

REVIEW

MEASUREMENT INSTRUMENTS REGARDING KNOWLEDGE, ADHERENCE, ATTITUDE AND SELF-EFFICACY IN SICKLE CELL DISEASE: AN INTEGRATIVE REVIEW

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ABSTRACT

Objective: To identify in Brazilian and international literature existing measurement instruments to measure the domains of knowledge, self-efficacy, attitude and treatment adherence in the context of sickle cell disease.

Method: This was an integrative review conducted by searching articles in journals indexed in the CINAHL, LILACS, PubMed and WoS databases, according to the following inclusion criteria: original articles that used instruments to measure at least one of the studied domains (knowledge or treatment adherence or self-efficacy or attitudes of people with sickle cell disease, regardless of age of population), in the last 15 years (2003 to 2018).

Results: Of the 379 articles found, 11 were included, and among these, five instruments were identified.

Conclusion: The instruments identified in the literature review can provide indicators relative to the psychosocial and behavioral domains of sickle cell disease.

DESCRIPTORS: Sickle Cell Anemia; Chronic Disease; Surveys and Questionnaires; Self Efficacy; Knowledge.


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INSTRUMENTOS DE MENSURAÇÃO RELACIONADOS AO CONHECIMENTO, ADESÃO, ATITUDE E AUTOEFICÁCIA EM DOENÇA FALCIFORME: REVISÃO INTEGRATIVA

RESUMO

Objetivo: identificar, na literatura nacional e internacional, instrumentos de mensuração existentes para medir os domínios conhecimento, autoeficácia, atitude e adesão ao tratamento no contexto da doença falciforme.

Método: revisão integrativa realizada por meio da busca de artigos nos periódicos indexados nas bases de dados: CINAHL, LILACS, PubMed e WOS, de acordo com os critérios de inclusão: artigos originais, que utilizaram instrumentos para medir algum dos domínios pesquisados (conhecimento ou adesão ao tratamento ou autoeficácia ou atitudes da pessoa com doença falciforme, independente da faixa etária da população alvo) dos últimos 15 anos (2003 a 2018).

Resultados: foram incluídos 11 artigos dos 379 levantados, com cinco instrumentos identificados.

Conclusão: Os instrumentos identificados poderão fornecer indicadores relacionados aos domínios psicossociais e comportamentais relacionados à doença falciforme.

DESCRITORES: Anemia Falciforme; Doença Crônica; Inquéritos e Questionários; Autoeficácia; Conhecimento.

INSTRUMENTOS DE MEDICIÓN RELACIONADOS AL CONOCIMIENTO, ADHESIÓN, ACTITUD Y AUTOEFICACIA EN ANEMIA FALCIFORME: REVISIÓN INTEGRATIVA

RESUMEN:

Objetivo: Identificar, en la literatura nacional e internacional, instrumentos de medición existentes para medir los dominios conocimiento, autoeficacia, actitud y adhesión al tratamiento en el contexto de la anemia falciforme.

Método: Revisión integrativa realizada a través de la búsqueda de artículos en los periódicos indexados en las bases de datos: CINAHL, LILACS, PubMed y WOS, de acuerdo con los criterios de inclusión: artículos originales que utilizaron instrumentos para medir alguno de los dominios investigados (conocimiento o adhesión al tratamiento o autoeficacia o actitud de la persona con anemia falciforme, independientemente de la faja etaria de la población objetivo) de los últimos 15 años (2003 a 2018).

Resultados: Fueron incluidos 11 artículos de los 379 relevados, habiéndose identificado cinco instrumentos.

Conclusión: Los instrumentos identificados podrán brindar indicadores relacionados a los dominios psicossociales y conductuales relativos a la anemia falciforme.

DESCRIPTORES: Anemia de Células Falciformes; Enfermedad Crónica; Encuestas y Cuestionarios; Autoeficacia; Conocimiento.

INTRODUCTION

Sickle cell disease is an inherited and chronic illness associated with changes in blood cells. Among its consequences, the most common are episodes of pain and damage to vital organs due to vaso-occlusive crises, the main pathophysiological mechanisms related to sickle cell disease complications⁽¹⁻²⁾.

Invariably, this demands that individuals follow self-care practices and treatment guidelines to best manage the disease and avoid its worsening. Thus, individuals with this condition must be monitored by interdisciplinary teams in specialized outpatient services and basic health units⁽³⁻⁴⁾.

