HHS Public Access

Author manuscript

West J Nurs Res. Author manuscript; available in PMC 2023 May 01.

Published in final edited form as:

West J Nurs Res. 2023 May ; 45(5): 425–431. doi:10.1177/01939459221142164.

Psychometrics of the Sickle Cell Disease Health-Related Stigma Scale-Short Form

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Abstract

Health-related stigma, a form of devaluation related to a health condition, is common in individuals with sickle cell disease (SCD). Pain is the hallmark symptom of SCD, and health-related stigma is often described during care-seeking for pain management. Few published instruments measure health-related stigma in individuals with SCD. This study builds on the psychometrics of 30 and 40-item Sickle Cell Disease Health-Related Stigma Scale (SCD-HRSS). In a sample of 197 adults with SCD, the results support the reliability and validity of a 21-item scale, the SCD-HRSS Short Form, with an overall Cronbach's alpha reliability of 0.91 and discriminant validity with the PROMIS 29 subscales (anxiety, depressive symptoms, pain interference, physical fatigue, sleep, and role satisfaction). A shorter yet reliable and valid scale may decrease the burden for this underrepresented, minoritized population while still providing important information regarding their experiences of stigmatization.

Sickle cell disease (SCD) is the most common genetically inherited blood disorder in the United States, with the Centers for Disease Control reporting approximately 100,000 being affected (Centers for Disease Control, 2020). There are limited cures for SCD to include bone marrow transplants (Meier, Abraham & Fassano, 2018) and more recently, the possibility of gene therapy (Gladwin et al., 2021). Thus, for most individuals born with SCD, it is a lifelong condition with many challenges. SCD can affect every body system and impact psychological and social health. However, the hallmark symptom of SCD is pain, which is the primary reason individuals with SCD enter the health care system. Interactions with healthcare providers provide insight into the health-related stigma experienced by individuals with SCD.

Health-related stigma is a form of devaluation based on a health condition. In SCD, individuals often report being dehumanized when seeking care for pain- especially in emergency departments. The reasons for stigma in SCD are multifaceted. However, given

that most individuals living with SCD in the United States are Black and there are myths about Blacks and their ability to tolerate pain (Hoffman et al., 2016; Staton et al., 2007), this is a contributing factor. Additionally, pain is subjective but most often has an objective correlate. In SCD, there are no objective correlates to support the patient's complaint of pain. Therefore, pain treatment is based on the healthcare provider's knowledge-informed assessment and whether they believe the patient's pain report. Patients with SCD experience health-related stigma when they are profiled, stereotyped, and labeled as drug seekers, frequent flyers, and their complaints of pain are not believed (Bulgin et al., 2018; Jenerette & Brewer, 2010).

Valid and reliable tools must be available to measure and intervene to mitigate health-related stigma in SCD. Three scales have been published specifically to measure health-related stigma in SCD: 1) the Sickle Cell Disease Health-Related Stigma Scale (Jenerette et al., 2012), The Measure of Sickle Cell Stigma (Bediako et al., 2014), and the Stigma in SCD Scale (Leger et al., 2018). Since the preliminary study of the 30 items Sickle Cell Disease Health-Related Stigma Scale was published with the Public, Doctor, and Family subscales, an additional Nurse Subscale was added for 40 items. This paper focuses on the 40-item Sickle Cell Disease Health-Related Stigma Scale and scale psychometrics and reduction to a 21-item measure.

Purpose

The purpose of this paper is to present the psychometrics of the Sickle Cell Disease Health-Related Stigma Scale Short Form (SCD-HRSS Short Form).

Methods

Before initiating the study, institutional review board (IRB) approvals were obtained from the Public Health-Nursing IRB at The University of North Carolina at Chapel Hill (#11-2076) and the Human Assurance Committee at Georgia Health Sciences University (Pro00000356). Written consent was received from each subject.

Design

A descriptive cross-sectional study provided the data for the psychometric evaluation of the SCD-HRSS. Adults with SCD completed a demographic questionnaire, the SCD-HRSS, and a measure of health-related quality of life (PROMIS 29).

