## TRANSLATION AND TRANSCULTURAL ADAPTATION OF SICKLE CELL DISEASE HEALTH-RELATED STIGMA SCALE FOR THE BRAZILIAN CONTEXT

# TRADUCÃO E ADAPTAÇÃO TRANSCULTURAL DA SICKLE CELL DISEASE HEALTH-RELATED STIGMA SCALE PARA O CONTEXTO BRASILEIRO

### TRADUCCIÓN Y ADAPTACIÓN TRANSCULTURAL DE LA *SICKLE CELL DISEASE HEALTH-RELATED STIGMA SCALE* PARA EL CONTEXTO BRASILEÑO

Sheila Santa Barbara Cerqueira<sup>1</sup>
Luana Santana Brito<sup>2</sup>
Katia Santana Freitas<sup>3</sup>
Coretta Melissa Jenerette<sup>4</sup>
Evanilda Souza de Santana Carvalho<sup>5</sup>

**How to cite this article:** Cerqueira SSB, Brito LS, Freitas KS, Jenerette CM, Carvalho ESS. Translation and transcultural adaptation of sickle cell disease health-related stigma scale for the brazilian context. Rev baiana enferm. 2019;33:e34572.

Objective: to describe the procedures applied in the process of transcultural adaptation and validation of the content of the instrument Sickle Cell Disease Health-Related Stigma Scale for the Brazilian context. Method: methodological study, which held conceptual and item equivalence, semantic equivalence and operational equivalence. The instrument, with 40 items divided into 4 subscales was assessed by a committee of 14 experts and 30 people with sickle cell disease in the state of Bahia, Brazil. Results: in the overall assessment, the instrument presented CVI of 0.80 and 0.73 for relevance and clarity, respectively. All items with CVI below 0.80 were reassessed by judges and readjusted. There were no added or removed items in relation to the adapted instrument and the final version was named Sickle Cell Disease Health-Related Stigma Scale-Br. Conclusion: the adapted version of the instrument is appropriate to the Brazilian context and brings contributions for nursing in facing and overcoming the stigma in health.

Descriptors: Anemia, Sickle Cell. Social Stigma. Chronic Disease. Social Discrimination. Validation Studies.

Objetivo: descrever os procedimentos aplicados no processo de adaptação transcultural e validação de conteúdo do instrumento Sickle Cell Disease Health-Related Stigma Scale para o contexto brasileiro. Método: estudo metodológico, que realizou equivalência conceitual e de itens, equivalência semântica e equivalência operacional. O instrumento, com 40 itens subdividido em 4 subescalas, foi avaliado por um comitê de 14 especialistas e público-alvo de 30 pessoas com doença falciforme, no estado da Babia, Brasil. Resultado: na avaliação total, o instrumento apresentou IVC de 0,80 e 0,73 para pertinência e clareza, respectivamente. Todos os itens com IVC inferiores a 0,80 foram reavaliados

Nurse. MSc in Collective Health. Universidade Estadual de Feira de Santana, Bahia, Brazil.. sheilinhabio@yahoo.com.br. https://orcid.org/0000-0002-3557-7200

Nurse. Universidade Estadual de Feira de Santana. Feira de Santana, Bahia, Brazil. https://orcid.org/0000-0002-7188-54972

Nurse. PhD in Nursing. Professor at the Universidade Estadual de Feira de Santana. Feira de Santana, Bahia, Brazil. https://orcid.org/0000-0002-0491-6759

Nurse. PhD in Nursing. Professor at the School of Nursing, University of North Carolina at Chapel Hill, Chapel Hill, North Carolina, USA. https://orcid.org/0000-0002-9851-4768

<sup>&</sup>lt;sup>5</sup> Nurse. PhD in Nursing. Professor at the Universidade Estadual de Feira de Santana. Feira de Santana, Bahia, Brazil. https://orcid.org/0000-0003-4564-0768

pelos juízes e realizadas adequações. Não foram retirados ou acrescidos itens ao instrumento adaptado e a versão final foi nomeada Sickle Cell Disease Health-Related Stigma Scale-Br. Conclusão: a versão adaptada do instrumento está adequada ao contexto brasileiro e traz contribuições para a Enfermagem no enfrentamento e na superação do estigma em saúde.

Descritores: Anemia Falciforme. Estigma Social. Doença Crônica. Discriminação Social. Estudos de Validação.