However, one of the challenges faced by professionals who work with people with sickle cell disease is to promote self-care behavior and consequent treatment adherence. Encouraging adherence is one of the directives of Brazilian and international policies to control this condition and its process must encompass influential psychosocial aspects, going beyond physical and predictable approaches⁽⁵⁻⁷⁾.

The psychosocial dimension considers that people's reality and experience, their feelings, attitudes, emotions, and knowledge and beliefs influence their health behavior. Authors argue that, to a greater or lesser degree, psychosocial factors contribute to adherence or nonadherence behaviors in chronic conditions⁽⁸⁾.

Thus, one way to identify subjective issues relative to treatment is to investigate the psychosocial and behavioral domains of people with sickle cell disease, which must be addressed by health professionals in order to promote health care. Assessing psychosocial domains such as knowledge, self-efficacy beliefs, and attitudes, and behavioral domains, such as treatment adherence, can provide indicators about aspects of treatment and underpin the development of educational interventions, in order to promote self-care and control of the chronic condition⁽⁹⁻¹¹⁾.

It is essential to use specific measuring instruments to measure these domains that have been created according to theoretical and methodological frameworks pertinent to the researched objects, demonstrating satisfactory psychometric properties. Thus, the choice of measuring instrument must be based on criteria pertinent to the psychosocial or behavioral domain addressed by the researcher⁽¹²⁻¹⁵⁾.

In light of the above, the aim of the present integrative review was to identify existing measuring instruments in the Brazilian and international literature that measure domains relative to self-efficacy, treatment adherence, knowledge and attitude in the context of sickle cell disease, to help researchers and professionals in the health area to choose adequate instruments to investigate psychosocial and behavioral indicators.

METHOD

This was an integrative review conducted between January and May 2018. This theoretical-methodological framework consists of the following steps: establishing a hypothesis or research question, conducting the search process and determining inclusion and exclusion criteria, extracting information, evaluating studies, interpreting results, and presenting a summarized knowledge review⁽¹⁶⁾.

The following question guided the integrative review: Which measurement instruments have been used to measure domains related to knowledge, treatment adherence, attitudes, and self-efficacy of people with sickle cell disease, both in the Brazilian and international literature?

The following databases were consulted: LILACS (Latin American and Caribbean

Center on Health Sciences Information), CINAHL (Current Index to Nursing and Allied Health Literature), PubMed (National Center for Biotechnology Information) and Web of Science. The controlled descriptors were extracted from Medical Subject Headings (MeSH) and Health Sciences Descriptors (DeCS), in English, Portuguese and Spanish: Surveys and Questionnaires, Sickle Cell Anemia, Sickle Cell Disease, Hemoglobin SC Disease, SS Disease, Beta Thalassemia, Self Efficacy, Attitude, Health Attitude, Adherence, and Knowledge. The search strategy consisted of using the association between the Boolean operators OR and AND.

Studies published as dissertations, theses, and books, as well as articles that did not describe the characteristics of the instrument or its original source, were excluded. Duplicates were considered only once. Inclusion criteria were: original articles, which used instruments to measure at least one of the researched domains (knowledge or treatment adherence or self-efficacy or attitudes of persons with sickle cell disease, regardless of the age of the target population) in the last 15 years (2003 to 2018).

The initial screening included reading the titles and abstracts. The articles resulting from this process were reviewed independently by two authors, twice. Next, a second analysis was conducted by reading the articles in full and assessing their pertinence to the purposes of the present study. The selected articles were imported to a library in Endnote Web and their data were recorded on a spreadsheet created by the researchers, as per the literature (Figure 1).

