecting stigma

**Personalized stigma.** Table 4 displays the results of multivariate analysis. Non-indigenous status and language version were significantly related (p<0.01; p=0.04).

**Disclosure concerns.** HIV transmission route other than homosexual was significantly related to disclosure concerns score (p<0.01) in multivariate analysis, while non-indigenous status was not (p=0.71).

Table 4. Multivariate analysis of factors associated with HIV stigma.

<table>
<thead>
<tr>
<th></th>
<th>Personalized stigma</th>
<th>Disclosure concerns</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>F=1.4, DF=7</td>
<td>F=3.9, DF=7</td>
</tr>
<tr>
<td></td>
<td>B</td>
<td>p</td>
</tr>
<tr>
<td><strong>Constant</strong></td>
<td>39.7</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td><strong>Country of birth</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Netherlands)</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Surinamese/Antillean</td>
<td>5.1</td>
<td>0.01</td>
</tr>
<tr>
<td>Sub Sahara African</td>
<td>6.6</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td><strong>HIV transmission route</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(homosexual)</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>3.0</td>
<td>0.09</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Male)</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>-1.1</td>
<td>0.45</td>
</tr>
<tr>
<td><strong>Age (each 5 years)</strong></td>
<td>0.1</td>
<td>0.71</td>
</tr>
<tr>
<td><strong>Years HIV positive (each 5 years)</strong></td>
<td>-0.6</td>
<td>0.43</td>
</tr>
<tr>
<td><strong>Language version</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(English)</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Dutch</td>
<td>-3.8</td>
<td>0.04</td>
</tr>
</tbody>
</table>

*Other HIV transmission route then homosexual HIV transmission route: heterosexual HIV transmission route, injecting drug use, blood transfusion, and other.

**Discussion**

In this study, we administered the subscales personalized stigma and disclosure concerns of the HIV stigma scale during a face-to-face interview among Dutch HIV-infected indigenous and non-indigenous patients. Although the Sub Sahara African patients more often needed explanation about the meaning of the items, adequate reliability of both subscales was found. Personalized stigma scores were higher among non-indigenous patients and disclosure concerns were higher among patients with a HIV transmission route other than homosexual. A remarkable finding was the relatively high percentage of patients with missing responses. A number of items of the HIV stigma scale asks patients who have not disclosed their HIV status to imagine that they did, and to answer the items based on how the patients think they would feel or how they think others would react. We found that missing items were primarily caused by these hypothetical items, because many patients had difficulties in answering them. For example, a response to ‘Most people with HIV are rejected when others learn’ was often missing because patients mentioned they did not know other HIV-infected patients. Some patients had only disclosed their HIV status to a few persons. These patients found it difficult...
to answer questions about actually experienced stigma such as ‘People do not want me around their children once they know’. They often reported that they would have provided a different response to this question, if they would have disclosed to other persons. We found it remarkable that other studies using the HIV stigma scale, including studies conducted in India, Peru and South Africa, did not report missing items or did not report such a large percentage of missing items. [19,20,29] Probably, the fact that we administered the scale during a face-to-face interview, whereas the scale was self-administered in most former studies, could explain this finding. Possibly, when patients are uncertain which answer to choose in a self-administered questionnaire they may be more inclined to answer as they did in response to items they are not certain of rather than skipping the item. In the present study, missing scores were present in all subgroups and therefore we expect no significant influence on the comparison across subgroups.

It is interesting that non-indigenous status was related to personalized stigma while HIV-transmission route other than homosexual was related to disclosure concerns. Different mechanisms may underlie the existence of both forms of stigma among the subgroups. For example, former studies showed higher correlations for high personalized stigma with poorer quality of life or increased depression, compared to disclosure concerns. [4,7,26,28,29] Mental health might be worse among non-indigenous patients leading to more personalized stigma but not to more disclosure concerns.