Objetivo: describir los procedimientos aplicados en el proceso de adaptación transcultural y validación del contenido del instrumento Sickle Cell Disease Health-Related Stigma Scale para el contexto brasileño. Método: estudio metodológico, que realizó la equivalencia conceptual y de elementos, la equivalencia semántica y la equivalencia operacional. El instrumento, con 40 elementos divididos en 4 sub-escalas, fue evaluado por un comité de 14 expertos y 30 personas con enfermedad de células falciformes en el estado de Babia, Brasil. Resultados: em la evaluación global, el instrumento presentó CVI de 0,80 y 0,73 para la relevancia y claridad, respectivamente. Todos los elementos con CVI por debajo de 0,80 fueron reevaluados por jueces y reajustados. No se eliminaron o agregaron elementos para el instrumento adaptado y la versión final fue nombrada Sickle Cell Disease Health-Related Stigma Scale-Br. Conclusión: la versión adaptada del instrumento es apropiada al contexto brasileño y aporta contribuciones a la enfermería para afrontar y vencer el estigma en la salud.

Descriptores: Anemia de Células Falciformes. Estigma Social. Enfermedad Crónica. La Discriminación Social. Estudios de Validación.

#### Introduction

The Sickle Cell Disease (SCD) is hereditary and very common in the world. It is distributed in all continents and, in Brazil, estimates show that between 25 and 30 thousand people live with the disease. Every year, 3,500 new cases are registered. The average life expectancy is 45 years, and affects mostly African-descendant people<sup>(1)</sup>.

The complications of SCD reach all organic systems. The visible changes produced give the sick person a fragile appearance<sup>(2)</sup>. Furthermore, the constant algic crises, severe anemia, and priapism lead to frequent search for emergency services. When judged by the appearance, people with SCD are constantly confused with carriers of contagious diseases. Since they require analgesics during the algic crises, they are identified as drug-dependents, which leads them to processes of stigmatization<sup>(1-4)</sup>.

The stigma has been considered a strong devaluation in the social environment of certain characteristics of individuals or population groups that are at odds with social, cultural, and economic conditions previously established<sup>(5)</sup>. Social exclusion, isolation, difficulty of insertion into the work, changes in self-esteem, low adherence to care, depression and other psychoemotional disorders are effects of stigma on the health of people with SCD documented in the

literature<sup>(3,6-9)</sup>. Researchers concerned with these effects on health have developed instruments that measure this phenomenon in various groups and health situations, including the SCD<sup>(3,6)</sup>.

The Sickle Cell Disease Health-Related Stigma Scale (SCD-HRSS) is an instrument with 40 items divided into four subscales that evaluates the stigma perceived by people with SCD in the interaction with the public, physicians, nurses and family. In general measure of SCD-HRSS, Cronbach's alpha was 0.84; in the subscales, Public = 0.73, Physicians = 0.68 and Family = 0.82 are considered acceptable. The subscale of nurses was subsequently added<sup>(6)</sup>. This tool differs from others found in the literature, as it is specific for people with SCD and brings in its subscales items that explore situations in which the stigma emerges in the Brazilian context, as evidenced in qualitative studies carried out in the country (9-10).

Thus, in view of the lack of instruments, in Brazil, that analyze the phenomenon of stigma in different social interactions of people with SCD, the existence of initial favorable psychometric properties of this measure in the original instrument of the North American context, and the need to deepen the knowledge about this phenomenon, the present study aimed to

describe the procedures applied in the process of transcultural adaptation and validation of the content of the SCD-HRSS instrument for the Brazilian context.

#### Method

Methodological study conducted at a City Reference Center for the Person with Sickle Cell Disease and at an Association for People with Sickle Cell Disease, both located in the state of Bahia, Brazil, between October 2017 and January 2018.

The SCD-HRSS was developed in the United States and aims to identify the stigma perceived by people with SCD in different social interactions. It has 40 items divided into four subscales. The first refers to the stigma perceived by people with SCD in the interaction with the public; the second, in the interaction with physicians; the third, with the family; and the fourth, with nurses. It is a Likert scale, with six degrees of answers, which vary from 1 (strongly disagree) to 6 (strongly agree). Thus, the larger the answer values assigned to the items, the higher the score and consequently the degree of stigma perceived by people with SCD <sup>(6)</sup>.