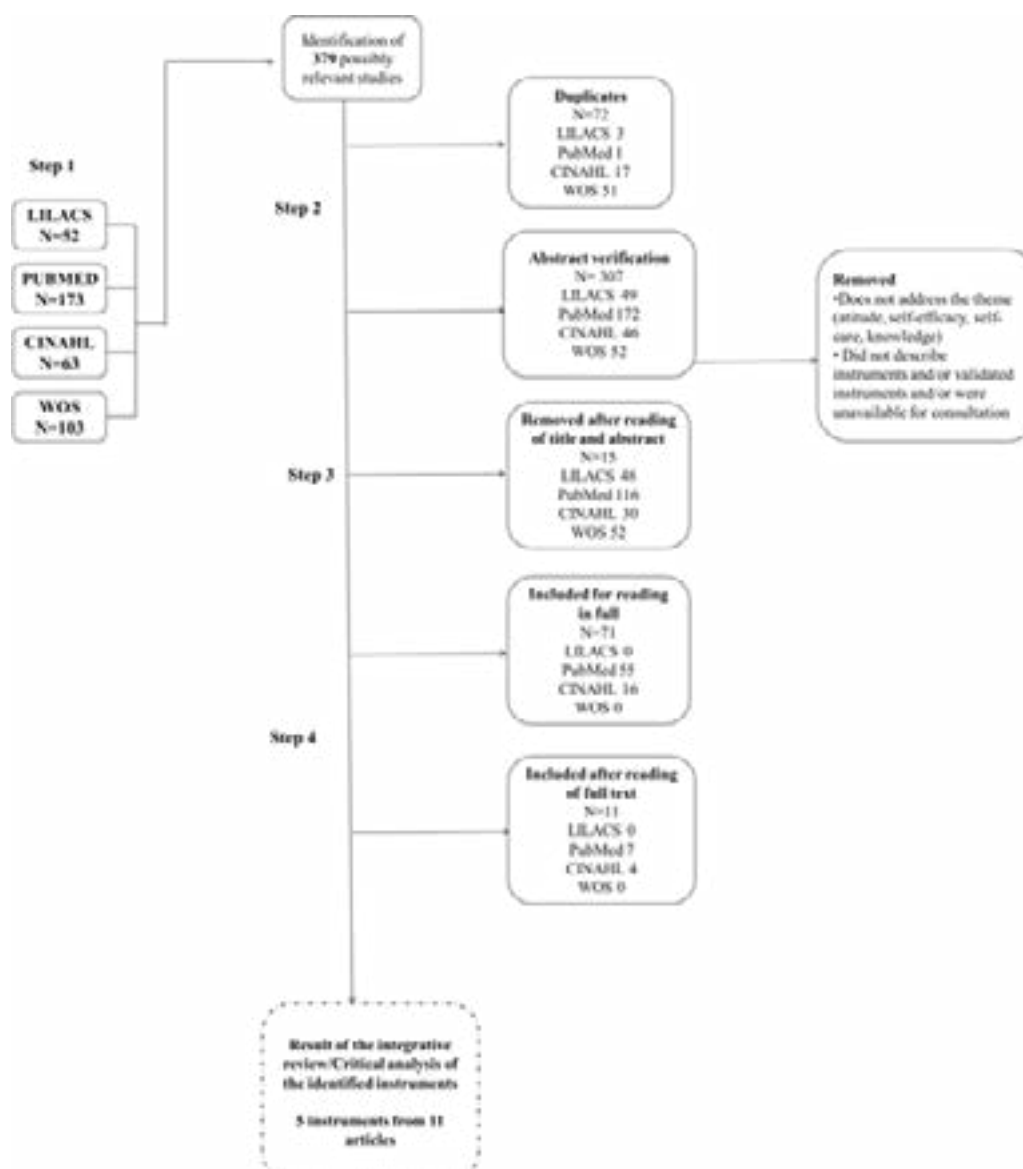


Figure 1 - Integrative review method about validated instruments related to psychosocial aspects of sickle cell disease. Belo Horizonte, Minas Gerais, Brazil, 2019

The assessment of the instruments' measurement properties and domains was carried out by the main author, who identified the characteristics that made these scales/questionnaires viable for use. The reliability of the measurement instruments was based on the value of Cronbach's alpha. It is worth mentioning that only validated instruments were considered pertinent for the present review.

The categories from the Agency for Healthcare Research and Quality (AHRQ) were used as criteria to classify the evidence, distributed into six levels: Level 1: Meta-analysis of multiple randomized control trials; Level 2: Evidence obtained from individual experimental studies; Level 3: evidence from quasi-experimental studies; Level 4: evidence from descriptive (non-experimental) or qualitative studies; Level 5: evidence from case reports and clinical examples; Level 6: evidence based on expert opinion.

STROBE (Strengthening the Reporting of Observational Studies in Epidemiology Statement) criteria were used to indicate the methodological quality of articles that conducted observational, cross-sectional, case-control and cohort methods. Assessment was divided into three categories and carried out by two independent raters. A - in cases of studies that met at least 80% of the criteria; B - studies that met between 80% and 50% of the established criteria; and C - if less than 50% of the STROBE criteria were met⁽¹⁷⁾.

A summary table was created with the characteristics of the articles, such as the name of the instrument used, year, author, objectives and Cronbach's alpha. General characteristics such as domains and number of items were presented descriptively.

