SPECIAL COMMUNICATION

Urdu translation and adaptation of the HIV stigma scale in Pakistani injectable drug users with HIV

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Abstract

Objective: To translate and adapt the human immunodeficiency virus stigma scale into Urdu language, and to determine its psychometric properties.

Method: The study was conducted at the Human Immunodeficiency Virus / Acquired Immunodeficiency Syndrome Treatment Centre at the Civil Hospital, Karachi, from February to April 2017. The scale was translated and administered on a sample of patients enrolled from the Centre who were aged 25-45 years and had been injecting drugs. The reliability of the measure was assessed by working out Cronbach's alpha, split-half reliability and test retest reliability. The construct validity was measured by correlating the scale with the constructs of depression and self-esteem. Statistical analysis was done using SPSS, 20.

Results: There were 150 subjects with a mean age of 31.65±5.88 years. Internal consistency of the Urdu version of scale was 0.94 and that of the subscales ranged 0.81-0.91. Gutman split-half coefficient was 0.93 and test retest reliability was 0.92. The Urdu version of the scale had significant positive correlation with depression ($p<0.01$) and significant negative correlation with self-esteem ($p<0.01$).

Conclusion: The Urdu version of the Human Immunodeficiency Virus Stigma Scale was found to have acceptable psychometric properties and it can be used in researches conducted in Pakistan.

Keywords: HIV/AIDS stigma, Personalised stigma, Disclosure concerns, Negative self-image, Public attitudes, Depression, Self-esteem. (JPMA 70: 505; 2019).

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Introduction

The first case of Human Immunodeficiency Virus (HIV) in Pakistan was diagnosed in 1987.[1] Since then, the number of HIV and Acquired Immunodeficiency Syndrome (AIDS) diagnoses have been increasing and the National AIDS Control Programme[2] estimates that approximately 0.133 million people are living with HIV/AIDS in Pakistan. HIV/AIDS is one of those illnesses that has stigma linked with it[3] thus making it more threatening and challenging for the victims and posing difficulties in its treatment. The stigma related to HIV/AIDS is known to have negative psychological impact on people living with HIV/AIDS. Findings suggest that due to the fear of the rejecting attitude of the others, people often cope with it by self-isolation[4] which leads to other psychological problems, such as depression.

HIV/AIDS is a stigmatised disease in Pakistan because of two major reasons; first, there is no cure for the disease yet and there is a threat that the virus can transmit from one person to another, and, second, the disease is believed to develop in people who are involved in morally wrong behaviours, such as extramarital sexual relationship, men having sex with men or intravenous (IV) drug use. All these behaviours are deemed morally and religiously wrong by the majority of people in Pakistan, and, therefore, people diagnosed with HIV/AIDS are subjected to stigma.

The stigma has gained worldwide attention due to its negative effects on care and treatment, and, therefore, several valid and reliable instruments have been developed to measure stigma faced by the affected people. These instruments help in assessing the effect of the stigma on prevention and treatment programmes, and they facilitate the development of interventions to reduce the stigma.

There is an increasing amount of work being done to understand and reduce the psychosocial issues of HIV/AIDS-related stigma around the world, but in Pakistan, due to its 'low prevalence-high risk' status, research related to HIV/AIDS is in its initial stages. There are very few findings

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available that can extend the existing knowledge about the stigma of HIV/AIDS in Pakistan. Loss of income, marriage, loss of hope, feeling of worthlessness, loss of reputation and poor adherence with treatment are few of the many under-researched consequences that people with HIV/AIDS face in Pakistan due to the stigma. The level of stigma in Pakistan can be reflected through the findings of a study conducted at workplaces across major cities of Pakistan. Findings revealed that 65% of the respondents were fired from their jobs after they disclosed that they had HIV, and 29% of the respondents were forced to resign.[6] Findings like this necessitate the need to study HIV/AIDS from psychosocial aspect in Pakistan. However, there is no such instrument available that can be used to measure HIV/AIDS-related stigma specifically in the Pakistani cultural context. Worldwide, the HIV stigma scale (HSS)[7] is used to determine the level of stigma.