The transcultural adaptation of the scale used the model of evaluation of conceptual and item, semantic and operational equivalence proposed by Herdman, Fox-Rushby and Badia<sup>(11)</sup>, with the adoption of five steps recommended by Beaton and colleagues<sup>(12)</sup> for validation of semantic equivalence (translation, synthesis of translation, back-translation, evaluation by a committee of experts and pre-test with the target population).

The first step sought the Conceptual and item equivalence, with the accomplishment of an integrative literature review on the stigma construct to understand the concept that substantiated the theory of the original instrument and to identify if the concepts present in the items and in the subscales of the instrument were relevant to the Brazilian culture. It also evaluated whether the items portrayed the stigma experienced by people with SCD in the interaction with the public, family members, physicians and nurses.

In the second stage, with the aim of achieving Semantic equivalence, two Brazilian translators translated the SCD-HRSS instrument, one health professional with knowledge in SCD and the other without approximation with the theme, both fluent in English, originating two different translations, which were called T1 and T2<sup>(12-13)</sup>.

The synthesis of translations T1 and T2 occurred in meetings and discussions. After the consensus of the team of researchers, the first version of the instrument in the Portuguese language (T12) was obtained, which was submitted to Back Translation, that is, it was retranslated into the source language (English) by an American translator fluent in Portuguese and with linguistic training. This re-translation aimed to verify whether the translated version reflected the same content from the original version or would require adjustments, originating version B1, evaluated and approved by the author of the original instrument. Thus, the version B1 was again translated into Portuguese and submitted for evaluation by a group of specialists (T12).

To compose the committee of judges, following criteria were obeyed: higher education in different areas of knowledge; work with the SCD thematic and stigma in health; participation in validation of instruments, identified through curriculum Lattes. Twenty professionals who met the inclusion criteria were invited.

All judges received, via e-mail, the invitation letter and the Informed Consent Form with the presentation of the study and its objectives. Once accepted, instructions on the assessment of the instrument in general were sent, as well as on the appropriateness of the items from the translated version of the instrument in comparison with the original instrument and the original and translated versions of the instrument. A deadline of 15 days was established to return the assessment. Fourteen professionals answered the invitation, with graduation in nursing, social services, nutrition, physiotherapy, speech-language therapy, sociology and pedagogy, with ages between 24 and 49 years, and time since graduation ranging from 2 to 27 years. All acted in teaching, research, extension and assistance. Regarding their degree, six had specialization, seven were MSc and one, PhD.

The judges held global assessment, focused on the completeness of the contents and their acceptability to the Brazilian target public, and individual assessment, focused on items for the clarity and relevance/representativeness criteria  $^{\left( 14\right) }.$  This evaluation consisted of assigning to each item one of the four answer options: regarding clarity - 1=unclear, 2=little clear, 3=clear and 4=very clear; relevance - 1=not relevant, 2=little relevant, 3=relevant and 4=very relevant. They were instructed to suggest changes in the instrument, in case they had marked the options "1=not relevant", "2=little relevant", "1=unclear" and "2=little clear" (15). Then, the Content Validity Index (CVI) was calculated. The items with CVI below 0.80 were reassessed by the research team, taking into consideration the specialists' suggestions (16).

In the third step, Operational equivalence, the instrument was subjected to a pre-test, when the target population evaluated the disposal of items and graduations of answers, presentation format of the instrument, visual elements used, time required to answer the instrument and evaluation of the application mode of the instrument, whether through an interview or questionnaire (11,17).

The pre-test was conducted between October and January 2018 at a Reference Center and an Association for People with Sickle Cell Disease, both located in Bahia, state with the highest prevalence of SCD in Brazil. The sample was composed of 30 adults who met the inclusion criteria: being an adult, of both sexes, with SCD. Through an in-person individual interview, the sociodemographic questionnaire and the SCD-HRSS were applied, to which was added space for participants to record impressions.

The recommendations of Resolution n. 466/2012 were met. The study was approved by Opinion n. 2.299.220 of the Research Ethics Committee of State University of Feira de Santana. All participants signed the Informed Consent Form.

#### Results

For the Conceptual and Item Equivalence, an extensive research in the literature was performed.

The discussion with specialists, including the author of the instrument, led to the acquisition of concepts that supported the original instrument. The concepts involved in the instrument in focus, originated in the American culture, converged to the Brazilian culture. Thus, the SCD-HRSS was considered relevant for the Brazilian culture, not requiring the introduction of new items to work non-evaluated facets.