RESULTS

The search yielded 11 articles whose scope was to measure at least one of the following variables: attitude, self-efficacy, adherence and/or knowledge of individuals with sickle cell disease, and, to this end, resorted to the measurement instruments available in the literature and validated by other authors. Regardless of the objective of the studies, this review aimed to identify the properties of the measurement instruments used by the studies and describe their characteristics. It is important to mention that the measurement instruments considered in this review were made exclusively for the context of sickle cell disease.

In some studies (group A1, A2, A3; group A4 and A5 and group A6, A7, A8 and A9), the same instrument was used, and therefore the number of instruments does not equal the total number of studies analyzed. The aim of studies A4 and A11 was to construct an instrument and present the values of the psychometric tests. The characteristics of the publications are described in Chart 1. The characteristics of the instruments, as well as each studied domain, are presented in Chart 2.

Chart 1 - Characteristics of publications included in the review. Belo Horizonte, Minas Gerais, Brazil, 2019 (continues)

Article (A) - Title	Level of evidence	STROBE	Objective of the study	Instrument used	Author of instrument /year
A1. Correlates of Pain-rating Concordance for Adolescents With Sickle Cell Disease and Their Caregivers ⁽¹⁸⁾	Descriptive study Level IV	A	To examine the relationship between pain and knowledge of adolescents with sickle cell disease.	i1. Children's Hospital of Philadelphia (CHOP) Transition Knowledge Questionnaire for SCD (TKQ)	Newland JA et al (2008) ⁽²⁰⁾

A2. A family-based randomized controlled trial of pain intervention for adolescents with sickle cell disease ⁽¹⁹⁾	Quasi-experimental study Level III	A	Two objectives: To determine the efficacy of a cognitive-behavioral intervention for teenagers with sickle cell disease and investigate psychosocial variables: knowledge of the disease, self-efficacy, and family communication.	i1. Children's Hospital of Philadelphia (CHOP) Transition Knowledge Questionnaire for SCD (TKQ)	Newland JA et al (2008) ⁽²⁰⁾
A3. Factors Influencing Independence in Adolescents With Sickle Cell Disease ⁽²⁰⁾	Descriptive study Level IV	A	To investigate the relationships among: knowledge about sickle cell disease, severity of the disease, and level of independence of adolescents with sickle cell disease.		
A4. Development of a Screening Instrument of Adherence in Pediatric Sickle Cell Disease ⁽¹²⁾	Descriptive study Level IV	A	To assess the psychometric properties of the Self Care Inventory - Sickle Cell (SCI-SC).	i2. Self Care Inventory-Sickle Cell (SCI-SC)	Hilker KA et al (2006) ⁽¹²⁾
A5. Predictors of Academic Achievement for School Age Children with Sickle Cell Disease ⁽²¹⁾	Descriptive study Level IV	A	To verify the association between psychosocial and behavioral factors and academic performance of children with sickle cell disease.		
A6. An Examination of Differences in Intra-Personal Resources, Self-Care Management, and Health Outcomes in Older and Younger Adults with Sickle Cell Disease ⁽²²⁾	Descriptive study Level IV	A	To assess the relationship between the practice of self-care and health outcomes in older and younger adults with sickle cell disease.	i3. Sickle Cell Disease Self-Efficacy Scale (SCSS)	Edwards R et al (2000) ⁽²⁸⁾
A7. Self-efficacy as a predictor of adult adjustment to sickle cell disease: one-year outcomes ⁽²³⁾	Individual experimental study Level III	A	To investigate self-efficacy as a predictor of adult adjustment to sickle cell disease.		
A8. Sleep Quality, Pain and Self-Efficacy among Community-Dwelling Adults with Sickle ⁽²⁴⁾	Descriptive study Level IV	A	To investigate the relationships between sociodemographic variables, sleep, pain and self-efficacy of adults with sickle cell disease.		

A9. The Influence of Maternal Behaviors During Childhood on Self-Efficacy in Individuals With Sickle Cell Disease ⁽²⁵⁾	Descriptive study Level IV	A	To investigate maternal overprotection during childhood and the self-efficacy of adults with sickle cell disease.	i3. Sickle Cell Disease Self-Efficacy Scale (SCSS)	Edwards R et al (2000) ⁽²⁸⁾
A10. Educational Intervention to Improve the Health Outcomes of Children With Sickle Cell Disease ⁽²⁶⁾	Quasi-experimental study Level III	A	To evaluate the effectiveness of an educational intervention to improve the knowledge of caregivers and children with sickle cell disease.	i4. Questionnaire to assess knowledge of sickle cell disease (QAK-SC)	Shahine R et al(2014) ⁽²⁶⁾
A11. A validated measure of adherence to antibiotic prophylaxis in children with sickle cell disease ⁽²⁷⁾	Descriptive study Level IV	A	To construct and validate the Sickle Cell Antibiotic Adherence Level Evaluation (SCAALE)	i5. Sickle Cell Antibiotic Adherence Level Evaluation (SCAALE)	Duncan et al (2016) ⁽²⁷⁾

Legend: A-article; i-instrument.

