Stigma Among People with Schizophrenia: Adaptation and Cross-Cultural Validation of the Explanatory Model Interview Catalogue in Berber, Morocco

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Abstract

**Background:** People with schizophrenia are more stigmatized than those with other mental illnesses. Stigmatization can be measured using the English version of Stigma Measurement Scale contained in the explanatory model interview catalogue (EMIC).

**Objectives:** This study aimed to translate the English version of Stigma Measurement Scale into Berber language and validate the translated version.

**Methods:** This study was conducted in public hospitals in southern Morocco, which are predominantly Berber-speaking. The psychometric properties of the stigma scale contained in the EMIC were validated on a sample including 128 individuals.

**Results:** According to the Cronbach’s alpha ($\alpha = 0.826$) and the internal convergence calculated by Pearson’s statistic, that the inter-item correlation was significant. Also, the intraclass correlation coefficient (ICC) was significant. The added item, concerning the COVID-19 situation has a similar psychometric value to the other items.

**Conclusions:** According to our results, the Berber version of the Stigma Measurement Scale is culturally acceptable and can be used in Moroccan society.

**Keywords:** Berber, COVID-19, EMIC, Stigma, Schizophrenia

1. Background

The publication of Goffman in 1963, is considered as a founding text and enunciator of the phenomenon of the stigmatization, although it is already found under the term of the social deviance in Durkheim (1). Goffman defines stigma as a deeply discrediting and reducing attribute of the people in question; it transforms them from complete and normal people to tainted and diminished ones (2). He also points out that the stigmatization of a disease is not expressed and experienced in the same way, depending on the country and social spaces. Stigmatization, as an ambiguous phenomenon, differs from one culture to another and has different consequences depending on how cultural groups deal with their differences (3).

Mental illnesses are associated with significant stigma; they are more stigmatizing than physical illnesses, and people with schizophrenia are more stigmatized than those with other mental illnesses (4). The World Health Organization (WHO) has often underlined in its reports the sufferings of mentally ill patients due to stigmatization, its direct consequences on quality of life, effects on socioeconomic rights, and even the access to care and treatment (5, 6).

In Morocco, about 340,000 people live with this chronic mental illness (7). However, the offer of care remains insufficient and is demanded by the citizens (8). People with schizophrenia and their families are no exception to this international reality; stigma is part of their experience of the illness (9). The reality of the stigmatization of people with schizophrenia in North Africa does not differ...
much from that in Europe (10). In one of the few writings on madness among the Berbers, Matthew Carey speaks of a madness that both isolates and integrates, with the impact depending on gender, social status, personality, and the form of the illness (11).

It is not easy to understand a dynamic, polymorphous, and multidimensional phenomenon such as stigmatization (12). Similarly, assessing its consequences and impact on the lives of patients and their families is challenging. A number of measurement scales have been developed and validated throughout the world to measure its prevalence, intensity, and various characteristics (13). The explanatory model interview catalogue (EMIC), developed by Michelle Weiss in 1997, is one of these scales. The strength of this tool lies not only in the fact that it was developed and validated in a non-Western culture, but also in its ability to collect qualitative data, thus allowing patients and their families to express themselves through their cultural prism.

Cultural differences are often the cause of measurement discrepancies, and the psychometric properties of the scale vary across cultures (14). There are several linguistic, cultural, and normative limitations to the direct use of the original scales or to a simple translation of the items (15). The use of transcultural adaptation of measurement scales is still a common practice in scientific circles. This is subject to a scientific approach that allows the cultural and linguistic differences to be reduced as much as possible, so that a scale in the local language with psychometric properties very close to those of the original scale can be obtained (16).

2. Objectives

The aim of this study was to translate the English version of Stigma Measurement Scale contained in the EMIC into Berber language and validate the translated version in the Souss-Massa region in Morocco.

3. Methods

The validation of the psychometric tests was done on a sample of 128 individuals, calculated by the method of Hulley Cummings, Browner, Newman, and Heart, 1988 considering two criteria as follows: (1) the diagnosis of schizophrenia by a psychiatrist; and (2) patients and family members who consented to participate in the study. The sample size was calculated by the method of Hulley Cummings, Browner, Newman, & Heart, 1988 considering two criteria as follows: (1) the diagnosis of schizophrenia by a psychiatrist; and (2) patients and family members who consented to participate in the study.