In the analysis of the specialists' committee, some suggestions were incorporated into the proposed synthesis version and there was agreement that the items that compose the original instrument properly represent aspects and concepts that involve the phenomenon of stigma perceived by people with SCD in the Brazilian cultural context.

For semantic equivalence, the researchers evaluated translations T1 and T2 to reach a synthesis version. All 40 items had similar translations, adopting the words most commonly used in the daily life of the Brazilian target population.

Regarding the Content Scope, the judges considered the relationship between the subscales presented and the 40 items appropriate. However, they suggested a change in the degrees of answers, going from six to five: strongly disagree, disagree in part, neither agree nor disagree, agree in part and strongly agree.

In the individual assessment, eight items had CVI smaller than 0.80 for relevance: items 3 (0.79), 9 (0.71) and 10 (0.71) of the first subscale; 2 (0.79) and 5 (50%) of the second subscale; 6 (0.64) and 9 (0.57) of the third subscale; and 5 (0.71) of the fourth subscale. Thus, the total instrument presented CVI for relevance of 0.80.

Regarding the evaluation of clarity, 11 items had CVI smaller than 0.80: items 3 (0.79) and 7 (0.50) of the first subscale; 1 (0,79), 4 (0,71), 5 (0,79), 6 (0,79), 7 (0,79), 8 (0,71) and 9 (0,79) of the second subscale; and 4 (0.79) and 7 (0.71) of the third subscale. The fourth subscale had no item with CVI for clarity smaller than 0.80. The total instrument presented CVI for clarity of 0.73. The assessment of clarity was not satisfactory. Therefore, after evaluation of the specialists, the items that presented agreement smaller than 80%

were rewritten, with addition and/or exclusion of some terms, to become understandable to the target population, and were submitted again to the evaluation of judges for approval.

Charts 1 and 2 show the CVI smaller than 0.80 of the Portuguese version of the instrument

before and after evaluation of the specialists' committee, with the considerations made for each item. Chart 1 shows the changes recommended for subscales 1 and 2, which explore the stigma in the public and in the interaction with physicians.

**Chart 1** – Content Validity Index for relevance, clarity and Portuguese version after evaluation of subscales 1 and 2 by the committee of judges

Question (item) before the judges' evaluation	Relevance	Clarity	Question (item) after the judges' evaluation
, ,	SUBSCALE	1 – Public	
3. People understand when they hear me talking about my pain condition.	0.79	0.79	People understand when I talk about my pain.
7. People think and despise someone who is unable to work because of sickle cell disease.	-	0.50	People think that someone with sickle cell disease is unable to work.
9. People think that someone who takes prescribed pain medications regularly is a "drug addict".	0.71	-	People think that anyone that is always taking pain medication is a drug addict.
	SUBSCALE 2	– Physicians	s
1. Most physicians believe that there is a real physical cause for sickle cell pain.	-	0.79	Most physicians believe that there is a real cause for sickle cell pain.
2. Physicians think people with sickle cell disease exaggerate their pain.	0.79	-	Physicians think people with sickle cell disease exaggerate when they talk about their pain.
4. Physicians think that sickle cell pain is mostly a mental or emotional problem.	-	0.71	Physicians think the pain of people with sickle cell disease is often a mental or emotional problem.
5. Most physicians think people with sickle cell disease use pain medication appropriately.	0.50	0.79	Most physicians think people with sickle cell disease use pain medication correctly.
6. Most physicians think people with sickle cell disease complain about their disease as much as people with other medical conditions do.	-	0.79	Most physicians think people with sickle cell disease complain more than others with other health problems do.
7. Many physicians believe that people with sickle cell disease could be more physically active if they wanted to.	-	0.79	Many physicians believe that people with sickle cell disease could be more physically active if they wanted to.
8. Many physicians think people with sickle cell disease are less emotionally stable than people with other health problems are.	-	0.71	Many physicians think people with sickle cell disease have more emotional problems than people with other health problems do.
9. Many physicians think people with sickle cell pain are "drug addicts".	-	-	Many physicians think that people with sickle cell disease who take pain medicine are "drug addicts".

Source: Created by the authors.