Chart 2 - Characteristics of validated measuring instruments relative to the psychosocial or behavioral aspects of sickle cell disease identified in the studies. Belo Horizonte, Minas Gerais, Brazil, 2019 (continues)

Instrument	Objective of instrument	Studied domain	Studied subdomains	No. of items Answer options And interpretation	CI*
Children's Hospital of Philadelphia (CHOP) Transition Knowledge Questionnaire for SCD	To measure knowledge of patients with sickle cell disease in the transition into adulthood	Psychosocial knowledge domain: knowledge about sickle cell disease and the necessary care and actions to control it.	a) pathophysiology; b) genetics; c) manifestations/physical complications d) treatment; e) self-care; f) psychosocial or developmental responsibilities; g) care provision system. ⁽²⁰⁾	25 Multiple choices (right/wrong) Considers number of right answers (> or <knowledge)	0.71
Questionnaire to assess knowledge of sickle cell disease	Measure knowledge of adult patients with sickle cell disease	Psychosocial knowledge domain: knowledge about sickle cell disease and the necessary care and actions to control it.	a) how the disease is transmitted; b) main complications of the disease; c) the role of the spleen; d) therapeutic interventions; e) managing fever and pain at home. ⁽²⁶⁾	25 Dichotomic (true/false) Number of right answers is considered (> or <knowledge)	0.76

Self Care Inventory–Sickle Cell	To assess adherence to self-care of pediatric patients with sickle cell disease.	Behavioral domain - adherence: measures parental reports about treatment adherence/self-care behaviors of children with sickle cell disease.	a) General health behavior (water intake, medications and diet); b) Managing sickle cell disease (self-care activities) c) Pain management d) Sleep patterns ⁽¹²⁾	19 Scale (Likert-type) Higher scores indicate greater adherence. Parents may indicate whether an item is not applicable to their child.	0.88
Sickle Cell Antibiotic Adherence Level Evaluation	To evaluate medication adherence (prophylactic antibiotics) of pediatric patients with sickle cell disease	Behavioral domain - adherence: measuring parental reports of medication adherence behavior of children with sickle cell disease.	a) medication regimen; b) medication dosages; c) pharmacokinetics; d) medication care plan; e) medication reminder; f) patient-professional communication; G) context of medication use ⁽²⁷⁾	28 Scale (Likert-type) The answer “always” reflects greater adherence for some issues and lower adherence for others. The questionnaire refers to the last three months of the respondent’s medication regimen.	0.89
Sickle Cell Disease Self-Efficacy Scale	To assess the self-efficacy of young adults and adults with sickle cell disease.	Psychosocial domain - self-efficacy: An individual’s belief in their ability to cope with and overcome challenges relative to self-care in sickle cell disease.	NA	9 Scale (Likert-type) Higher scores indicate greater self-efficacy belief ⁽²⁸⁾	0.89

*CI: internal consistency measured using Cronbach’s Alpha (α)

Limitations: In general, the authors of the five instruments highlighted methodological limitations regarding the characteristics of the sample of the target population involved in the pre-tests. All the authors associated this limitation with the samples’ low heterogeneity in addition to the specificity of the geographical region, thus not allowing for the “cross-cultural” adaptation of the instruments.

DISCUSSION

The studies identified in this review that assessed the psychosocial domain of self-efficacy⁽²²⁻²⁵⁾ of persons with sickle cell disease used a specific instrument called the Sickle Cell Disease Self-Efficacy Scale⁽²⁸⁾. Although there are few studies on the topic, those that do exist demonstrated positive correlations between self-efficacy and good outcomes relative to health management, such as reducing clinical (episodes of pain, hospitalizations, and blood transfusions) and psychological complications, because the studied individuals believed in their capacity to follow through with care actions and were better able to manage their emotions. Invariably, the more individuals with sickle cell disease believed in their self-efficacy, the greater treatment adherence they displayed⁽²²⁻²⁵⁾.