Setting and Sample

A convenience sample of 206 adults with SCD was recruited from two comprehensive sickle cell centers in the Southeastern United States. All participants met the following eligibility criteria: (a) aged 18 years or older, (b) able to understand English, (c) diagnosis of SCD as evidenced by patient status in the respective SCD center. Individuals were screened by SCD center staff and excluded from participating if they had a known cognitive impairment that would preclude study completion.

Measures

Adults with SCD completed a demographic questionnaire, the SCD-HRSS, and a measure of health-related quality of life (PROMIS 29). The PROMIS 29 was selected to be used for construct validity.

Demographics—The demographics questionnaire requested information to describe the sample by age, gender, education, employment, and relationship status. Participants also were asked questions specific to SCD, such as the number of crises per year that require hospitalization and the SCD genotype. There are several genotypes of SCD, with the type and severity of the disease being dependent on the inherited gene containing the "instructions" for abnormal hemoglobin (CDC, 2022). The most common genotype is HbSS or sickle cell anemia which occurs when an individual inherits an abnormal hemoglobin S from each parent. This is usually the most severe form of SCD. A common but often milder form of SCD is HbSC, where individuals inherit an abnormal hemoglobin S gene from one parent and an abnormal hemoglobin C gene from the other parent. The 3rd most common type of SCD in the US is HbS beta thalassemia. In this case, an individual inherits one abnormal hemoglobin S from one parent and an abnormal beta thalassemia gene from the other. There are two types of beta thalassemia- beta^{0} (beta zero) and beta^{+} (beta plus). Individuals with SCD HbS beta^{+} thalassemia usually have milder disease than those with SCD HbS beta^{0} thalassemia.

Health-Related Stigma Scale (SCD-HRSS): The original SCD-HRSS has 30 items and three subscales measuring adults' with SCD perceived health-related stigma from doctors (physicians), family, and the general public, using a 5-point Likert scale. Preliminary reliability and validity were reported previously (Jenerette et al., 2012). A 10-item nurse subscale was added to address perceived health-related stigma from nurses based on the doctor subscale from the SCD-HRSS (Jenerette et al., 2012). Thus, the 40-item SCD-HRSS was used in this study. Items in the SCD-HRSS-SF pertain to stigmatization regarding disease status (e.g., Most nurses would prefer not to care for people with sickle cell disease.), use of pain medication (e.g., People believe that sickle cell is used as an excuse to get pain medication.), and ability to participate in social roles (e.g., My family feels that I exaggerate how much I hurt in order to get out of doing things that I don't want to do.).

PROMIS 29: Health-related quality of life was measured using the PROMIS 29, which contains 29 items and comprises eight subscales (physical function, pain intensity, pain interference, fatigue, depression, anxiety, sleep disturbance, and social role-participation) (Cella et al., 2019). Each subscale is measured by four items using a 5-point Likert scale, except pain intensity, measured by a single item using an 11-point Likert scale. The physical function subscale asks the participant to broadly affirm how difficult it is to perform various tasks (e.g., "Are you able to do chores such as vacuuming or yard work?"), whereas the remaining subscales ask the participant about their experience in the last seven days. (e.g., In the past 7 days "I felt uneasy" or "My sleep was refreshing" or "I felt depressed.")

Data Collection: Once a patient was deemed eligible for this study, the PI or a trained research assistant approached the patient in a private clinic area where the patient was

receiving routine outpatient care. The study was described, questions answered, and written informed consent from those who agreed to participate. Data were collected between 2011–2013 via paper and pencil questionnaires and were double-entered into Statistical Package for the Social Sciences (SPSS) for data analysis.