The HSS[7] was developed to measure the stigma as perceived by HIV/AIDS infected people. Based on the conceptual model of perceived stigma, the four different dimensions of the scale cover the three main mechanisms of HIV stigma which can be experienced by HIV/AIDS infected people, as enacted stigma involving experiences of discrimination and prejudice; anticipated stigma involving fear of stigma; and internalised stigma refers to negative feelings and beliefs that HIV/AIDS infected people have about themselves due to their disease.[8] Perceived stigma may cause various negative consequences on the psychosocial level, such as a negative change in self-concept and negative emotional reactions.[7] Thus, people with HIV/AIDS may not disclose their status due to the fear of a stigmatising response, and try to avoid social interactions, thus leading to isolation. This potential for stigmatisation may also lead to unwillingness to be tested for HIV, which can cause serious threat to HIV/AIDS prevention and early treatment.[9]

The HSS[7] has been used in researches to study the association of HIV/AIDS related stigma with a wide range of variables such as psychological disorders,[10] quality of life,[11] psychological symptoms,[12] disclosure concerns,[13] social support and self-esteem.[14] Further, it has been used to measure HIV/AIDS stigma in different countries, including south India[15] and eastern Nigeria,[16] and various age groups.[17,18] The scale has also been translated and adapted to different languages, including Swedish,[19] Tamil[20] and Spanish.[21]

The current study was planned to translate the HSS[7] into Urdu language so that it can contribute to the assessment of HIV-related stigma in Pakistan by adapting a culture-based scale. The objective was to evaluate the reliability and construct validity of HSS[7] and to evaluate the association of HIV/AIDS stigma with depression and self-esteem.

Materials and Method

The study was conducted at the HIV/AIDS Treatment Centre at the Civil Hospital, Karachi, from February to April 2017. To determine the size of sample which could be effective in showing the significant results, G*Power 3[22] software was used. A priori analysis was done according to the parameters of effect size 0.15, alpha level 0.05 and power level 0.95. The sample size was decided considering the fact that the study population was not expected to be large, and identifying such cases would be difficult. Pakistan has a 'high risk but low prevalence' rate of HIV/AIDS, therefore the sample size was determined considering the size of the specific population registered with the Enhanced HIV/AIDS Control Programme at the Sindh Health Department in Karachi and focused on those who were actively attending the antiretroviral therapy owing to IV drug use. Patients with all other modes of HIV transmission were excluded. In order to raise the sample, purposive sampling was used. To acquire access to the target population, a list of medical centres was made that provided treatment to HIV/AIDS patients. There were three such hospitals in Karachi that worked under the National HIV/AIDS Control Programme, providing antiretroviral viral therapy for HIV/AIDS. After permission from the office of the Provincial Programme Manager of Sindh Enhanced HIV/AIDS Control Programme, data was collected from Civil Hospital, Karachi, as it served the majority of the registered HIV/AIDS patients in the city. Patients at the other public-sector hospital and the private facility under the programme were excluded.

The process of translation and adaptation was divided into two phases. In phase I, the scale was translated into Urdu, and in phase II, the psychometric properties of the Urdu version of the scale were derived by administering it on the sample.

The process of translation and adaptation was carried out according to the guidelines in literature.[23] The category of symmetrical translation was chosen for the translation process, as it facilitates the comparison of responses from one culture to responses from other culture, thus ensuring

یہ تحقیق ایچ آئی وی کے چند سماجی اور جذباتی پہلوؤں کے متعلق کچھ سوالات کرتی ہے۔زیادہ تر سوالات کے جوابات دینے کیلئے اپنے مطلوبہ جواب کا انتخاب کریں۔کوئی بھی جواب غلط یا صحیح نہیں۔سوال کے جواب میں اپنی آزادانہ رائے کا اظہار کیجئے۔

سوالات کا یہ پہلا مجموعہ ایچ آئی وی سے متاثرہ افراد کے احساسات اوران کے ساتھ ہونے والے برتاؤ سے متعلق آپ کے کچھ تجربات، جذبات اور رائے سے متعلق ہے۔