Treatment adherence in a chronic condition is related to the subjectivity of those suffering from the disease and must take into account the social, cultural, and emotional dynamics of individuals. Furthermore, the sense of autonomy and co-responsibility between professionals and persons with sickle cell disease are the pillars of treatment, which prevents adherence from becoming an authoritative and impersonal factor⁽²⁹⁾.

The studies that measured this behavioral domain used the Sickle Cell Antibiotic Adherence Level Evaluation and Self Care Inventory-Sickle Cell, which refer to sickle cell disease care guidelines^(12,26-27) and represent an important contribution for clinical management, research programs and health intervention initiatives. In the studies, treatment adherence focused on the pediatric public and mainly addressed the issues of medication and pain management.

Regarding the psychosocial domain of knowledge⁽¹⁸⁻²⁰⁾, the studies that assessed used the Children's Hospital of Philadelphia Transition Knowledge Questionnaire for SCD and the Questionnaire to assess knowledge of sickle cell disease. These two studies found that most people with sickle cell disease and their caregivers had an inadequate level of knowledge about the disease and its management. The authors indicated that the psychosocial variable "knowledge" can be investigated both after an educational intervention, to assess its effectiveness, and prior to the intervention, as a way to obtain a general idea about what needs to be addressed. Thus, one method used in the studies to increase the knowledge of youths, adults and caregivers of children with sickle cell disease was to create educational and informative materials with clear and culturally-sensitive guidelines for the target population⁽¹⁸⁻²⁰⁾.

The present review did not find any articles that used validated instruments to measure the psychosocial domain of "attitude", thus indicating a gap that needs to be filled. The literature shows that people with a positive attitude towards life and their chronic conditions tend to adopt coping behaviors that contribute to health care^(8,30).

In sum, adherence to self-care refers to the process in which persons with sickle cell disease carry out behaviors to improve their health and well-being, which requires attitudes compatible with those recommended by lines of care for sickle cell disease, coupled with efforts to minimize disease-related complications. In this context, knowledge has considerable impact, as it contributes to adherence to self-care practices and better adjustment to the disease⁽⁹⁾. Regarding self-efficacy, this psychosocial variable was a predictor of behavior, in which higher self-efficacy results in greater adherence to self-care practices and better attitudes before the adversities imposed by the disease⁽¹⁰⁾.

Regarding the construction of the instruments found in this review, they were based on theories pertinent to the studied psychosocial and behavioral domains and were on three methodological pillars recommended in the field of psychometrics: 1) theoretical procedures, 2) empirical procedures (experimental, such as tests with the target-population, and interviewing and consulting with health professionals), and 3) analytical procedures (statistical). The literature recommends that the statistical analysis of psychometric properties, the instruments should display values regarding validity and reliability, usually represented by the following tests: linear correlation coefficient, intra-class correlation coefficient, and Cronbach's alpha (α)⁽³¹⁻³²⁾.

However, in the present study, the criterion most adopted by the authors of the analyzed instruments was reliability based on internal consistency (homogeneity/Cronbach's Alpha), which presents the instrument's ability to reproduce the same result consistently over time and space or with different observers. As a measure of internal consistency, Cronbach's Alpha estimates the reliability of the questionnaire items. Higher values of Cronbach's Alpha indicate greater internal consistency⁽³¹⁻³²⁾.

Even though Brazil presents a high incidence of sickle cell disease⁽¹⁻²⁾, there are no validated instruments pertinent to the studied domains in the literature. However, constructing an instrument is a complex and expensive process. Thus, translating instruments is a viable option in terms of costs, time and human sources, in addition to fostering the

development of cross-cultural studies^(14,31-32). It is worth emphasizing that the use of some of the instruments presented here must consider the stages of translation and cultural adaptation, in cases when these were chosen by Brazilian authors.

A limitation of this study was the fact that some studies that could have contributed were excluded because they were not available in full, even after several attempts to contact the original authors.

CONCLUSION

Measuring the psychosocial and behavioral domains relative to care aspects should be an integral task of caring for persons with sickle cell disease. The use of specific and validated measuring instruments can help investigate and understand these aspects and, therefore, are important work tools for health professions involved who work with sickle cell disease.

This review found five validated instruments that measure the four studied domains (self-efficacy, attitude, knowledge and treatment adherence). The most frequently evaluated domain was self-efficacy, measured with the Sickle Cell Disease Self-Efficacy Scale. No instruments were found to measure attitude, despite the literature recognizing the importance of its assessment.

The present review contributed by presenting instruments aimed at generating psychosocial and behavioral indicators in sickle cell disease care. The authors hope that it can be a source of consultation for health researchers and professionals.

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