Data Analysis

Approaches to the Assessment of Validity and Reliability—Evaluation of the validity and reliability of the SCD-HRSS was conducted using SPSS Version 25. Descriptive statistics were used to describe sample characteristics and the endorsement of scale items. While the construct and criterion validity of the 30-item SCD-HRSS have been assessed previously (Jenerette et al., 2012), confirmatory factor analysis was not appropriate because the original measure had not been evaluated via factor analysis previously. In addition, ten nurse-related items were added to the revised SCD-HRSS that have not previously been evaluated through any psychometric testing. Therefore, construct validity, consisting of factorial and discriminant validity, was assessed through exploratory factor analysis (EFA) and correlations with PROMIS 29 subscales. Internal consistency reliability of the SCD-HRSS was evaluated by evaluating Cronbach's alpha coefficients.

Validity

Factorial Validity.: Factorial validity was assessed by conducting EFA using principal axis factoring and an oblique rotation method, direct oblimin rotation. An EFA was conducted because our measure is intended to measure a latent construct, health-related stigma. Principal axis factoring was used because it is less likely to produce improper factor solutions, and does not require the variables to be normally distributed (Brown, 2015). Oblique rotation was used because the underlying factors in the SCD-HRSS were expected to be correlated (Brown, 2015). Skewness and kurtosis for the variables were evaluated and were adequate. The Kaiser-Meyer-Olkin measure of sampling adequacy (KMO= .86) was above the recommended value of .60, suggesting a proper ratio of participants to the number of scale items. Bartlett's test of sphericity was statistically significant (<.001), suggesting correlations between variables could be analyzed by factor analysis (Mertler & Vanatta, 2005); together, these statistical tests conferred the appropriateness to proceed with the EFA. The factor structure was determined using scree plots, assessment of model fit, and the K1 method to evaluate eigenvalues. Due to the number of variables and the presence of many communalities < 0.7, using the K1 method alone to determine the number of factors was not supported (Mertler & Vanatta, 2005). The interpretation of the scree plot suggested a 3-factor or 4-factor solution. Parallel evaluations of EFAs were used to examine possible best factor structures; for the SCD-HRSS, 2-factor, 3-factor, 4-factor, 5-factor, and 6-factor solutions were considered. During the parallel EFAs, items from the SCD-HRSS were retained if they had primary factor loadings > .40 and dual loadings < .30. Factors labels were considered after determining the best factor structure by the authors.

Discriminant Validity.: Discriminant validity was assessed through the bivariate correlations between the SCD-HRSS and a subset of PROMIS 29 subscales, consisting of anxiety, depressive symptoms, pain interference, and role satisfaction. These variables were selected for validity testing because health-related stigmatization may lead to increased anxiety,

depressive symptoms, pain, and a decrease in role satisfaction. However, health-related stigma is a distinct construct from all of these variables, and the expected correlation coefficients should reflect this. Based on the hypothesized relationships among these variables, discriminant validity was confirmed through bivariate correlation coefficients ($|r| \leq .45$) (DeVon et al., 2007).

Evaluation of reliability

Internal Consistency Reliability.: Once the factor structure was identified through EFA, the internal consistency reliability estimates were calculated to assess the total scale and subscale reliability and to determine if additional items could be removed for parsimony. Sufficient internal consistency reliability coefficients (Cronbach's α) > .70 were deemed reliable for this study (DeVon et al., 2007).

Results

Sample Characteristics

In this convenience sample, 206 adults with SCD were recruited for the study. Only subjects with complete data for the SCD-HRSS were included; therefore, the final sample was n = 197. The majority of the sample were women (59%), had a diagnosis of hemoglobin SS sickle cell disease (70%), and had completed at least high school education (87%). The mean age of the sample was 35.8 years (SD = 12.3). Sample characteristics are further described in Table 1.