ہرسوال کیلئے اپنے مطلوبہ جواب،'زیادہ اختلاف'،'اختلاف'،'متفق'،'زیادہ متفق'، میں سے کسی ایک کا انتخاب کریں۔	زیادہ اختلاف	اختلاف	متفق	زیادہ متفق
1۔میری زندگی کے بہت سے حلقوں میں کوئی نہیں جانتا کہ مجھے ایچ آئی وی ہے۔				
2۔میں قصوروار محسوس کرتا/کرتی ہوں کیونکہ مجھے ایچ آئی وہ ہے۔				
3۔ایچ آئی وی کے متعلق لوگوں کے رویے، مجھے خود کے بارے میں بہت برا محسوس کراتے ہیں۔				
4۔کسی کو یہ بتانا کہ مجھے ایچ آئی وی ہے،خطرناک ہے۔				
5۔جب آجر کو پتا چلتا ہے تو ایچ آئی وی سے متاثرہ لوگ اپنی نوکری کھو بیٹھتے ہیں۔				
6۔میں ایچ آئی وی کو چھپانے کیلئے سخت محنت کرتا/کرتی ہوں۔				
7۔میں محسوس کرتا/کرتی ہوں کہ میں اتنا اچھا فرد نہیں ہوں جتنے کہ دوسرے ہیں کیونکہ مجھے ایچ آئی وی ہے۔				
8۔مجھے ایچ آئی وی ہونے پر کبھی شرمندگی محسوس نہیں ہوتی۔				
9۔ ایچ آئی وی سے متاثرہ لوگوں کے ساتھ غیروں جیسا برتاؤ کیا جاتا ہے۔				
10۔زیادہ تر لوگ یقین رکھتے ہیں کہ ایچ آئی وی سے متاثرہ فرد گندا ہوتا ہے۔				
11۔نئی دوستی سے اجتناب کرنا زیادہ آسان ہے،بانسبت اس پریشانی کے کہ کسی کو یہ بتایا جائے کہ مجھے ایچ آئی وی ہے۔				
12۔ ایچ آئی وی ہونے کی وجہ سے میں اپنے آپ کو صاف محسوس نہیں کرتا/کرتی ہوں۔				
13۔ ایچ آئی وی ہونے کے بارے میں جاننے کے بعد سے میں خود کو دنیا کے باقی لوگوں سے الگ اور علیحدہ محسوس کرتا/کرتی ہوں۔				
14۔زیادہ تر لوگ سوچتے ہیں کہ ایچ آئی وی سے متاثرہ فرد قابل نفرت ہے۔				
15۔ ایچ آئی وی کی بیماری مجھے یہ محسوس کراتی ہے کہ میں ایک برا فرد ہوں۔				
16۔زیادہ تر لوگوں کے ایچ آئی وی میں مبتلا ہونے کے بارے میں جب دوسروں کو علم ہوتا ہے تو وہ دھتکار دیئے جاتے ہیں۔				
17۔میں اس معاملے میں بہت محتاط رہتا/رہتی ہوں کہ میں کس کو بتاؤں کہ مجھے ایچ آئی وی ہے۔				
18۔کچھ لوگ جن کو یہ علم ہے کہ مجھے ایچ آئی وی ہے، وہ مجھ سے زیادہ دور ہو چکے ہیں۔				
19۔یہ جاننے کے بعد کہ مجھے ایچ آئی وی ہے،لوگوں کا میرے خلاف تعصب کے بارے میں، میں پریشان رہتا/ رہتی ہوں۔				
20۔زیادہ تر لوگ ایچ آئی وی سے متاثرہ کسی فرد کے آس پاس خود کو بے سکون محسوس کرتے ہیں۔				
21۔مجھے کبھی بھی کسی سے یہ حقیقت چھپانے کی ضرورت محسوس نہیں ہوئی کہ مجھے ایچ آئی وی ہے۔				
22۔میں پریشان ہوتا/ ہوتی ہوں کہ لوگ میرے بارے میں خود سے نتائج اخذ کریں گے جب انہیں یہ پتا چلے گا کہ مجھے ایچ آئی وی ہے۔				
23۔اپنے بدن میں ایچ آئی وی ہونے سے مجھے کراہیت محسوس ہوتی ہے۔				

