



ORIGINAL ARTICLE

## Self-stigma, depression, and anxiety levels of people living with HIV in Turkey



O.F. Demirel<sup>a,\*</sup>, P.Y. Mayda<sup>b</sup>, N. Yıldız<sup>a</sup>, H. Sağlam<sup>c</sup>, B.T. Koçak<sup>d</sup>, Z. Habip<sup>e</sup>, M.T. Kadak<sup>f</sup>, İ. Balcıoğlu<sup>a</sup>, B. Kocazeybek<sup>b</sup>

<sup>a</sup> Department of Psychiatry, Cerrahpaşa Faculty of Medicine, İstanbul University, İstanbul

<sup>b</sup> Department of Microbiology, Cerrahpaşa Faculty of Medicine, İstanbul University, İstanbul

<sup>c</sup> Cerrahpaşa Faculty of Medicine, İstanbul University, İstanbul

<sup>d</sup> Erenköy Psychiatry Research Hospital, İstanbul

<sup>e</sup> Fatsa State Hospital, Department of Microbiology, Ordu

<sup>f</sup> Department of Child and Adolescent Psychiatry, Cerrahpaşa Faculty of Medicine, İstanbul University, İstanbul

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### KEYWORDS

Internalized stigmatization; HIV stigma scale; Stigmatization factors

### Abstract

**Background and objectives:** This study examines self stigma levels of patients living with human immune-deficiency virus (HIV), and relation of stigma, anxiety and depression.

**Methods:** Study was conducted in patients ( $n:71$ ) of Department of Microbiology in Cerrahpaşa Medical School and people who are linked with 'Association of HIV positive Life' between June 2015 and December 2016. Sociodemographic form, HIV stigma scale, Beck Anxiety (BAI) and Beck Depression Inventory (BDI) was applied to study group.

**Results:** Mean age of study group was  $32.98 \pm 9.41$ . Fifty three percent (53.5%) of the group was educated more than high school. Mean scores of total HIV-stigma scale was  $92.48 \pm 19.86$ , BDI score was  $16.9 \pm 10.97$  (moderate level of depression), and BAI score was  $16.57 \pm 11.22$  (moderate level of anxiety). When HIV-stigma scale, BDI and BAI scores were compared according to sociodemographic and clinical variables; non-disclosure group ( $n:35$ ) had significantly high scores than disclosure group in BDI ( $p=0.032$ ,  $z=-2.14$ ), BAI ( $p=0.007$ ,  $z=-2.67$ ), total HIV stigma scale ( $p=0.004$ ,  $z=-2.90$ ) and sub-scales of HIV-stigma scale 1 ( $p=0.019$ ,  $z=-2.34$ ), scale 2 ( $p=0.022$ ,  $z=-2.29$ ), scale 3 ( $p=0.001$ ,  $z=-3.39$ ), and scale 4 ( $p=0.002$ ,  $z=-3.16$ ). Besides, HIV-stigma scale 1 (Personalized Stigma) scores of unknown transmission group was significantly more than sexually transmitted group ( $p=0.049$ ,  $z=-1.97$ ). BDI and BAI scores were positively correlated with total HIV-stigma score and all subscores.

**Conclusion:** This preliminary Turkish study showed that perceived stigma of people living with HIV is correlated with anxiety and depression, partner non-disclosure increase anxiety and depressive mood, and knowing the way of transmission may decrease the anxiety.

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\* Corresponding author.

E-mail address: [ofdmed@yahoo.com](mailto:ofdmed@yahoo.com) (O.F. Demirel).

## Introduction

There are more than 35 million people infected with the human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS) worldwide.<sup>1</sup> With combined antiretroviral therapy, people living with HIV (PLH) may have much longer life expectancies than they did in the past. However, most PLH struggle with psychological distress and psychiatric symptoms as a result of multiple stressors.<sup>2</sup>

Although stigma is associated with many health-related conditions, a health-related stigma may result from functional restriction such as a limb amputation or from a hidden disease such as asymptomatic HIV infection.<sup>3</sup> Being rejected and fearing rejection have been reported as major stressors of having HIV; therefore, concern about stigma is widespread among people with HIV.<sup>3</sup> Despite global efforts to reduce and eliminate AIDS-related stigma and discrimination, it has been reported that stigma and discrimination persist against PLH in many countries around the world.<sup>4,5</sup> AIDS-related stigma leads to negative outcomes such as infringements of socio-political and economic rights, including access to health care, via larger discriminatory processes.<sup>4,5</sup>