This study has several limitations. The difference in reported stigma among subgroups might be a true difference, but could also reflect a difference in cultural interpretation of the items. Although we found a relation between language version and personalized stigma, we believe we found a genuine difference. During the interview, patients often explained their answers and non-indigenous patients tended to have more examples of stigmatization. Moreover, our results are in line with other studies that have reported higher stigma scores among non-indigenous patients or ethnic minority populations. [25,31]

Another possible limitation of our study is selection bias. We instructed the physicians and HIV counselors to ask all eligible patients whether they were willing to participate in a study on how they experience their HIV-infection. However, they may have been tempted to ask only patients who they believed were willing to participate or they perceived as nothing many difficulties in life. In addition, patients might be less willing to participate when they are afraid of stigmatization. This may have resulted in selection bias.

A third limitation of the present study is that we included patients from several countries of Sub Sahara Africa and classified them all in one group. However, Sub Sahara Africa consists of many different cultures, tribes, and countries. However, when arriving in the Netherlands, non-indigenous patients from Sub Sahara Africa tend to gather together in, for example, the same neighborhoods and religious institutions. In addition, the persons from the different groups share the same experiences e.g. being hardly integrated considering in the Dutch society and having to learn Dutch language as second, third or even fourth language. [37] We believe that being in the Netherlands makes the experience of their disease sufficiently comparable to warrant grouping them into one. Related to this limitation is that we were not able to include non-indigenous men with a homosexual transmission route because the known number of these patients is small and these patients might not be registered as such. This group of patients might experience or perceive more stigmatization, because their communities have less tolerant attitudes toward MSM than the Dutch indigenous population in general.

Finally the generalizability of our study sample to the entire population of HIV infected patients is limited. We included a relatively small number of patients from one HIV treatment centre in the Netherlands. However, the goal of this study was to investigate whether stigmatization is more experienced or perceived by patients of non-indigenous origin. We found such higher prevalence in those immigrant patients who form the largest group of the HIV population. Thus stigma is indeed perceived more among immigrant patients in the Netherlands, at least in those patients from Sub Saharan Africa, Suriname and the Dutch Antilles.

Strength of our study was that the HIV stigma scale was administered in an interview format, allowing for explanation of items. Although face-to-face interview are known for their high chance of social desirability bias, it was needed as some of the non-indigenous patients were not fully literate. In addition, this study was unique because it included a large group of Sub Sahara African patients and the use of a previously validated and widely used questionnaire. Consequently, meaningful results for this particular group were found.

Our study has several implications for future research and policy. When the HIV stigma scale is used in non-indigenous populations in Western Europe, it should preferably be used in a face-to-face interview format. Our study showed that explanation of items is needed in this group. In addition, one should be alert to hypothetical items. We suggest making a distinction in scores on the hypothetical items and the non-hypothetical items. Group targeted interventions are needed to decrease stigmatization, especially among immigrant HIV infected patients. Such interventions should account for the variety of stigma conditions that go along with HIV stigma. [11]

Conclusions

The results of this quantitative study are a first step in acquiring more knowledge on stigmatization among non-indigenous groups in Western Europe. We showed that non-indigenous HIV-infected patients experience or perceive more personalized stigmatization and that HIV-infected patients with HIV-transmission routes other than MSM have more disclosure concerns. Future studies should attempt finding out mechanisms underlying stigmatization in the different subgroups so that interventions to decrease stigmatization can be developed and examined specifically for the subgroups. Findings of the present study suggest that stigmatization is a large problem among non-indigenous patients and requires to be taken seriously by policy-makers. As shown in other studies, stigmatization impacts many factors such as treatment adherence, health seeking behavior and mental health. Therefore, efforts to reduce stigmatization are needed and require a distinctive approach for different subgroups of HIV-infected people.
Acknowledgements

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Reference List

HIV stigma and depression influence nonadherence or virological response to antiretroviral treatment among immigrant and indigenous HIV infected patients

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