Descriptive Scale and Item Statistics

Estimates were generated for the 40-item version of the SCD-HRSS, including scores for the Public (e.g., people in the general public who are not family nor healthcare providers), Doctor, Family, and Nurse subscales, and the total score that constructed the previous version of the SCD-HRSS. The mean scores for the Public, Doctor, Family, and Nurse subscales were 32.9 (SD = 9.2), 32.0 (SD =8.7), 21.1 (SD =8.4), and 31.3 (SD = 9.0), respectively, and the mean for the total score was 117.3 (SD = 28.1)

Evaluation of Construct Validity

A series of parallel evaluations of 2-factor, 3-factor, 4-factor, 5-factor, and 6-factor solutions identified parsimonious 2 and 3-factor solutions. After carefully considering both solutions in light of the Theory of Self-care Management for Sickle Cell Disease (Jenerette & Murdaugh, 2008; SCMSCD) and the psychometric properties of both solutions, the 3-factor solution was selected as the most consistent with the conceptualization of stigma in the context of patients with SCD. Additionally, this solution displayed slightly better psychometric indicators, explaining an additional 7.6% more variance than the 2-factor solution, and had a lower number of reproduced correlations exceeding .05 (20%) compared to the 2-factor solution (38%).

The final 3-factor solution retained 21 items. The factor loading coefficients for the 21-item version of the SCD-HRSS or SCD-HRSS- Short Form are displayed in Table 2. The first subscale, retitled P^2 or Public & Physician/Doctor, consists of 8 items that belonged to

the Public and Doctor subscales in the original 40-item version. The second subscale is the Family subscale, reduced to 7 items from the 10 in the original subscale. The final subscale is the Nurse subscale, reduced to 6 items from the 10 in the original subscale. The P^2, Family, and Nurse subscales explain 37.8%, 14%, and 7.6% of the latent construct of stigma variance, respectively. Structural validity was further supported by factor or subscale correlations < .6 between all factors.

Discriminant validity was demonstrated by evaluating correlation coefficients between the SCD-HRSS and related measures included in the PROMIS instruments used in this study. All three factors of the SCD-HRSS SF demonstrated adequate discriminant validity with low bivariate correlations ($|r| \leq .45$) with anxiety, depressive symptoms, role satisfaction, and pain interference subscales from the PROMIS 29. The bivariate correlations are displayed in table 3.

Internal Consistency Reliability

Internal consistency reliability was examined by assessing the Cronbach's α for the total scale score and the subscales of the SCD-HRSS SF. The total scale had a Cronbach's α = .91, and the P^2 (Public/Physician), Family, and Nurse subscales had Cronbach's α of .88, .86, and .88, respectively, thus demonstrating sufficient internal consistency.

Discussion

Our findings indicate that a significantly reduced version of the SCD-HRSS, the SCD-HRSS-SF, contains a 3-factor structure and demonstrates discriminant validity and internal consistency, both across the three subscales and the scale as a whole, in a sample of adults with SCD. The shift from four theorized subscales to three final subscales was based on statistical analyses that revealed a 3-factor structure as the most parsimonious structure. The "Doctor" and "Public" subscales from the original questionnaire have been merged to form a new subscale, "P^2," e.g., Physician & Public, while the Family and Nurse subscales remain the same, albeit with a reduced number of items contained within each subscale. Additionally, the number of items about perceived physician stigmatization is significantly reduced compared to public stigmatization. While different from the original scale construction, these results are consistent with the literature. Analysis of the scale that the SCD-HRSS was derived from, the Chronic Pain Stigma Scale (CPSS), has also shown that public and physician items tend to factor together (Reed, 2006). While the physician and public subscales have previously been treated as distinct, it appears that individuals with SCD perceive stigma from these groups similarly. This likeness is consistent with the preliminary psychometrics of the 30 and 40 item SCD-HRSS where perceived stigma was highest among doctors and the public, as reported in this paper and the preliminary psychometrics (Jenerette et al., 2012). The data are also consistent with perceptions of family stigma being the lowest of all subscales in the scale's 30 and 40-item versions.