There have been inconsistent reports related to interventions to reduce AIDS-related stigma. Successful strategies suggest that increasing people's tolerance toward PLH might have short-term effects on people's attitudes.<sup>6</sup> However, in one case, an educational program that attempted to reduce negative attitudes toward PLH in a South African high school resulted in rumors that caused a great deal of distress, including the claim that HIV was prevalent in teachers and students at that school.<sup>4,7</sup>

According to the literature, disclosing one's HIV status often has contradictory results. Although some people are accepting and supportive, others overtly reject or subtly distance themselves from the person with HIV.<sup>3</sup> Despite previous positive disclosure experiences, each new disclosure brings fear about being stigmatized to many people with HIV. This potential for stigmatization may also make people less willing to be tested for HIV, which in turn may interfere with prevention and early treatment efforts.<sup>3,8</sup>

PLH have to cope with problems in daily life such as social issues (interpersonal relationships with friends or family as well as stigma), physical problems (pain, vulnerability to infection, low energy), and emotional factors (concentration, problem-solving, and stress). In the long term, maintenance of optimal physical, social, and emotional health in this population may require reliance on psycho-spiritual strength or resilience for coping, robust social support from friends, family and care providers, compassionate care at the interface of health care delivery, and positive-reframing for self-management.<sup>9</sup> HIV-infected patients reported higher levels of psychosocial problems such as depression, anxiety, and stigma that extended to race, sex, or sexual orientation, all of which may impair long-term functional capacity.<sup>10,11</sup>

According to the Global Network of People Living with HIV/AIDS, one of the most important challenges for PLH is stigma and discrimination.<sup>12</sup> HIV-related stigma has been defined as discrediting, discounting, and discriminating against people perceived to have HIV.<sup>13-15</sup> The impact of stigma on mental health can affect HIV treatment

management strategies because a decrease in self-stigma in PLH may lead to increases in coping strategies, compliance, and maintenance of treatment. Although there are studies revealing the relationship between anxiety and depression and self-stigma in people living with HIV, there is little knowledge. Moreover, in the Turkish PLH population, there are limited data on HIV and self-stigma. In this preliminary study, we aimed first to analyze the self-stigma levels of patients living with HIV, and second, to explore the relationship between stigma, anxiety, and depression.

## Material and methods

The study was conducted on 71 patients of the Department of Microbiology at the Cerrahpaşa Medical School and members of the Association of HIV Positive Life between June 2015 and December 2016. A sociodemographic form, the HIV stigma scale, the Beck Anxiety Inventory (BAI), and the Beck Depression Inventory (BDI) were administered to the study group. Informed consent was obtained from all participants. Eligible subjects had to meet the following criteria: HIV-positive status, aged 18 years or more, and having been treated with antiretroviral therapy for at least for 6 months. Patients with severe psychiatric illness were not included.

*The HIV stigma scale:* Berger et al. developed the HIV stigma scale in 2001 to measure perceived stigma among HIV-infected individuals.<sup>3</sup> A Turkish version of this scale did not exist, so the original scale was administered after translation to the Turkish language. On the HIV stigma scale, using a 4-point Likert scale (strongly agree=4, agree=3, disagree=2, and strongly disagree=1), respondents indicated their level of agreement with each of the 40 items on the questionnaire. Higher scores reflect a greater perceived HIV stigma. The four subscales (personalized stigma, disclosure concerns, negative self-image, and concern about public attitudes toward people with HIV) contain between 10 and 20 items, many of which are shared among the subscales.<sup>3</sup>

*BDI:* Depressive symptoms and the severity of depression were evaluated using the Turkish version<sup>16</sup> of the BDI.<sup>17</sup>

*BAI:* Anxiety symptoms and the severity of anxiety were evaluated using the Turkish version<sup>18</sup> of the BAI.<sup>19</sup>

## Statistical analysis

For statistical analyses, SPSS 21 was used. Basic descriptive data for the study variables are provided in the form of means and standard deviations in order to illustrate the general trends in the sample. Independent variables were analyzed with the Mann-Whitney *U* test, and Spearman's correlations were used to examine relationships among the study variables.