سوالات کے اس اگلے حصّے میں یہ فرض کیا گیا ہے کہ آپ نے دوسروں کو بتادیا ہے کہ آپ کو ایچ آئی وی ہے یا دوسروں کو آپ کے ایچ آئی وی کا علم ہے۔ضروری نہیں کہ آپ کے معاملے میں یہ سچ ہو۔اگر کوئی سوال کسی ایسے معاملے کے بارے میں ہو جو آپ کے ساتھ پیش نہیں ہوا تو برائے مہربانی خود کو اس صورت حال میں تصور کریں۔پھر اپنا جواب (زیادہ اختلاف،اختلاف،متفق،زیادہ متفق) اس بنیاد پر دیں کہ آپ کیسا محسوس کریں گے یا آپ کے خیال میں دوسروں کا رویہ آپ کے ساتھ کیسا ہوگا۔

	زیادہ اختلاف	اختلاف	متفق	زیادہ متفق
24۔میرے ایچ آئی وی ہونے کے بارے مین جاننے کے بعد لوگوں کے ردعمل نے مجھے ٹھیس پہنچائی۔				
25۔میں پریشان ہوتا/ ہوتی ہوں کہ جن لوگوں کو میرے ایچ آئی وی ہونے کا علم ہے وہ دوسروں کو بتادیں گے۔				
26۔کچھ لوگوں کو اپنے ایچ آئی وی ہونے کے بارے مین بتانے پر میں پچھتاتا/ پچھتاتی ہوں۔				
27۔اصولاً دوسروں کو اپنے ایچ آئی وی ہونے کے بارے میں بتانا غلط ثابت ہوا ہے۔				
28۔کچھ لوگوں کو جب یہ پتا چلا کہ مجھے ایچ آئی وی ہے تو مجھے چھونے سے گریز کرتے ہیں۔				
29۔جن لوگوں کا میں خیال رکھتا/ رکھتی ہوں،انہوں نے یہ جاننے کے بعد مجھ سے رابطہ ختم کردیا کہ مجھے ایچ آئی وی ہے۔				
30۔لوگ مجھے بتا چکے ہیں کہ جیسے میں نے اپنی زندگی گذاری ہے،میں ایچ آئی وی کا مستحق ہوں۔				
31۔کچھ لوگ جو میرے قریب ہیں انہیں اس بات کا خدشہ ہے کہ میرے ایچ آئی وی کا علم ہونے کے بعد دوسرے انہیں دھتکار دیں گے۔				
32۔لوگ ان کے بچوں کے قریب میرا جانا پسند نہیں کرتے جب انہیں یہ پتا چلتا ہے کہ مجھے ایچ آئی وی ہے۔				
33۔لوگ مجھ سے جسمانی طور پر پیچھے ہٹ چکے ہیں جب سے انہیں پتا چلا کہ مجھے ایچ آئی وی ہے۔				
34۔کچھ لوگ اس طرح برتاؤ کرتے ہیں جیسے مجھے ایچ آئی وی ہونا میری غلطی ہے۔				
35۔کچھ لوگوں کے ساتھ میرے سماجی تعلقات ختم کرنے کی وجہ ان کا میرے ایچ آئی وی ہونے کے متعلق دیکھا جانے والا ردعمل ہے۔				
36۔میں نے دوستوں کو یہ بتا کر کھو دیا ہے کہ مجھے ایچ آئی وی ہے۔				
37۔میں اپنے قریبی لوگوں کو بتایا ہے کہ وہ میرا ایچ آئی وی ہونے کی حقیقت کو راز رکھیں۔				
38۔وہ لوگ جن کو یہ علم ہے کہ مجھے ایچ آئی وی ہے،ان میں میری اچھائیوں کو نظر انداز کرنے کا رجحان ہے۔				
39۔لوگ مجھ سے ڈرے ہوئے لگتے ہیں جیسے ہی انہیں علم ہوتا ہے کہ مجھے ایچ آئی وی ہے۔				
40۔جب لوگوں کو یہ علم ہوتا ہے کہ آپ کو ایچ آئی وی ہے تو آپ کے کردار میں خامیوں کی تلاش کرنے لگتے ہیں۔				