The interviews were conducted from January to March 2021.

3.1. Structure of the Scale

The EMIC was developed by Michel Weiss in 1997. It is a semi-structured interview framework that elucidates the experience of illness from the perspective of patients and their families. The structure of the EMIC is based on three distinct components: the experience of the illness, the meaning of the illness, and the behaviors resulting from it. The present study focuses on the Stigma Measurement Scale, which is composed of 13 items. In this scale, items 11 and 12 are transformed into two sub-questions, with only one response required, depending on the family situation. The cross-cultural adaptation of this scale has been validated in several languages and cultures to measure the prevalence, intensity, and distribution of stigma in different study populations (19-23). Since professor Weiss proposed to add an item related to the COVID-19 situation in the email correspondences, we included 14 items in the scale. So, this item is specific to the current study, and it is not a permanent item for the scale.

3.2. Translation Process

The process of translation and semantic adaptation into the local Berber language and culture of Souss-Massa was done according to the six-step methodology developed by Beaton et al. (16). The items were translated from English into Berber by two bilingual translators. The synthesized Berber version, TBI-TB2, was back-translated into the original language by a bilingual translator, a native teacher from the Souss-Massa region, who has been living in New York for over 15 years. The semantic and cultural equivalence was validated by a team, including a psychiatrist at the psychiatry department of the provincial hospital of Inezgane, an anthropologist from the Ibn Zohr University of Agadir, a linguist from the Royal Institute of Amazigh (Berber) culture, and one of the first two translators.

The pre-final version was tested on a small group of 20 people (10 patients vs. 10 healthy controls) to test the comprehension difficulties of the items translated into the Berber language. The level of comprehension of the items was performed according to a Likert scale (very clear = 2, clear = 1, not clear = 0). The total score of comprehension of the scale varies between 0 and 28. All responses exceeded the median score.
The complete file with the translation versions and the reports of each step were sent to the scale designer, Michelle Weiss. The professor praised the work and expressed satisfaction with the pre-final version.

3.3. Statistical Analysis and Psychometric Properties

The analysis was done in accordance with the recommendations of professor Weiss in the Cultural Epidemiology Handbook. Quantitative data were entered and processed with SPSS statistical analysis software (ver. 13.0; SPSS Inc., Chicago, IL, USA). Means, standard deviation, and reliability, as well as floor and ceiling effect percentages were evaluated. The retest reliability of the Berber version was evaluated on a sample including 18 individuals. The internal consistency of the scale was assessed by calculating Cronbach’s alpha. Convergent validity was determined by Pearson’s coefficient.

3.4. Ethical Considerations

The authorization for the translation, validation, and use of the EMIC was given by professor Mitchell Weiss via email correspondences. Also, the ethics committee of the Faculty of Medicine in Rabat approved the study protocol (code: C37/20 on 27/01/2021). Before conducting the interviews, the study aims were explained to all patients and their families, and an informed consent was obtained.

4. Results

4.1. The Translation

Due to the COVID-19 pandemic, the Berber synthetic version was carried out by holding videoconferences. The researcher was simply a reporter. After debate and consensus between the two translators, the final version of each item was fixed and transcribed.