## Results

The study group as consisted of 71 HIV-positive people; 58 were male and 13 were female. The mean age of the study group was  $32.9 \pm 9.4$ . Thirty-eight (53.5%) subjects had more

**Table 1** Socio-demographic and clinical variables of people with HIV.

	<i>n</i>	%
Age (year)	32.98 ± 9.4	
Gender (male/female)	58/13	81.7/18.3
Marital status (married/non-married/widowed)	10/51/10	14.1/71.8/14.1
Education (under/more than high school)	33/38	46.5/53.5
Employment (yes/no)	41/30	57.7/42.3
Smoker (yes/no)	46/25	64.8/35.2
Chronic alcohol misuse (yes/no)	14/57	19.7/80.3
Substance abuse (yes/no)	11/60	15.5/84.5
Mean age of diagnosis (year)	29.4 ± 8.3	
Mean time between diagnosis and treatment (year)	5.44 ± 7.6	
Mean duration of treatment (month)	33.76 ± 52.4	
Way of transmission (sexual/unknown)	53/18	74.6/25.4
Taking antiretroviral treatment (yes/no)	66/5	93/7
Disclosure to partner (yes/no)	36/35	50.7/49.3
Taking psychotropic medication (yes/no)	10/61	14.1/85.9

**Table 2** HIV-stigma scale and beck depression and anxiety scale variables.

<i>n</i> :71	Mean ± std. deviation
Personalized stigma (HIV-stigma scale 1)	42.47 ± 11.6
Disclosure concerns (HIV-stigma scale 2)	24.32 ± 5.5
Negative self-image (HIV-stigma scale 3)	23.69 ± 7.6
Concern with public attitudes (HIV-stigma scale 4)	51.29 ± 11.1
Total HIV-stigma scale	92.48 ± 19.8
BDI score	16.9 ± 10.9
BAI score	16.57 ± 11.2

BDI: Beck Depression Inventory; BAI: Beck Anxiety Inventory.

than a high school education. The socio-demographic and clinical variables of the PLH are given in Table 1. The mean score from the HIV stigma scale was 92.4 ± 19.8, the BDI score was 16.9 ± 10.9 (moderate level of depression), and the BAI Score was 16.5 ± 11.2 (moderate level of anxiety). The HIV stigma scale, BDI, and BAI scores are given in Table 2.

When the HIV stigma scale, BDI, and BAI scores were compared to the sociodemographic and clinical variables, there were significant differences between the partner disclosure and non-disclosure groups. In this comparison, the non-disclosure group (*n* = 35) had significantly higher scores than the disclosure group on the BDI (*p* = 0.032, *z* = -2.14), the BAI (*p* = 0.007, *z* = -2.67), the total HIV stigma scale (*p* = 0.004, *z* = -2.90), and all of the subscales of the HIV stigma scale: personalized stigma (*p* = 0.019, *z* = -2.34), disclosure concerns (*p* = 0.022, *z* = -2.29), negative self-image (*p* = 0.001, *z* = -3.39), and concern about public attitudes (*p* = 0.002, *z* = -3.16). In addition, the scores on HIV stigma scale 1 (personalized stigma) for the unknown transmission group were significantly higher than for the sexually transmitted group (*p* = 0.049, *z* = -1.97). However, similar significant differences were not present when the intra-group comparison was done according to the other sociodemographic and clinical variables. The BDI and BAI scores were positively correlated with the total HIV stigma scores and the scores on all subsections. Spearman correlation values are given in Table 3.

## Discussion

According to the Global Network of People Living with HIV/AIDS, some important challenges for PLH are stigma and discrimination.<sup>12</sup> HIV-related stigma has been defined as discrediting, discounting, and discriminating against people perceived to have HIV.<sup>13-15</sup> Hence, we aimed to represent the impact of perceived stigma on mental health. In our study, depression and anxiety scores were at a moderate level. These results are compatible with similar study findings. A recent meta-analysis conducted by Rueda et al.<sup>15</sup> analyzed 22 articles (24 studies) and reported a moderate correlation between HIV-related stigma and depressive symptoms. Similar to depressive symptoms, a meta-analysis of six studies revealed a moderate correlation between HIV-related stigma and heightened anxiety.<sup>15</sup> In addition, Shacham et al.<sup>20</sup> propose that an increase in anxiety symptoms significantly increases the risk of felt stigma. These findings are important to highlight as they suggest that because anxiety symptoms tend to fluctuate more frequently, it is easier to intervene, and these symptoms are potentially manageable with simple behavioral interventions even though the diagnostic criteria of anxiety disorder are not met.<sup>20</sup>

HIV/AIDS is perceived as contagious and threatening, and it is also associated with the possibility of suffering a painful death. Beyond these medical disadvantages,