6

Chart 2 shows the changes in four items of subscale 3 and in one item of subscale 4, which seek to know the stigma perceived in

interactions between people with SCD in the family and with nurses.

**Chart 2** – Synthesis version in Portuguese T12, Content Validity Index for relevance, clarity and Portuguese version after evaluation of subscales 3 and 4 by the committee of judges

Question (item) before the judges' evaluation	Relevance	Clarity	Question (item) after the judges' evaluation		
SUBSCALE 3 – Family					
4. My family understands that I can use only the prescribed amount of pain medication.	-	0.79	My family understands that I can use only the amount of pain medication in the prescription.		
6. My family thinks that taking pain medication regularly makes me a "drug addict".	0.64	-	My family thinks that taking pain medication regularly makes me a "addicted to medications".		
7. My family understands that sickle cell disease is a real medical condition.	-	0.71	My family understands that sickle cell disease is an actual health problem.		
9. My family thinks that sickle cell pain is more of a mental or emotional problem than a physical problem.	0.57	-	My family thinks that my pain is more of a mental or emotional problem than a physical problem		
SUBSCALE 4 – Nurses					
5. Most nurses think people with sickle cell disease use pain medication appropriately.	0.71	-	Most nurses think that people with sickle cell disease use pain medication correctly.		

Source: created by the authors.

In the "pre-test" phase, the instrument was applied with the target population, after changes in the basic instrument with specialists' considerations. In this phase, there were consensuses, disagreements and difficulties to understand the items highlighted by adults with SCD.

The participants suggested modifications in writing of items 1 and 5 of subscales 2 and 4, proposing replacing the term "real physical cause" by "actual cause"; in item 4, they suggested replacing the term "appropriately" by "correctly". They argued that the terms could transmit the idea of referring to the "cause" of the pathophysiology of the disease, medical knowledge or origin of the disease in the population. The suggestions were discussed, accepted and the writing of the items was revised.

In item 5, of subscales 2 and 5, participants suggested putting the enunciation of the question in a negative way, to make it more understandable. The suggestion was accepted and the enunciation was then rewritten: "Most physicians think that people with sickle cell disease *do not* use pain medication correctly" and "most nurses think that people with sickle cell disease *do not* use pain medication correctly".

The participants with lower level of schooling presented difficulties understanding the Likert scale, and the researcher had to repeat some questions, so that the item content could be understood.

Regarding the operational equivalence of the instrument, the participants observed the disposal of items and their aesthetics and suggested reducing the options of the Likert scale for five answers, and organizing the scale as a booklet, with a subscale in each page, or its fractional application. The application of the instrument to each individual lasted from 15 to 30 minutes and had the researcher's aid, who, in the end, indicated the use of supervised application. The instrument was accepted by the audience, which

reinforced the importance of being heard. During the reading of the items, many felt motivated to talk about their experiences more deeply.

#### Discussion

In the Brazilian context, there are no instruments measuring the perceived stigma in SCD. The transcultural adaptation has considerable advantages in relation to the creation of a new instrument, because its items have already been validated in other cultures, in relation to the content validity and psychometric qualities, which saves the researcher's time and effort, in addition to enabling the comparison of data obtained in different cultures<sup>(12,18-19)</sup>.

This process not only involves the translation into the new language, but also draws attention to cultural issues, for subsequent application in the new context. Meeting the equivalence between the original source and the target population requires the use of rigorous methodology<sup>(12)</sup>. Having the presence of professionals who know linguistics and of a multidisciplinary committee of judges, with extensive knowledge about SCD was essential to ensure the content quality and validity during the adaptation process.

The construction of the original instrument based on the concept of health-related stigma, which includes the co-occurrence of components - labelling, stereotypes, loss of status, discrimination, devaluation, judgment or disqualification of individuals or groups - basing on a health-related condition (6,20).

Initiated by the review of the theory of stigma and of characteristics of the phenomenon adopted in the original instrument, the process of translation and cultural adaptation of the SCD-HRSS followed all the steps systematically and judiciously, a condition required to ensure its validity. During the evaluation of the translated and synthesized versions, there was application of both qualitative, with assimilation of experts' individual opinion, and quantitative strategies, with application of statistical measures, to measure the degree of agreement between these<sup>(15)</sup>.