Figure: Urdu Human Immunodeficiency Virus (HIV) Stigma Scale (U-HSS).

the maintenance of semantic and conceptual equivalence.[23]

A panel of experts was formed. Function of the panel was to do critical evaluation and confirmation of the final adapted Urdu version of the HSS.[7] In the first stage of phase I, three translators proficient in English and Urdu were briefed about the content of scale, aim of the study and the population under consideration before they were provided with the original English version of the HSS to translate it into Urdu language, working independently.

In the second stage, once the scale was translated into Urdu, the instructions, items and response format of the translated version were compared with each other and with the original version by the members of panel. They critically evaluated the items to resolve any kind of discrepancies and ambiguities. Items in Urdu that retained the conceptual, linguistic and cultural aspects were combined to form one draft from the three translations. Alternative words suggested by the translators were also taken into consideration and no items were eliminated in the process of forward translation.

In the third stage, the Urdu version of HSS, finalized by comparing the forward translations, was given to another three expert translators who were completely blind to the original version of the instrument so that a bias-free translation could be produced.[23] These three translators also worked independently and translated the Urdu version back to English language. The backward translations were evaluated item by item and comparisons were made with the original English version. Some of the items after backward translation did not retain the original concepts, therefore they were modified and rephrased by the translators. After the detailed evaluation, a final Urdu version of the HSS (U-HSS) was formulated and was ready to be administered and tested for empirical analyses (Figure).

In phase II, after getting informed consent from each participant, socio-demographic data was gathered before administering the U-HSS individually in the form of semi-structured interviews along with Siddiqui Shah Depression Scale (SSDS)[24] and Urdu Rosenberg Self-Esteem Scale (U-RSES)[25] on the subjects. The participants were aged 25-45 years men diagnosed with HIV/AIDS due to injecting drug use.

To assess the test-retest reliability, the U-HSS was re-administered on some of the participants after a gap of 7-15 days. The scores obtained on the two administrations of the test by the same participants were then correlated using Pearson product moment coefficient of correlation.

Internal consistency reliability (Cronbach alpha), split-half reliability, temporal stability (test-retest reliability) and construct (discriminant and convergent) validity coefficients were computed using SPSS 20.

Results

Of the 3799 HIV/AIDS patients, 150(4%) met the inclusion criteria and represented the study sample. The mean age was 31.65±5.88 years. Of the total, 86 (57.3%) were married; 54(36%) were unmarried; 8(5.3%) were divorced; 2(1.3%) were widower; 23(15.3%) were unemployed; 127 (84.7%) had some source of earning; 88(58.7%) belonged to lower socioeconomic status (SES); 55(36.7%) had middle SES; 7(4.7%) were from upper SES; 145(96.7%) were Muslim; 3(2%) Hindus; 2(1.3%) Christians; 111(74%) were from Sindh; 24(16%) from Khyber Pakhutunkhwa (KP); 7(4.7%) from Balochistan; 6(4%) from Punjab; and 2(1.3%) were from Azad Jammu and Kashmir (AJK). The duration of HIV status known to the sample ranged from 6 months to 9 years.

Internal consistency of U-HSS was 0.94 and that of the subscales ranged 0.81-0.91. Gutman split-half coefficient was 0.93 and test retest reliability was 0.92. U-HSS had

Table-1: Descriptive statistics for the measures of Urdu Human Immunodeficiency Virus (HIV) Stigma Scale, Rosenberg Self-Esteem Scale and Siddiqui Shah Depression Scale (n=150).

