

Translation, back-translation and cultural adaptation of the 8-item Stigma Scale for Chronic Illness to Portuguese

Tradução, retrotradução e adaptação cultural da Escala de Estigma para Doença Crônica (8 itens) ao Português

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ABSTRACT

Cultural diversity limits cross cultural understanding of diseases. Stigma has been studied in neurological disorders, chronic pain and migraine, but instruments are not available in Portuguese. We aimed to translate the 8-item Stigma Scale for Chronic Illness to Portuguese. **Methods:** We followed the 5 steps advised by guidelines for transcultural validation. **Results:** Translation, backtranslation and cultural validation has been performed following the 5 steps, and a final version of the instrument was achieved. **Discussion/Conclusion :** Stigma is an important issue in migraine management. Measurement of stigma in headache sufferers in Brazil may be started. The final version of the instrument is provided.

Keywords: Stigma; Work productivity; Migraine.

RESUMO

A diversidade cultural é cada vez mais comum no mundo e limita a compreensão transcultural de doenças. O estigma foi estudado em distúrbios neurológicos, dor crônica e enxaqueca, mas os instrumentos não estão disponíveis em português. Nosso objetivo foi traduzir a escala de estigma de oito itens para doenças crônicas para o português. **Métodos:** Foram seguidas as 5 etapas recomendadas pelas diretrizes para validação transcultural. **Resultados:** A tradução, a retrotradução e a validação cultural foram realizadas seguindo as 5 etapas, e uma versão final do instrumento foi alcançada. **Discussão/ Conclusão:** O estigma é uma questão importante no tratamento da enxaqueca. A mensuração do estigma em pessoas com dor de cabeça no Brasil pode ser iniciada. A versão final do instrumento é fornecida.

Descritores: Estigma; Perda produtiva; enxaqueca.

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INTRODUCTION

Cultural diversity has been growing worldwide due to globalization and migration. Countries in Europe and others such as the United States have populations with significant diverse cultural, language and ethnicity¹. Developed instruments, scales for diseases measurements, have been conceived in English, leaving cross cultural studies limited because of the lack of translation and cultural validation².

Stigma has been first mentioned in 1963 in medical literature³, becoming an increasingly studied topic in medical research. Stigma is a social science construct meaning a flaw that discredits individuals for being socially unacceptable eliciting prejudice, discrimination, and loss of status. When someone experience stigma, a negative attitude toward treatment appears, affecting treatment adherence.

Stigma has been studied in several neurological disorders, including multiple sclerosis, stroke, epilepsy, spinal cord injury, and Parkinson's disease, showing greater distress and decreased quality of life^{4,5}. Pain conditions have also been determined to be affected by stigma, but headache disorders, although very influenced, have never been studied. The Stigma Scale for Chronic Illness has been used to evaluate the issue in chronic conditions⁶ and a short version, 8-item scale developed⁷.

Headache disorders are prevalent and a major debilitating condition in Brazil⁸. We aimed to start the validation process of the SSCI by translating, back-translating, and performing the cultural adaptation for Portuguese and Brazilian culture.

METHODS

Translation and cultural adaptation of the SSCI

We choose the symmetrical category warranting faithfulness of meaning and colloquialness in both the source language (OS; original language of the instrument) and the target language (BPS; Brazilian Portuguese). The purpose of translation was to achieve equivalence between both instruments.

The scale consisted in a 8-item instrument, each item can be scored from 1 to 5, being 1 = never, 2 = rarely, 3 = sometimes, 4 = often, and 5 = always. The higher the score the higher frequency of experiencing stigma.

Guidelines for transcultural validation advise that the full project be divided into steps, so a more careful process occur². The first 5 steps were:

Step 1: translation of the scale into the target language (Portuguese)

Step 2: comparison of the two translated versions of the instrument (TL1 and TL2): synthesis I

Step 3: blind back-translation of the preliminary initial translated version of the instrument

Step 4: comparison of the two back-translated versions of the instrument (B-TL1 and B-TL2): synthesis II

Step 5: pilot testing of the pre-final version of the instrument in the target language with a monolingual sample: cognitive debriefing

RESULTS

We followed the 5 steps suggested by Sousa *et al.*².

Step 1

The original SSCI with 8 items (OS) was translated into Brazilian Portuguese Scale (BPS) producing two versions (BPS-1 and BPS-2) by two bilingual and bicultural translators whose mother language is Brazilian Portuguese, both knowledgeable about health terminology and one (JPM) in psychology.

Step 2

A third independent translator, fluent in both languages, who lived in the United States and Brazil, compared BPS-1 and BPS-2, resolved ambiguities resolved ambiguities and discrepancies and produced the BPS-TL.

Step 3

BPS-TL was then back-translated by two neurologists, well-versed in both languages, to OS (OS-1 and OS-2) making two versions.

Step 4

OS-1 and OS-2 were then compared, also between the original scale. Wording, sentence structure, relevance and meaning were ascertained. A multidisciplinary committee, one neurologist, one psychologist, one physical educator. Discrepancies and ambiguities were resolved, resulting in a final and similar version. retaining the original meaning. Additional translation and back-translation were not necessary.

Step 5

The final BPS-TL was test piloted among an expert panel of 10 people, PhD students, and scholars, so clarity of the instructions, items and format were further examined, without additional changes.

The final result of the Brazilian Version of SSCI is shown in Table 1.

DISCUSSION

The SSCI is an English-language Neuro-QOL instrument developed by Rao *et al.*⁴ to measure stigma experienced by individuals with chronic neurological disorders, including stroke.

Its first version included 24 items with two subscales: felt (13 items) and enacted (11 items) stigma. The felt stigma questions were about embarrassment, worry and self-blame. Enacted stigma, asked about behavior of others, such as avoiding contact, staring, and being

Table 1. Final Version of the 8-item Stigma Scale for Chronic Illness to Portuguese. Responda a cada pergunta do enunciado marcando uma alternativa por linha.

	Nunca	Raramente	Às Vezes	Na Maior Parte Do Tempo	Sempre
Por causa da minha doença, algumas pessoas pareceram desconfortáveis comigo.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Por causa da minha doença, algumas pessoas me evitaram.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Por causa da minha doença, me senti deixado de fora das coisas.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Por causa da minha doença, as pessoas foram duras comigo.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Por causa da minha doença, as pessoas evitavam me olhar.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Eu me senti envergonhado com a minha doença.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Eu me senti envergonhado por causa das minhas limitações físicas.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Algumas pessoas agiram como se fosse minha culpa eu ter essa doença.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

unkind⁹. A short version with 8 items has shown to be as reliable and valid, therefore we used this one⁷.

Stigma has been studied in chronic pain patients¹⁰, however, only four patients had a head pain diagnosis. Stigma has been identified as an important issue in migraine management¹¹. Young et al.¹¹ studied 123 episodic, 123 chronic migraine patients, comparing with 62 epilepsy patients. Subjects with migraine reported greater inability to work than epilepsy subjects. Stigma correlated most strongly with inability to work, and was greater for chronic migraine than epilepsy or episodic migraine.

CONCLUSION

Measurement of stigma in headache sufferers in Brazil is important, with a translated instrument further studies are possible. The final version of the instrument is provided.

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