- Item 1: For the word "problem" the translators agreed to translate it either as "tamaDunt" which means "disease" or "mayad k yaghn" which is a phrase meaning "what you have". The phrase "keep people from knowing" was translated as "ad thd ut" which means "to hide".
- Item 2: The translators agreed that the expression "less of yourself" should be translated as "is atahgart ikhf nk" meaning "You despise yourself" or "self-contempt".
- Item 3: The expression "been made to feel shamed or embarrassed" was translated as "tsHassat s ugayyu nk/nm, tnachmt, nghd tyaHrajt". The word "tyaHrajt", equivalent to "embarrassed", is borrowed from Arabic, but is well used by the Berber-speaking population.
- Item 4: The translators chose to translate "they think less of you" as "tnaqSt gh walIn nsn", which literally means "you are deficient in their eyes".
- Item 5: For "contact with you" we had two proposals "willit tZrrat" (meaning: those who are with you), and "tamunt nk" (meaning: "companionship" or "being with you"). For the expression "bad effects", the translators did not come to a decision and they kept the two possibilities: "ad iDurruru" which means "it causes harm to" and "kra n ta’atir ikhchen f" which means "any bad effects" by borrowing the word "ta’atir" from Arabic.
- Item 6: For the expression "others have avoided you" the translators kept the proposition "ar ak tanfn midn" which is the direct equivalent of "avoided" in Berber.
- Item 7: The expression "people refuse to visit your home" was translated as "Is a ttagwin midn ad darun tikkan gh tigmmi", which literally means "people refuse to visit your home".
- Item 8: For "think less of the family", the translators used "is a THgarn ayt dark", which literally means "do they despise your family".
- Item 9: For the expression "were to find out about", the translators used "Igh d inwIn lkhbar", meaning "if others discover the information" or "others are discovering", and for "any problems for your family" "kra n lmachakil", they opted for the word "machakil" for "problems" borrowed from Arabic and commonly used by Berber speakers.
- Item 10: For the phrase "to keep others from finding out", the translators used "ad hbun khf", which literally means "to hide information from...".
- Item 11: For the expression "if unmarried", the translators suggested "Igh ur ttahlt", which literally means "if you are not married". The expression "difficult to marry" was translated as "is rad ak/am iccqu ad ttahlt", which literally means "make it difficult for you to marry". Also, for the expression "suppose you were not married", the translators adopted "igh ur ttahlt", which literally means "if you’re not already married".
- Item 12: For "cause problems in your marriage", the translators used "ak isbbib lmacakil gh zmam nk". The marriage, which is "littithal", was replaced by "ZZman nk" meaning more "ongoing marriage" or "married life".
- Item 13: The expression "problem make it more difficult for", the translators agreed on "ad tcciqu uggar liti hal", which literally means "to make the marriage more difficult".
- Item 14: This item was added because of the COVID-19 pandemic, and both translators agreed on the translation. The multidisciplinary committee enriched the version with the following changes:

- Item 1: The discussion focused on the term "disease" and "what you have" to designate a health problem in Berber. The anthropologist pointed out that sometimes schizophrenia is not considered a disease in Berber...
culture. Therefore, he preferred to keep the expression "mayad llik yaghn", which literally means "what you have" but understood in the local culture as "what you suffer from". The team agreed to remove the term "disease".

- Item 2: The expression "less of yourself" was translated as "is atahgart ikhf nk", meaning "you despise yourself". This part was changed to "is a tshassat s naqS", which literally means "you feel inferior".

- Item 4: The team members agreed to replace the expression "is rad tnaqSt gh waln n midn" with the expression "is rad timZiyt gh waln n midn", which means the same but is more explicit.

- Item 5: The team members kept the term "tamunt nk", which means "company" to translate the term "contact with you" and rejected the term "anmuggar", which literally means "meet".

- Items 4 and 8: For the expression "Igh t snn wadjjarn nnk...", which translates "if they knew about it, would your neighbors", the linguist mentioned that in the Berber language the "e" is equivalent to "it", which replaces "problem" in English, is not put at the beginning of the sentence. In Berber, the object complement pronoun is used after having already evoked what it replaces. The question was rephrased in this sense.

4.2. Statistical Analysis and Psychometric Tests

In this study, 128 participants were included. The mean age of patients was 30.88 years (standard deviation (SD)-9.69; range: 18 - 66 years). There was a clear predominance of males (67%), which may have an origin in what Matthew Carey has argued about insanity and gender among Berbers, speaking of an insanity that integrates in men and isolates in women. Also, there was a dominance of single patients (67.2%), despite an average age of 30.88 years. Only 24.2% of the participants were married. In addition, 11.7% were illiterate and 85.2% did not have an educational level higher than secondary school (Table 1).

4.3. Ceiling and Floor Effect

No items in the Berber version of the scale showed a floor effect or a ceiling effect (Table 2). The percentage of respondents with the highest and/or lowest score remained within acceptable values. Floor or ceiling effects are considered present if more than 15% of respondents scored the lowest or highest, respectively (24).