Discriminant validity between the SCD-HRSS-SF and depression, anxiety, satisfaction with social role, and pain interference, as measured by the PROMIS 29, was supported. The size and direction of these correlations establish SCD-related stigma as a distinct construct related to important patient-reported outcomes in this population. The very nature of SCD

increases the risk of anxiety and depression and dissatisfaction in social roles and pain interference due to the unpredictable nature of pain crises and the presence of chronic pain in between acute pain crises. Prior studies of sickle-cell-related stigma have shown that stigmatization negatively influences the physical and psychological well-being of SCD patients and their social status and roles in their community (Bulgin et al., 2018). The previous study of the 30-item SCD-HRSS found that patients who reported higher levels of stigmatization were also more likely to report higher depressive symptoms (Jenerette et al., 2012); this is consistent with the current study's findings. Other studies have also shown that patients who experience more stigmatization are more likely to report symptoms of anxiety and depression (Bulgin et al., 2018). It is well-established that health-related stigma impacts perceptions of pain among patients living with SCD (Bulgin et al., 2018; Haywood et al., 2014; Mathur et al., 2016). A prior study has also found evidence that higher levels of perceived stigma are associated with pain interference (Martin et al., 2018). Patients with SCD have also reported health-related discrimination from family and the general public, having their pain experiences discredited and experiencing social status loss in their communities (Bulgin et al., 2018); our finding of an inverse correlation between satisfaction in social roles and the experience of health-related stigma reinforces these findings.

Previous research supports that young adults delay care-seeking due to past health-related stigma (Jenerette et al., 2014). However, the same study suggests that young adults who have achieved higher levels of education may seek care at lower pain levels. In the current study, 13% of the subjects reported less than a high school education. Children and young adults may miss a significant amount of school due to sickle cell and face public and family-related stigma as a part of the social challenge of living with SCD. Further research needs to be conducted to understand the influence of health-related stigma on education (Leger et al., 2018).

There are several limitations to this study. While the study had an adequate sample size (N = 197) to conduct an EFA, the analytic sample was recruited from the outpatient clinics of two different SCD programs located in the southeast United States. Although testing and confirming the psychometric properties of the SCD-HRSS across multiple SCD populations supports the validity of this measure for all patients with SCD, characteristics that may be unique to the two study sites were not controlled for in this study. Likewise, because all of the participants in the study were recruited from SCD programs, we could not assess how individuals who may not have access to a specialized SCD clinic responded to the questionnaire. Future studies should continue to determine the validity and reliability of the SCD-HRSS Short Form among diverse SCD cohorts, both geographically diverse and diversity in access to care. In addition, an alternate stigma measure was not used for comparison in this analysis. The psychometric properties of this instrument could be strengthened by assessing convergent validity with another measure examining internalized or externalized stigma among patients with SCD. Finally, data for this study were collected ten years ago. While recent studies indicate that individuals with SCD still experience health-related stigma, it will be important to continue to measure stigma and develop interventions to mitigate it. Despite these limitations, this analysis provides evidence that the SCD-HRSS-SF is a reliable and valid measure of perceived sickle cell-related stigmatization in adults with SCD.

In conclusion, the SCD-HRSS-SF is a valid and reliable measure of SCD-related stigma that reduces the administration time and burden of the original 40-item instrument. We identified three subscales in the short form that measure perceptions of stigma from physicians and the public, from family, and nurses. These subscales will help delineate further the impact of stigma from different sources on health behaviors and well-being in the population. Furthermore, all three subscales had small to moderate correlations with anxiety, depression, satisfaction with social roles, and pain interference. Measuring perceptions of stigmatization, and strategizing to improve the healthcare profession and the public's perceptions of SCD while giving patients the tools needed to improve their self-esteem, may have a crucial impact on the well-being of individuals with SCD. These findings may be further enhanced by evaluating the SCD-HRSS-SF across additional samples of patients living with SCD and confirmatory factor analysis to support our conclusions.

Acknowledgment and Funding

We thank the individuals living with sickle cell who participated in this study. This work was supported by funding from the NC NIH Clinical and Translational Science Award at UNC-Chapel Hill (2KR321107) and a National Institute of Nursing Research Award Number T32NR008857. The content is solely the authors' responsibility and does not necessarily represent the official views of the National Institutes of Health.