The target public of the pre-test of the instrument was composed of 30 individuals. The literature recommends that this step should involve 30-40 participants individually interviewed about the understanding of items, words and answers, ensuring greater breadth of opinions and the quality of the instrument for the future psychometric tests (12,14). The data collection through interviews favored a detailed critical analysis of the instrument, as it allowed for knowing aspects of expression of participants, such as spoken and written language, body language, emotions, gestures and glances, as recommended by the Systemic-Functional Theory (14).

The individual analysis of the items of the instrument showed the content relevance regarding the studied phenomenon, but there was need for adequacy of some words, replacement of terms and expressions by synonyms, as well as adaptations of tenses. These changes are already expected, as they aim to keep the semantic equivalence, since cultural particularities, beliefs, religion, ethical and moral values of certain population group can influence the understanding and operationalization of the instrument and make its applicability not viable, if not appropriate to the context of its application (17,21-22).

Although the research team has sought participants from different levels of literacy, the comprehension difficulties observed in the audience were decisive for the adjustments in the language of the adapted instrument, for better understanding of this group in the Brazilian context (9-10,23).

A study developed with women showed that "[...] although the scale was applied by researchers, difficulties have arisen regarding the understanding of some items" (24:302). In the present study, the individuals from the target population with less schooling demanded more time to answer it and presented limitations to suggest adaptations of language and reformulations of items of the instrument. This difficulty was not found in the original study, in which all participants answered the instrument individually<sup>(6)</sup>.

Due to the diversity of manifestations that can be expressed in the body, people with SCD are vulnerable to suffering discrimination and being stigmatized due to the difference and disabilities caused by the disease in their bodies in various social contexts<sup>(4,9-10)</sup>. Thus, the organization of the SCD-HRSS in subscales allows for knowing the stigma perceived by the sick in different groups of interaction, revealing aspects that can be directed to cope with the stigma in each of these groups.

In health services, the stigma perceived in interactions with health professionals may be related to racial issues, invisibility of the disease in society, unawareness of clinical signs and symptoms by health professionals and to the idea of a disease related to disadvantaged groups, such as black people, with low schooling and low socioeconomic power<sup>(9-25)</sup>. In this sense, the content validity allows for achieving a version of an instrument that is able to understand these nuances of experience in the context of its application. The SCD-HRSS-Br reached index of agreement among the judges, who confirmed that the instrument properly explores the stigma in people with SCD in the Brazilian context.

Among the items of the SCD-HRSS-Br, judges agreed that many explore the discrimination that emerges in moments of pain, basing their opinions on studies that show that the person with SCD presents frequent painful crises. These influence the quality and expectations of interactions established between the sick and other social subjects. The instrument allows for exploring the existence of disrepute, guilt assignment, label application, isolation attitudes and discrimination in relation to the pain narratives<sup>(9,25)</sup>.

The importance of painful crisis events for expansion of stigma in people with SCD was verified in the original study, in which more hospitalizations per year, to treat algic crises, showed greater stigma in interactions with physicians<sup>(6)</sup>.

Judges and the research team considered that, although the instrument SCD-HRSS-Br have covered stigma characteristics, it can undergo future modifications, because an instrument can be improved to keep pace with the changes of the phenomenon it intends to measure and the context in which it is applied<sup>(17)</sup>.

In the present study, the author of the original instrument directly participated in the whole process of transcultural adaptation of the SCD-HRSS, aspect that adds value and certifies the safety and the quality of the final product<sup>(15)</sup>.

The SCD-HRSS-Br can support studies and evaluations before and after implementation of plans for coping with the stigma in healthcare, allowing for comparing the effects of the life dimensions that tend to be affected in stigmatized individuals, such as physiological, psychological and social well-being<sup>(6,20)</sup>, upon application in conjunction with other instruments.

The subscales intended to evaluate the stigma in the interaction with several audiences may produce specific knowledge about attitudes and discriminatory practices that occur in the care contexts and support plans to overcome them, involving both the training curricula and the qualifications of permanent education and information campaigns about the disease<sup>(1-2)</sup>.

A limitation of this study is the absence of national studies on cross-cultural adaptation and reliability of instruments for the phenomenon of stigma, which hindered possible comparisons. The original scale was widely used in the context of origin, but it was the first exposure to a different context and culture.

#### Conclusion

The evaluation of the instrument by experts and by the target population allowed for content adaptations in the SCD-HRSS, allowing for affirming that it is appropriate to the Brazilian context, provides content validity to be applied and brings contributions for Nursing in coping with and overcoming the stigma in health.