4.4. Internal Consistency

In this study, the data from 128 patients was used to evaluate the internal consistency of the scale. The Cronbach’s alpha coefficient was 0.826, so the inter-item correlation was satisfactory. The internal convergence calculated by Pearson’s statistic showed that the inter-item correlation was significant (Figure 1).

4.5. The Reliability and Test-Retest

The test-retest reliability of the Berber version was evaluated on a sample of 18 individuals. The intraclass correlation coefficient (ICC) between the two assessments was significant (0.880) (-0.030; 0.975).

4.6. Item 14 Added Due to COVID-19 Pandemic

Regarding the COVID-19 pandemic, we added the following item: "Do you think that the community experience of the COVID-19 pandemic might make people less accepting and supportive of you than they would be for others without mental health problems like yours?". The item had similar psychometric values to the other items and Cronbach’s alpha was equal to 0.824 when the item was deleted, which was similar to the total Cronbach’s alpha of the scale (0.826); its correlation with other items was also significant (Figure 1).

<table>
<thead>
<tr>
<th>Variables</th>
<th>Values</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>30.88 ± 9.69</td>
</tr>
<tr>
<td>Median</td>
<td>28.50 (24, 34)</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>86 (67.2)</td>
</tr>
<tr>
<td>Female</td>
<td>42 (32.8)</td>
</tr>
<tr>
<td>Level of education</td>
<td></td>
</tr>
<tr>
<td>Illiterate</td>
<td>15 (11.7)</td>
</tr>
<tr>
<td>Koranic b</td>
<td>2 (1.6)</td>
</tr>
<tr>
<td>Primary</td>
<td>28 (21.9)</td>
</tr>
<tr>
<td>Secondary</td>
<td>64 (50.0)</td>
</tr>
<tr>
<td>University</td>
<td>19 (14.8)</td>
</tr>
<tr>
<td>Family status</td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>86 (67.2)</td>
</tr>
<tr>
<td>Married</td>
<td>31 (24.2)</td>
</tr>
<tr>
<td>Divorced</td>
<td>6 (4.7)</td>
</tr>
<tr>
<td>Remarried</td>
<td>2 (1.6)</td>
</tr>
<tr>
<td>Widowed</td>
<td>3 (2.3)</td>
</tr>
</tbody>
</table>

* Values are expressed as No. (%) unless otherwise indicated.
* Schools established at the level of mosques where elementary teaching of Arabic language and religion is done.
Table 2. Mean Ceiling and Floor Effect

<table>
<thead>
<tr>
<th>Items</th>
<th>N°</th>
<th>Mean ± SD</th>
<th>Floor: No. (%)</th>
<th>Ceiling: No. (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Keep others from knowing</td>
<td>128</td>
<td>2.18 ± 1.139</td>
<td>23 (18)</td>
<td>73 (57)</td>
</tr>
<tr>
<td>Think less yourself</td>
<td>128</td>
<td>2.21 ± 1.06</td>
<td>18 (14.1)</td>
<td>70 (54.7)</td>
</tr>
<tr>
<td>Shamed or embarrasses</td>
<td>128</td>
<td>2.52 ± 0.98</td>
<td>11 (0.8)</td>
<td>76 (59.4)</td>
</tr>
<tr>
<td>Others think less of you</td>
<td>128</td>
<td>2.02 ± 0.7</td>
<td>5 (3.9)</td>
<td>56 (42.1)</td>
</tr>
<tr>
<td>Adverse effect on others</td>
<td>128</td>
<td>1.63 ± 0.77</td>
<td>7 (5.5)</td>
<td>16 (12.5)</td>
</tr>
<tr>
<td>Others avoided you</td>
<td>128</td>
<td>1.98 ± 1.03</td>
<td>14 (10.9)</td>
<td>52 (40.6)</td>
</tr>
<tr>
<td>Others might refuse to visit</td>
<td>128</td>
<td>1.59 ± 1.95</td>
<td>24 (18.8)</td>
<td>12 (9.4)</td>
</tr>
<tr>
<td>Others would think less family</td>
<td>128</td>
<td>1.76 ± 0.839</td>
<td>11 (8.6)</td>
<td>22 (17.2)</td>
</tr>
<tr>
<td>Problems for the family</td>
<td>128</td>
<td>1.65 ± 0.749</td>
<td>9 (7)</td>
<td>12 (9.4)</td>
</tr>
<tr>
<td>Family concern about disclosure</td>
<td>128</td>
<td>1.83 ± 1.08</td>
<td>20 (15.6)</td>
<td>45 (35.2)</td>
</tr>
<tr>
<td>Problem getting married</td>
<td>128</td>
<td>2.57 ± 0.636</td>
<td>1 (0.8)</td>
<td>82 (64.1)</td>
</tr>
<tr>
<td>Problem in ongoing marriage</td>
<td>128</td>
<td>2.18 ± 0.873</td>
<td>8 (6.3)</td>
<td>54 (42.2)</td>
</tr>
<tr>
<td>Problem for relative to marry</td>
<td>128</td>
<td>1.42 ± 0.819</td>
<td>17 (13.3)</td>
<td>10 (7.8)</td>
</tr>
<tr>
<td>COVID-19, less accepting and supportive</td>
<td>128</td>
<td>1.86 ± 1.07</td>
<td>10 (7.8)</td>
<td>20 (15.6)</td>
</tr>
</tbody>
</table>