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Table 1.

Sample Characteristics (N=197)

Variables	n	(%)
Gender[†]		
Female	115	(59.3)
Male	79	(40.7)
Education[†*]		
Less than high school	26	(13.3)
High School	74	(37.9)
Some college/College	95	(48.7)
Employment		
Full-time	23	(11.9)
Part-time	19	(9.8)
Not employed	30	(15.5)
Disabled	117	(60.3)
Retired	5	(2.6)
Relationship Status [†*]		
Single/never married	116	(59.5)
Married	39	(20.0)
Divorced	14	(7.2)
Widowed	1	(0.5)
Separated	6	(3.1)
Living with domestic partner	11	(5.6)
Other	7	(3.6)
Do not wish to answer	1	(0.5)
Type of SCD [†**]		
Hemoglobin SS Disease	135	(70.3)
Hemoglobin SC Disease	22	(11.5)
Hemoglobin S Beta0 Thalassemia	6	(3.1)
Hemoglobin S Beta+ Thalassemia	12	(6.3)
Don’t Know/Not Sure	17	(8.9)

Note:

[†] n = 194

[†*] n = 195

[†**] = 192

Table 2.

Descriptive statistics of study measures. (n = 197)

Variables	Mean	Median	SD	Range	Quartiles 25	Quartiles 75
PROMIS Anxiety (n = 187)	8.2	8	3.6	4 – 19	5	11
PROMIS Depression (n = 186)	7.5	6	3.7	4 – 20	4	10
PROMIS Satisfaction with Social Role (n = 190)	12.5	12	4.9	4 – 20	9	16
PROMIS Pain Interference (n = 192)	11.9	12	4.4	4 – 20	8	20
SCD-HRSS- Short Form Family Subscale	15.8	14	7.5	7 – 40	10	20
SCD-HRSS- Short Form Public & Doctor Subscale	26.8	26	9.8	8 – 48	18	35
SCD-HRSS- Short Form Nurse Subscale	19.4	19	7.6	6 – 36	13	25
SCD-HRSS- Short Form Total Score	61.9	60	20.1	21 – 112	44.5	78.5

Table 3.

Final 3-Factor Structure of the Sickle Cell Disease Health-Related Stigma Scale or SCD HRSS-Short Form (n=197)

Items	Factor 1	Factor 2	Factor 3
stigmaP8	**.770**	--	.174
stigmaP7	**.732**	--	--
stigmaD3	**.658**	--	−.201
stigmaP9	**.650**	--	−.264
stigmaP2	**.552**	--	--
stigmaD4	**.537**	.152	−.169
stigmaP10	**.526**	.158	--
stigmaP4	**.492**	.114	−.275
stigmaF9	--	**.850**	--
stigmaF6	--	**.770**	--
stigmaF2	--	**.707**	--
stigmaF3	--	**.706**	--
stigmaF8	.149	**.612**	--
stigmaF10	--	**.586**	--
stigmaF5	--	**.559**	--
stigmaN2	--	--	**−.845**
stigmaN3	.150	--	**−.809**
stigmaN10	--	--	**−.750**
stigmaN9	.270	−.150	**−.715**
stigmaN4	--	.200	**−.591**
stigmaN10	--	--	**−.524**

Note. Extraction method was principal axis factoring with oblique rotation (direct oblimin rotation using the following parameters: $\delta = 0$, $\kappa = 4$).

Table 4.

Bivariate Correlations of SCD-HRSS SF and PROMIS Subscales (n=187–192)

	Factors		
Variables	**Physician/People**	**Family**	**Nurses**
Anxiety (n = 187)	**.250** **	**.275** **	**.312** **
Depression (n = 186)	**.331** **	**.371** **	**.233** **
Satisfaction with Social Role (n = 190)	**−.205** **	**−.172** *	**−.232** **
Pain Interference (n = 192)	**.252** **	**.159** *	**.308** **

Notes:

* p < .05

** p < .01.