**Table 3** Spearman correlations of depression, anxiety and HIV-stigma scores.

n:71	Personalized stigma (HIV-stigma scale 1)	Disclosure concerns (HIV-stigma scale 2)	Negative self-image (HIV-stigma scale 3)	Concern with public attitudes (HIV-stigma scale 4)	HIV-stigma scale total
BDI score	$r = 0.346^*$ $p = 0.003$	$r = 0.415^*$ $p < 0.001$	$r = 0.646^*$ $p < 0.001$	$r = 0.412^*$ $p < 0.001$	$r = 0.503^*$ $p < 0.001$
BAI score	$r = 0.426^*$ $p < 0.001$	$r = 0.372^*$ $p = 0.001$	$r = 0.601^*$ $p < 0.001$	$r = 0.427^*$ $p < 0.001$	$r = 0.498^*$ $p < 0.001$

BDI: Beck Depression Inventory; BAI: Beck Anxiety Inventory.

\* Correlation is significant at the 0.01 level.

HIV stigma may manifest itself through social isolation and rejection, shame, and economic discrimination.<sup>21,22</sup> Although there are several efforts to decrease myths about HIV and AIDS, concern about stigma is widespread among PLH. Being rejected and fearing rejection have often been mentioned as major stressors of living with HIV.<sup>3</sup> In our study, the non-disclosure group showed significantly higher depressive, anxiety, and HIV stigma scores than the disclosure group. This indicates that disclosure of HIV status might improve the anxiety and mood state of PLH. With respect to the relationship between HIV-related stigma and social support, previous research indicates that disclosure of one's HIV status to family, friends, or healthcare professionals may be a stigmatizing social process that can result in fear of rejection<sup>3</sup> or isolation and exclusion by support networks.<sup>23,24</sup> Studies investigating the impact of social support in relation to stigma and depression in PLH<sup>25-28</sup> point to the importance of social support in mitigating depression. However, people experiencing an increased level of anticipated stigma may be less likely to disclose their HIV status in unknown conditions, where there may be a fear of social exclusion.<sup>15,23,24</sup>

Furthermore, personalized stigma in people who do not know the mode of transmission was significantly higher than in the sexually transmitted group. This result may also be related to fear of the unknown. As we reported before, disclosure anxiety may also have a link with this finding. Anxiety of transmitting the virus to others may be decreased by increasing knowledge about the ways the microorganism can be transmitted, the disease itself, therapeutic processes, and prognosis. Myths about HIV may increase self-stigma and anxiety, as we have revealed.

Some evidence suggests that various coping strategies have been shown to moderate the effects of HIV-related stigma on depression. For instance, avoidance strategies, including disengagement from the stressor, denial, and/or wishful thinking were found to moderate the relationship between stigma and depression<sup>29</sup> whereas mastery, which is a psychological resource related to personal control and self-efficacy, was found to be associated with lower levels of depression.<sup>15,30</sup> As we found that depression and anxiety scores were positively correlated with total HIV stigma scores and all of the sub-scores, mastery of coping strategies should be increased in PLH. Some studies support the notion that perceived stigma of PLH was associated with decreased access to care<sup>31</sup> or delayed admission to care,<sup>32</sup> possibly arising from perceived discrimination by healthcare

professionals.<sup>15,33,34</sup> Therefore, increasing the coping skills of this group would improve health quality.

In our study, only 14.1% of the group was receiving psychiatric support. More purposeful screening and treatment of depression and anxiety are necessary components of HIV care.<sup>20</sup> Ezeamama et al. (2016) demonstrate that the quality of life at enrollment increased with social support but declined with increasing numbers of reported stigmatizing events, depressive symptoms, and anxiety levels.<sup>10</sup> Therefore, encouraging PLH to seek psychiatric support may improve anxiety and depression, in addition to a possible decrease in perceived stigma.

## Conclusion

Our study showed that the perceived stigma of PLH is correlated with anxiety and depression, partner non-disclosure increases anxiety and depressive moods, and knowing the mode of transmission may decrease anxiety. Besides being a preliminary study in Turkey using Berger's HIV stigma scale, this study has several limitations. First, the number of subjects is limited. Including more subjects might increase the quality of the data. The other limitation was the absence of a control group. However, as Berger's HIV stigma scale is only used with PLH, any control subjects would need to be tested using other scales. Therefore, we did not use a control group. Additionally, our study group mostly consisted of members of the Positive Life Association, so a more conscious group might affect the findings. These preliminary findings about Turkish people living with HIV may contribute new evidence about stigma, anxiety, and depression in HIV-positive patients, but these findings should be replicated with further evidence.

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## Conflict of interest

There is no financial support that may pose conflict of interest.

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