Measure	Min	Max	Mean±SD
Total HIV Stigma	52	149	101.95±20.24
Personalized stigma	21	67	42.42±9.837
Disclosure	12	39	27.45±6.828
Negative self-image	16	49	34.02±6.869
Public attitudes	24	74	51.28±10.176
Rosenberg Self-Esteem Scale	15	38	27.77±5.905
Siddiqui Shah Depression Scale	2	84	29.16±17.348

Table-2: Analysis of Split-Half Reliability.

		Split-Half Reliability	
Cronbach's Alpha	Part 1	Value	0.894
		N of Items	20[a]
	Part 2	Value	0.886
		N of Items	20[b]
	Total N of Items		40
Correlation Between Forms			0.877
Spearman-Brown Coefficient	Equal Length		0.934
	Unequal Length		0.934
Guttman Split-Half Coefficient			0.933

Table-3: Internal consistencies, Test-retest Reliabilities and Construct Validity of Urdu Human Immunodeficiency Virus (HIV) Stigma Scale.

Scales	Reliability Analysis		Validity Analysis	
	Cronbach's Alpha (n=150)	Test-Retest (n=50)	RSES	SSDS
Total HIV Stigma	0.941*	0.963*	-0.533*	0.641*
Personalized stigma	0.907*	0.942*	-0.548*	0.632*
Disclosure	0.896*	0.940*	-0.359*	0.447*
Negative Self-Image	0.813*	0.920*	-0.532*	0.645*
Public Attitudes	0.911*	0.948*	-0.511*	0.611*

*p<00.01 (2-tailed)

significant positive correlation with depression (p<0.01) and significant negative correlation with self-esteem (p<0.01) (Tables 1-3).

Discussion

The study was conducted to translate the HSS into Urdu and assess its psychometric properties through analysis of its reliability and validity. Internal consistency of the items was analysed using Cronbach's alpha and split-half reliability as was done in the development of the original HSS.[6] Values of Cronbach's alpha coefficients exceeding 0.7 mean that the scale is internally consistent. The Cronbach's alpha for the total HSS and for the subscales ranged from 0.81 to 0.94 in the current study, indicating that there is an adequate internal consistency for U-HSS and its subscales. The Gutman split-half coefficient for the present study was 0.93 which showed that the Urdu version of the scale had good split-half reliability. Similarly the test retest reliability of the scale and subscales showed adequate stability over time.

The correlation of the scale with depression and self-esteem showed good level of construct validity. The scores of U-HSSS significantly and positively correlated with SSDS scores, indicating convergent validity, and it negatively correlated with the scores of U-RSES, indicating discriminant validity. The findings in this study were consistent with previous studies.[7]

Additionally, considering that one of the major reasons of HIV transmission in Pakistan is injecting drugs, therefore U-HSSS was specifically administered on people who had been diagnosed with HIV due to injecting drug use. This was one of the major studies where the interaction of a social aspect (stigma) with a medical problem (HIV/AIDS) was studied among injectable drug users in Pakistani context. The translation and adaptation of the HSS can help in assessing the stigma associated with HIV/AIDS and this assessment can help the researchers to explore what psychological and social threats this stigma pose to the people diagnosed with HIV/AIDS, specifically due to injectable drug use in Pakistan.

The U-HSS can be used confidently for further research within the limitation of the findings of this study. The psychometric data provided the needed support for the utility of this scale among injectable drug users diagnosed with HIV/AIDS in Pakistan. However, like every other study in the field of social sciences, this study has its limitations. Although the HSS is reliable and valid with a large, diverse sample of people living with HIV/AIDS, the psychometric properties of U-HSS have been analysed for only injectable drug using men across different areas of Pakistan. Therefore, results should be interpreted carefully when generalising the outcomes. In future, data with more diverse population i.e., both men and women, should be included to have data that may be generalised.

Conclusion

U-HSS was found to be a reliable and valid instrument to be used among injectable drug users in Pakistan. It further showed that HIV/AIDS stigma was associated with high level of depression and low level of self-esteem, thus directing towards the negative psychological impact of HIV/AIDS stigma and highlighting the importance of measuring stigma in clinical practice.

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