5. Discussion

The translation into Berber and the semantic equivalence of the EMIC stigma scale developed by Weiss (1997) (25) was a very important step in the realization of this work. The predominant character of the oral language in the Berber culture, the absence of standardization of the Berber language, the semantic equivalence, and the choice of vocabulary were factors that complicated the study. Some choices were the result of a consensus between the translators, approved afterwards by the committee of experts. The comprehension of the items was tested on 20 individuals (10 patients vs. 10 healthy controls); no participant had problem in comprehending the items; and the judgments varied between clear and very clear, and there was no unclear answer.

The internal consistency of the scale was 0.826, which is considered satisfactory. It is similar to the internal consistency of the version conducted in Bangalore under the direction of Michelle Weiss Cronbach 0.8 (19). The inter-item correlation and Pearson’s coefficient were significant. Also, the items of the Berber version of the scale showed no floor effect and no ceiling effect, and the percentages of respondents with a higher or lower score was less than 15%. The ICC (test-retest) evaluated on 18 individuals in a one-week interval between the two assessments was 0.880, which was considered highly significant.

Pearson’s coefficient showed a significant correlation between the item added in relation to the COVID-19 situation and the rest of the items in the scale. This item also had similar psychometric values to the other items; the Cronbach’s alpha was stable ($\alpha = 0.826$) when the item was deleted.

5.1. Conclusion

In this study, we validated the stigma scale contained in the EMIC developed by Weiss in 1997 in Berber language. The Berber version of the EMIC stigma scale had good psychometric properties. The availability of this culturally acceptable Berber version will allow further studies of stigma in Berber-speaking patients in Morocco.

Footnotes

Authors’ Contribution: SA designed the study, analyzed the data, and wrote the manuscript. OM participated in the design, analysis, interpretation of the data, and revision of the manuscript. KA and BMA participated in the statistical analysis, interpretation of the data, and were involved in drafting the manuscript. AB participated in translation and linguistic revision of the scale. DJ was involved in the revision of the manuscript, including the clinical component of the study and data collection. AR participated in the statistical analysis, interpretation of the data, and was involved in writing the manuscript. RR participated in the design, analysis, interpretation of the data, revision of the manuscript, and gave final approval to the published version. All authors had access to the data and participated in writing the manuscript. All authors read and approved the final version of the manuscript.

Conflict of Interests: There are no conflicts of interest in relation to this research.
Data Reproducibility: The data presented in this study are openly available in one of the repositories or will be available on request from the corresponding author by this journal representative at any time during submission or after publication. Otherwise, all consequences of possible withdrawal or future retraction will be with the corresponding author.

Ethical Approval: The ethics committee of the Faculty of Medicine in Rabat approved the study protocol (code: C37/20 on 27/01/2021).

Funding/Support: No external funding was provided for this study.

Informed Consent: Written informed consent was obtained.

References
5. World Health Organization. Santé mentale: relever les défis, trouver...