Health care professionals and researchers will be able to access a valid instrument to analyze the experiences of stigma of people with SCD in different social relations, with direct implications for the health, which can act in overcoming the stigma in health through health education and inclusion of the theme in the training curricula. Moreover, there stands out the contribution of the study for measurement of stigma in interactions with the nurses.

This translation and adaptation of the SCD-HRSS-BR concludes the step that enables the future application of psychometric tests of the instrument with a view to its reproducibility in the Brazilian context.

#### **Collaborations:**

- 1 conception, design, analysis and interpretation of data: Sheila Santa Barbara Cerqueira;
- 2 writing of the article and relevant critical review of the intellectual content: Sheila Santa Barbara Cerqueira, Luana Santana Brito, Katia Santana Freitas and Evanilda Souza de Santana Carvalho;
- 3 final approval of the version to be published: Sheila Santa Barbara Cerqueira, Katia Santana Freitas, Coretta Melissa Jenerette and Evanilda Souza de Santana Carvalho.

#### References

- Soares EPB, Silva DS, Xavier ASG, Carvalho ESS, Cordeiro RC, Araújo EM. Care for people with sickle cell in the emergency room: accessing the knowledge of a multiprofissional team. Cienc Cuid Saude. 2014;13(2):278-85. DOI: 10.4025/ cienccuidsaude.v13i2.19505
- Maia HAAS, Alvaia MA, Carneiro JM, Xavier ASG, Bessa Júnior J, Carvalho ESS. Access of men with sickle cell disease and priapism in emergency services. BrJP. 2019;2(1):20-6. DOI: http://dx.doi. org/10.5935/2595-0118.2019000
- Bediako SM, Lanzkron S, Diener-West M, Onojobi G, Beach MC, Haywood CJr. The measure of sickle cell stigma: initial findings from the improving patient outcomes through respect and trust study. J Health Psychol. 2016;21(5):808-20. DOI: 10.1177/1359105314539530
- 4. Goffman E. Estigma: notas sobre a manipulação da identidade deteriorada. Tradução Nunes MBML [Internet]. Rio de Janeiro: LTC; 1975 [cited 2018 Feb 18]. Available from: http://www.aberta.senad.gov.br/medias/original/201702/20170214-114707-001.pdf

- Jenerette C, Brewer CA, Crandell J, Ataga KI. Preliminary validity and reliability of the Sickle Cell Disease Health-Related Stigma Scale. Issues in Ment Health Nurs. 2012;33(6):363-9. DOI: https://doi.org/10.3109/01612840.2012.656823
- Matthie N, Hamilton J, Wells D, Jenerette C. Perceptions of young adults with sickle cell disease concerning their disease experience. J Adv Nurs. 2016;72(6):1441-51. DOI: 10.1111/jan.12760
- Adam SS, Flahiff CM, Kamble S, Telen MJ, Reed SD, De Castro LM. Depression, quality of life, and medical resource utilization in sickle cell disease. Blood Adv. 2017;1(23):1983-92. DOI: 10.1182/bloodadvances.2017006940
- Adeyemo AT, Ojewunmi OO, Diaku-Akinwumi IN, Ayinde OC, Akanmu AS. Health related quality of life and perception of stigmatisation in adolescents living with sickle cell disease in nigeria: a cross sectional study. Pediatr Blood Cancer 2015;62(7):1245-51. DOI: 10.1002/pbc.25503
- Figueiró AVM, Ribeiro RLR. Vivência do preconceito racial e de classe na doença falciforme. Saude soc. 2017;26(1):88-99. DOI: http://dx.doi.org/10.1590/ s0104-12902017160873
- Carvalho SC, Carvalho LC, Fernandes JG, Santos MJS.Em busca da equidade no sistema de saúde brasileiro: o caso da doença falciforme. Saude soc. 2014;23(2):711-8. DOI: http://dx.doi. org/10.1590/S0104-12902014000200029
- 11. Herdman M, Fox-Rushby J, Badia X. "Equivalence" and the translation and adaptation of health-related quality of life questionnaires. Qual Life Res. 1997;6(3):237-47. DOI: https://doi.org/10.1023/A:1026410721664
- Beaton DE, Bombardier C, Guillemin F, Ferraz MB. Guidelines for the Process of Cross-Cultural Adaptation of Self-Report Measures. Spine. 2000;25(24):3186-91. DOI: http://dx.doi. org/10.1097/00007632-200012150-00014
- 13. Cassepp-Borges V, Balbinott MAA, Teodoro MLM. Tradução e validação de conteúdo: uma proposta para a adaptação de instrumentos. In: Pasqual L. Instrumentação psicológica: fundamentos e práticas. Porto Alegre: Artmed; 2010. p. 506-20.
- 14. Coluci MZO, Alexandre NMC, Milani C. Construção de instrumentos de medida na área da saúde. Ciênc saúde coletiva. 2015;20(3):925-36. DOI: http:// dx.doi.org/10.1590/1413-81232015203.04332013
- Lino CRM, Brüggemann OM, Souza ML, Barbosa SFF, Santos EKA. The cross-cultural adaptation of research instruments, conducted by nurses

- in Brazil: an integrative review. Texto contexto-enferm. 2017;26(4):e1730017. DOI: http://dx.doi.org/10.1590/0104-07072017001730017
- 16. Polit D, Beck C. Fundamentos de pesquisa em enfermagem: avaliação de evidências para a prática da enfermagem. 7a ed. Porto Alegre: Artmed; 2011.
- 17. Reichenheim ME, Moraes CL. Operationalizing the cross-cultural adaptation of epidemological measurement instruments. Rev Saúde Pública. 2007;41(4):665-73. DOI: http://dx.doi.org/10.1590/S0034-89102006005000035
- 18. Guillemin F, Bombardier C, Beaton D. Cross-cultural adaptation of health-related quality of life measures: literature review and proposed guidelines. J Clin Epidemiol. 1993;46(12):1417-32. DOI: https://doi.org/10.1016/0895-4356(93)90142-N
- Borsa JC, Damásio BF, Bandeira DR. Crosscultural adaptation and validation of psychological instruments: some considerations. Paidéia (Ribeirão Preto). 2012;22(53):423-32. DOI: https:// dx.doi.org/10.1590/S0103-863X2012000300014
- 20. Link GB, Phelan JC. Conceptualizing Stigma. Annu Rev Sociol. 2001;27:363-85. DOI: https://doi.org/10.1146/annurev.soc.27.1.363
- 21. Sampaio PF, Moraes CL, Reichenheim M. Equivalência conceitual, de itens, semântica e operacional da versão brasileira do s-EMBU para aferição de

- práticas educativas parentais em adolescentes. Cad Saúde Pública. 2014;30(8):1633-8. DOI: http://dx.doi.org/10.1590/0102-311X00036614
- 22. Epstein J, Santo RM, Guillemin F. A review of guidelines for cross-cultural adaptation of questionnaires could not bring out a consensus. J Clin Epidemiol [Internet]. 2015;68(4):435-41. DOI: 10.1016/j.jclinepi.2014.11.021
- 23. Silva RBP, Ramalho AS, Cassorla RMS. A anemia falciformecomoproblemadeSaúdePúblicanoBrasil. Rev Saúde Pública. 1993;27(1):54-8. DOI: http://dx.doi.org/10.1590/S0034-89101993000100009
- 24. Fernandes ETBS, Dias ACS, Ferreira SL, Marques GCM, Pereira COJ. Cultural and reliable adaptation of the Reproductive Autonomy Scale for women in Brazil. Acta paul enferm. 2019;32(3): 298-304. DOI: http://dx.doi.org/10.1590/1982-0194201900041
- 25. Puri Singh A, Haywood C, Beach MC, Guidera M, Lanzkron S, Valenzuela-Araujo D, et al. Improving Emergency Providers' Attitudes Toward Sickle Cell Patients in Pain. J Pain Symptom Manage. 2016;51(3):628-32. DOI: http://dx.doi. org/10.1016/j.jpainsymman.2015.11.004

Received: November 13, 2019

Approved: November 14, 2019

Published: March 11, 2020



The *Revista Baiana de Enfermagem* use the Creative Commons license – Attribuition -NonComercial 4.0 International. https://creativecommons.org/licenses/by-nc/4.0/

This article is an Open Access distributed under the terms of the Creative Commons (CC BY-NC). This license lets others remix, adapt and create upon your work to non-commercial use, and although new works must give its due credit and can not be for comercial purposes, the users do not have to license such derivative works under the same terms.